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*Shaping policy, sharing solutions, strengthening communities*



# Alliance Conference

June 19, 2014

**Disability Trends and the ANCOR Town Hall Connection**

Renee Pietrangelo, CEO

Diane McComb, Liaison to State Associations

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SHAPING POLICY, SHARING SOLUTIONS, STRENGTHENING COMMUNITY

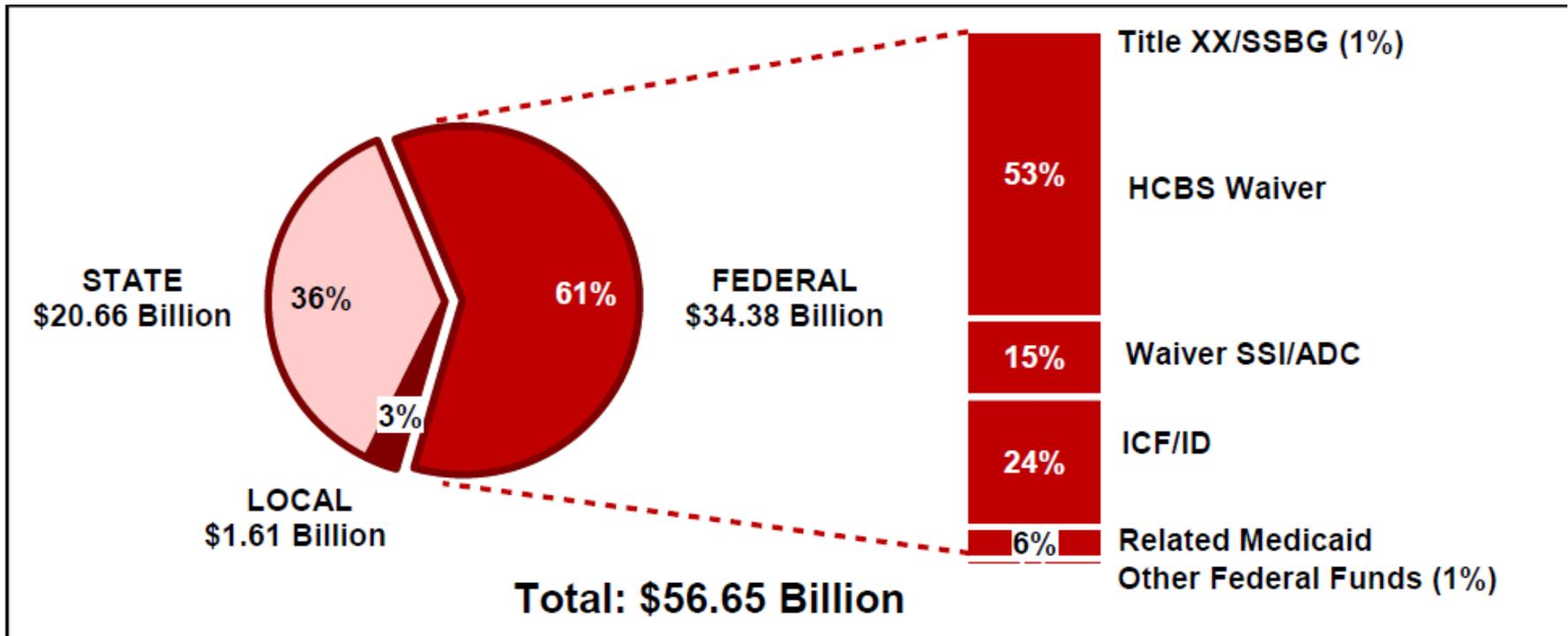
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# Future Uncertainties



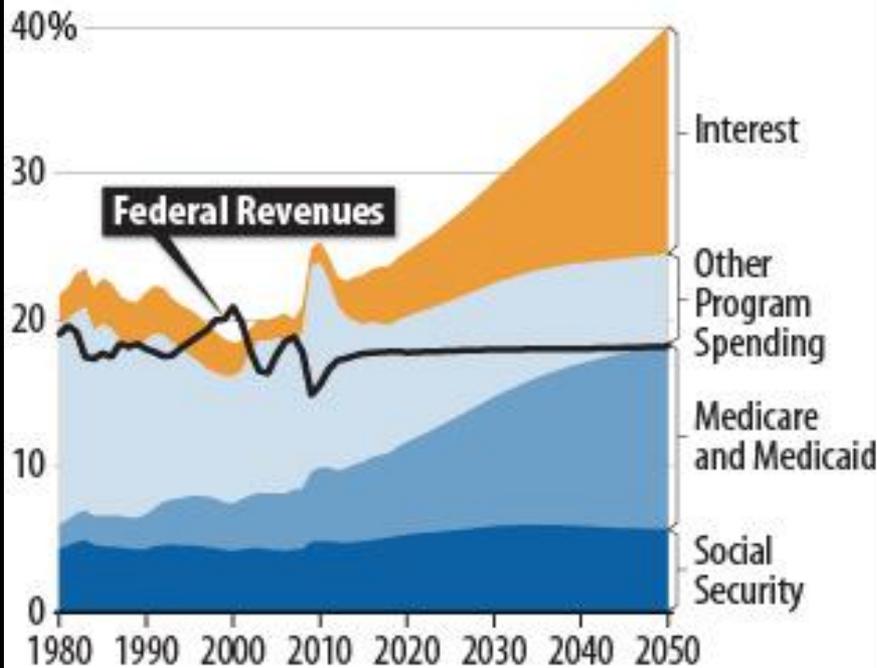
- State Budget Instabilities
- Health Reform - Medicaid Reform - Managed Care, Exchanges, Expansion, Duals
- Changes to Federal Rules - Companion Care, Employment, new HCBS Rule
- Less Money: Federal, state, and local deficits
- Workforce Issues - DSPs
- DOJ Olmstead Enforcement

