
Challenges and Opportunities for Collaboration in Health Care for Persons with I/DD

Developmental Disabilities Nurses Association
18th Annual Education Conference
American Academy of Developmental Medicine and Dentistry
7th Annual Conference

Reno, Nevada
May 16th, 2010

Nancy Thaler
Executive Director
NASDDDS

NASDDDS

National Association of State Directors of Developmental Disabilities Services

The Topics

Part 1. Where people live

Part 2. What we know

Part 3. What is the problem?

Part 4. What are the opportunities?

Part 1

Where People Live

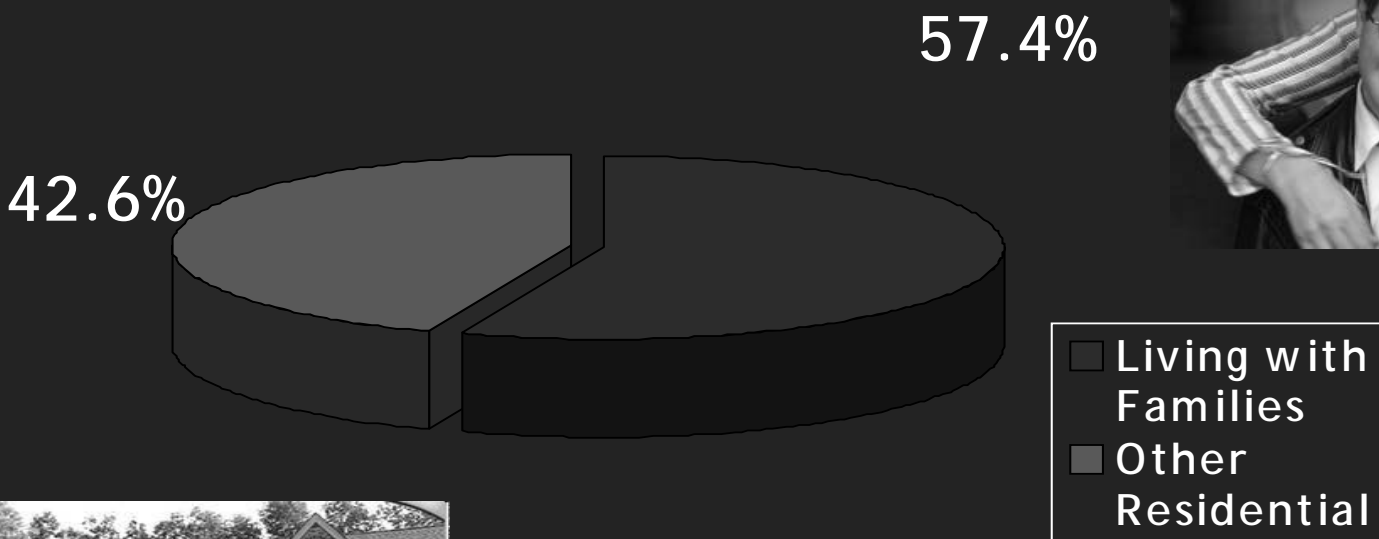
About 1 Million People Receive Publically Funded Services

Incidence of IDD is 3.5 Million

- 428,803 Family Support
- 532,830 Residential Services
- 38,262 – Shared Living/Host Homes
- Most people are living in the community without public services – 2.5 million

The State of the States in Developmental Disabilities
(Braddock, Hemp, & Rizzolo, 2008)

In 2008 Most Individuals with DD Receiving Services are Living with Families



This does not include the 2.5 million who do not Receive services

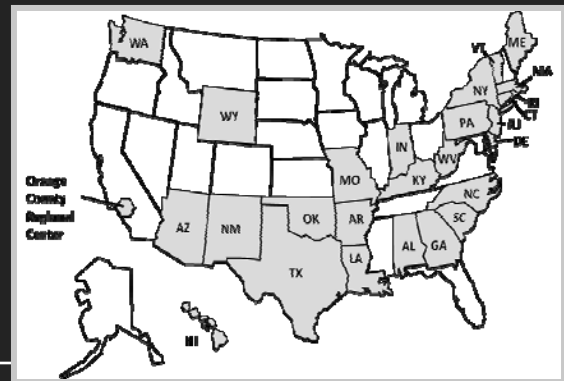
Part 1

What We Know



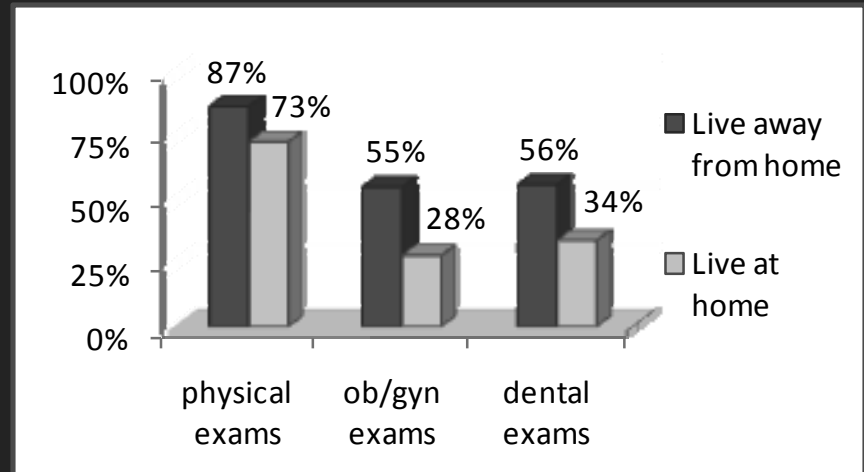
National Core Indicators NCI

- National Core Indicators is a common set of data collection protocols that participating states use to gather information about the performance of service delivery systems for people with intellectual and developmental disabilities. The 2007-08 Consumer Survey Report provides descriptive and outcome data on 11,447 adults from 24 states. Almost one-third of these individuals (3,559, or 31%) lived at home with their parents or other relatives



