

State of the States
Best Approach to Advocacy in Current
Economic Crisis

AUCD Directors' Retreat
April 6, 2011

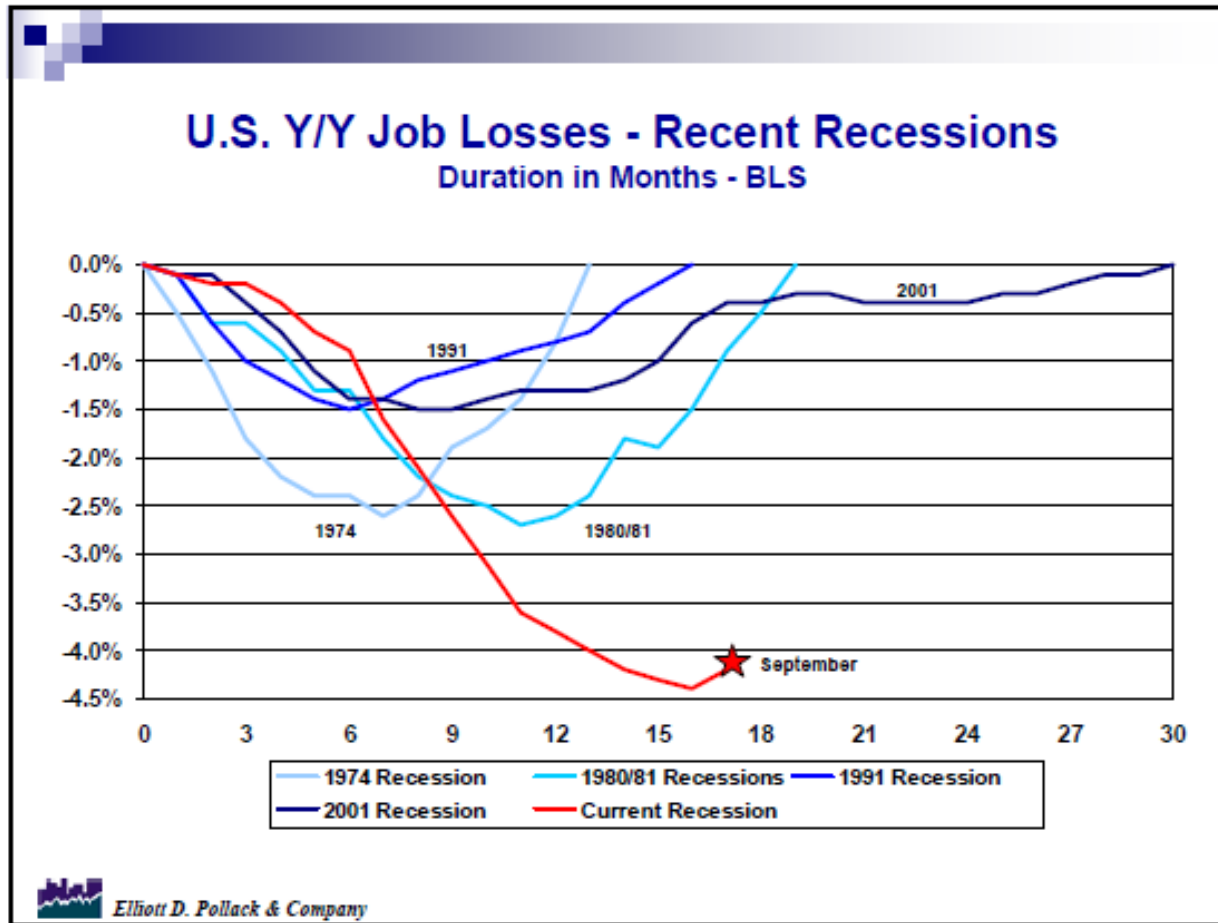
Nancy Thaler, Executive Director
National Association of State Directors of Developmental Disabilities Services
NASDDDS

Three Big Problems That will be With Us for a Decade or More

- 1.** Economic Recession - Unemployment at 8.8%
- 2.** Structural Budget Deficits - Spending more money than we have each year contributes to overall debt
- 3.** Aging Baby Boomers - increasing demands puts pressure on budgets and service delivery systems

Problem No. 1

Economic Recession



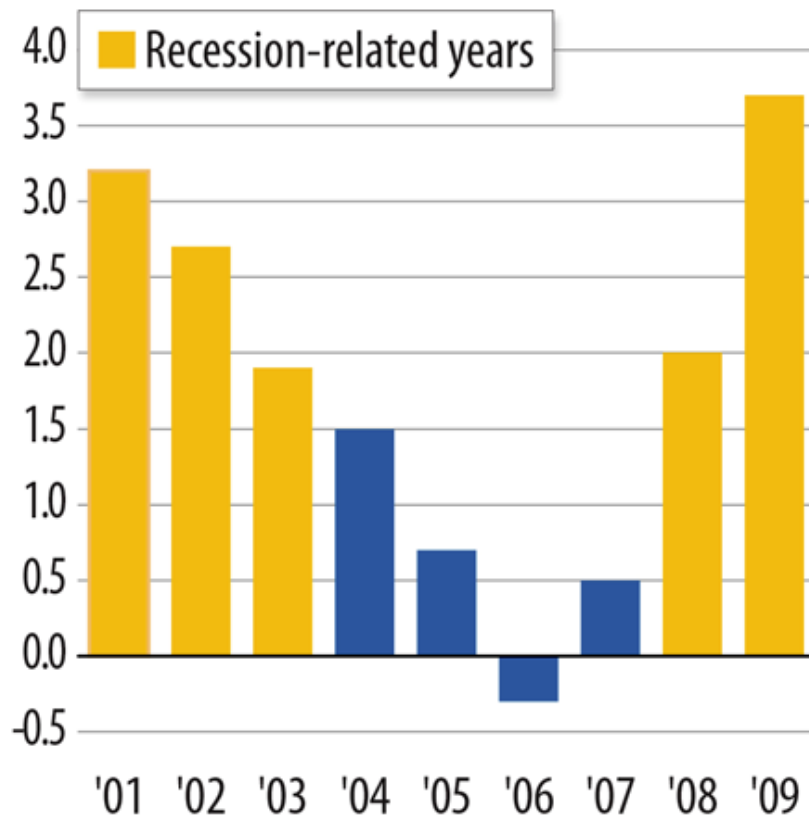
January 2011
13 million
people were
unemployed.
(8.8%)

2010
1 million new
jobs created.

