

# Planning Indiana's Future

## The BIG Picture

### 2015-2030

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# Agenda

**The Challenge of today's demographics**

**The Role of Families**

**How states are building sustainable support models**

- Promoting employment
- Rethinking how to support families
- Developing relationship-based living arrangements
- Exploring technology

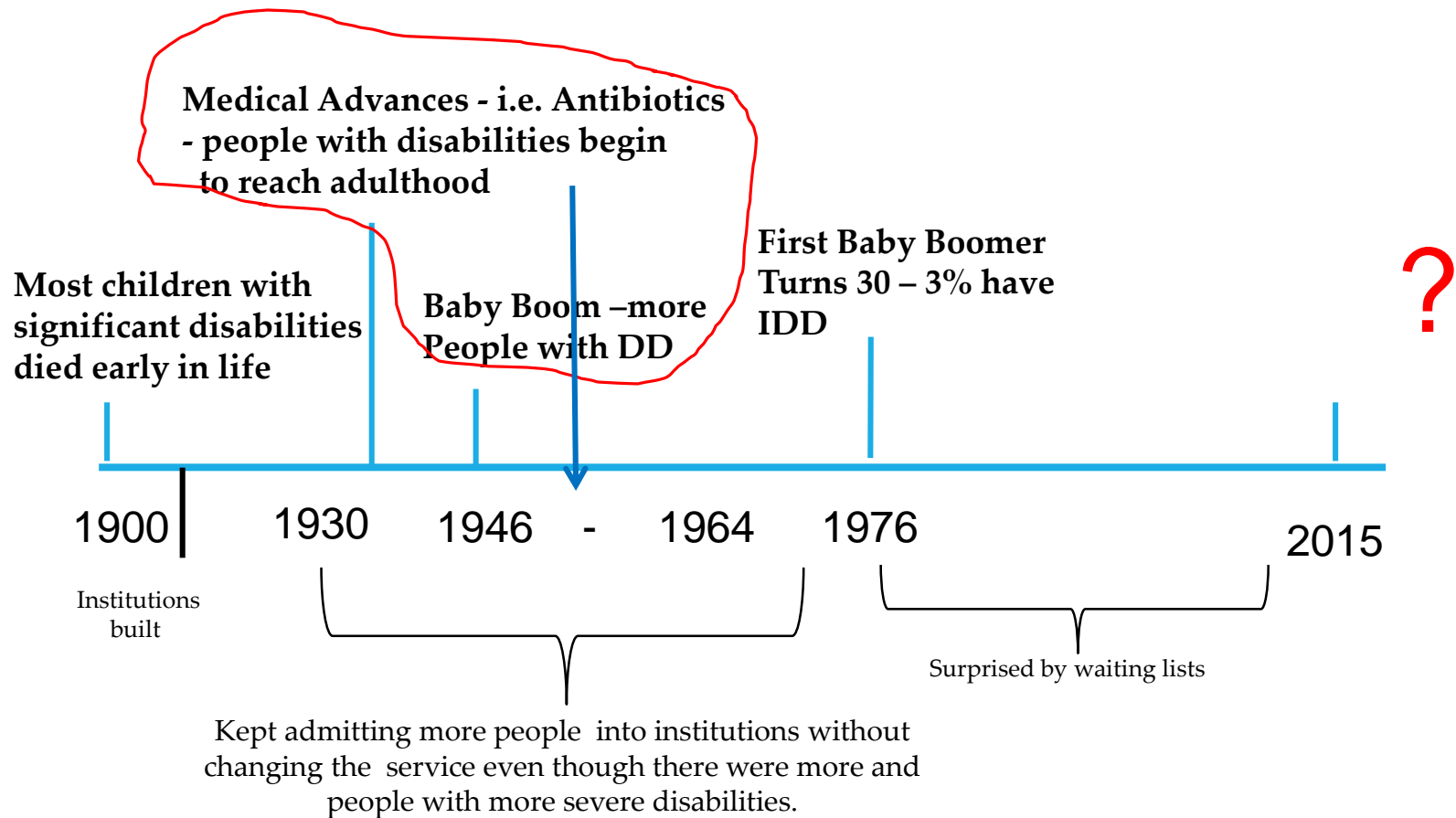
**How States are building sustainable systems**

- Individual budgeting
- New state plan options
- Managed care

**HCBS Regulations**



# We Don't Seem to See What's Coming



# What's Coming Next?

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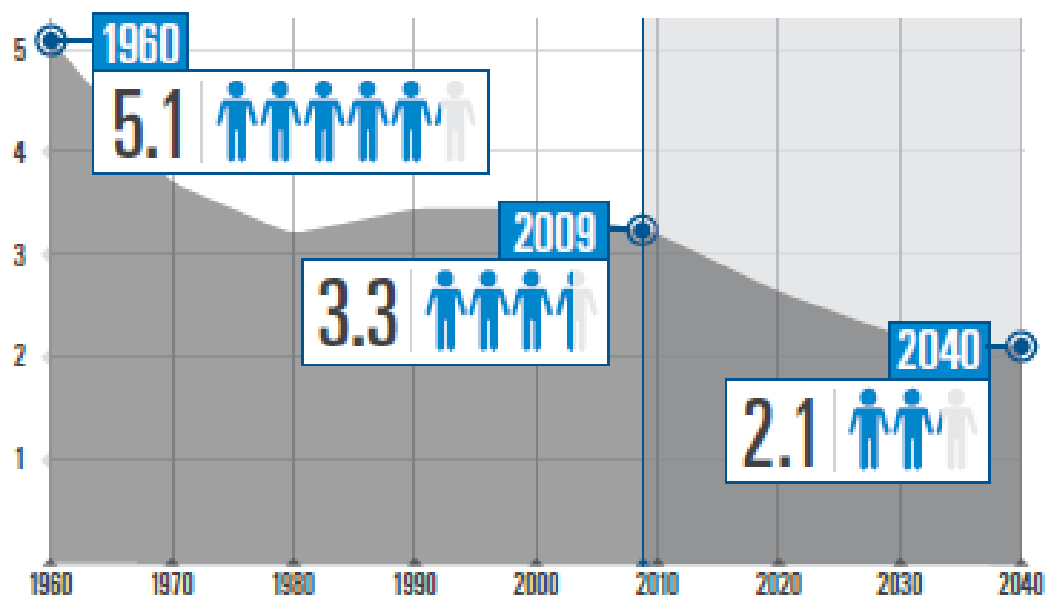
# Demographic Climate Change

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# Aging Baby Boomers

COVERED WORKERS PER SOCIAL SECURITY BENEFICIARY



SOURCE: Social Security Administration

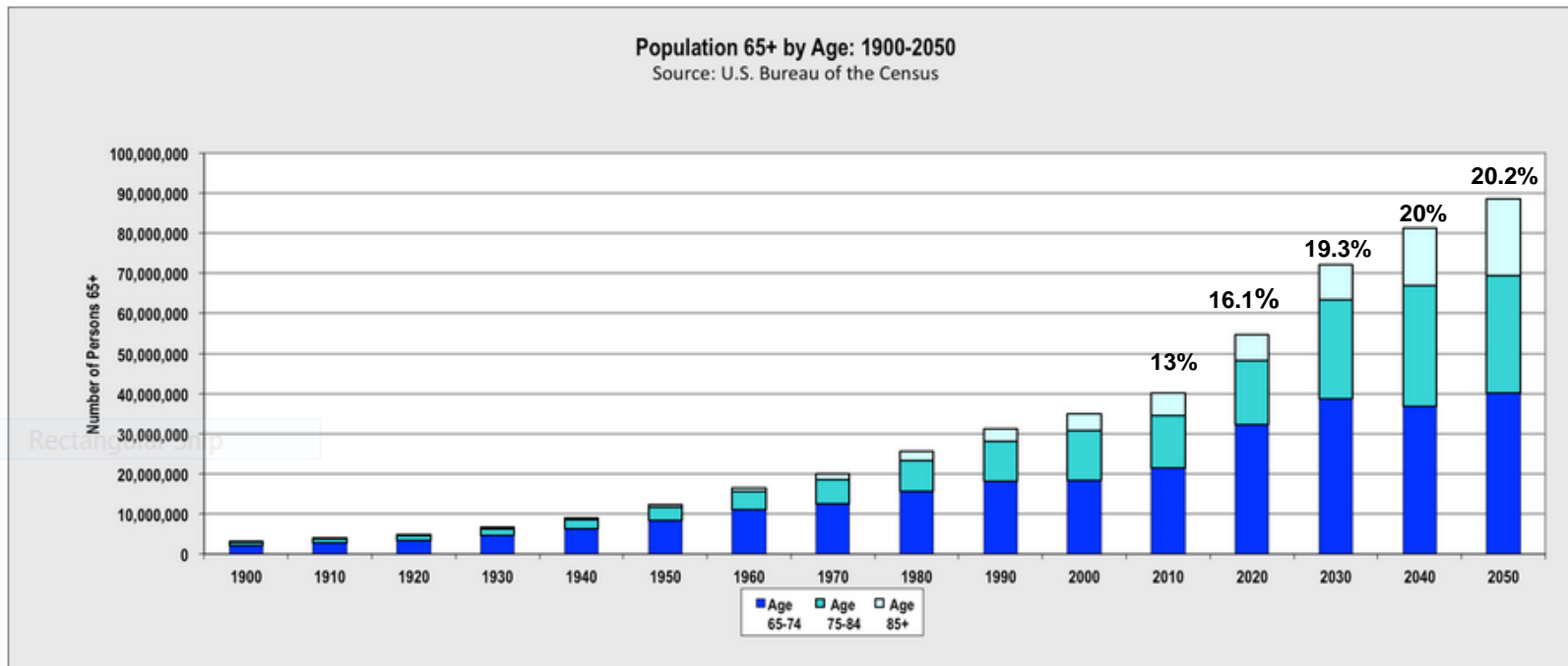
**Baby Boomer Tsunami**  
**Every day 10,000 Baby Boomers qualify for Social Security**



