

Interagency Autism Coordination Committee
2010 IACC Services Workshop

November 8, 2010

Where We Are Today and Where We Want to Be in 10 Years

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NASDDDS

Humble Beginnings 1970s



- **The primary service available for people with any disability was institutions. There were very few community services.**
- **The federal Medicaid program was amended to create a state entitlement to institutional services – ICF/MR***
- **MR was the predominant diagnosis applied across the board to people who could not speak and/or had significant disabilities**
 - ❑ **The diagnosis was defined by the American Association on Mental Deficiency and was widely adopted in public policy**
 - ❑ **As people with the label demonstrated competencies, they lost the MR diagnosis; parents often fought to keep the MR diagnosis to hold onto services**

* Intermediate Care Facilities for the Mentally Retarded

Humble Beginnings 1970s

- **Parents began to advocate for schooling and services that would help them at home**
- **States began to provide modest family support programs with state funding**
- **States began to create offices of mental retardation – often as units within the mental health agency**
- **The concept of developmental disability was introduced with the Developmental Disabilities Act but had little impact on state policy**

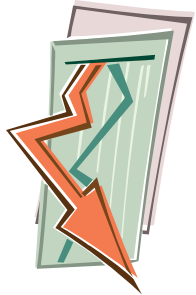
Opportunity in the 1980s

- **The Medicaid Waiver, which allowed states to use Medicaid funds to develop home & community services stoked rapid growth in services in most states that continues to the present**
 - **First in response to pressure to close institutions**
 - **Secondly in response to growing waiting lists and litigation**
- **Even though mental retardation became less and less acceptable as a diagnostic label - it was both useless and insulting – it was the basis for eligibility for home and community based services**

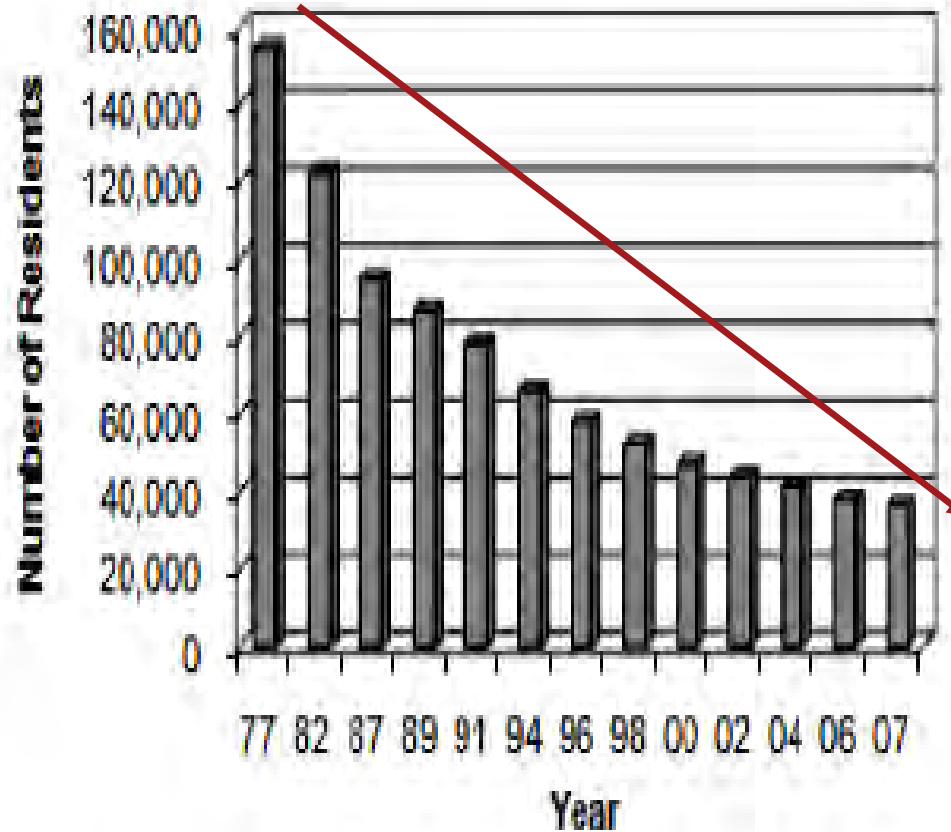
Why? Medicaid funding availability is based on the person's need for institutional care i.e. eligibility for ICF/MR because the purpose of the program is to provide a less costly an alternative to institutions.