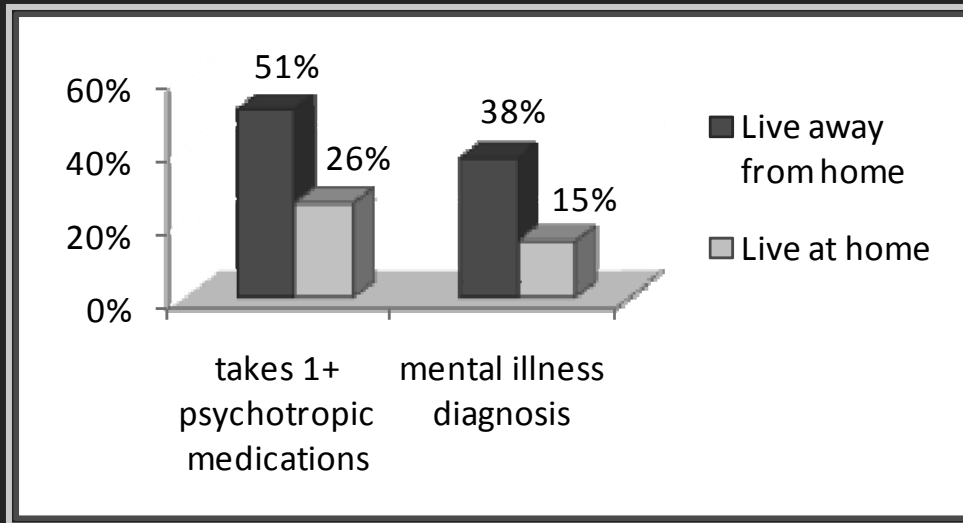
What Do We Know ?

- Compared to adults in other residential settings, people living with family are least likely to:
 - Have had a physical or ob/gyn exam in the past year
 - Have been to the dentist in the past 6 months



What Do We Know ?

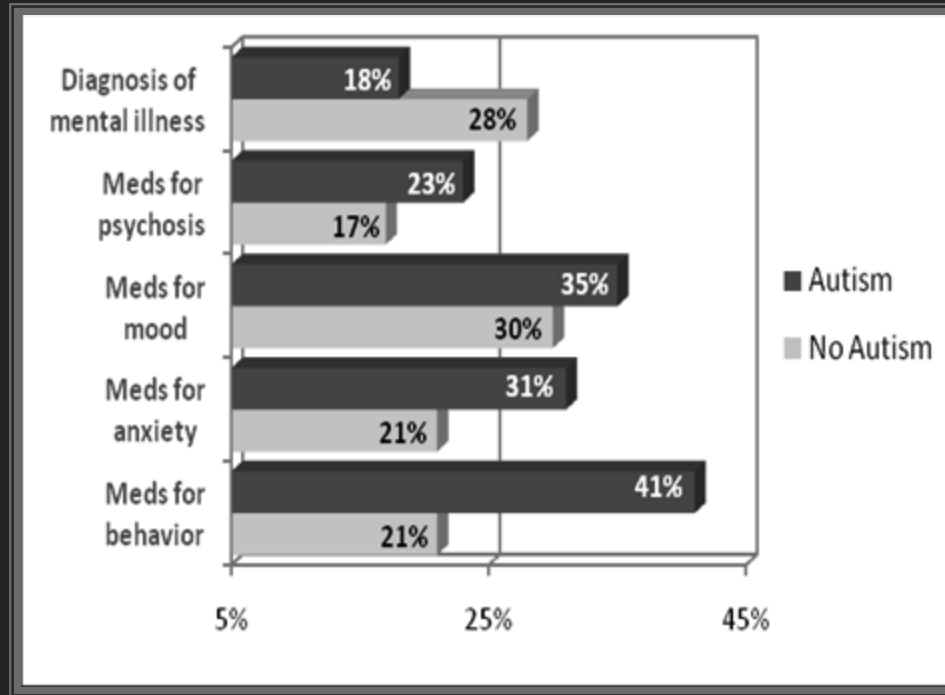
High rates of mental illness



Even higher rates of psychotropic medication.