We need
13 million jobs!

Impact of a Recession on Medicaid Roles

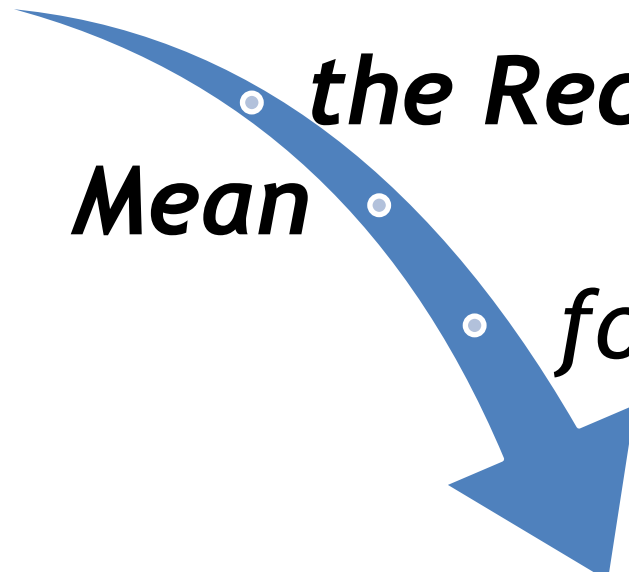
Medicaid Enrollment Growth, in millions



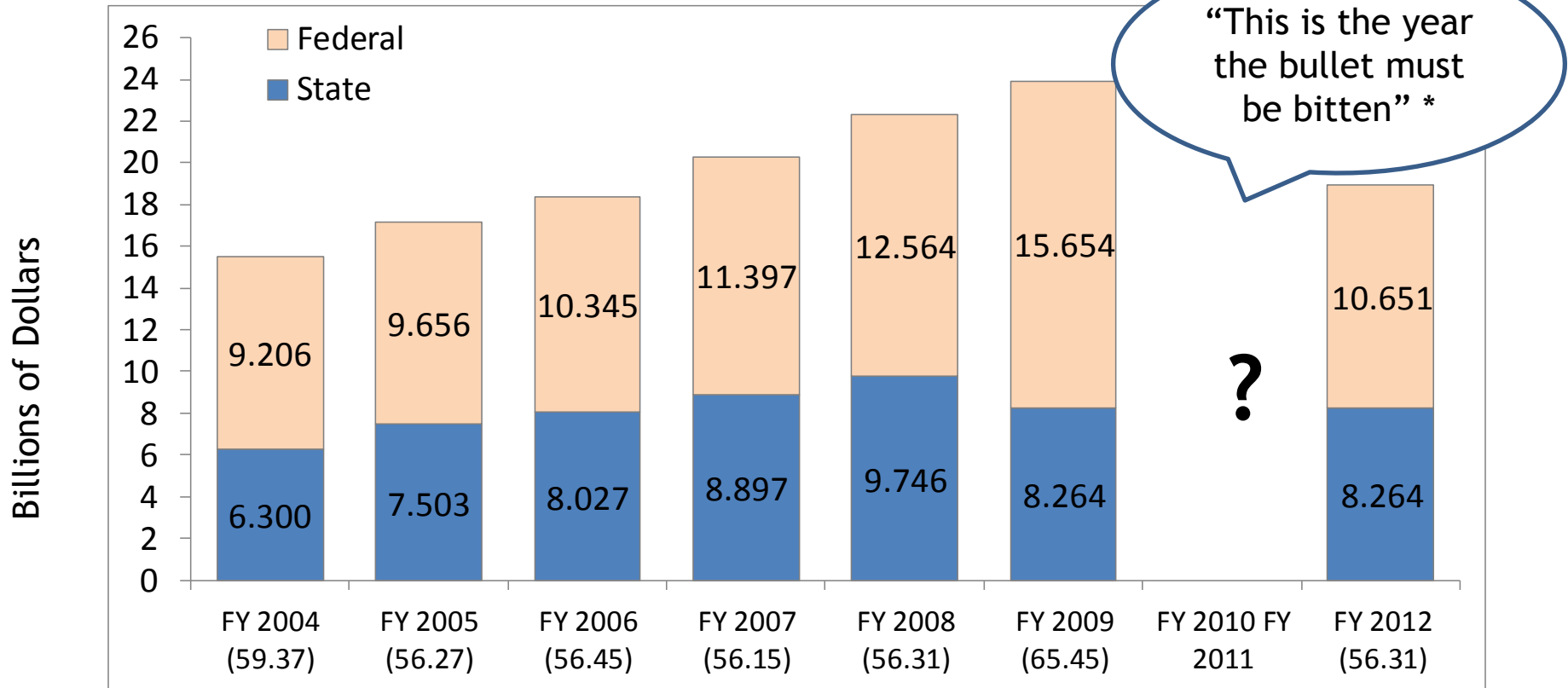
Each 1% increase in the unemployment rate results is a 1 million person increase in Medicaid enrollment among children and non-elderly adults.

- *Urban Institute*

What does

the Recession
Mean  ***for***
States ?