Change to be Proud Of



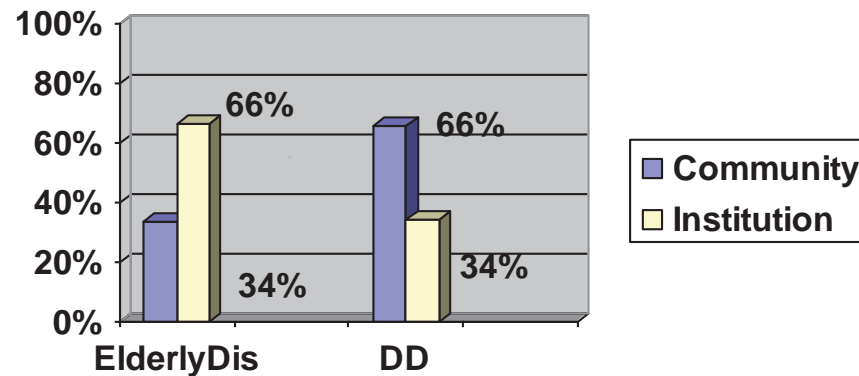
State Institution Residents



Source: UMN RTC/ICI

Institution/Community Balance

**Community/Institutional Funding
2007**



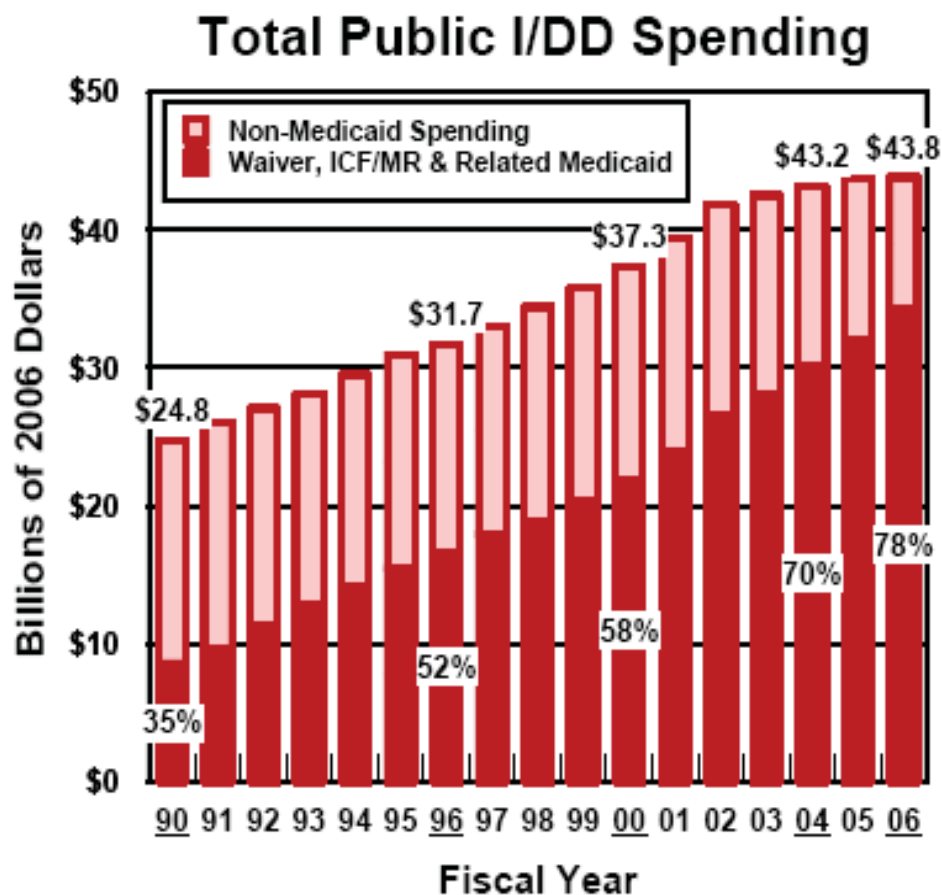
Elderly Disabled	Community	\$25,563,370,163	33.8%
	Institution	\$50,141,681,141	66.2%

DD	Community	\$24,520,350,785	65.6%
	Institution	\$12,884,108,686	34.4%

Thompson/CMS

The 1990s and Beyond

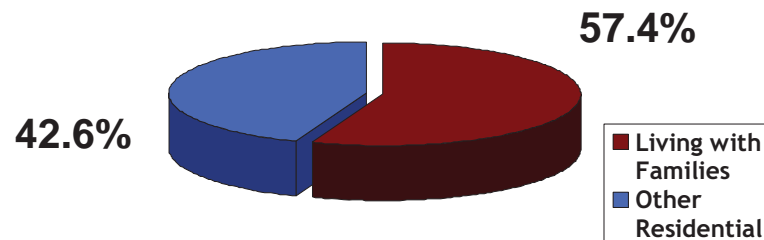
State & Federal Funds Combine to Fuel Growth



U.S. \$43.8 Billion in Supports & Services

About 1 Million People Receive Services Prevalence is 4.5 Million

- 428,803 Family Support
- 115,919 Employment Services
- 532,830 Residential Services – most in small settings
- Most people live with their families...
and the percentage is growing



Source: UMN RTC/ICI



The Evolution of Services

- **Group Homes and Sheltered Workshops**
- **Family Support**
- **Supported Living**
- **Employment Programs**
- **Self Determination**
- **Consumer Controlled Budgets**
- **Micro Boards**
- **Self-Advocacy**
- **Peer Support**

People are Still on Waiting Lists

Residential Services Recipients	Persons Waiting	Growth Needed
437,707	88,349 (Lakin) 240,000 (Kaiser)	20.2%

What About People with Autism?

- DD systems have been serving many children and adults with Autism throughout the decades. In the 1970s and 1980s...
 - Significant disabilities were diagnosed as mental retardation so many children with Autism were eligible for MR services
 - Adults were rarely diagnosed as Autistic & so were enrolled in MR services
 - Children and adults were often diagnosed as mentally ill and enrolled into mental health systems
 - Many children and adults were admitted to MR and MH institutions

What About People with Autism?

- 1990s - Knowledge about Autism exploded and states were caught unprepared
 - Parents learned about new treatments faster than professionals
 - Requested services were often intensive and costly
 - Much of the information about the effectiveness of services was confusing and contradictory
- The growth in the number of children diagnosed with Autism was and is unprecedented
- The state systems are not entitlement programs and did not grow in response to a growth in service population. There have been and continue to be waiting lists for services of people with DD who do not have Autism