# Aging Baby Boomers

This graph shows that the number of older Americans will increase three times as fast as the total population by 2050.

- The number of people 65 years old and older will increase from 35 million to nearly 87 million by the year 2050.
- In the year 2008, one of every eight Americans is age 65 or older. By the year 2050, one of every five Americans will be age 65 or older.
- The number of people with developmental disabilities age 60 and older will nearly double to 1.2 million in 2030.







# Needing Care

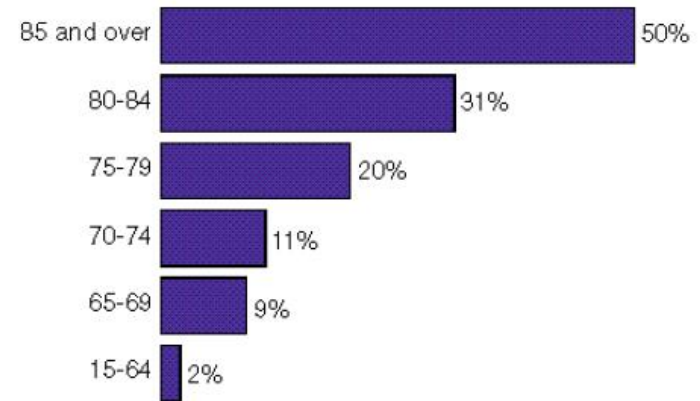
70% of Americans who reach age 65 will need some form of long-term care for an average of three years.



SCAN Foundation

## The Need for Personal Assistance With Everyday Activities Increases With Age

Percentage of persons needing assistance with everyday activities, by age: 1990-91  
(Civilian noninstitutional population)



Source: U.S. Census Bureau, Population Division

# Cost of Long Term Care

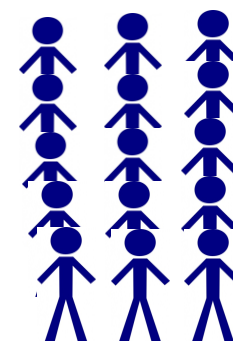
	USA	Indiana
Adult Day Health	\$17,904	\$20,800
Assisted Living	\$43,200	\$44,310
Nursing Home Semi-Private	\$80,300	\$78,475
Nursing Home Private	\$91,250	\$91,250

National Data from the Genworth 2013 Cost of Care Study  
Home Care Providers, Adult Day Health Care Facilities,  
Assisted Living Facilities and Nursing Homes

<https://www.genworth.com/corporate/about-genworth/industry-expertise/state-maps.html>

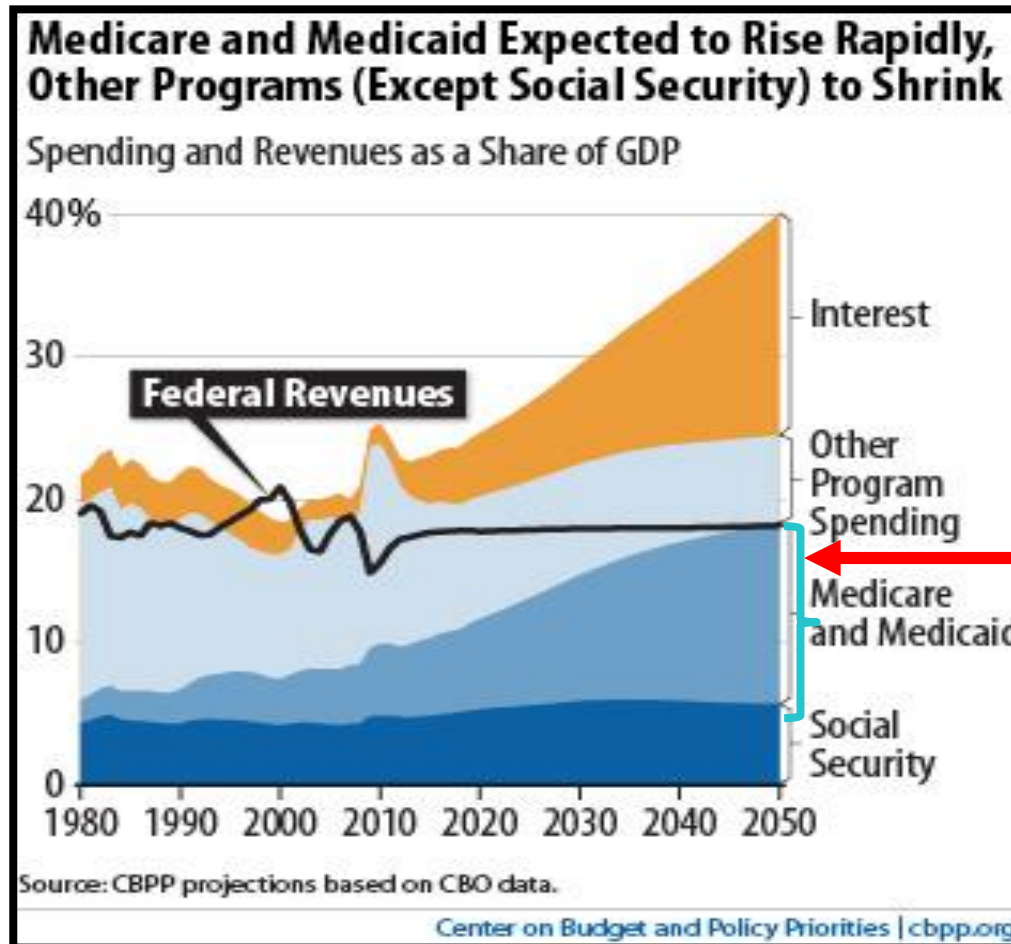
# Long Term Costs in I/DD – Vt. 2014

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
ICF/MR Institution	\$212,504	\$4,250,080	\$6,375,120
HCBS 24 hr. staffed Residential	\$84,127	\$1,682,540	\$2,523,810
Shared Living	\$30,944	\$618,880	\$938,320
Support in Own or Family Home only	\$13,424	\$268,480	\$402,720