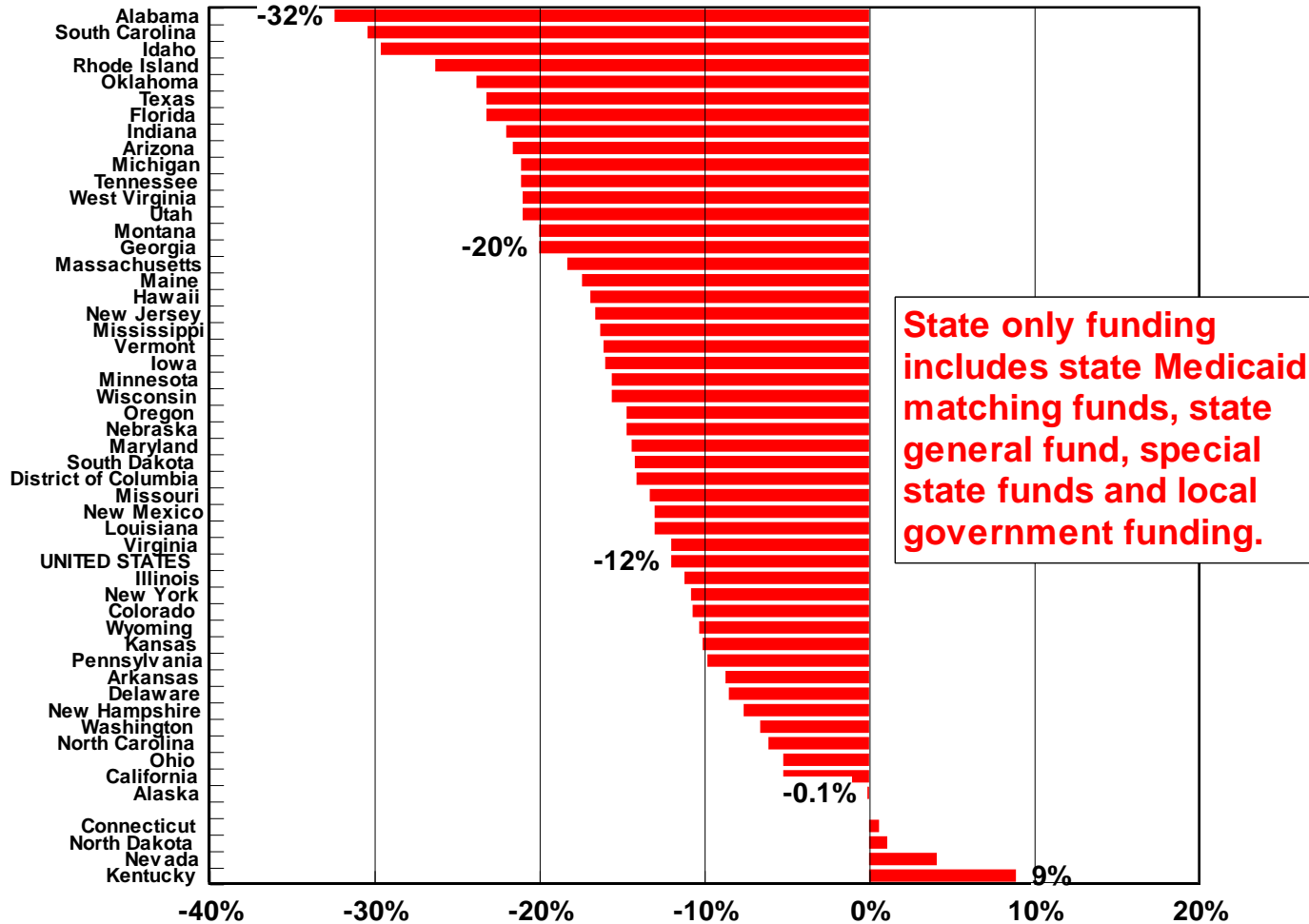
This Year the Stimulus Funds Will be Gone



Lakin University of Minnesota

* Warren Deschenaux, the Maryland Legislature's top fiscal analyst.

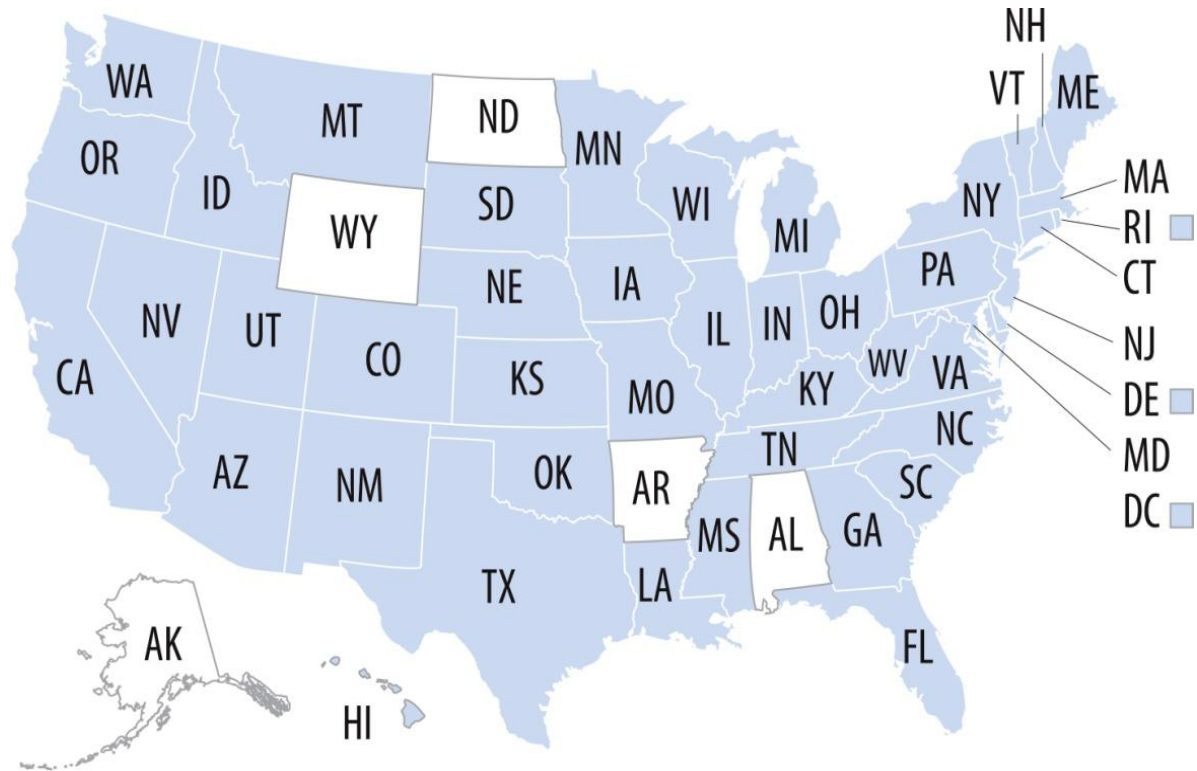
REDUCTIONS IN STATE ONLY FUNDING: FY2009



Source: Braddock, D., State of the States in Developmental Disabilities, 2010, preliminary.