*National Core Indicators Annual Report 2009

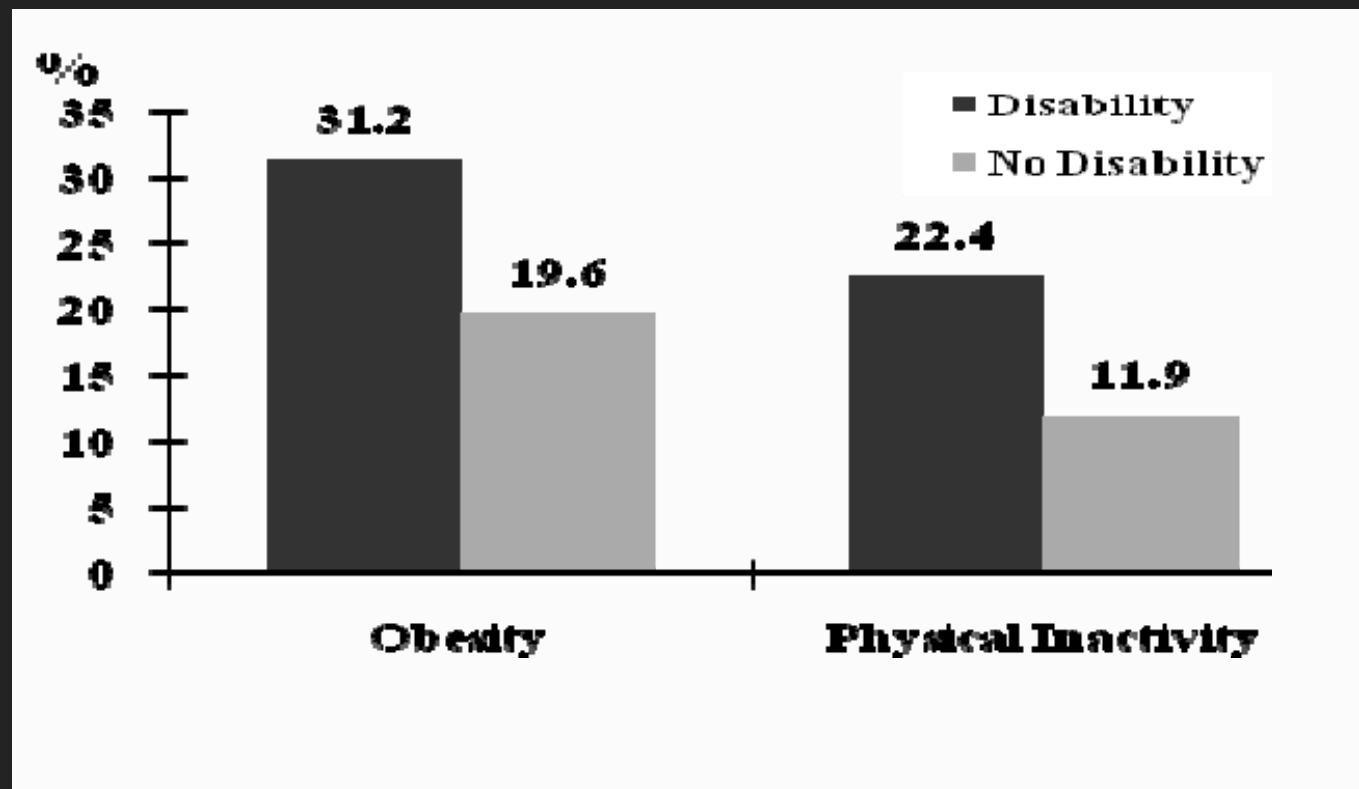
The Numbers for Taking Medications are Higher for People with Autism



Respondents with autism are less likely to have a co-existing diagnosis of mental illness and more likely to be taking medications for psychotic, mood, anxiety, and behavioral disorders than those without a diagnosis of autism.*