# \$56.65 Billion Public Funds



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

Spending and Revenues as a Share of GDP

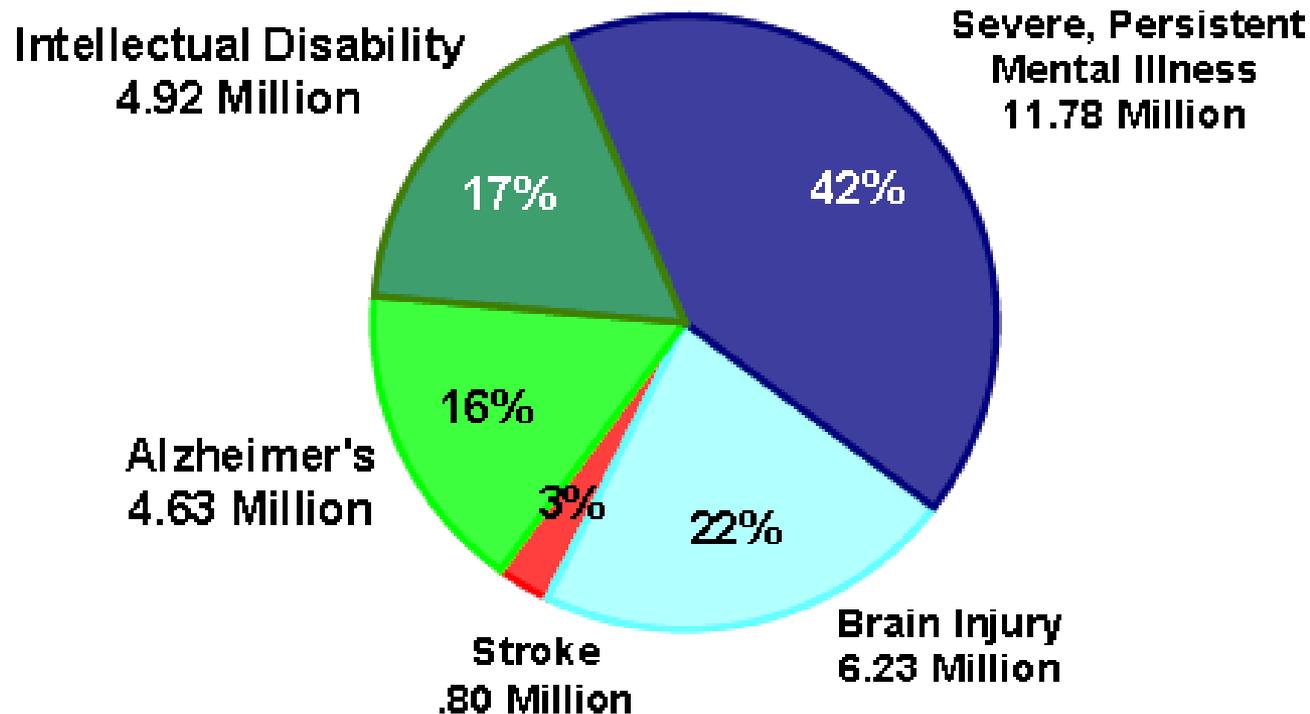


Source: CBPP projections based on CBO data.