Estimated State Budget Shortfalls 2012

- **FY' 2010**
46 states
- **FY' 2011**
36 states
- **FY' 2012 est.**
45 states



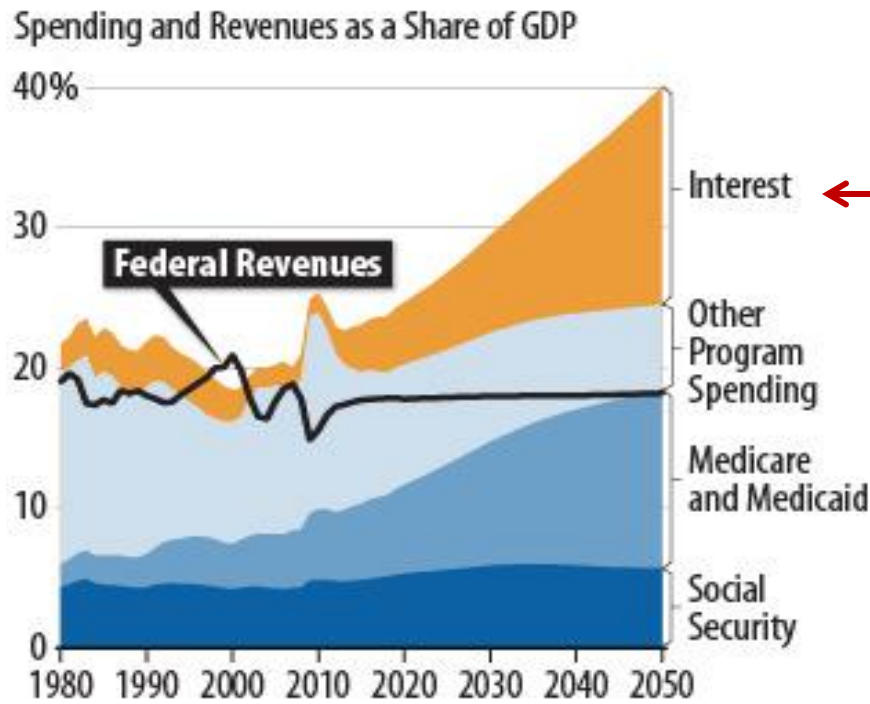
Source: CBPP survey.

Governors Proposing Deep Cuts in Services

- Nearly all states (41) are proposing to spend less money than they spent in 2008
- The majority - 32 of 41- are proposing major cuts in core public services

Problem No. 2

The National Structural Budget Deficit



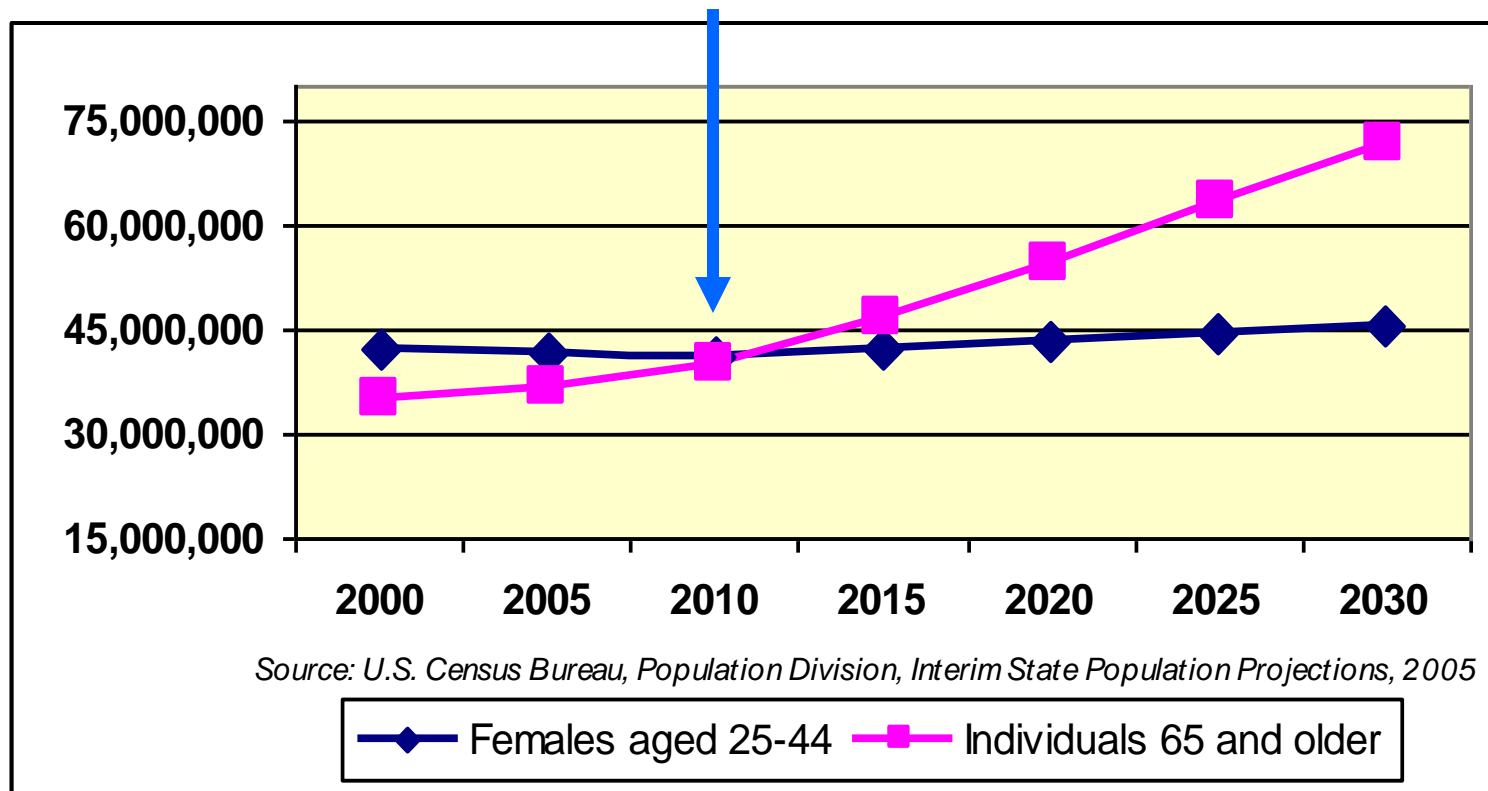
We are spending more money than we are taking in.