*National Core Indicators Annual Report 2009

Obesity and Physical Inactivity by Disability Status

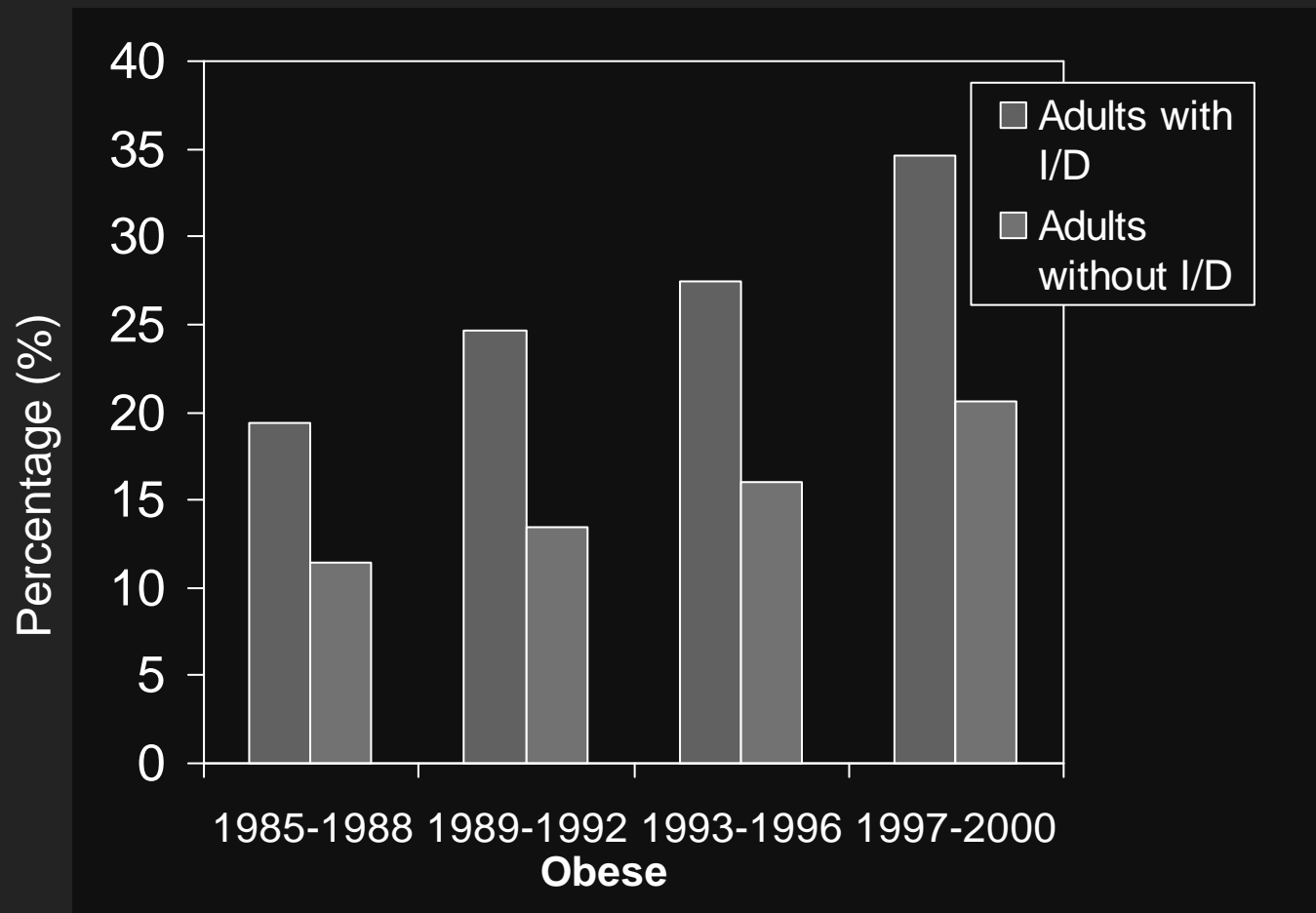


Centers for Disease Control and Prevention. Disability and Health State Chartbook, 2006: Profiles of Health for Adults with Disabilities. Atlanta (GA): Centers for Disease Control and Prevention: 2006
Data source: 2001 and 2003 BRFSS (Behavioral Risk Factor Surveillance System)

Obesity Prevalence: Adults with Disabilities

- Results of data from the 1994-1995 National Health Interview Survey Disability Supplement (NHIS-D), and the 1995 Healthy People 2000 Supplement indicate that among adults with physical disabilities, there was a 66% higher rate of obesity compared to people without disabilities.
- Obesity appears to be more prevalent in adults with sensory, physical, intellectual and mental health conditions.

A growing problem: Obesity in adults with intellectual disabilities



Yamaki (2005). Body Weight Status Among Adults With Intellectual Disability in the Community. *Mental Retardation*, 43, 1-10. Data source: National Health Interview Survey.

12

Working

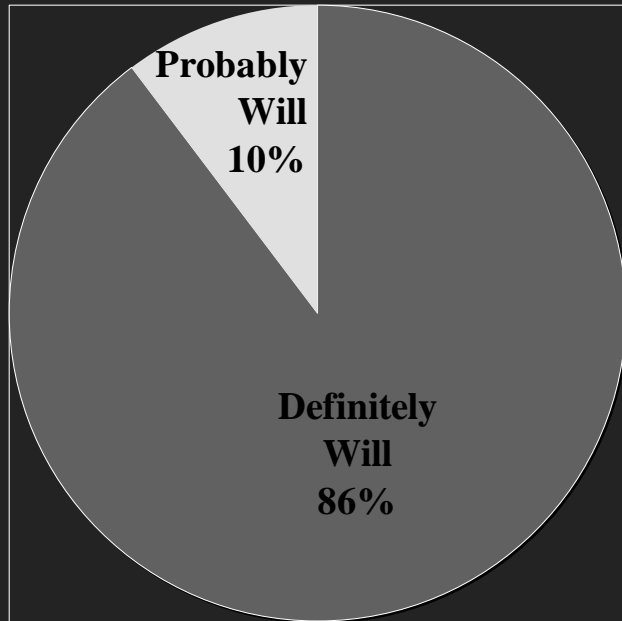
“It's what most of us do for half our waking lives. It's how we feed and clothe ourselves and how we support our families. It shapes our sense of who we are, and of where we fit in the scheme of things.”

Market Place American Public Media

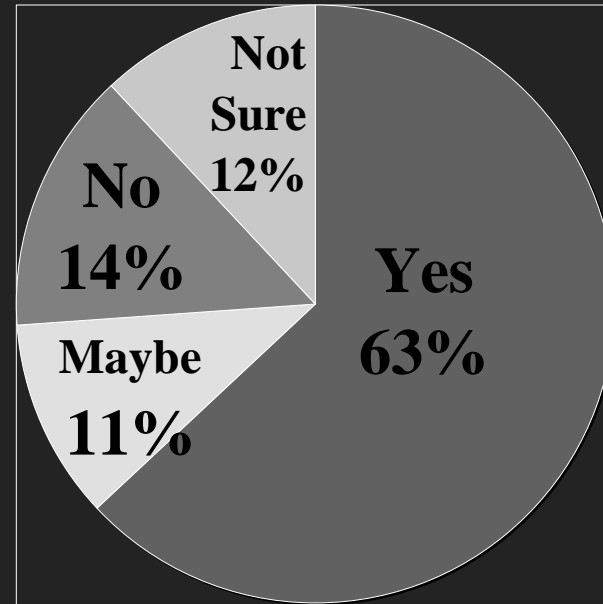
<http://marketplace.publicradio.org/segments/working/>