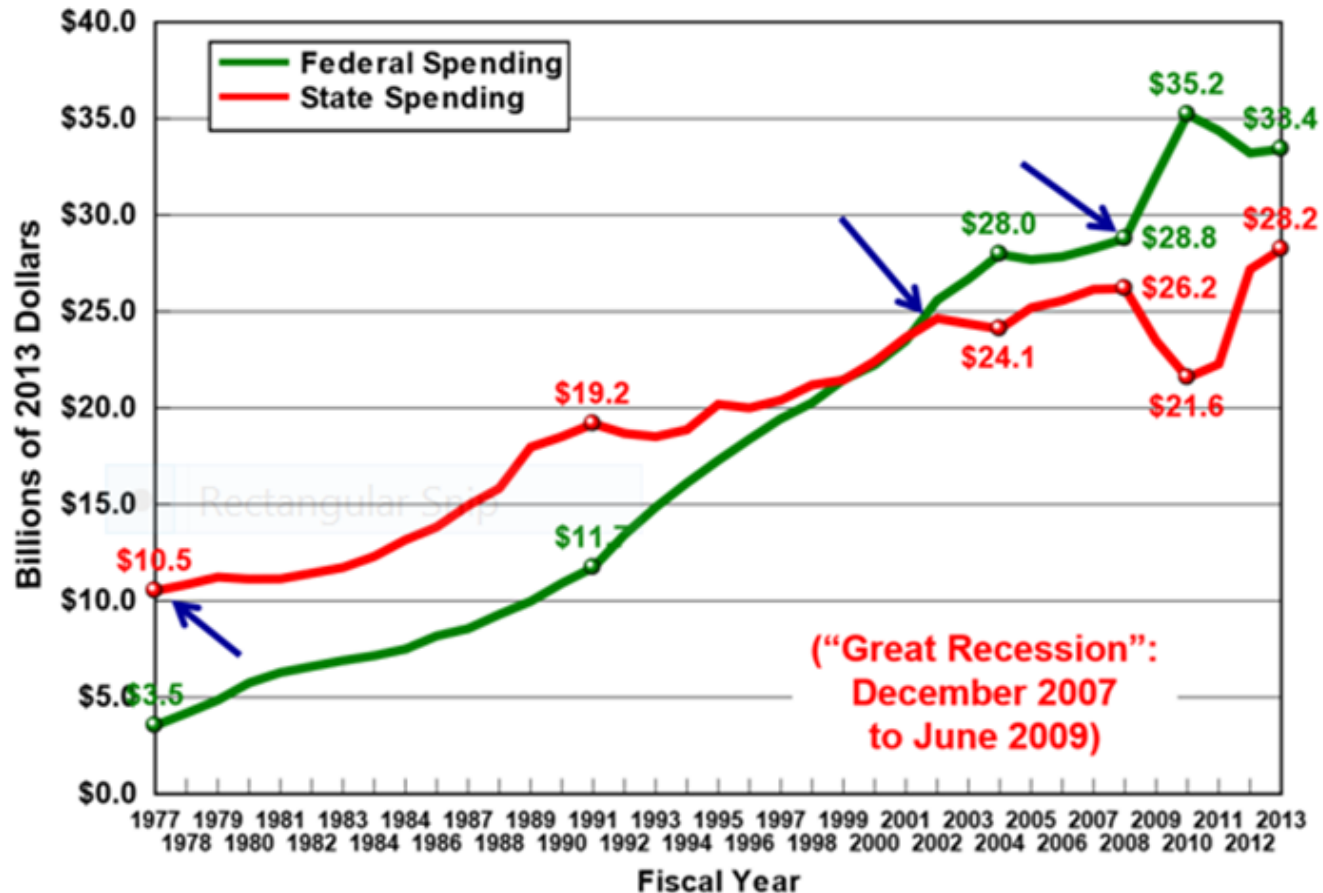
State of Vermont Developmental Disabilities Services State Fiscal Year 2014 Annual Report

# Competition for Funds in the Future



← Social  
Services  
Funding

# Growth in Federal/State/Local Spending 1977-2013



Source: Braddock, D. et al., *State of the States in Developmental Disabilities*, 2015 (preliminary).

# I/DD SPENDING IN FY 2013 INCREASED IN 38 STATES, DECLINED IN 13 STATES

State	Change	State	% Change	State	% Change
Missouri	12%	North Dakota	4%	Illinois	1%
Kentucky	10%	Oklahoma	3%	Kansas	1%
Mississippi	9%	South Carolina	3%	Oregon	0%
Alaska	9%	Michigan	3%	Delaware	0%
Georgia	8%	Washington	3%	Arizona	-0.5%
West Virginia	8%	Iowa	3%	Maine	-1%
Nebraska	7%	Nevada	3%	Indiana	-1%
Virginia	7%	Texas	2%	Louisiana	-1%
Massachusetts	6%	Maryland	2%	North Carolina	-1%
Pennsylvania	6%	Montana	2%	Minnesota	-2%
Wisconsin	6%	New Jersey	2%	Connecticut	-3%
Vermont	5%	New York	2%	Colorado	-3%
District of Columbia	5%	South Dakota	2%	Hawaii	-3%
New Hampshire	4%	Rhode Island	2%	Florida	-4%
Utah	4%	New Mexico	1%	Idaho	-4%
Tennessee	4%	Ohio	1%	Wyoming	-5%
California	4%	Alabama	1%	Arkansas	-7%
				UNITED STATES	2.4%

Source: Braddock, D. et al., *State of the States in Developmental Disabilities*, 2015 (preliminary).



# FEDERAL-STATE HCBS WAIVER SPENDING PER CAPITA IN FY 2013\*

1 New York	\$277	18 Maryland	\$128	35 Virginia	\$78
2 Maine	\$241	19 Nebraska	\$127	36 Oklahoma	\$76
3 Vermont	\$240	20 South Dakota	\$125	37 Hawaii	\$74
4 District of Columbia	\$232	21 Oregon	\$122	38 Colorado	\$63
5 Minnesota	\$231	22 Massachusetts	\$118	39 Alabama	\$62
6 Connecticut	\$212	23 Indiana	\$117	40 North Carolina	\$61
7 Alaska	\$211	24 Ohio	\$117	41 Arkansas	\$61
8 Rhode Island	\$198	25 Kansas	\$113	42 California	\$60
9 North Dakota	\$193	26 Kentucky	\$107	43 South Carolina	\$59
10 Wyoming	\$182	27 Missouri	\$104	44 Utah	\$57
11 West Virginia	\$181	28 Delaware	\$99	45 Illinois	\$49
12 New Hampshire	\$161	29 Arizona	\$98	46 Florida	\$44
13 Louisiana	\$157	30 Michigan	\$97	47 Georgia	\$43
14 Wisconsin	\$152	31 Tennessee	\$96	48 Texas	\$42
15 Pennsylvania	\$140	32 Montana	\$91	49 Idaho	\$40
16 New Mexico	\$137	33 New Jersey	\$88	50 Mississippi	\$30
17 Iowa	\$130	34 Washington	\$87	51 Nevada	\$27

\*Per capita of the state general population

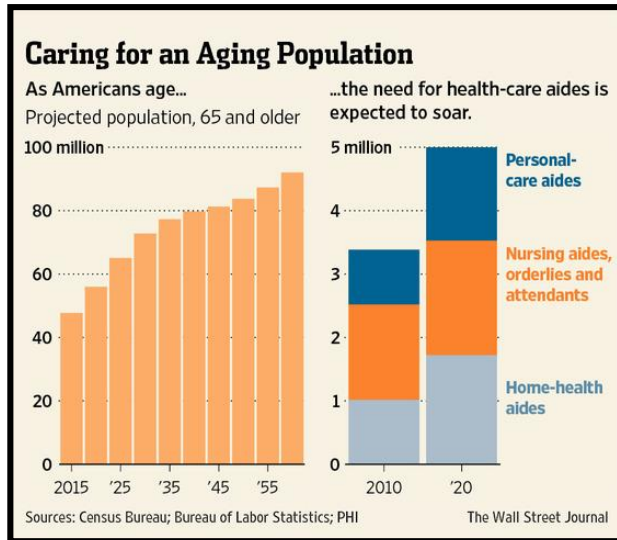
**UNITED STATES \$100**

Source: Braddock, D. et al., *State of the States in Developmental Disabilities*, 2015 (preliminary).