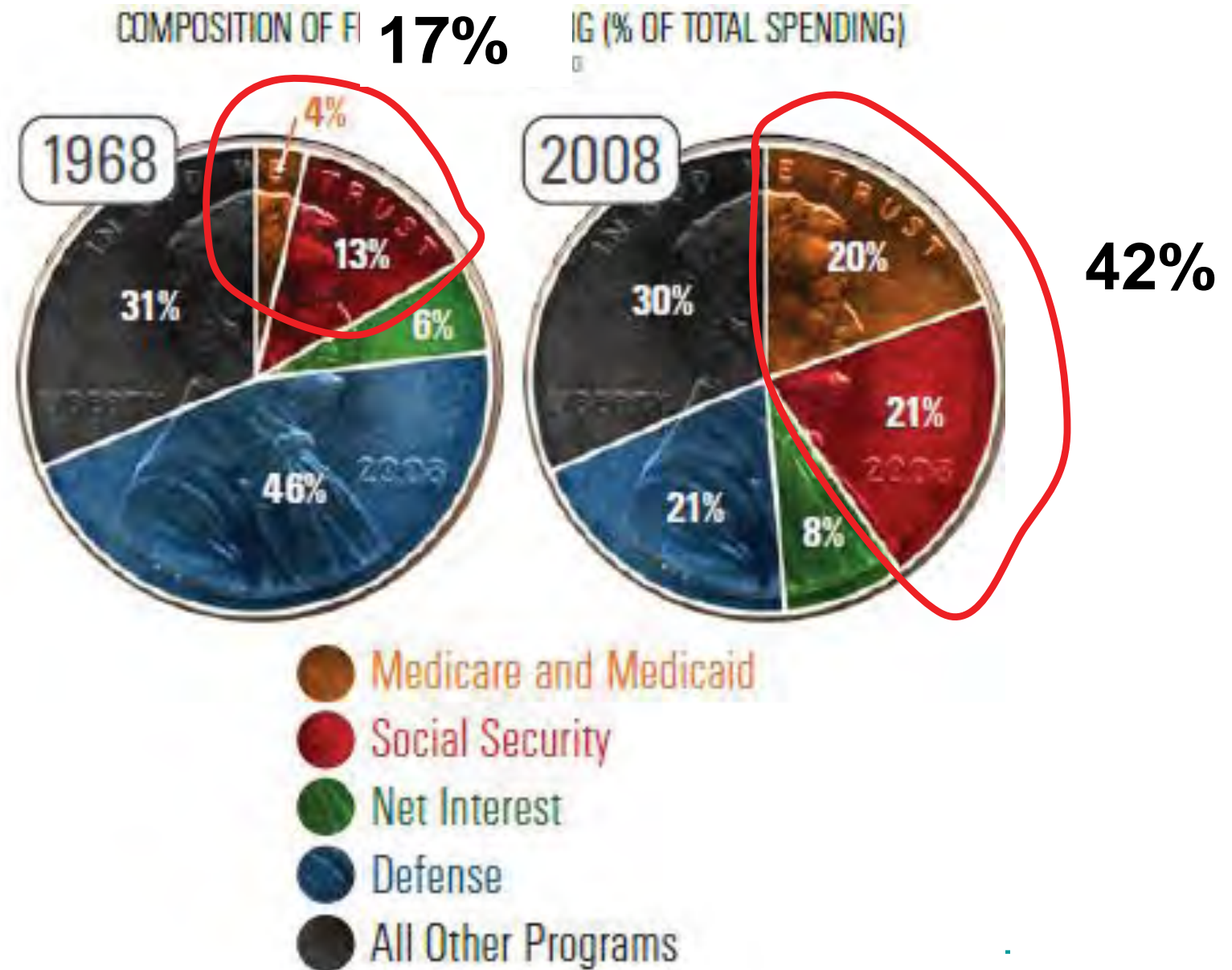
So where are we?

- Most states now have services for children with Autism
- Few states apply the definition of developmental disability for eligibility
- Conflict over the types of services, frequency and duration continues
- The needs of adults with Autism who need life long supports are becoming more prominent
- The concept of early identification and early intensive treatment is widely accepted but we do not yet know...
 - How to match the intervention/treatment to the child
 - How frequently and for what length of time the intervention/treatment should provided
- The issue of children and adults with Autism who clearly have no intellectual disability and do not meet eligibility criteria remains a challenge

Understanding Our Economic Challenges

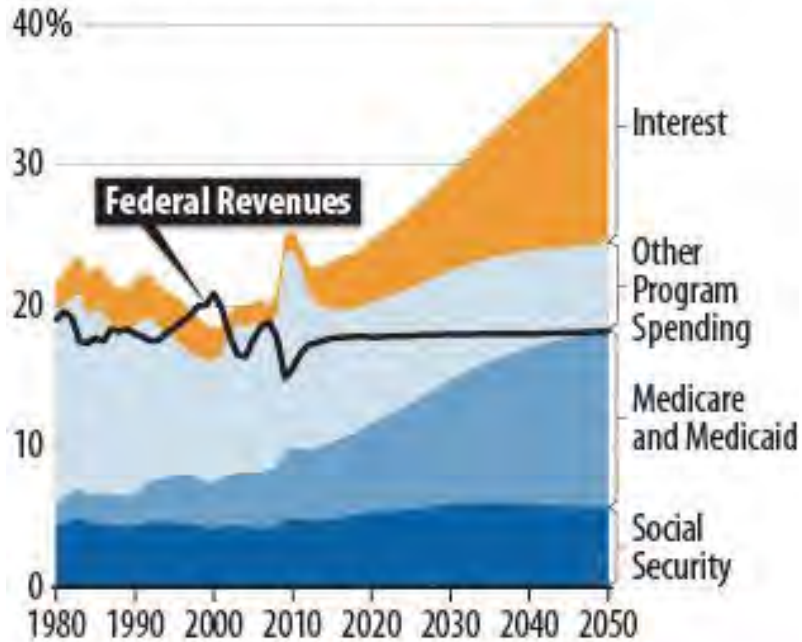


Challenges at the Federal Level



Medicare and Medicaid Expected to Rise Rapidly, Other Programs (Except Social Security) to Shrink