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

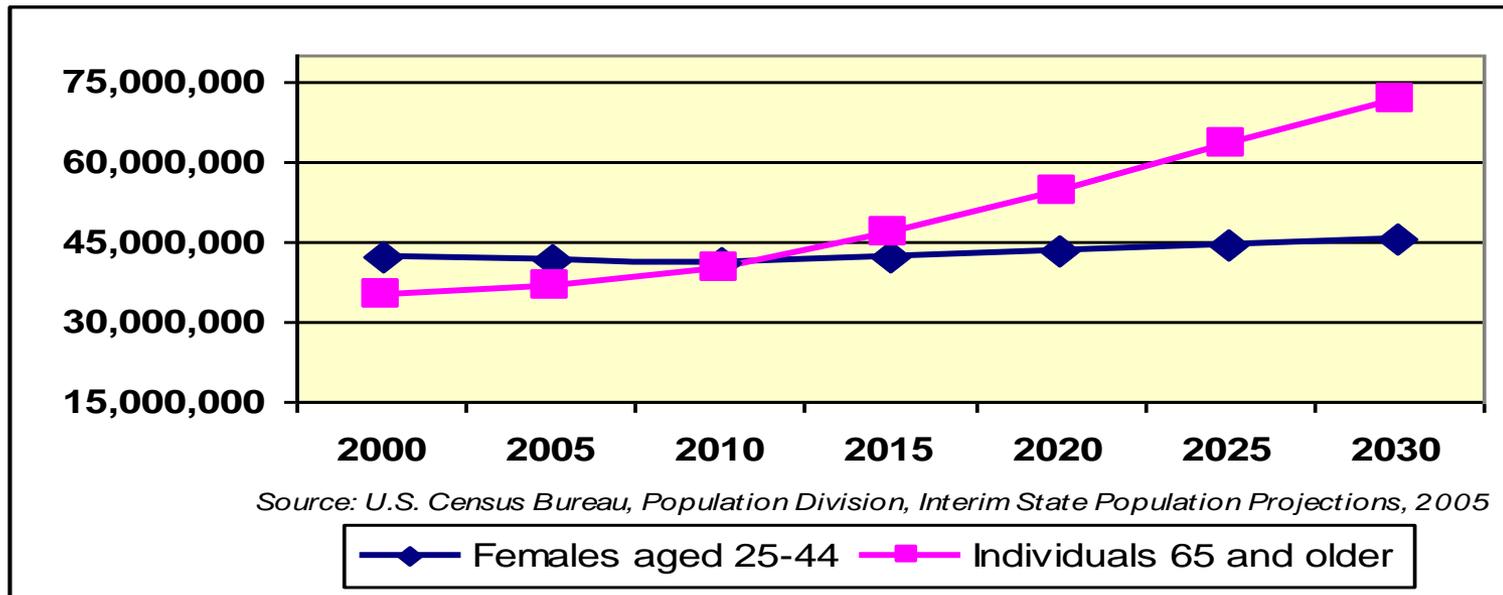
**Federal  
Spending on  
Medicaid and  
Medicare is  
Unsustainable**