# Comparisons

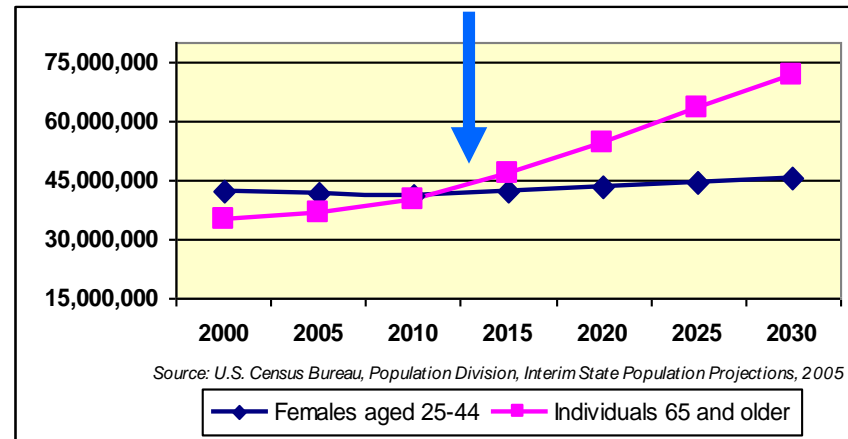
	Indiana	United States
% of Residential Service Recipients with ID/DD Living in Places of 6 or Fewer Residents	69.2%	73.9%
% of All Residential Service Recipients with ID/DD Living in Places of 3 or Fewer Residents	52.1%	44.8%
Number in service living with family	33%	54.1%
Number of People with ID/DD Receiving Residential Support in their Own Home (Owned or Rented) as a % of All Residential	44.8%	28%
% of People with IDD living nursing homes 1555 people	8.5%	2.5%
Persons Receiving Medicaid Home and Community-Based Services (HCBS) Per 100,000 of the General Population	173.4	191.8
Annual HCBS Expenditure per State Resident (\$)	\$54.50	\$93
HCBS Expenditures for Persons with ID/DD Per End of Year Recipients in Fiscal Year	\$45,301	\$44,396
Total HCBS Expenditures Per State Resident in Fiscal Year	\$78.57	\$85.14

# Shortage of Caregivers



*A labor shortage is worsening in one of the nation's fastest-growing occupations — taking care of the elderly and disabled — just as baby boomers head into old age.*

Wall Street Journal  
April 15, 2013



Larson, Edelstein, 2006

# **The New York Times**

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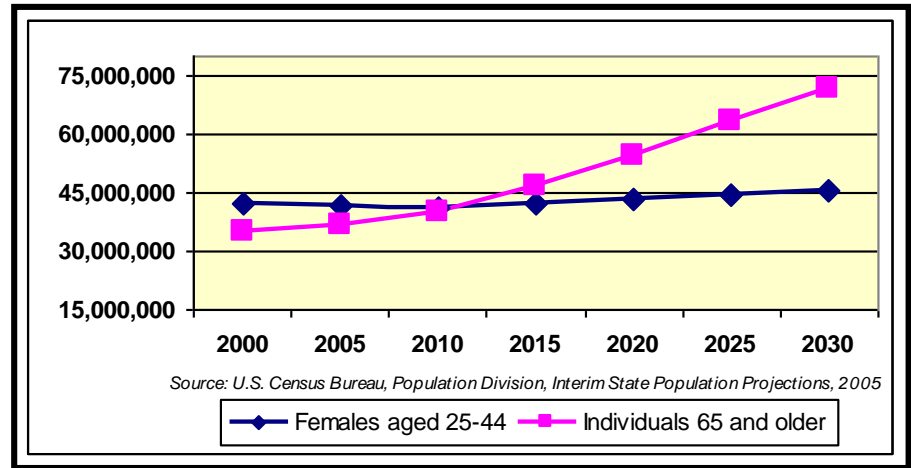
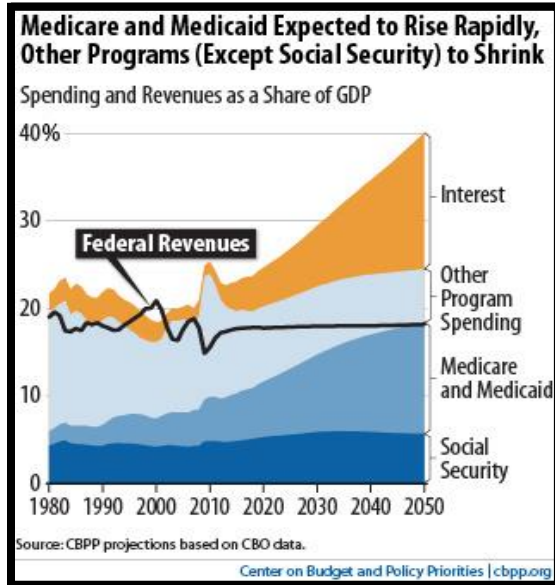
***Walmart Raising Wage to at Least \$9***

***McDonald's raising wages to \$9.90 in 2014  
and \$20 in 2016***

# Confronting Reality

Growth in public funding will slow

Workforce will not keep pace with demand



## The Waiting List

People Waiting For Services	Residential Capacity	Growth Needed
76,677 <i>RISP 2011</i>	460,597	16.6%

# The Conclusion?

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We are facing decades of

- ✓ **Tight Funding**
- ✓ **Workforce shortages**
- ✓ **More people who need support to live in the community**

We have to find a way to reach as many people as possible which means a service system that is

- ✓ **Affordable**
- ✓ **Sustainable**
- ✓ **Supports people in community life**

# Part 3

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## The Role of Families



# Family Caregivers are the Backbone of the Nation's Long-Term Care System

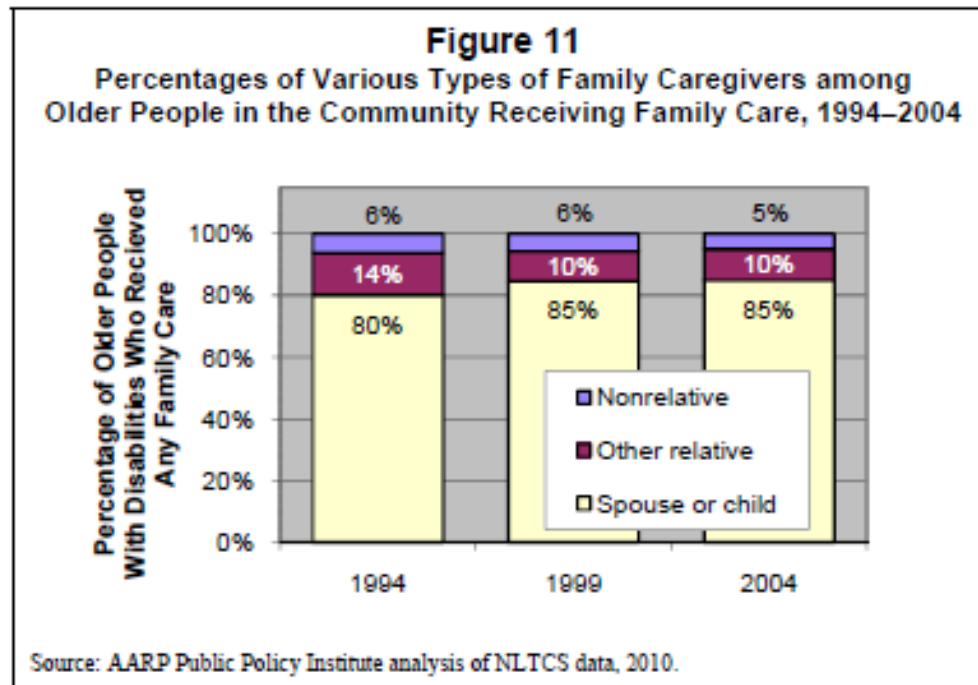
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**39% of all adult Americans (2 of every 5) care for a loved one who is sick or disabled, an increase from 30 % in 2010.**

**It is not just women doing the caregiving.**

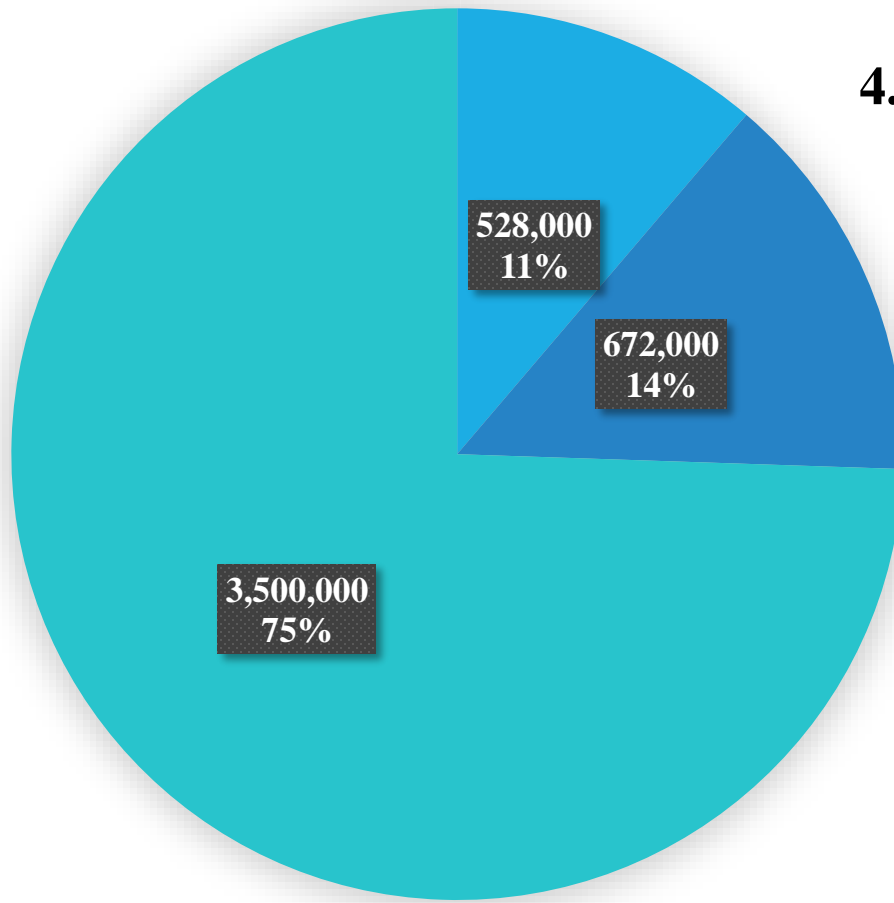
- Men are almost as likely to be caregivers as women (37% m; 40% w)
- 36% of Americans between ages 18 & 29 are caregivers
- Almost half of family caregivers perform complex medical/nursing tasks for their loved ones — such as managing multiple medications, providing wound care, and operating specialized medical equipment.