Spending and Revenues as a Share of GDP

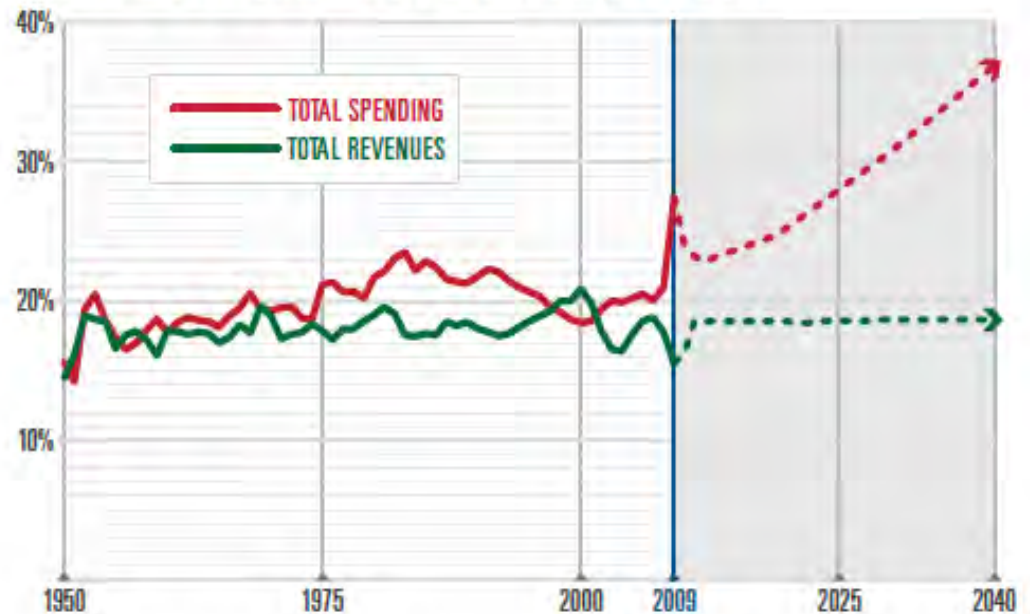


Source: CBPP projections based on CBO data.

Center on Budget and Policy Priorities | cbpp.org

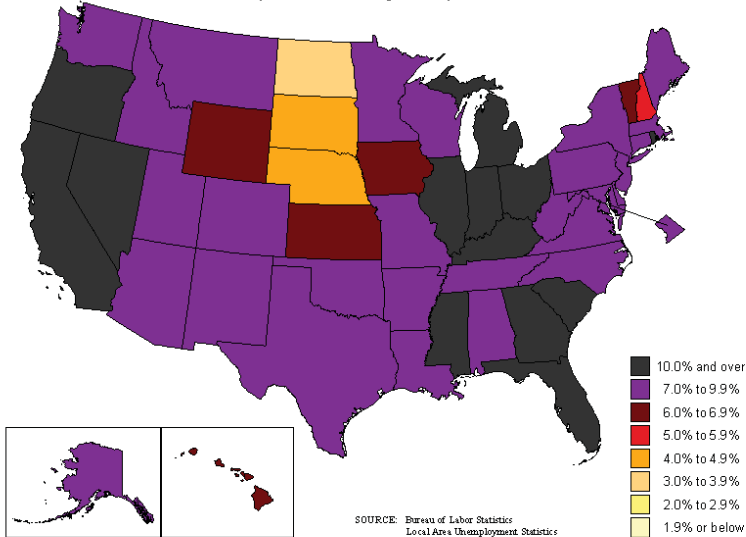
An Unsustainable Fiscal Trajectory

FEDERAL SPENDING AND REVENUES (% OF GDP)



**Unemployment rates by state,
seasonally adjusted, August 2010**

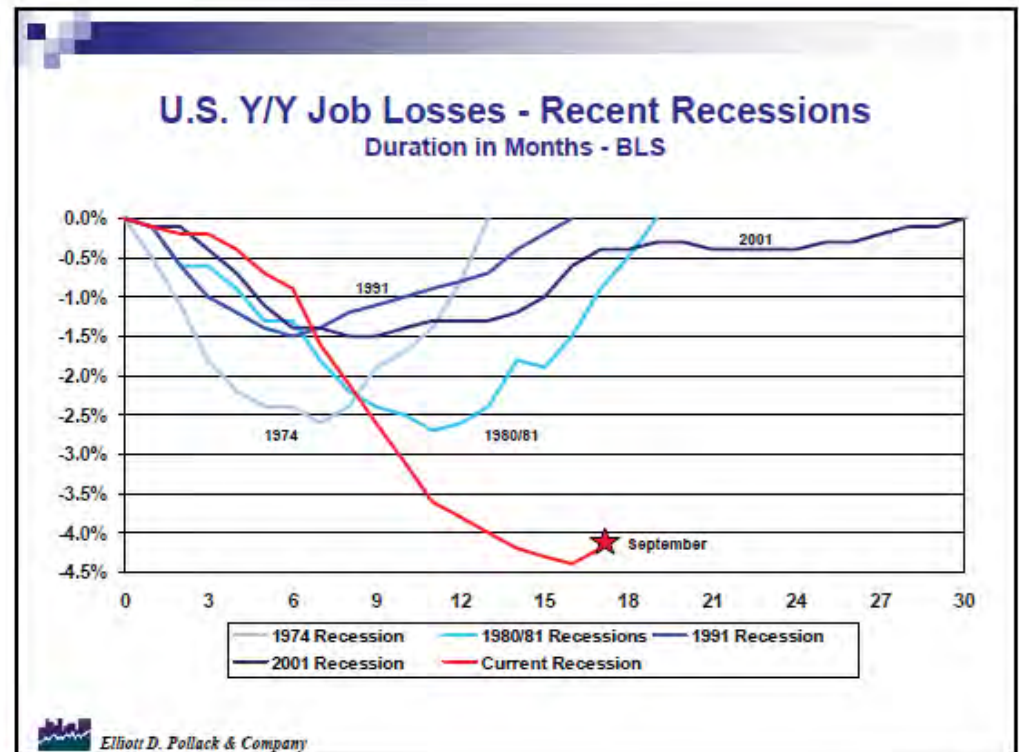
(U.S. rate = 9.6 percent)