Source: CBPP projections based on CBO data.

Center on Budget and Policy Priorities | cbpp.org

Problem No. 3

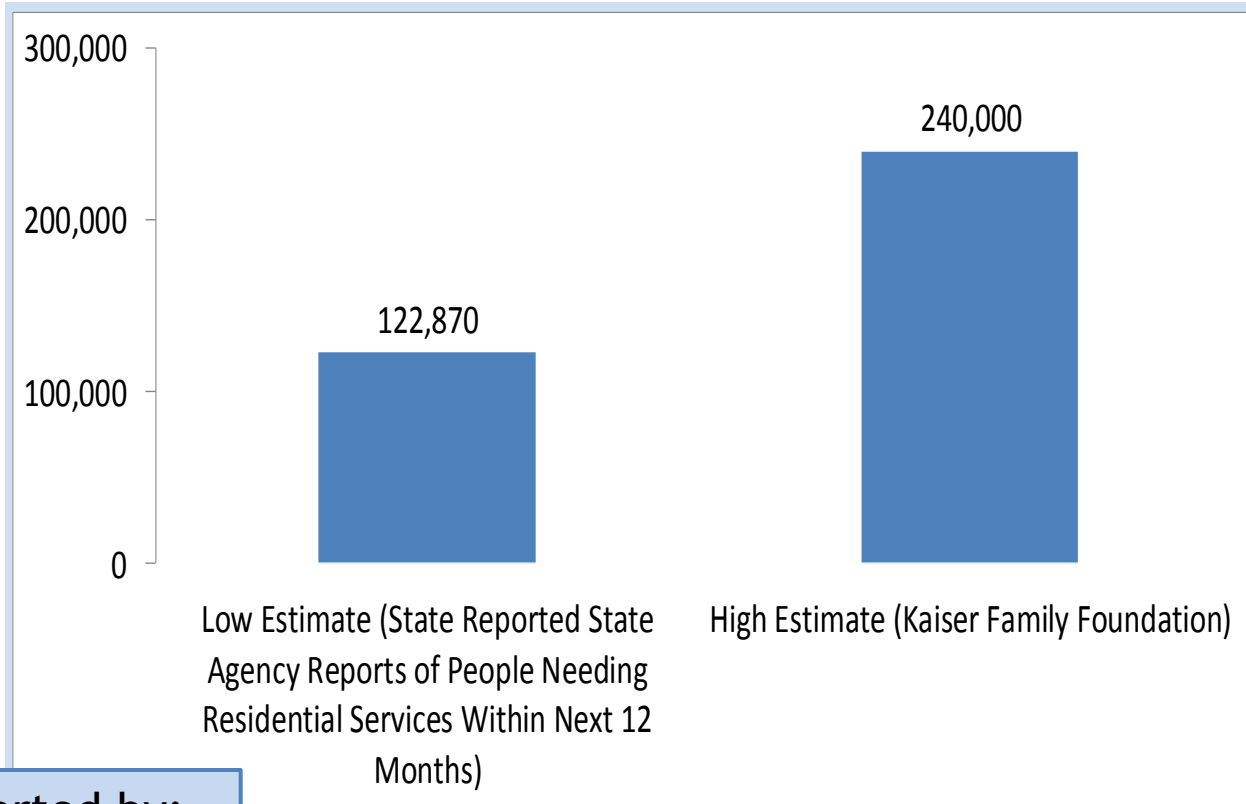
Demographic Shift- Not Enough Workers to Take Care of the Baby Boomers



At least 29 states and DC cut medical, rehabilitative, home care, or other services

- **AZ, CO, IL, MS, NH, OH** and others eliminated or reduced community mental health services for thousands of Medicaid eligible children and adults.
- **Kansas** cut Centers for Independent Living funding, resulting in a loss of services for nearly 2,800 individuals with disabilities.
- **Florida** is proposing a 17% cut in funding
- **Michigan** froze enrollment for long term services and supports that help people avoid institutionalization, resulting in 300 people being placed on a waiting list.
- **Minnesota** capped enrollment a healthcare program for people with disabilities and restricted enrollment in in-home services for the elderly and disabled.
- **New Hampshire** is freezing admissions to DD services and is reducing reimbursements to 10 mental health centers for children's support services in FY11.
- Other states that have capped or reduced funding for programs that serve people who have disabilities or are elderly: **CA, DC, FL, IN, KS, LA, ME, MD, MO, NC, SC, RI, TN, UT, VT, and VA.**