# The Role of Family Members is Critical



**85% of older family care recipients receive care from their spouses or children.**

# People with IDD Living with Family - 89%



## 4.7 Million people with I/DD

- Receiving Services Out of Home 11%
- Receiving Services Living at Home 14%
- Not Receiving Services - Living at Home 75%

**Figure 5.1** Size and Type of Residence for People with IDD on the Caseloads of State IDD Agencies by Year 1998 to 2012 (US Estimated Totals)

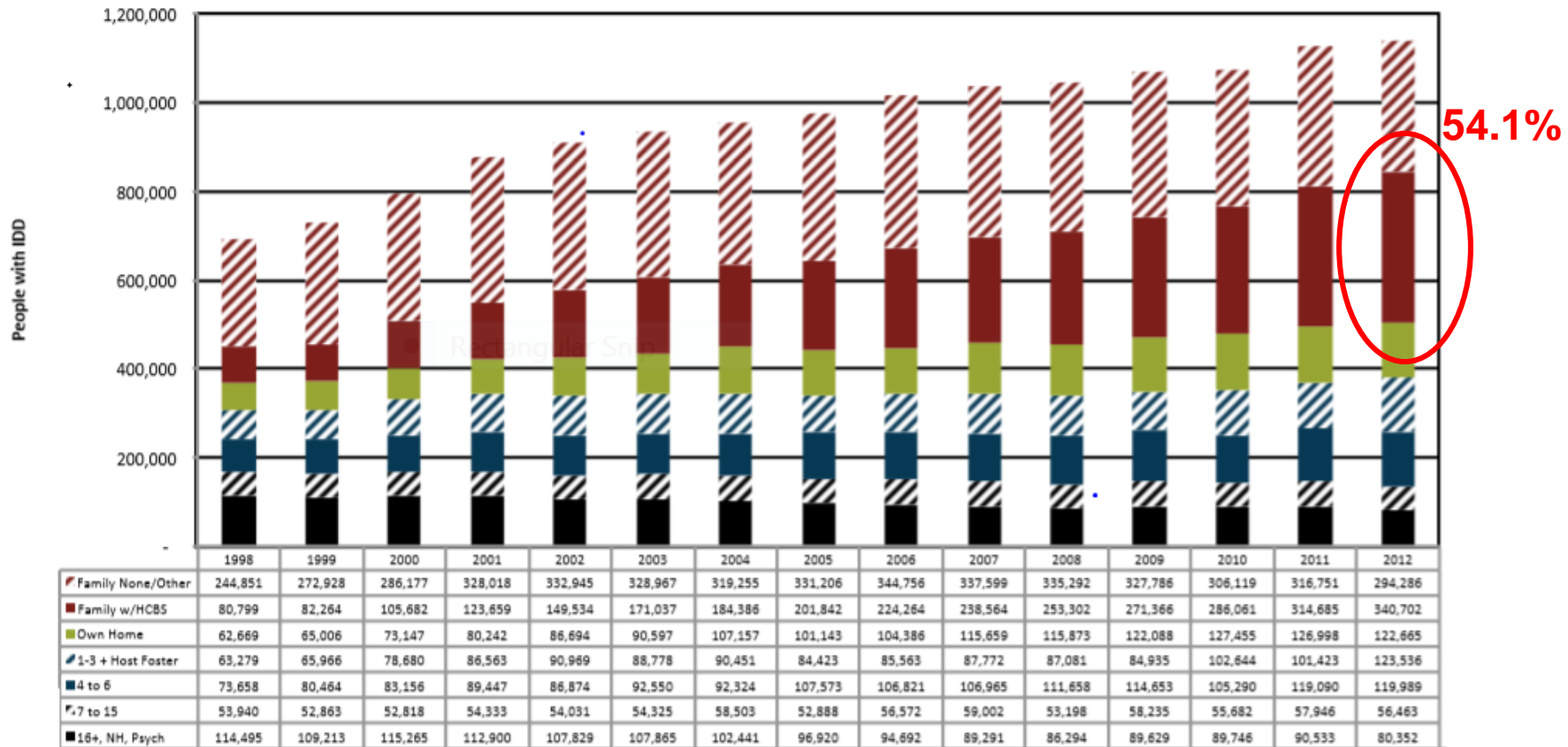
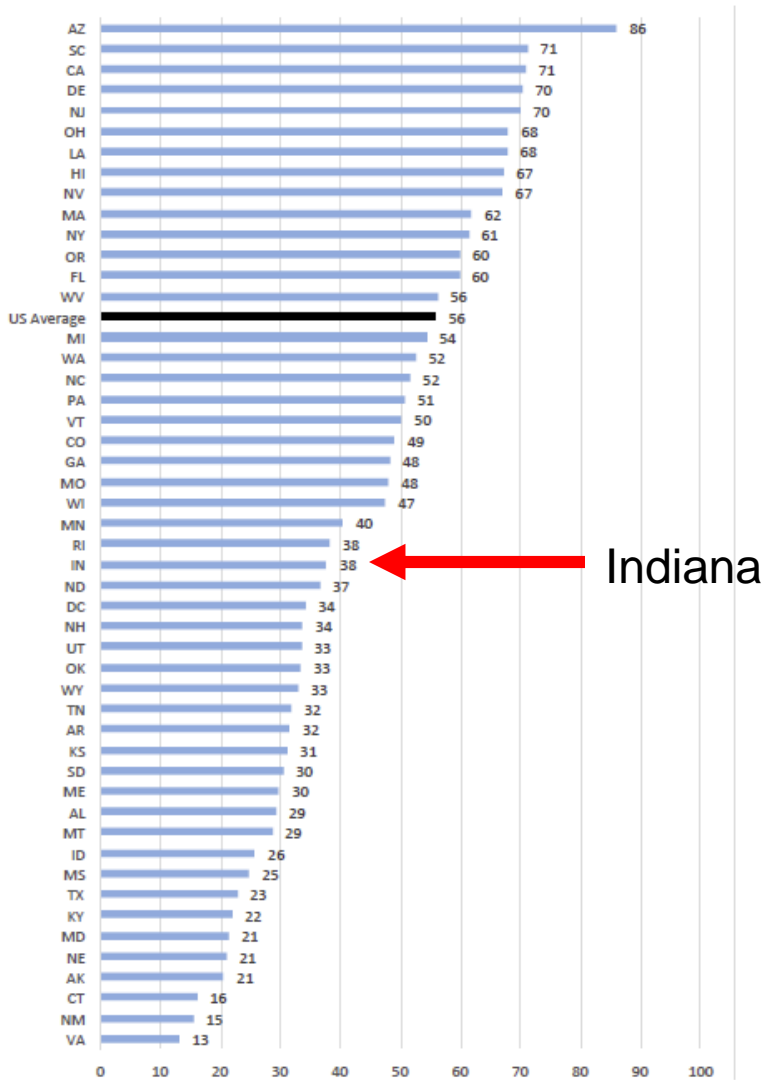


Figure 1.2 Proportion of People with IDD on the Caseloads of State IDD Agencies Who Live in the Home of a Family Member



Proportion of people with I/DD on state caseloads who live in the home of a family member

Arizona 86%  
 S.C. 71%\*  
 Calif. 71%  
 De. 70%  
 N.J. 70%

Ohio 68%  
 Louisiana 68%  
 Hawaii 67%  
 Nevada 67%  
 Mass 62%  
 NY 61%  
 Oregon 60%  
 Florida 60%

# The Questions Is.....

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Not whether people who are aging and/or disabled will be living with and relying on their families for support but..... whether they 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.