## Prevalence of Cognitive Disability in US

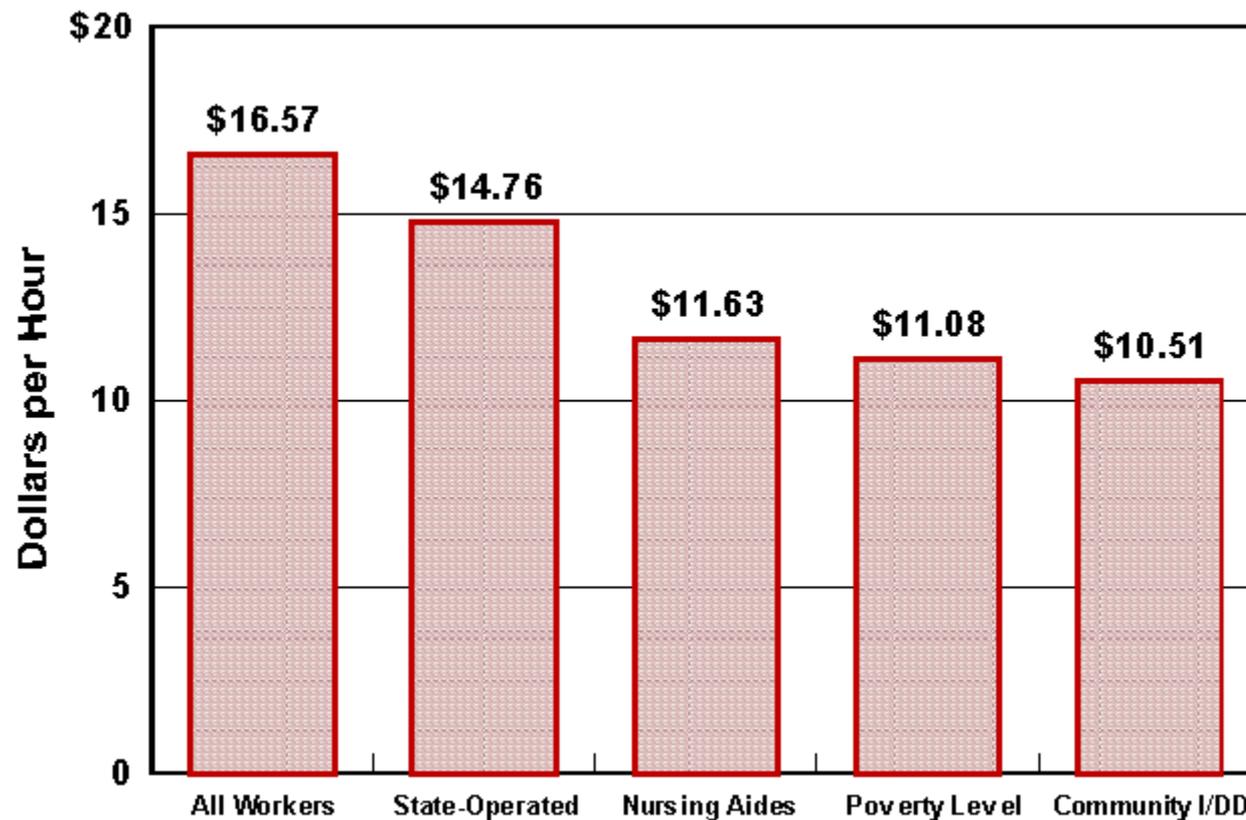


**Total: 28.36 Million Persons**

# Workforce is Shrinking

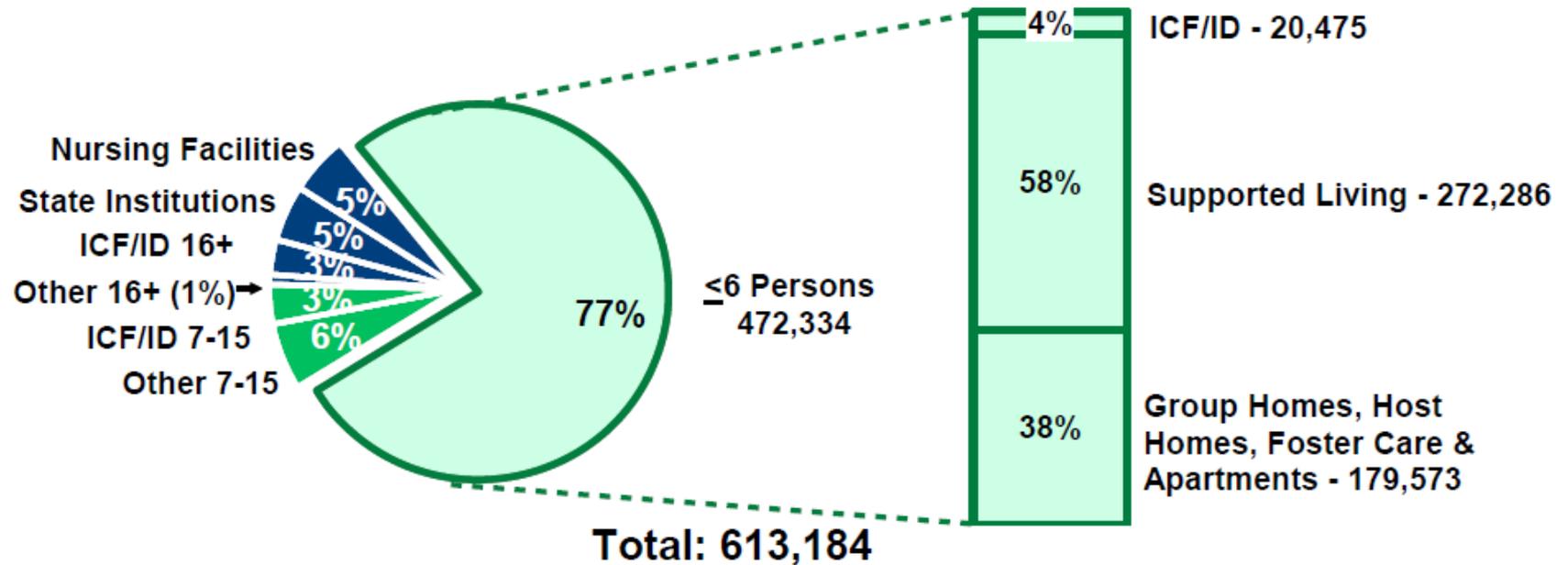


# DSP Wages are Below Federal Poverty Level



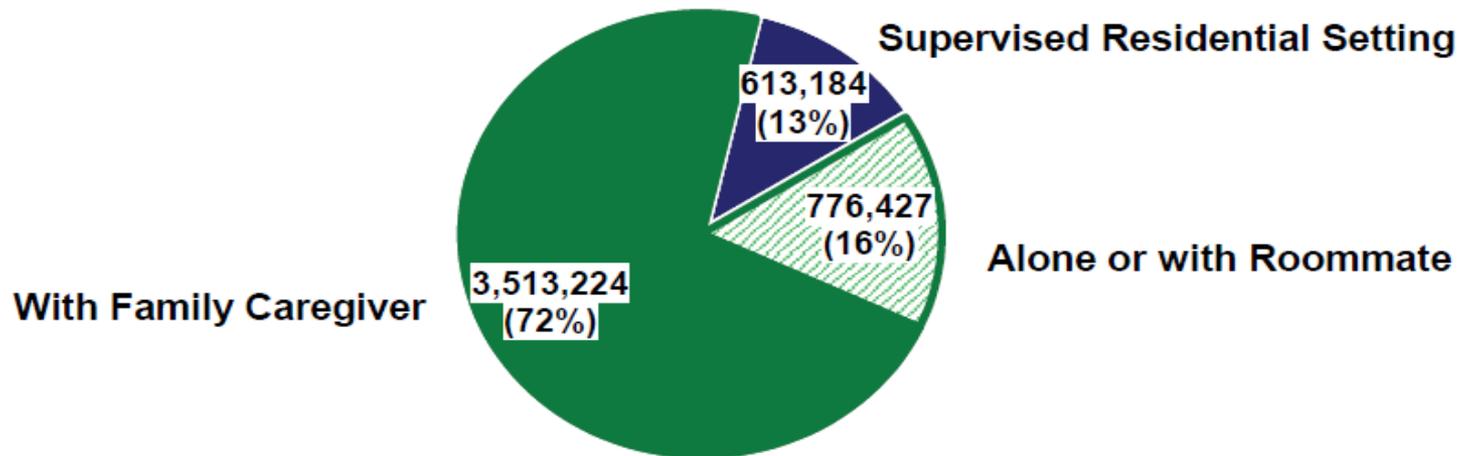
**Sources:** "All workers" and nursing aides for 2011 (Bureau of Labor Statistics, 2012); "state-operated I/DD" for 2010 (Larson, Ryan, Salmi, Smith & Wuorio, 2012); "community I/DD" 2009 (and inflation-adjusted to estimate 2011 value (ANCOR, 2010), and "poverty level" for 2012 (Assistant Secretary for Planning and Evaluation, 2012).

# Most People Are Supported in <6 Person Settings



## More People with I/DD Live with Family Caregivers than in our Publicly Funded System

### ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD BY LIVING ARRANGEMENT: FY 2011



**TOTAL: 4,902,835 PERSONS**

Braddock et al. 2013, based on Fujiura 2012



# **Federal Changes**

## **Companionship Rule**

**DOL Final Rule on Fair Labor Standards Act (FLSA)**

- Exemption no longer available to anyone paid by a third party
- 20% threshold for non-companionship activities (which is not relevant to anyone being paid by third party)
- People that perform medically-related services are not considered companionship workers

## **Companionship Rule**

**DOL Final Rule on Fair Labor Standards Act (FLSA)**

### **Third Party Employers**

- Employment relationship determined by the subjective “economic realities” test.
- No one factor controls, must look at totality of relationship to determine whether employment relationship exists.
- Rules governing independent contractors are unchanged



## **Companionship Rule**

**DOL Final Rule on Fair Labor Standards Act (FLSA)**

### **Shared Living Models**

- If paid by a third party, minimum wage and overtime rules apply for all hours worked
- Time the worker is off the clock does not require payment
- Employer must keep records of actual time worked

# **Workforce Investment Act (WIA)**

## Workforce Investment Act (WIA) of 2013

- Reauthorization long overdue; championed by Senator Harkin
- Bipartisan bill passed in Senate HELP Committee
  - Strong focus on transition age/presumption of competitive/non-sheltered work