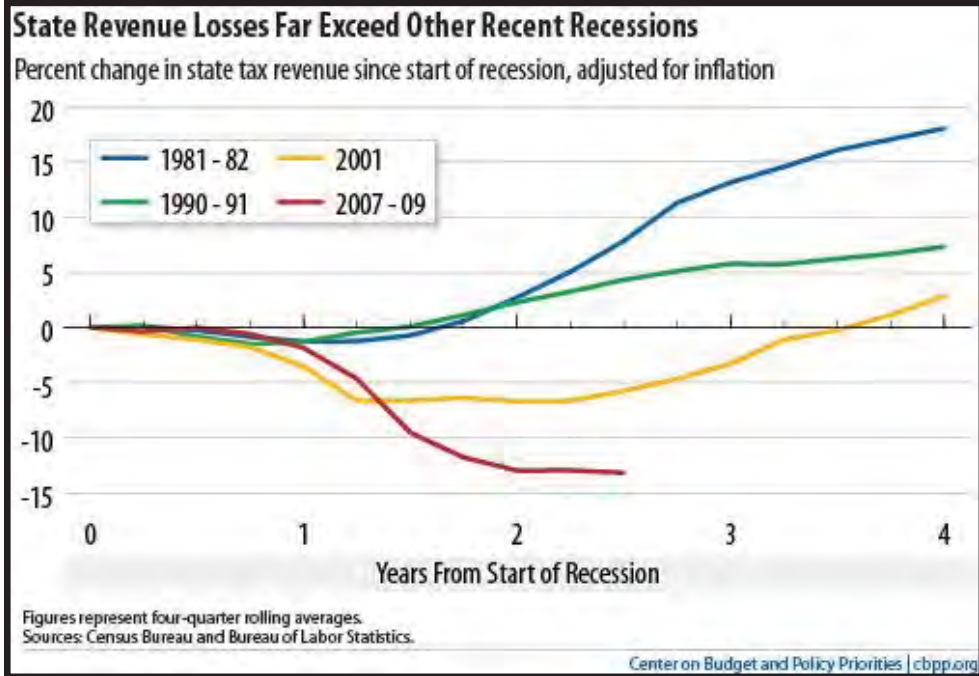


December 2009
15.3 million
unemployed (10%)