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*Supporting families and helping people get a competitive job – the foundation of a sustainable service system..*



# Part 3

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## How States are Building Sustainable Support Models

- **Promoting Employment**
- **Supporting Families**
- **Developing Relationship Based Living Arrangements**
- **Exploring Technology**

# Promoting Employment

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- ✓ 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

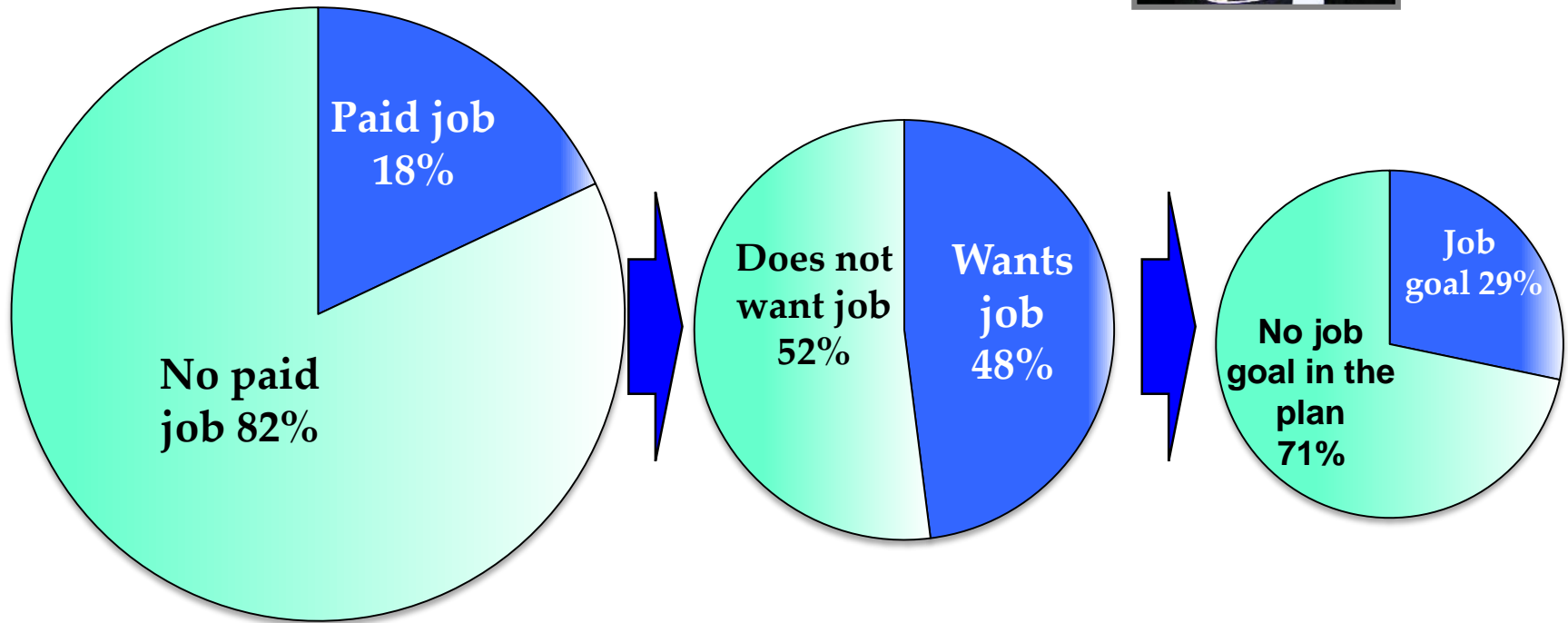


# Thinking About Cost - Employment for the Long Term

Type of Service	1 yr. Cost	3 yr. Cost	10 yr. Cost
Sheltered Work/Day Habilitation	\$20,000	\$60,000	\$200,000
Employment Services	\$20,000	\$50,000 <ul style="list-style-type: none"><li>• \$20,000 yr. 1</li><li>• \$20,000 yr. 2</li><li>• \$10,000 yr. 3</li></ul>	\$85,000 <ul style="list-style-type: none"><li>• \$50,000 1-3 yrs.</li><li>• \$35,000 4-10 yrs.</li></ul>

Estimated figures – use your own figures and do the math

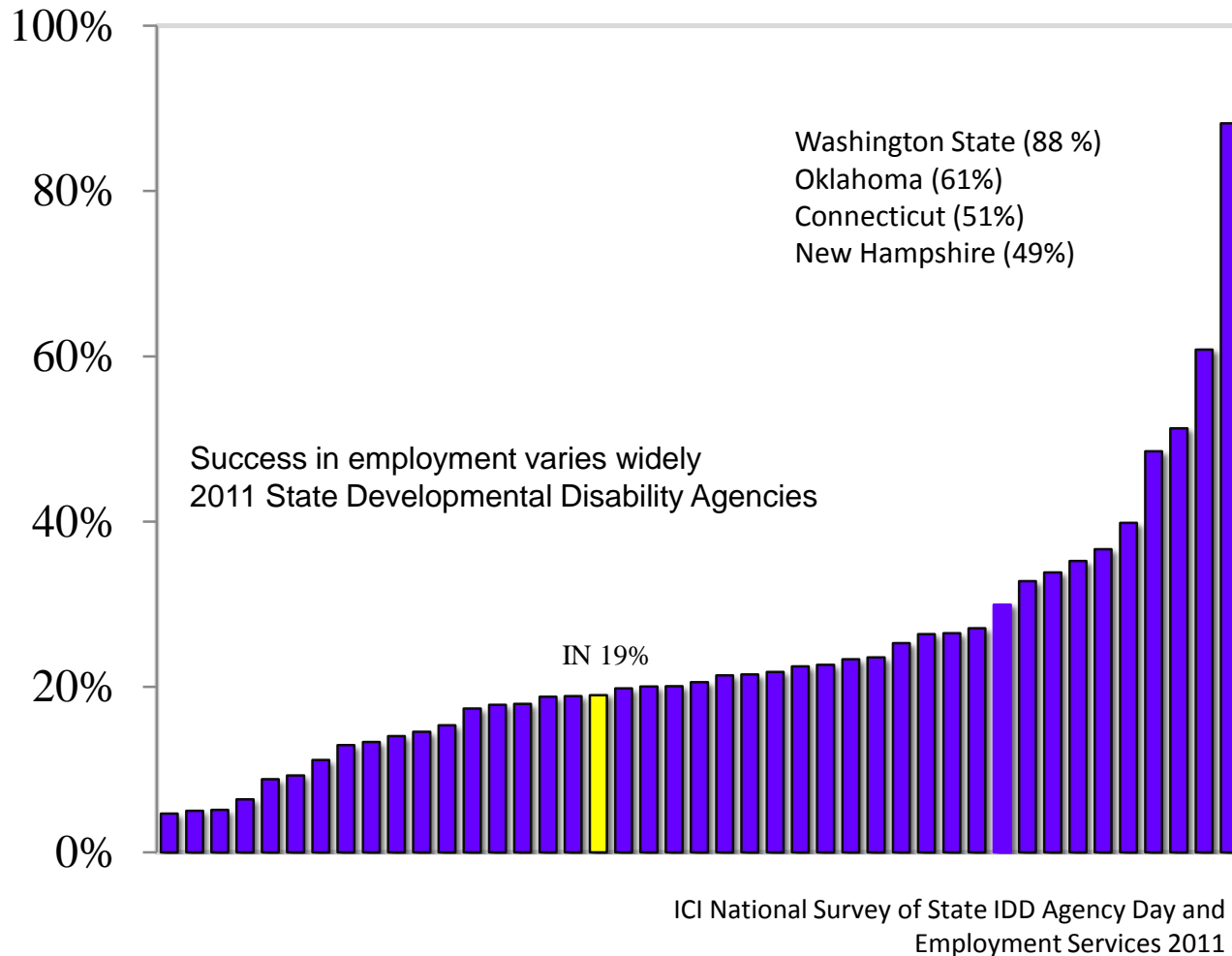
# People Want to Work



INDIANA

2012-2013 NCI Data

# People Can Work When States Focus Services on Employment





# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Community of Practice States : Washington; Tennessee; Oklahoma; Connecticut; DC; Missouri

## **Individual with Disability:**

achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life.