  - Continues 14C Special Wage Certificates but layers in more frequent reviews of appropriateness (Sec. 511)



# **Disability Employment Requirements for Federal Contractors**

## **DOL Finalizes Disability Employment Requirements for Federal Contractors**

- Changes Section 503 of the Rehabilitation Act of 1973
- Establishes a “nationwide 7% utilization goal for qualified IWDs.”
- Contractors with more than 100 employees will apply this goal to each of their job groups
- Contractors with 100 or less employees will apply it to their entire workforce
- Provisions require contractors to
  - keep and analyze certain data with regard to the employment of IWDs
  - invite applicants and employees to self-identify as IWDs
  - incorporate specific equal employment opportunity language in their subcontracts; and
  - allow the OFCCP to review documents as part of either a compliance check or focused review.



# **CMS Definition of Community**



## New HCBS Rule

- Released January 10, 2014, effective date of **March 17, 2014**
- **Defines** and describes **home and community based settings** under section 1915(c) waivers and section 1915(i)/1915(k) state plan options
- Sets forth requirements for **person-centered planning process**
- Allows states to **combine multiple target populations** under one 1915(c) waiver
- Allows **five-year renewal cycle** to align waivers and state plan amendments for dual eligible programs



## CMS Definition of Community

- The setting is integrated in and supports **full access to the greater community**, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community;
- Supports are **selected by the individual** from among setting options, including non-disability specific settings and an option for a private unit in a residential setting, as identified in the person-centered service plan;
- Ensures an individual's rights of privacy, dignity and respect, and **freedom from coercion and restraint**;
- Optimizes but does not regiment individual initiative, autonomy, and **independence in making life choices**, including but not limited to, daily activities, physical environment, and with whom to interact;
- **Facilitates individual choice regarding services and supports, and who provides them.**