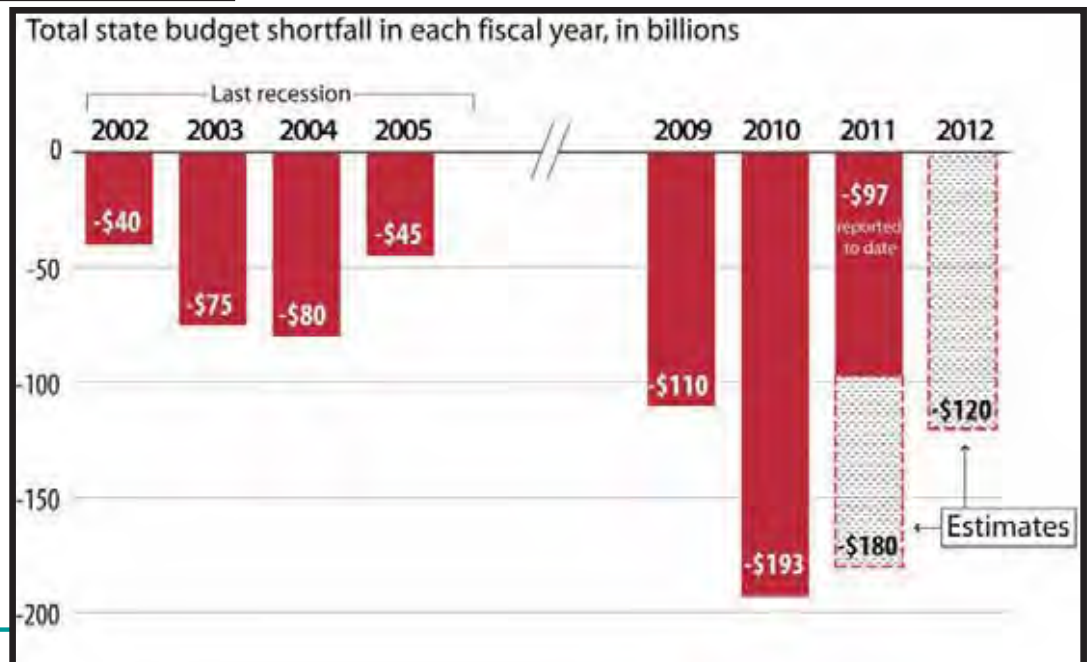
Challenges at the State Level

A Recession Like No Other Adds to Our Structural Problem





Revenue Losses Lead to Budget Shortfalls in States



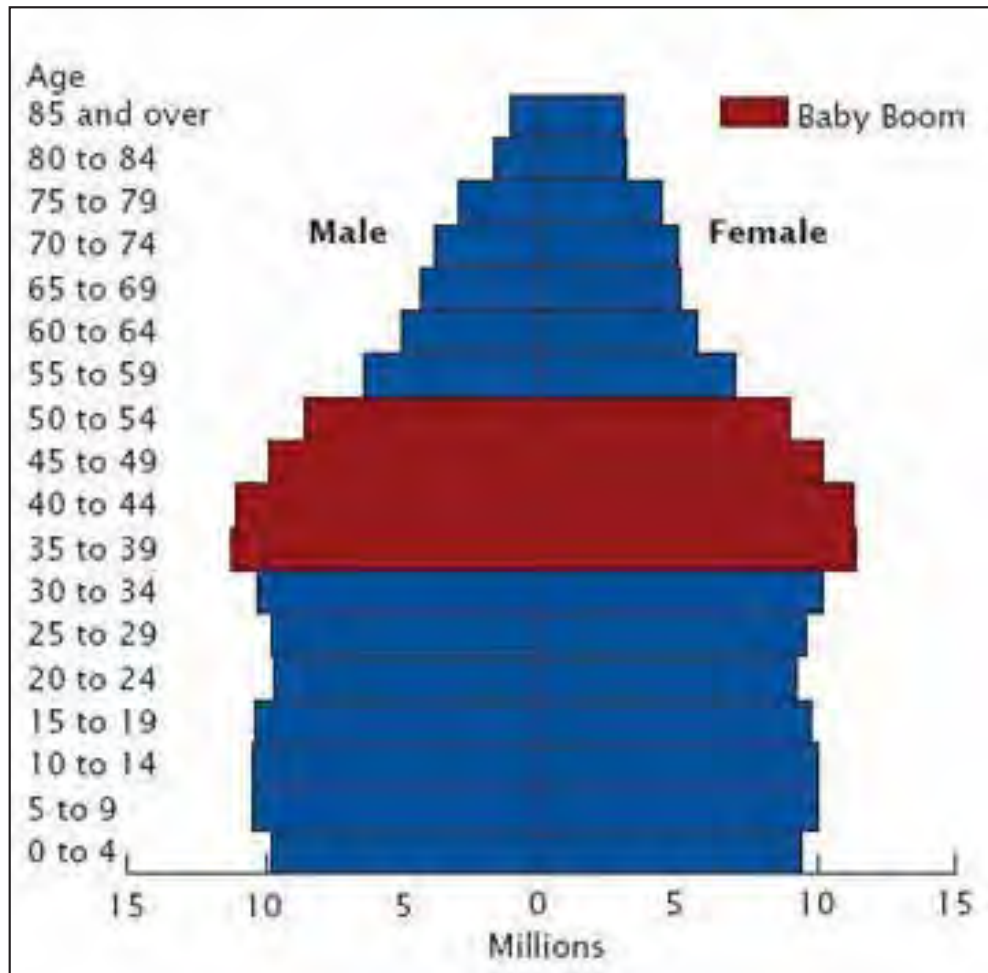
The Big Reset

State Government Response to the Recession

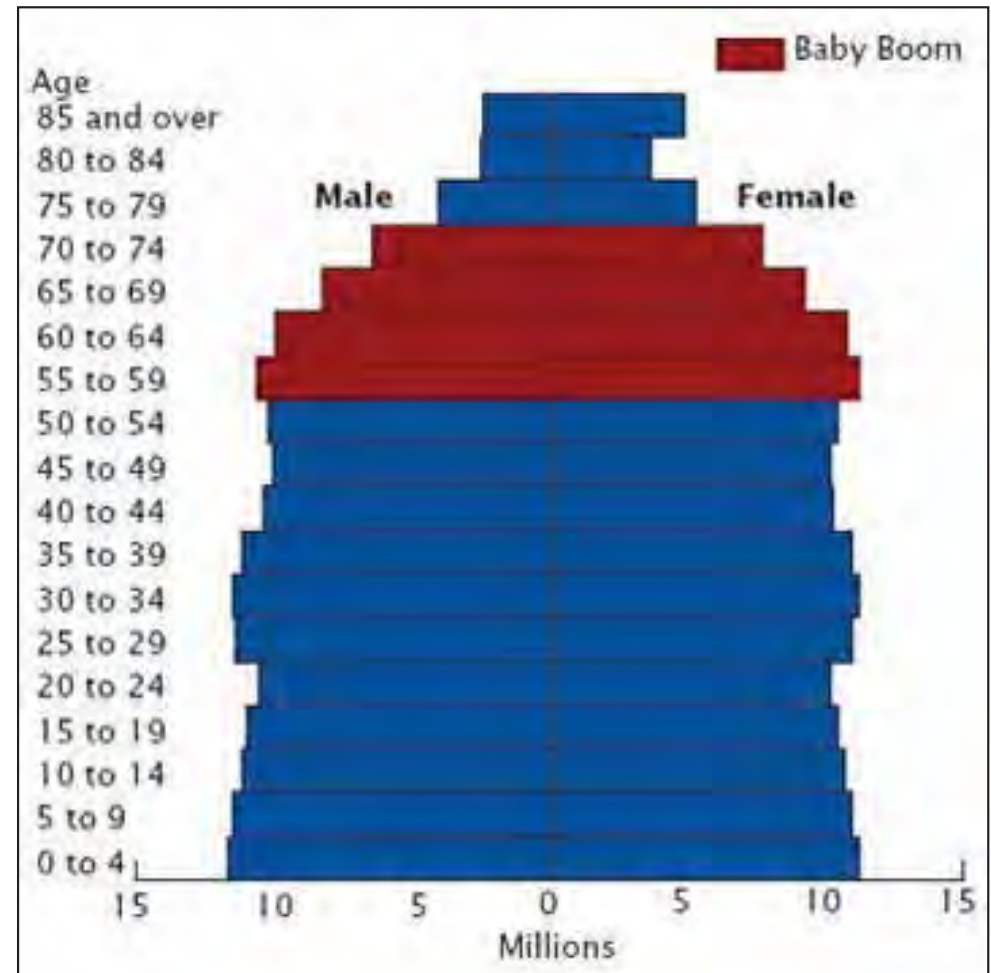
- 31 states have implemented cuts that will restrict low-income children's or families' eligibility for health insurance or reduce their access to health care services.
- 29 states plus D.C. are cutting medical, rehabilitative, home care, or other services needed by low-income people who are elderly or have disabilities
- 33 states and the District of Columbia are cutting aid to K-12 schools and various education programs.
- 43 states have cut assistance to public colleges and universities, resulting in reductions in faculty and staff in addition to tuition increases.
- 43 states and the District of Columbia have made cuts affecting state government employees.