## **\*Families:**

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



# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

## New Charter for Supports



### DISCOVERY AND NAVIGATION

Knowledge & Skills

### CONNECTING & NETWORKING

Mental Health  
& Self-Efficacy

### GOODS & SERVICES

Day-to-Day  
& Caregiving/Supports



# Supporting Individuals and Families Across the Life course

## **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 Life Course

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

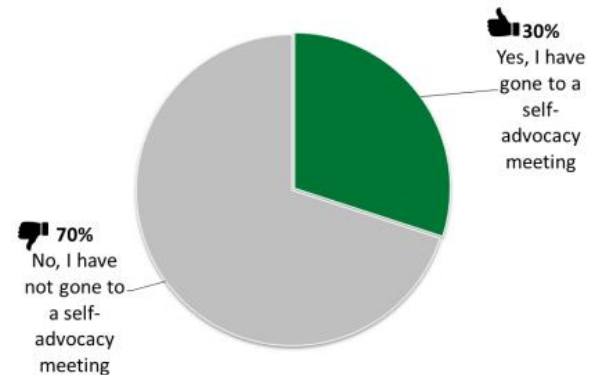
## **Information and Training Supports:** *Knowledge and Skills*

- 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*

# Self-Advocates Networking

Have you gone to a self-advocacy meeting?



NCI tells us **3** out of every **10** people said they **have gone to a self-advocacy meeting.**

# Supporting Individuals and Families Across the Life Course

**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

# Taking a Life Course Perspective

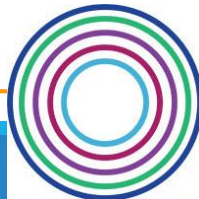


# Coming Soon: LifeCourseTools.com

The mockup features a dark blue header with the site name 'LIFE COURSE TOOLS' on the left, a search bar with a magnifying glass icon, and social media icons for Facebook, Twitter, Pinterest, and YouTube on the right. Below the header is a horizontal navigation bar with seven colored buttons: a home icon, 'TOOLS FOR' with a dropdown arrow, 'LEARNING' (purple), 'PLANNING' (red), 'CONNECTING' (orange), 'LEADING' (dark blue), and 'JOIN' (green).

The main content area is divided into three sections. On the left, a yellow card titled 'WHAT WILL I DO DURING THE DAY NOW THAT I'M AN ADULT?' contains a paragraph of text and a 'READ MORE' button with a right-pointing arrow. In the center, a photograph shows a young man in a firefighter's uniform, smiling and adjusting his helmet. The helmet has 'EDELSON SPRINGS', 'CAPTAIN', '107', and 'C. WHITE' on it. On the right, a dashed-line box titled 'I want to ...' contains three icons (speech bubbles, a computer monitor, and a calendar) and a list of four bullet points: 'Search for information', 'Explore a topic', 'Access tools for planning', 'Talk to another parent', and 'Connect to resources'.

Below the main content are three large colored circles: a light blue circle with the text 'for families', a green circle with 'for professionals', and a purple circle with 'for organizations'. To the right of these circles is a login form with a dark blue 'LOGIN' button, an 'Email' input field, a 'Password' input field, and a light blue 'GO' button.

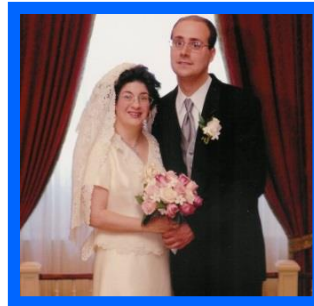


# Focusing on Relationship Based Living Options

- ✓ Living with Mom and Dad
- ✓ Living with siblings or other relatives



- ✓ Living with Friends
- ✓ Living with a partner



- ✓ Supported Living – supports provided in the person's own home
- ✓ Roommate/companion
- ✓ Shared Living – one person matched to live with another

# What Shared Living is Not

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- Not a place or a “placement”
- Not a “facility” or a group home
- Not traditional foster care or a bed in a boarding home
- Not a “setting” serving three or four people
- Not a supported setting with multiple “come-in” staff
- Not just “rebranding” old models



# What Shared Living Is

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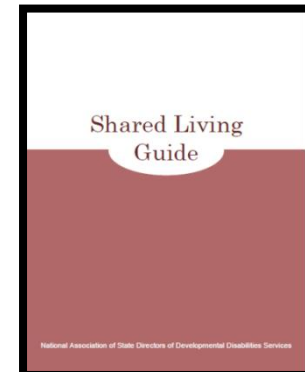
The purpose of Shared Living is to enrich the lives of people with disabilities by matching those who choose this lifestyle with a family or an individual who chooses to open their homes and their hearts.

Sharing presupposes a mutual experience....not a hierarchical one.

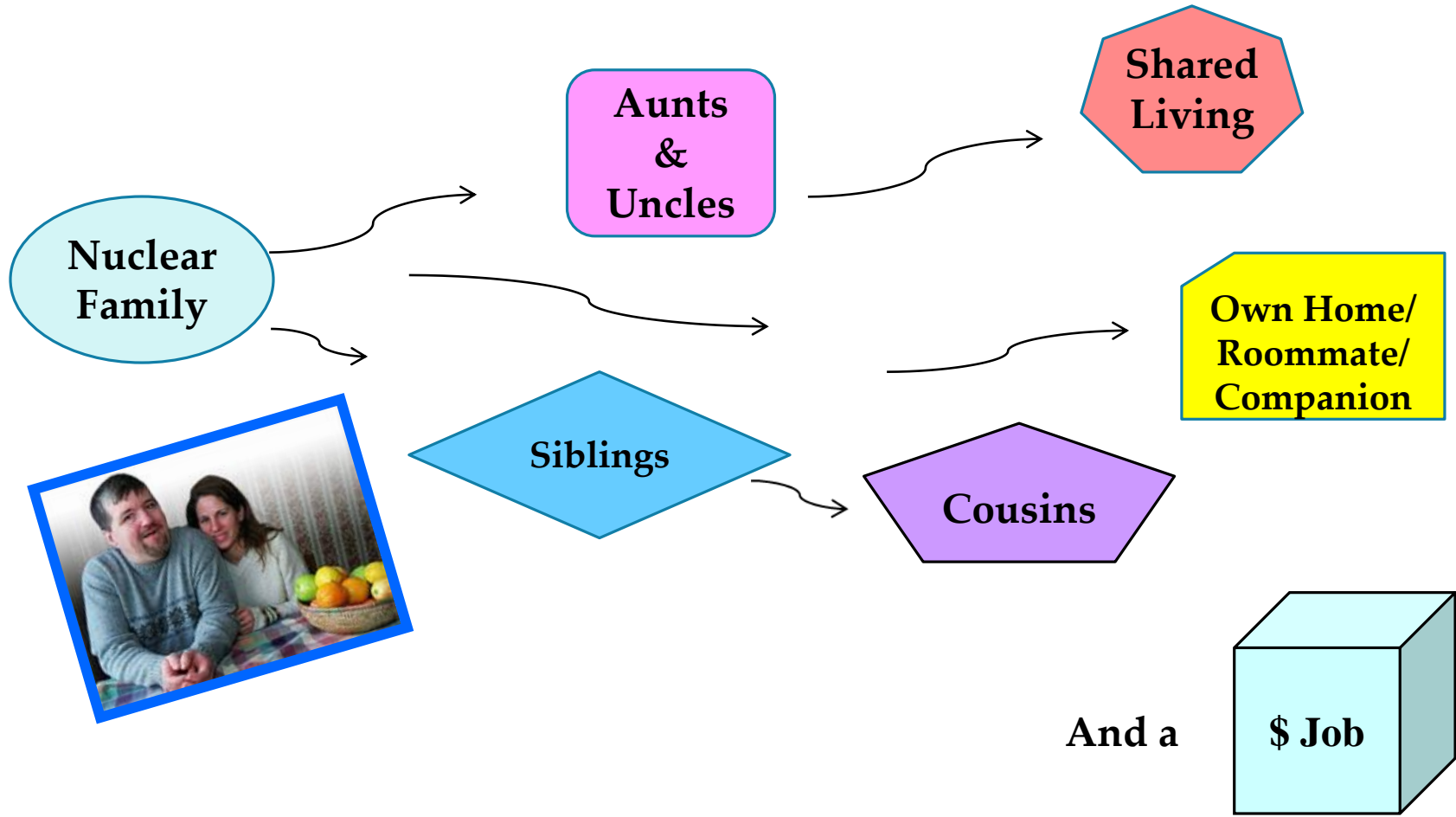
Payment is involved

Who can be a shared living provider?