## CMS Definition of Community

### Settings that are always excluded from HCBS

- Nursing facilities
- Institutions for mental diseases, intermediate care facilities for individuals with intellectual disabilities (ICF/IID)
- Hospitals providing long-term care services
- Any other location that has the qualities of an institution, as determined by the Secretary

*Note – CMS expressly declined to categorically exclude congregate settings from the definition of HCBS, though they must meet the criteria set forth in the rule.*

## Provider-Controlled Settings

- The unit or dwelling is a **specific physical place** that can be owned, rented or occupied under a **legally enforceable agreement** with the same responsibilities and protections from eviction that tenants have under the jurisdiction's landlord tenant law.
- Each individual has **privacy in their sleeping or living unit**:
  - Units have entrance doors **lockable by the individual**, with only appropriate staff having keys to doors as needed.
  - Individuals sharing units have a **choice of roommates** in that setting.
  - Individuals have the **freedom to furnish and decorate** their sleeping or living units within the lease or other agreement.

## Provider-Controlled Settings (cont'd)

- Individuals **control their own schedules** and have **access to food** at any time;
- Individuals are able to have **visitors of their choosing at any time**;
- The setting is **physically accessible**;
- Any modification to additional conditions must be supported by a specific assessed need and justified in the person-centered plan.



## Provider-Controlled Settings (cont'd)

- The following requirements must be documented in the **person-centered service plan**:
  - Identify a specific and individualized assessed need.
  - Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
  - Document less intrusive methods have been tried but did not work.
- Include a **clear description of the condition** directly proportionate to the specific assessed need.
- Include **regular collection and review of data** to measure the ongoing effectiveness of the modification.
- Include established **time limits for periodic reviews** to determine if the modification is still necessary or can be terminated.
- Include the **informed consent** of the individual.
- Include an **assurance** interventions and supports will cause **no harm** to the individual.



# Regulations and DOJ Oversight

## DOJ and Olmstead Settlement Agreements

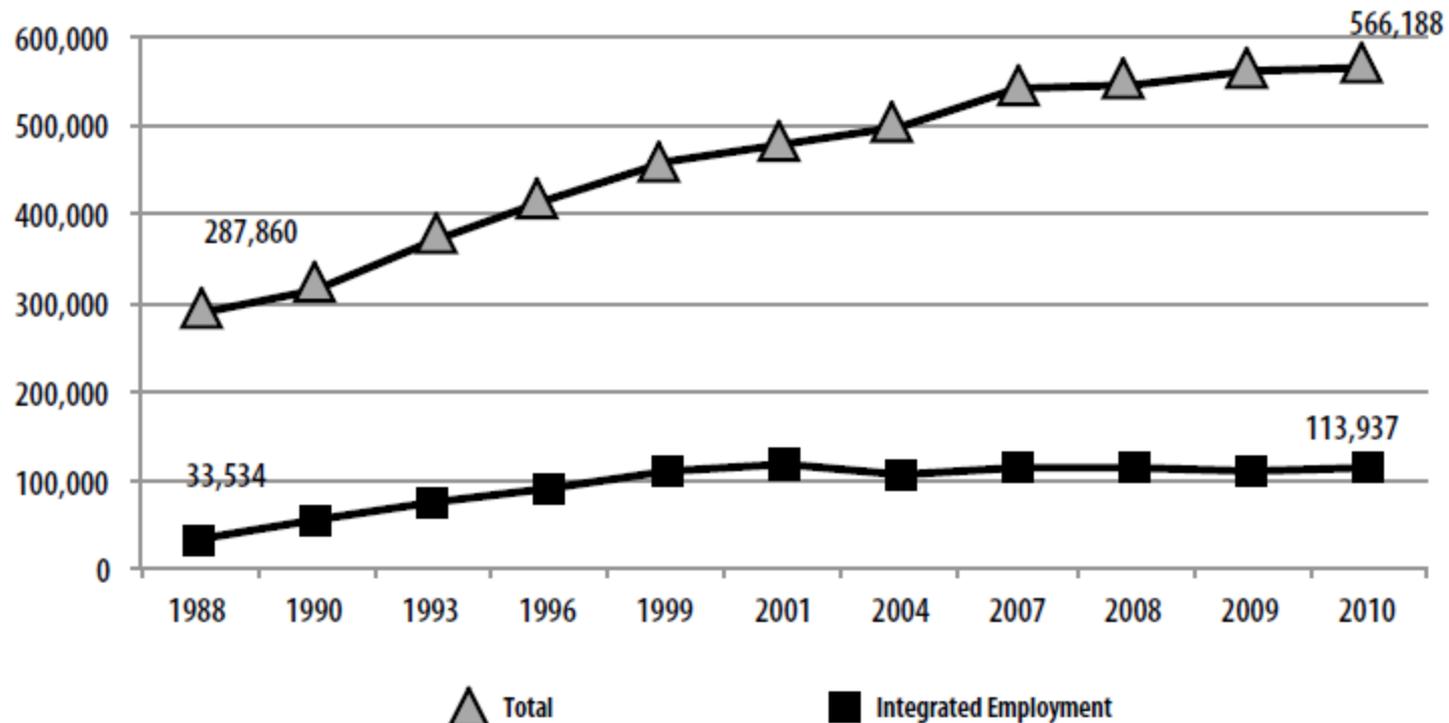


The State fails to provide services to individuals with intellectual and developmental disabilities in the most integrated setting appropriate to their needs as required by the ADA and Olmstead.