Significant Numbers are Waiting for Services

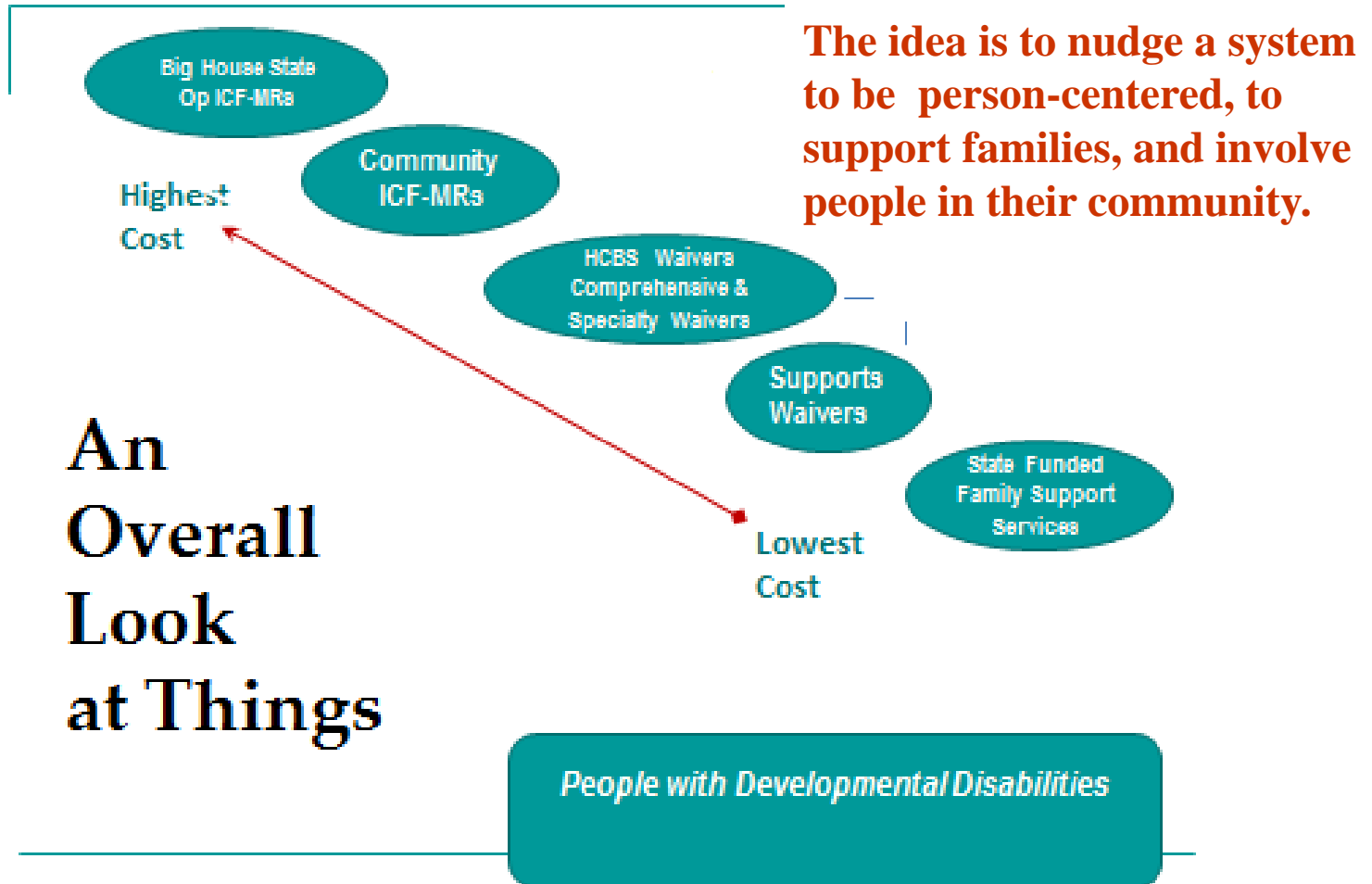


Data not reported by:
MS, NJ, NC, OH, TX, or
WA

**So,
what are
state DD agencies
doing**




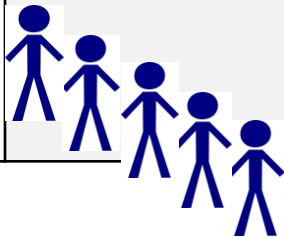


Nudging the System

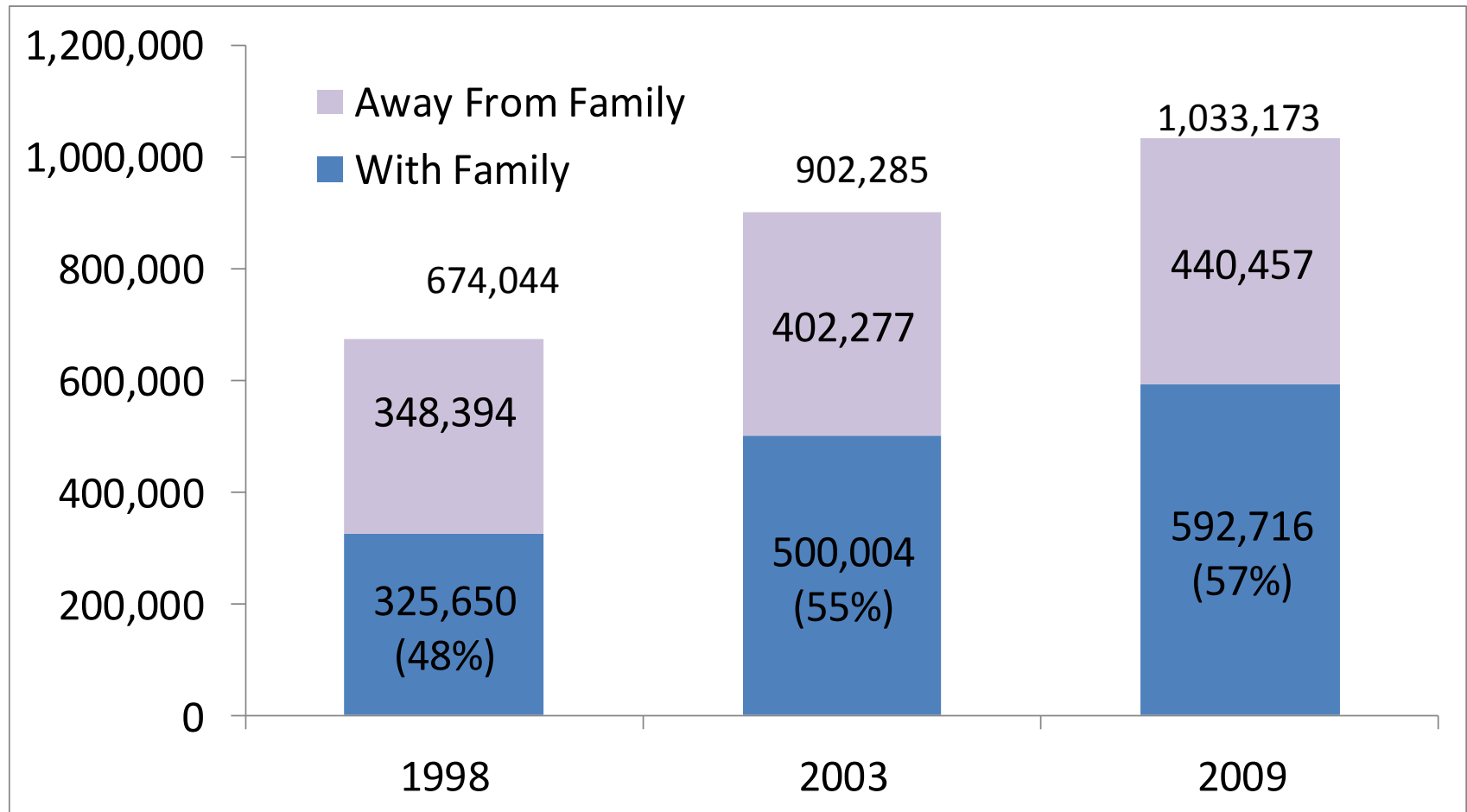


John Agosta, Human Services Research Institute

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

Type of Service	Cost per Person	Cost to Serve the Waiting List	People Served with \$5 M
ICF/MR	\$128,275	\$15,761,149,250	 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