The Desire to Work

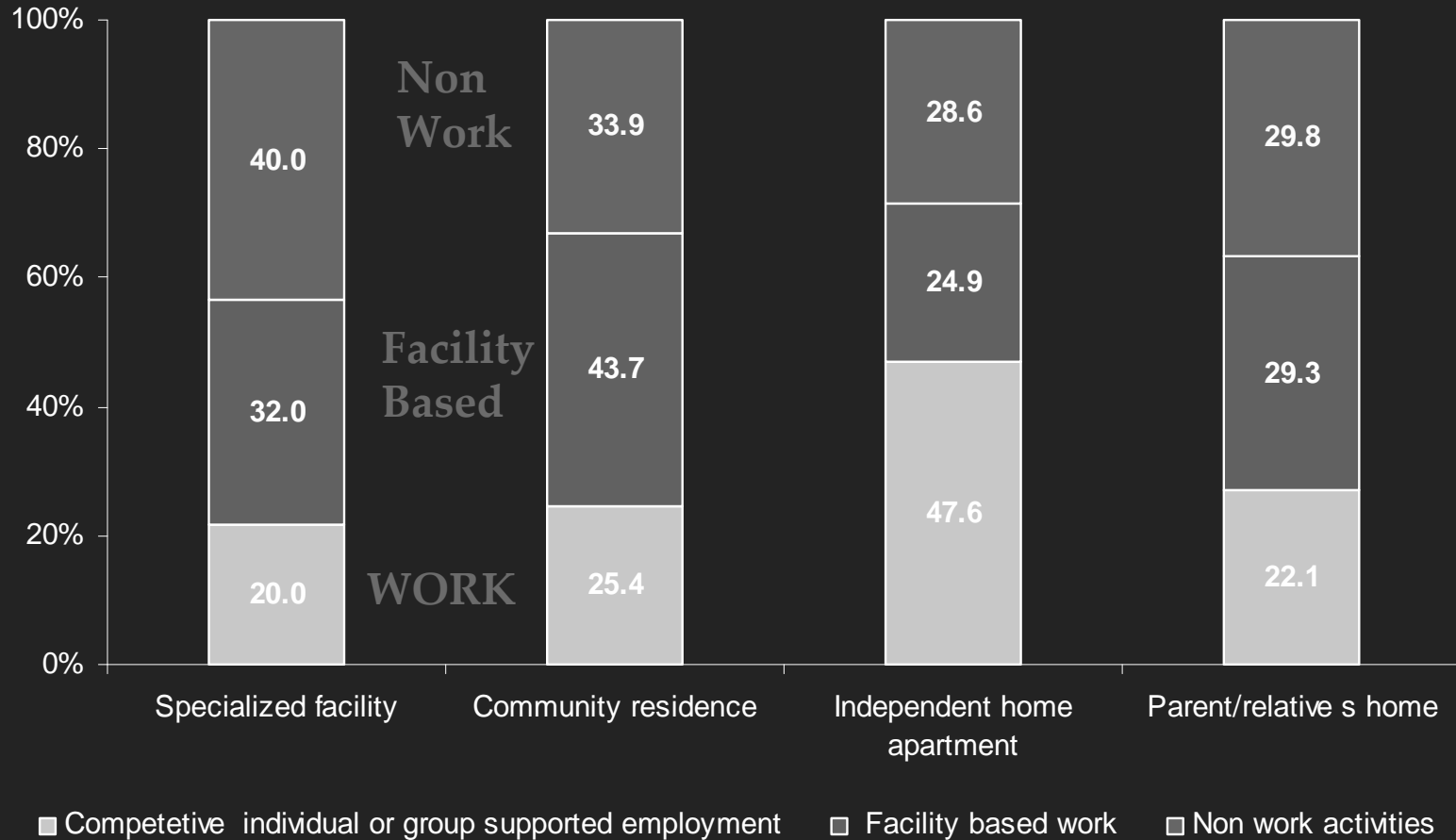


*Students:
I will eventually get a paid job*



*Workshop participant prefers
employment outside of workshop*

How Many People Actually Work?



John Butterworth, U Mass ICI

Demographic trends are going to result in more and more people living with their families and longer periods of time

The service paradigm must encompass people living with their families.

What Do We Know About People Living with their Families?

- Compared to adults in other residential settings, people living with family are:
 - ❑ Less lonely
 - ❑ Less likely to feel afraid at home
 - ❑ More likely to feel happy
 - ❑ More likely to like where they are living