Understanding Our Demographic Challenge

2000



2020

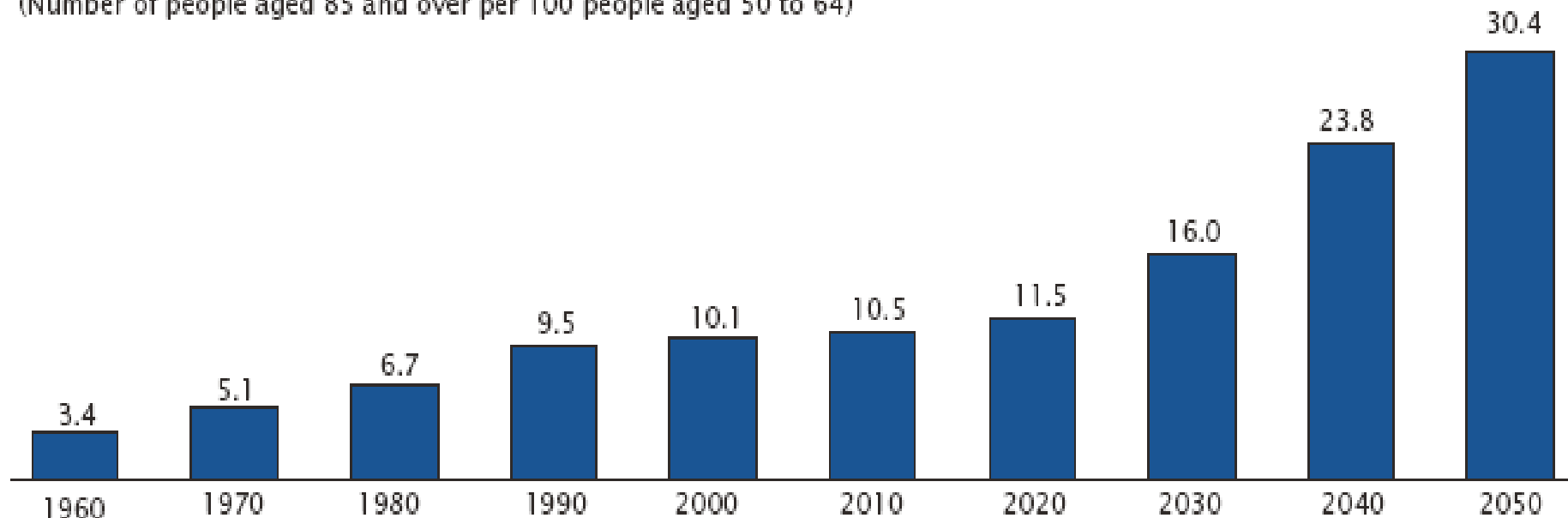


Source of charts: U.S. Census Bureau, "65+ in the United States: 2005," December 2005.

Labor Force /Parent Support Ratio

Parent Support Ratios: 1960 to 2050

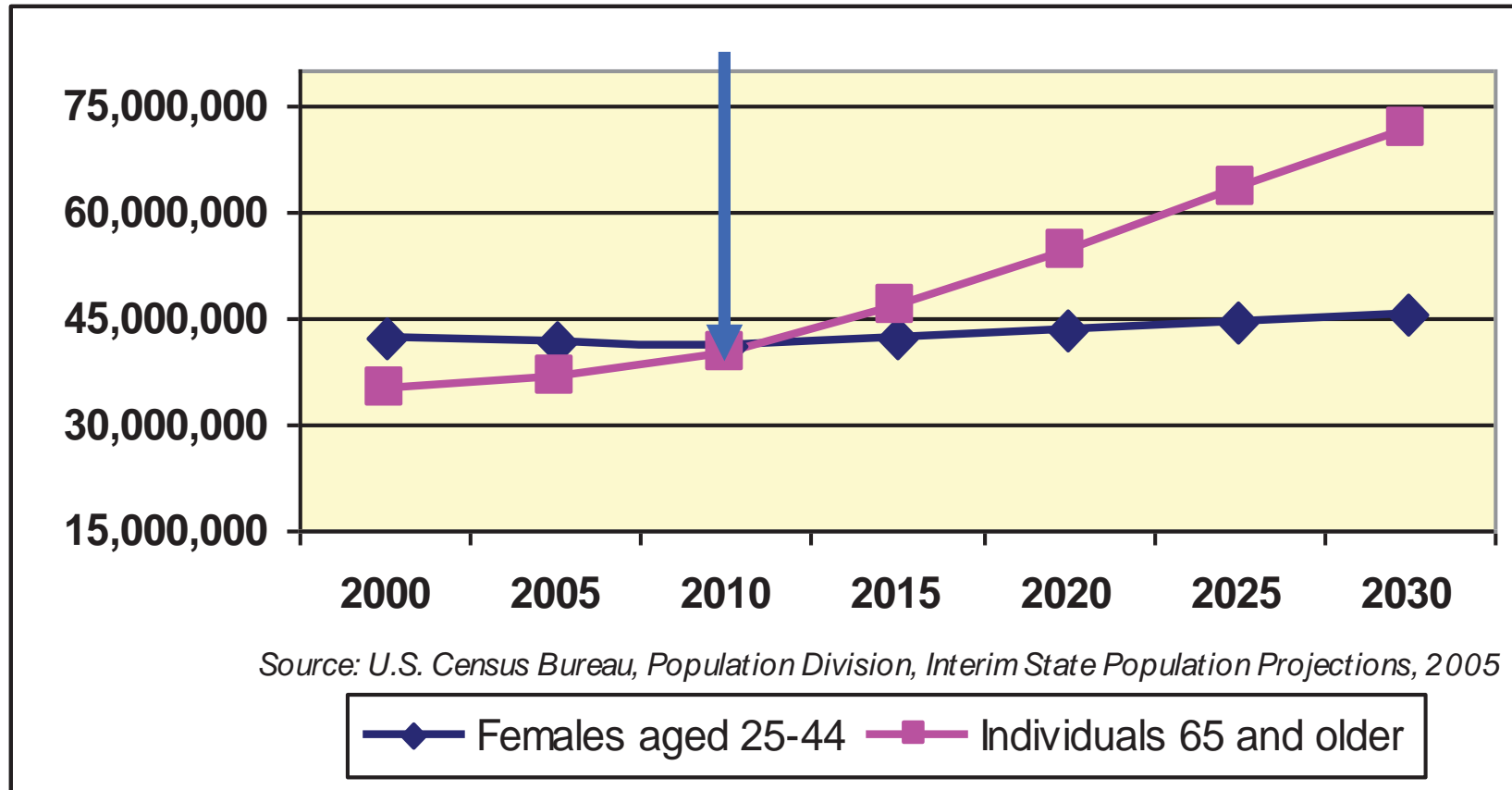
(Number of people aged 85 and over per 100 people aged 50 to 64)



Note: The reference population for these data is the resident population.