Expanding supports to adults in the family home



Strategic Actions

- Extending family care-giving as long as possible by strengthening systems of supports for families
- Implementing flexible “support waivers”
 - Expand home-based services to support individuals at a lower cost than the “full package” of waiver services
- Getting more people into real jobs
- Creating real life options for people who have no family
 - Shared living - people living together sharing life experiences and expenses
- Adopting managed care models



Building a New Paradigm One that Supports Self-Advocates and the Families They Live With

- ❖ Just because we provide family support services doesn't mean families feel supported.
- ❖ The self-advocates interests and choices must be honored



Families

❖ Think of family broadly - parents; siblings; grandparents; other relatives.

❖ Families are complicated. Family

- ❖ 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
- ❖ Do the impossible
- ❖ Commit abuse and take advantage of other families members
- ❖ Can't do everything
- ❖ Etc. etc. etc.



❖ The family is the context for everything; personal outcomes will be influenced by the family

A new paradigm of service

- ❖ Develop and maintain essential non-direct services:
 - ❖ Support coordination - small ratios; training in family dynamics; conflict resolution; strong clinical supervision
 - ❖ Self Advocacy organizations
 - ❖ Peer Support
 - ❖ 24 hour help line
 - ❖ Crisis intervention with immediate respite
 - ❖ Monitor health and wellness
 - ❖ Protect people from abuse and neglect

A new paradigm of service

❖ Innovate

- ❖ Self directed services;
- ❖ Individual budgets;
- ❖ Hiring relatives;
- ❖ Paid peer support;
- ❖ Using state dollars for things not Medicaid eligible

❖ Create real life options for people who have no family

- ❖ Shared living - matched arrangements in the person's home or in the home of someone else. Expect them to last a long time

The Questions are...

- ❖ Not whether people who are older and/or disabled 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.
- ❖ How much and what kind of support do we provide so that
 - ❖ When a “bed” is available, the person and the family say “never mind. We are having a great life” and
 - ❖ Siblings and other family members open their homes and hearts because they have confidence in the supports.

Create Shared Living Options

- Shared Living is exactly that: people sharing their lives by living together under the same roof as a family. Rhode Island
- An arrangement in which an individual, couple or family in the community share life's experiences with a person with a disability.
- The person who lives with and provides support to the person with a disability is typically referred to as the Shared Living provider. Other terms include mentor, host family or family home, foster care or family care, and life sharing.

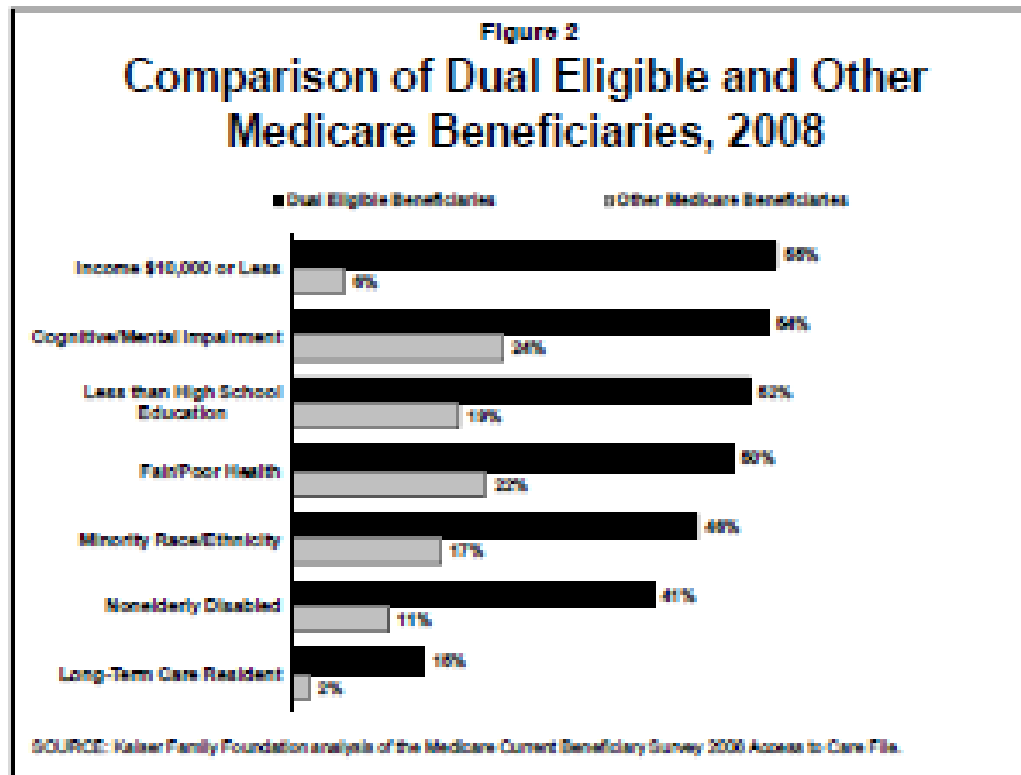
How Can UCEDS Help?