National Core Indicators 2006-2007

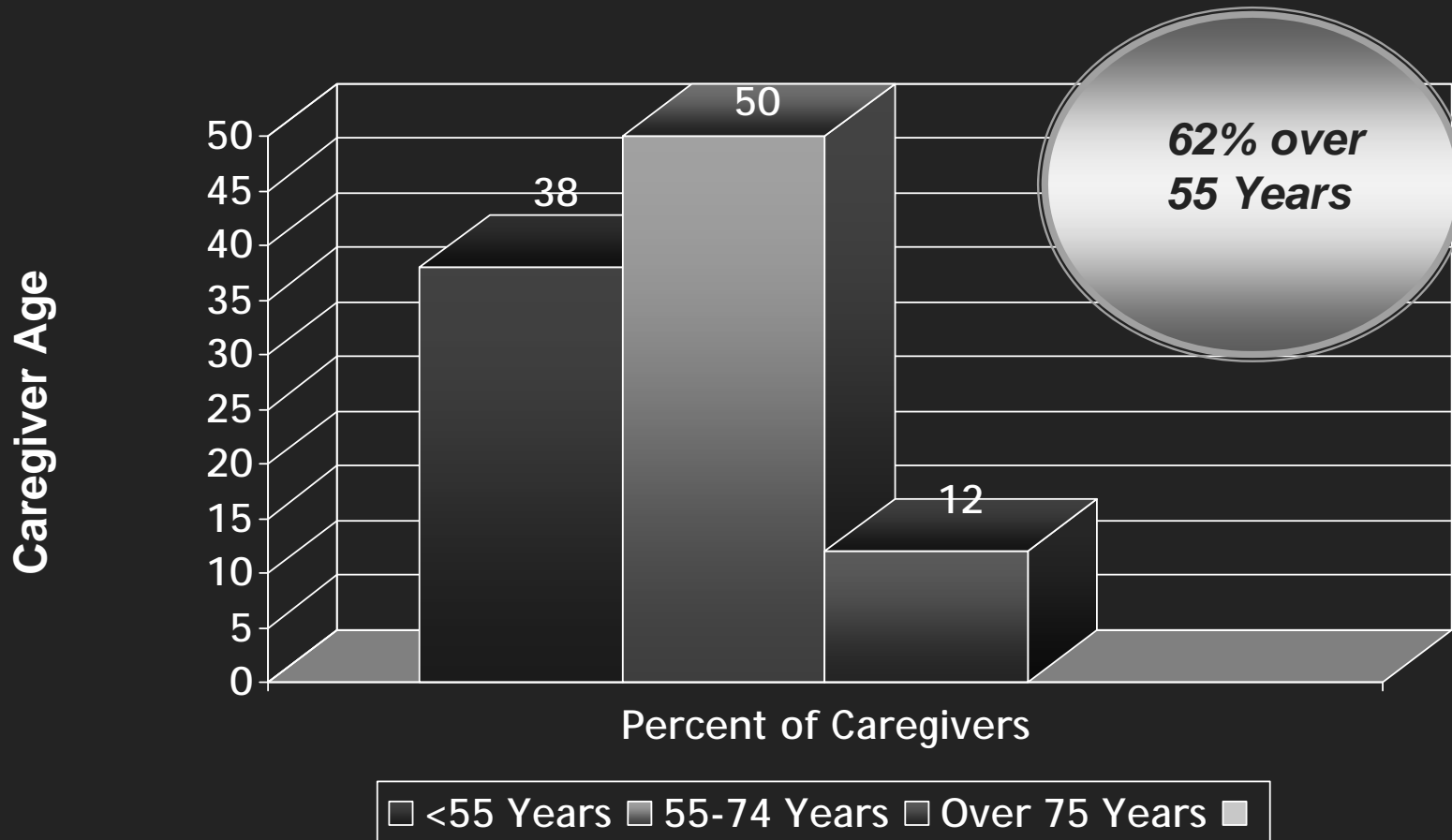
12,193 people interviewed across 19 states and one regional area

What Do We Know About People Living with their Families ? – Red Flags

- Compared to adults in other residential settings, people living with family are least likely to:
 - Report having a best friend
 - Report having any friends
 - See friends when they want to
 - Have had a physical exam in the past year
 - Have been to the dentist in the past 6 months