Sources: 1960, U.S. Bureau of the Census, 1964, Table 155; 1970 and 1980, U.S. Bureau of the Census, 1983, Table 42; 1990, U.S. Bureau of the Census, 1991, Table QT-P1; 2000, U.S. Census Bureau, 2001, Table PCT12; 2010 to 2050, U.S. Census Bureau, 2004. For full citations, see references at end of chapter.

Demographic Shift = America's Care Gap



Demographic trends are going to result in more and more people living with their families and longer.

- **In 1980, only 11% of 25-to-34-year-olds were living in multi-generational households**
- **By 2008, before the full effect of the recession was being felt, their ranks had increased to 32 percent nationwide, and by nearly 40 percent in Manhattan.**

Roberts, Sam, "Facing a Financial Pinch, and Moving In With Mom and Dad", *New York Times*, March 21, 2010.`

The % of people with developmental disabilities receiving services who are living with families members is growing

2002	391,859	51%
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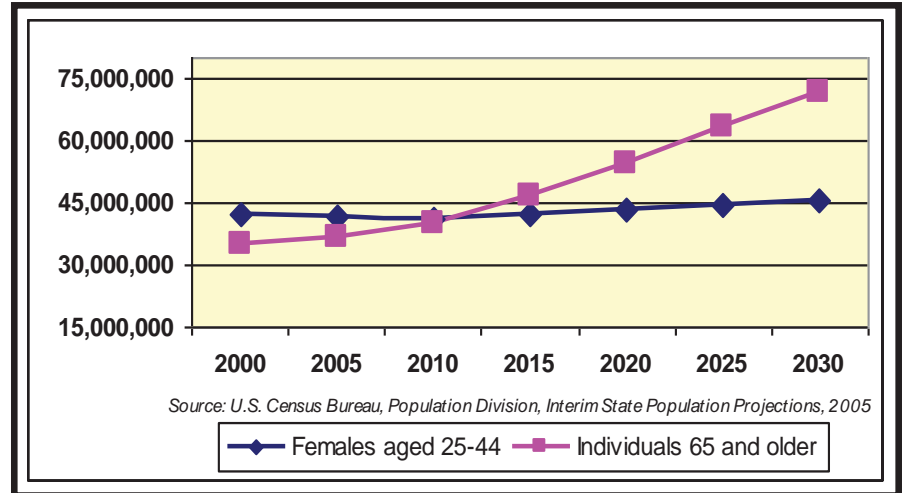
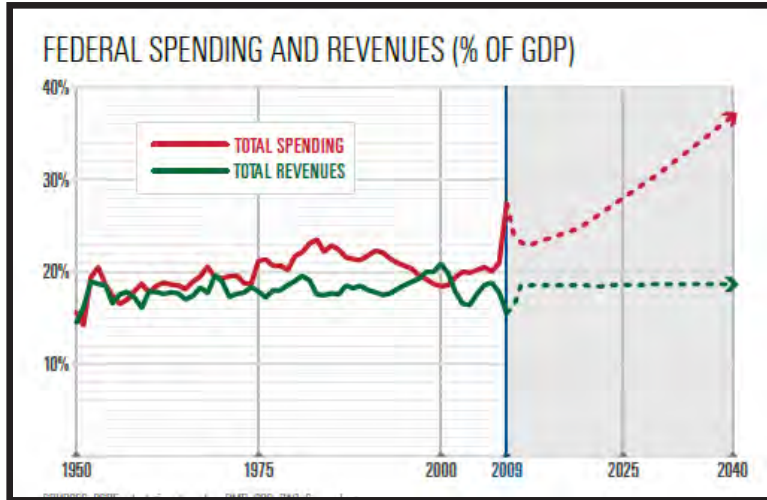
2008 **588,594** **57.4%**

Service Cost Comparisons Explain Why

16+ private ICFMR	16+ State Operated	<15 private	<15 public	HCBS Waiver*	Supported living; personal assistance*
\$69,055	\$171,355	\$79,336	\$86,365	\$40,000	\$25,482
Integration	→				
Satisfaction	→				
Likelihood of working;	→				
Having Friends	→				

* Less than 24 hr

Confronting Reality



Persons Waiting-Under reported	Residential Services Recipients	Growth Needed
88,349 Lakin 240,000 Kaiser	437,707	20.2%

- We can't afford to pay for 24 hr. residential services for everyone.
- We can't staff 24 hr. residential services even if we could afford to.
- We have waiting lists.

Creating a New Service Paradigm

Supporting People

&

The Families They Live With



Families

- Think of family broadly – parents; siblings; grandparents; other relatives.
- Families are complicated. Family members...
 - 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
 - Are Resourceful but they can't do everything alone
- Families are the primary support for people with developmental disabilities. They are resourceful but they need support.
- The family is the context for everything; personal outcomes will be influenced by the family



A new paradigm of service

Principles

- Keep the SELF in self-determination. Focus on the person's desired outcomes...with consideration of family members' needs too. The individual's identity, personal preferences and dreams must be primary.
- Employ person-centered planning and practices
- Give self advocates and families control over funding and services
- Assume employment; it is a path to self-determination and inclusion

A new paradigm of service

- ❖ Provide a full array of services to people in their homes and community

- ❖ Develop and maintain essential non-direct services:
 - Support coordination with small ratios; provide training in family dynamics, conflict resolution, recognizing natural supports and helping people connect to community resources
 - Peer Support Networks; Support for self-advocacy
 - Parent to Parent Networks
 - 24 hour help line
 - Crisis intervention
 - Monitor health and provide wellness programs
 - Protect people from abuse and neglect

A new paradigm of service

- ❖ Innovate
 - ❖ Individual budgets – so that people can direct their services
 - ❖ Individual hiring authority
 - ❖ Hiring relatives
 - ❖ Paid peer support
 - ❖ Technology for personal support
 - ❖ Evidence based mental health practices (trauma informed care; EMDR for trauma and Dialectical Behavior Therapy)

- ❖ 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.

People Want a Good Life

- ✓ **Family**
- ✓ **Friends**
- ✓ **A job**
- ✓ **Self advocacy**
- ✓ **And a little fun**



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