- Be part of the dialogue -
 - Advisory groups
 - Partners in Policy Making
- Support system transformation to a new paradigm
 - Training programs
 - Technical Assistance (Employment; Person-centered practices, positive behavioral practices; sexuality training)
 - Conduct quality oversight
 - Promote Evidence Based Policy
 - AUCD/NASDDDS Evidence-Based Policy Initiative
- Create a partnership between DD Councils, DD Agencies, & UCEDS
- Lead - the advantage of tenure is you can speak truth to power

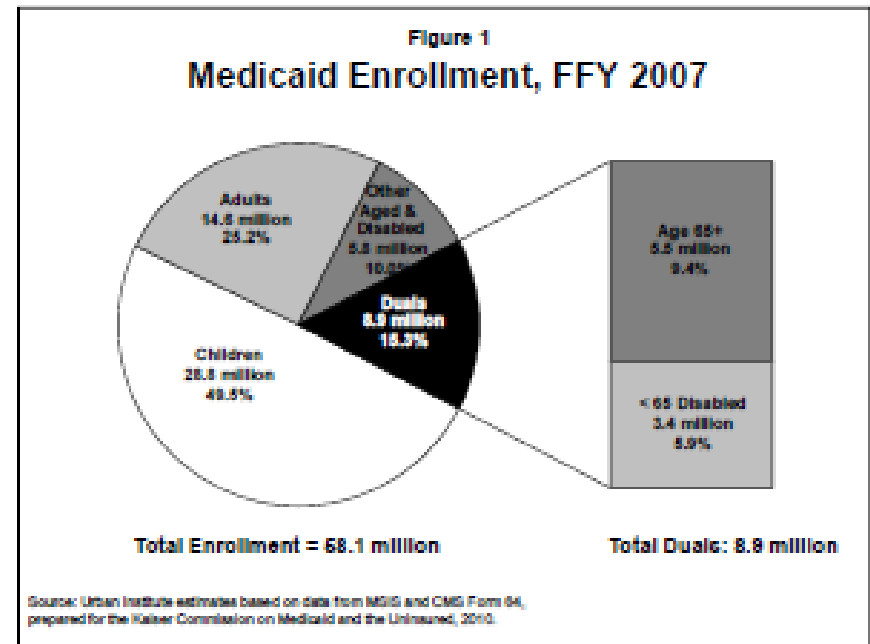
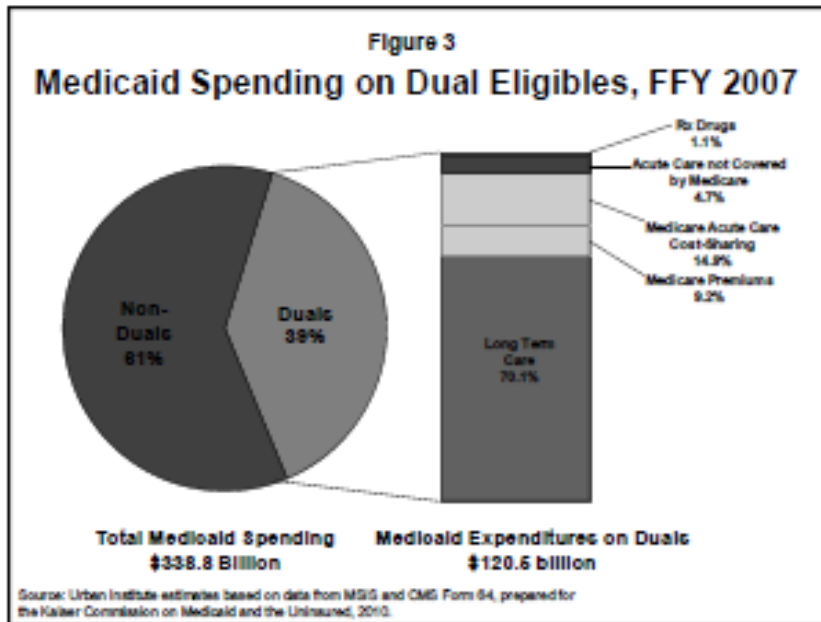
The 2012 Challenges

**Managed Care - State Initiatives
Programs for Dual Eligibles
2012 Budget**

Why Focus on Dual Eligibles?



Why Focus on Dual Eligibles?



Initiatives for Dual Eligibles?

**TABLE
3-4**

Dual eligible beneficiaries are more costly than others, 2001

Source of spending	Nondual eligibles	Dual eligibles
Total	\$10,054	\$20,844
Medicare	5,399	8,559
Medicaid	85	8,603
Other	4,570	3,682

**TABLE
3-6**

Aged mentally or cognitively impaired dual eligibles are most costly

Subgroup	Medicare spending	
	Dual eligibles	Nondual eligibles
Disabled		
Mentally or cognitively impaired	\$6,405*	\$3,657
Limitations in two or more ADLs	7,299*	4,416
Limitations in fewer than two ADLs	3,425*	2,605
Aged		
Mentally or cognitively impaired	12,370	11,864
Limitations in two or more ADLs	9,603	8,933
Limitations in fewer than two ADLs	4,415	3,992

“The Path to Prosperity” FY2012 Budget Resolution

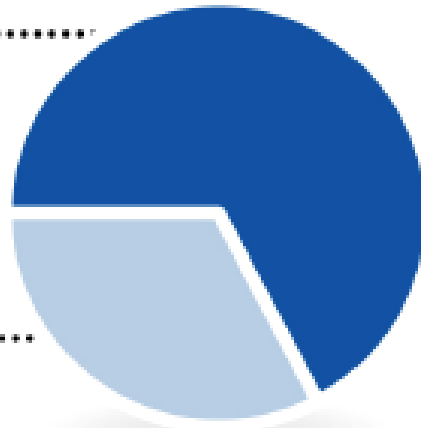
Chairman Ryan gets roughly 2/3 if the \$4 Trillion budget comes from programs for lower-income Americans

Figure 1

Two-Thirds of Proposed Cuts in Ryan Plan Come from Low-Income Programs

Low-income program cuts
(e.g. Medicaid, Pell Grants, food stamps, low-income housing)
\$2.9 trillion

Other program cuts
\$1.4 trillion



Source: “The Path to Prosperity” FY2012 Budget Resolution

\$2.17 trillion reductions from Medicaid & related health care. Medicaid cuts of \$771 billion; \$1.4 trillion from repealing the health reform

\$350 billion in cuts in mandatory programs serving low-income Americans (other than Medicaid).

NASDDDS

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