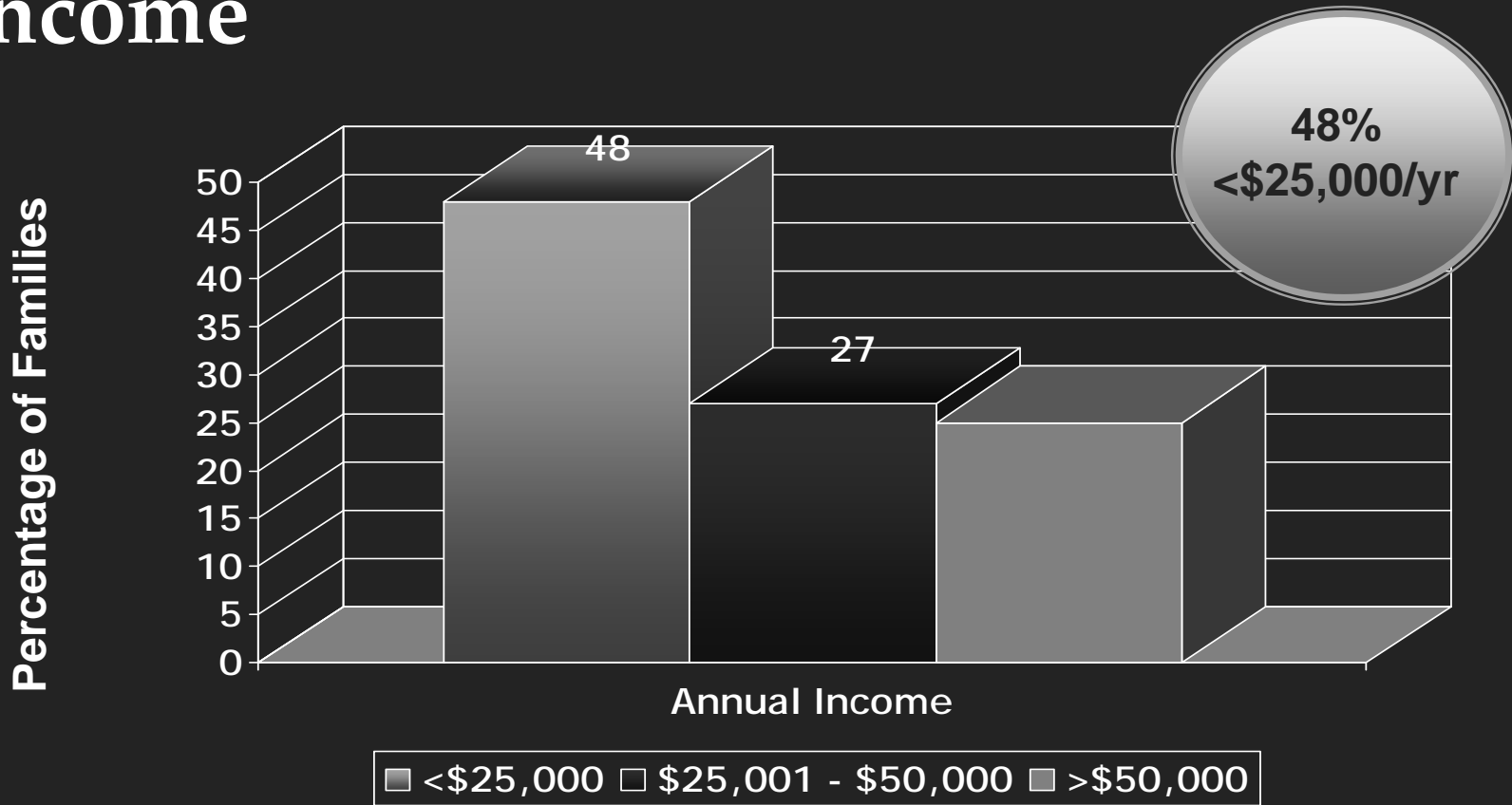
National Core Indicators

Age of Family Caregivers



Source: NCI 2006-07 Adult Family Survey

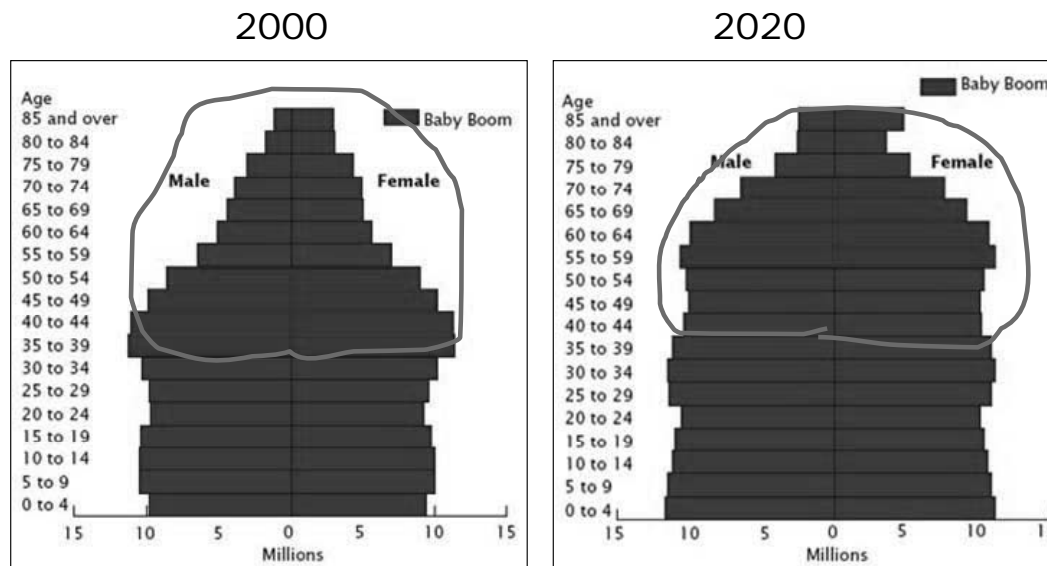
Family Caregivers Annual Household Income