## Most Integrated Setting

- Movement away from institutions and other segregated settings
- Enhancement of community settings
- Integrated day and employment services
- Stepped up training
- Quality improvement activities

# A Word about Employment



**Figure 1. Trend Line for Estimated Total Number of People Served by State IDD Agencies and Estimated Number Served in Integrated Employment**

Butterworth, John, Frank A. Smith, Allison Cohen Hall, Alberto Migliore, Jean Winsor, Daria Domin, and Jamie Cuilla Timmons. "StateData: The National Report on Employment Services and Outcomes." *Www.statedata.info*. Institute for Community Inclusion, Winter 2012.

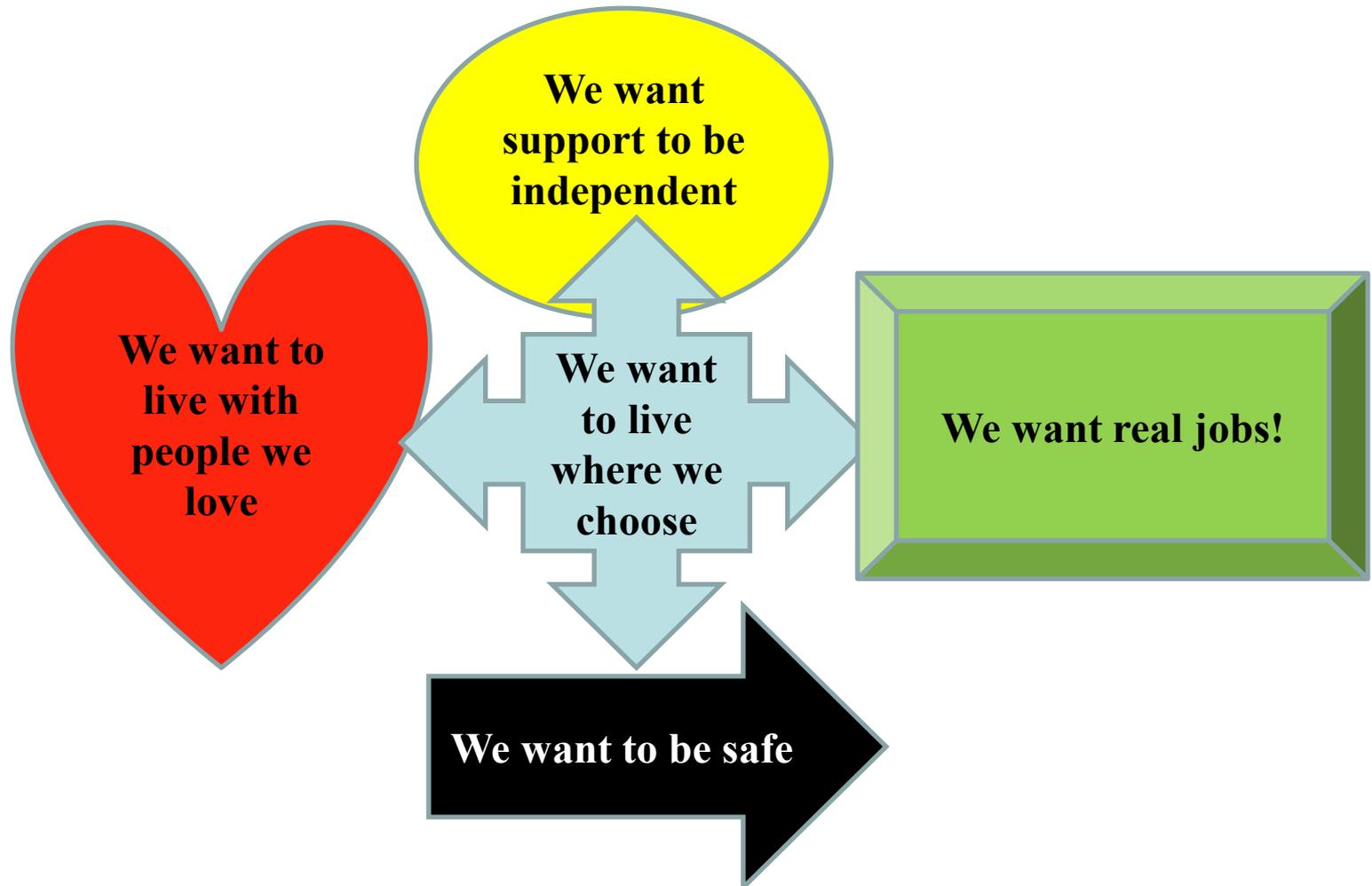
**So What Do We Know?**

- We've lived through the best of times as far as funding goes. The money isn't coming back.
- What we've been doing is very, very expensive and not necessarily what people want.
- The workforce for the work we do is not growing.
- The number of people needing support IS growing
- We are in for a lot of change...