- Relatives
- Friends of friends
- Someone one new but matched to the person



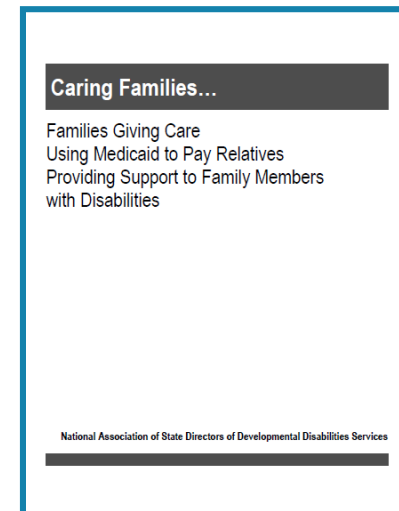
# Relationship Based Living Arrangements All Need Thoughtful Support



# Paying Family Care Givers

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- Things can be great and things can go wrong.....It's Life !
- Have expectations for outcomes for the person - everything starts with the individual plan
- Provide support/supervision that honors the plan and supports the care givers
- Establish rules about which and how many family members can be paid
- “Prenuptial agreement” ...decide what reasons would result in termination of the arrangement



# Technological Advances

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- Wearable sensors that infer cognitive state and health state
- Residential monitoring systems for safety and independence
- Prompts, reminders and other automatic interventions
- Assistance for navigation and memory
- Behavioral self-regulations and guidance with ADLs
- Assist animals
- Robots

# Part 4

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## How States are Building Sustainable Systems

- Individual resource allocation
- New state plan options
- Managed care

# Searching for Equity and Fairness - Individual Allocations with Consumer-Directed Options

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## Individual Resource Allocation

- Equity and Fairness
- Predictable costs

## Consumer-Directed Services

- Hire and Fire Staff
- Hire relatives
- Control a budget

Colorado, Georgia  
Louisiana, Oregon  
Wyoming, Conn.  
Missouri, Maryland  
Oregon  
North Dakota

Thirteen states offered individual budgets and consumer control statewide for at least some individuals in Jan. 2009

# New Medicaid HCBS State Plan Options

## **1915 (i) State plan - Home and Community Based Services**

- May define and limit target groups
- HCBS for people who require less than institutional level of care as well as those who do
- Waive comparability and income rules for medically needy pops

## **1915 (j) State plan - Self-Directed Personal Assistance Services**

- May define and limit target groups
- Participant directed personal care for people who qualify for State Plan Personal Care
- Waive state-wideness and comparability

## **1915 (k) State plan - Community First Choice Option**

- No targeting of populations – must provide to everyone in need of the service state wide
- Consumer controlled , community based attendant care services – broadly defined
- Community income rules for medically needy populations
- 6% FMAP increase

# Managed Care

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## IN ACUTE HEALTH CARE

- 1 in 5 Americans are enrolled in managed care
- 65% of Medicaid participants are in managed care
- All states except Alaska, Wyoming and New Hampshire have managed care for Medicaid participants



# States Are Doing Managed Care

- Allows states to achieve budget stability and predict costs
- Limits states' financial risk, passing part or all of it on to contractors by paying a single, fixed fee per enrollee
- Allows one or more entities to be held accountable for controlling service use and providing quality care
- Creates the potential to provide services to more people and create flexibility in service provision - if done very carefully and all components in place

# Managed LTSS Care in I/DD

## In Managed Care

Arizona (1115) IDD – gov't

Michigan (b/c) BH/IDD – gov't

Wisconsin (b/c) all pops – gov't & private

North Carolina (b/c) BH/IDD – gov't

Kansas (1115) all pop - private

New Hampshire (1115) - private

Texas – (1115) piloting IDD - private

## In Planning Stages

Louisiana (1115)(all pops)

Iowa – scheduled for 2016 (all pops all services)

New York (b/c) IDD

\* pre-implementation

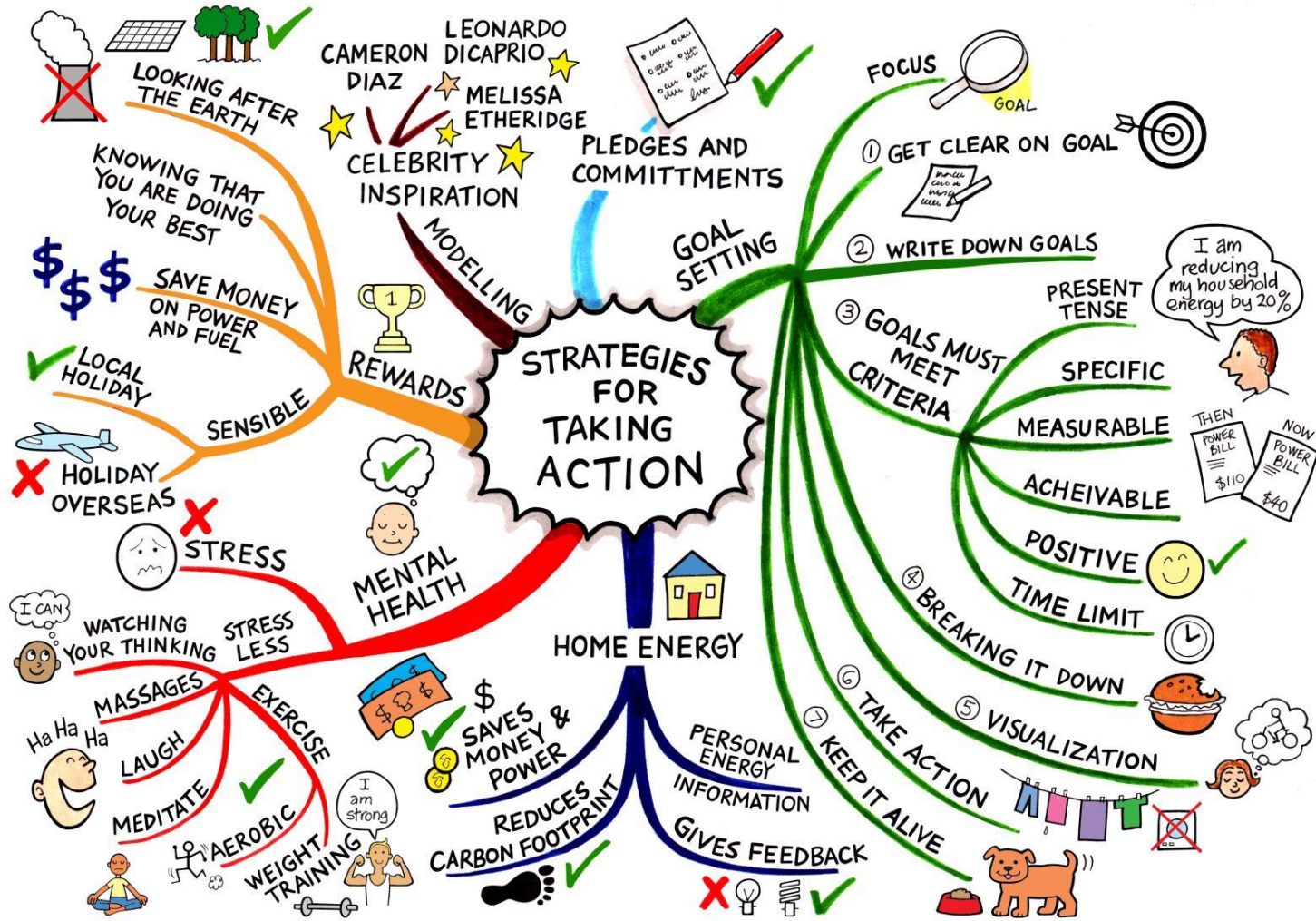
Tennessee proposing to add IDD

New Jersey (1115) – IDD delayed

Florida – legislative interest

Georgia - interest

# We Have to Do a Lot of Things at Once



# Implementing the HCBS Regulations

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## IMPLEMENT HCBS REGULATIONS

**Peron-Centered  
Planning**

**Settings Rule**

**Conflict Free  
Case management**

**National Association of State Directors of Developmental Disabilities**  
**301 N. Fairfax St.**  
**Alexandria, Va. 22314**

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