Source: NCI 2006-07 Adult Family Survey

Demographic Trends

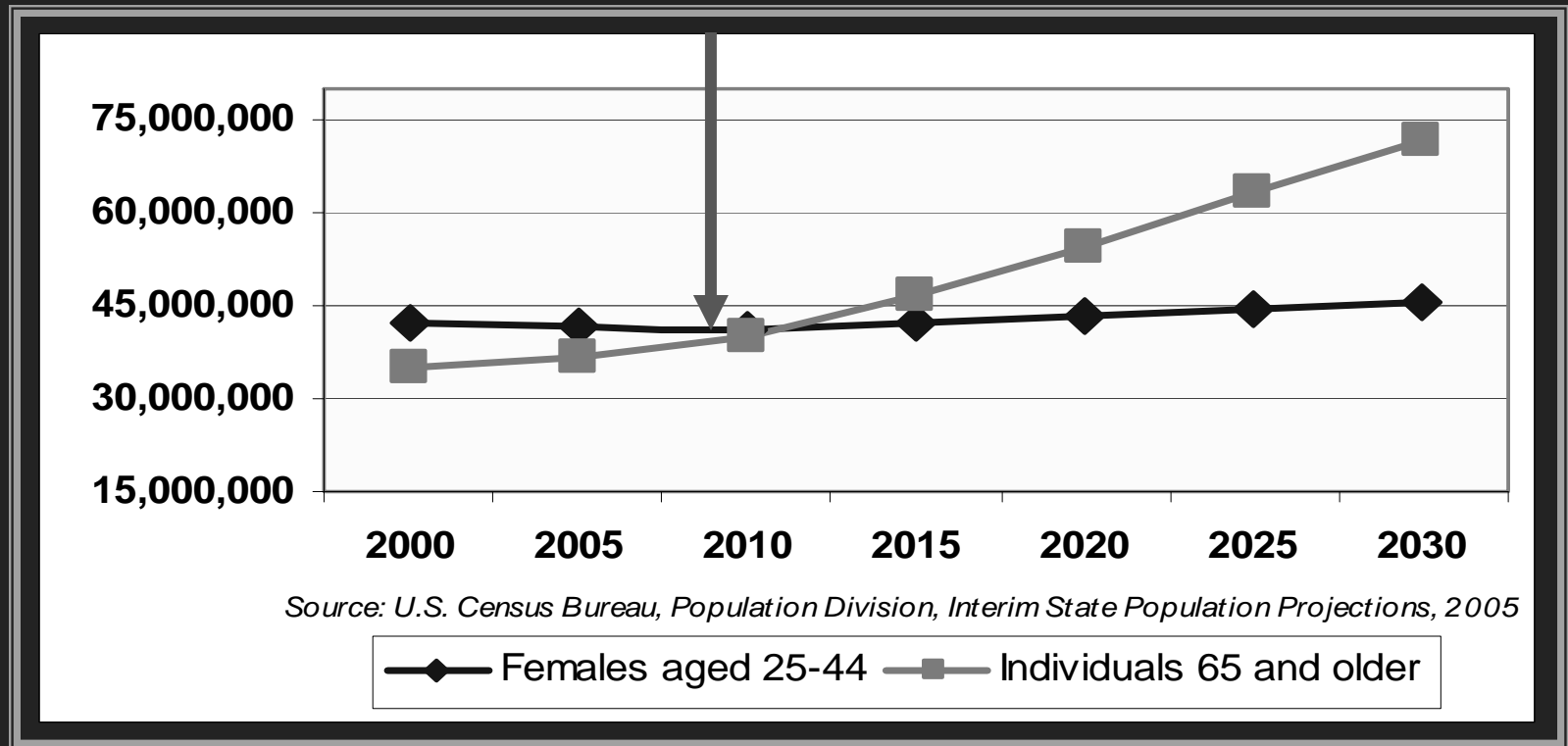
Changing Demographics:



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

Each day, for the next two decades, more than 10,000 Baby Boomers will become eligible for Social Security each day. (The Peterson Foundation)

Demographic Shift = America's Care Gap



Larson, Edelstein, 2006

Abuse and Post Traumatic Stress

- Abandonment; feeling of not belonging – left out
- Ridicule and scapegoating
- Physical and sexual abuse
 - The sexual exploitation of people with disabilities is estimated to be 1.5 times greater than that of the general public.* Sobsey, Dick, R.N., Ed.D.,
 - One study reported that 25 percent of girls and women with intellectual disabilities who were referred for birth control had a history of sexual violence (Sobsey, 1994). Other studies suggest that 49 percent of people with intellectual disabilities will experience 10 or more sexually abusive incidents (Sobsey & Doe, 1991).

Abuse and Post Traumatic Stress

- Any type of disability appears to contribute to higher risk of victimization but intellectual disabilities, communication disorders, and behavioral disorders appear to contribute to very high levels of risk, and having multiple disabilities (e.g., intellectual disabilities and behavior disorders) result in even higher risk levels (Sullivan & Knutson, 2000).
- Children with intellectual disabilities are also at risk of being sexually abused. A study of approximately 55,000 children in Nebraska found that children with intellectual disabilities were 4.0 times as likely as children without disabilities to be sexually abused. (Sullivan & Knutson, 2000).
- Women are sexually assaulted more often when compared to men whether they have a disability or not, so men with disabilities are often overlooked. Researchers have found that men with disabilities are twice as likely to become a victim of sexual violence compared to men without disabilities (The Roeher Institute, 1995).

Restrictive and Aversive Procedures

- We know they are used
- We don't know to what extent
- There are no requirements to report

Part 3.

What are the Challenges?

Health Challenges

- Improving access to health screening and preventive care, so that health problems across the lifespan are promptly identified and treated by nurses, physicians, mental health professionals and dentists who are knowledgeable in the care of persons with I/DD?
- Changing people's lifestyle to increase physical activity and reduce obesity
- Reducing the incidence of physical and sexual abuse and treating post traumatic stress

Part 4.

**Opportunities to Improve the Lives of
People with Intellectual and
Developmental Disabilities**

Health Care Reform

- Increase access to medical care
- Elimination of preexisting conditions
- Emphasis on prevention and healthy life style
- Behavioral health parity
- Medicare/Medicaid integration demonstrations

The Role of States in Health Care Reform

- Health Information Technology – Electronic Medical Record- who will the users be?
- Expansion of Medicaid – people with mild developmental disabilities who will be added to roles
- Health Exchanges – providing information to consumers to make good choices

Working with the State DD Agency

- Policy Development and Program
 - Waiver application to CMS
 - Managed care applications to CMS
 - Provider standards
 - State Quality improvement projects
 - Integration of health practice into program requirements, standards and guidelines
 - Wellness programs
 - Promote employment

Build Capacity

- Mental Health
- Sexuality
- Consumer training and empowerment
- Family instruction

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