What People with Disabilities Tell Us...

## What People with Disabilities Tell Us...





## **The Future will be Dramatically Different than the last 40 years**

- 2014 ANCOR Town Hall Meeting Feedback



## **Town Hall Feedback**

### **Top Ten: What community services will look like in 2034**

1. More services will be supported by and delivered with technology
2. Decentralized services
3. Fewer providers
4. Technology replaces direct staffing
5. More services through home care, health home, and/or managed care model
6. Family members serving as provider
7. Group homes will no longer be funded.
8. People with IDD will spend days no differently than anyone else.
9. There will be a shortage of providers
10. There will be less state control.



## What providers need to be doing to prepare for 2034

1. Develop a culture of innovation: invest in technology and training
2. Develop/broaden community partnerships and collaborations
3. Increase natural supports
4. Educate and empower DSPs. Get younger people involved in the field
5. Educate families
6. Start specializing
7. Diversify services
8. Let go of traditional models; no longer invest in bricks and mortar. Be prepared to give things up.
9. Pray
10. Succession planning; invest in board development



## Where ANCOR Should Head

- More socio/economic and demographic research and education
- Integrate DSP viewpoint and feedback; more meaningful engagement with DSPs; continue to involve DSPs
- Support development of next generation of leaders
- Greater connection to families; better educate families
- Become international in scope
- More tech summits; technical assistance for applying technology strategies; showcase new technologies. More presentations like “Google Glass”. We need to be exposed to and hear more about new applications and advances.

## Where ANCOR Should Head

- More exercises like this one – assist with regional futuring summits on rethinking supports and services delivery.
- Ensure flexibility in service delivery through public policy advocacy.
- Continue to focus on workforce
- More education and training on managing change
- More peer-to-peer learning opportunities



## Questions for the Future

- How do we best position our battle for civil rights and social justice so it's fueled by empowerment and not protectionism?
- How do we effectively communicate and advocate on behalf of the dignity of risk?
- What will it take to communicate with society at large that it's in our mutual best interest to recognize the impressive capacity and encourage the aspirations of people with disabilities?



## UCP Study Results: Framing Our Messaging

- Personal: “People with disabilities and their families and friends”
- Relatable: “Same goals, different paths” rather than different goals with different needs
- Universal: “We deserve opportunities that include access to supports and services”  
NOT we NEED supports and services



## Other Messaging Pointers

- Before addressing need for supports and services, *celebrate* the advances that have already been made (e.g., ADA, HCBS Ruling, Employment First Initiatives).
- Instead of focusing on the disability community, talk about how people with disabilities *are part of their communities*. We're your friends, neighbors and coworkers.



## Other Messaging Pointers

- Frame the issue as something that ensures everyone's needs, disabled or not, are taken into account.
- Focus on universality. We all have the same goals, just different challenges and paths for achieving them.
- Focus on **equality of opportunity**.
- Common goals are a powerful way to connect---full and meaningful lives; our own home; rewarding and fairly compensated work; starting our own families.



## **Renee's Advice Column for 2034 and Beyond**

- Do more empowering; allow for dignity of risk; and proactively address states' penchant for over-regulation in the name of health and safety.
- Funders need to allow for more "blue space" that fosters innovation, creativity and more rapid technology applications.
- It's all about people served AND their families and friends.
- Collaboration as we've never experienced or applied it before.

## Renee's Advice Column for 2034 and Beyond

- Individual capacity and social biases *will* change with time. Keep working at it.
- We must promote newer, freer service models -- nuanced models that are progressive and malleable.



***Thank you and congratulations  
Chris Collins from the ANCOR  
family. Heartfelt best wishes in  
the future. XXOOXX***



## Additional Resources

<http://www.medicaid.gov/mltss/>

<http://www.ncd.gov/publications/2013/20130315/>

DOL Final Rule of Companionship Exemption

[http://www.dol.gov/whd/homecare/final\\_rule.pdf](http://www.dol.gov/whd/homecare/final_rule.pdf)

Affirmative action and nondiscrimination obligations of federal contractors and subcontractors regarding individuals with disabilities

[http://www.dol.gov/ofccp/regs/compliance/section503/503\\_rule\\_qa\\_508c.pdf](http://www.dol.gov/ofccp/regs/compliance/section503/503_rule_qa_508c.pdf)

CMS Home and Community Based Services Rule

<http://www.medicaid.gov/HCBS>