

# **Supporting People with Developmental Disabilities: Changes Patterns and Emerging Practices**

*PASRR Webinar  
December 13, 2011*

Barbara Brent, M.S.

**NASDDDS**

**National Association of State Directors of  
Developmental Disabilities Services**

# ADMINISTRATION OF DEVELOPMENTAL DISABILITIES ACT DEVELOPMENTAL DISABILITIES DEFINITION

➡ *Severe, lifelong disabilities attributable to mental and/or physical impairments, which are manifested before age 22 and are likely to continue indefinitely. They result in substantial limitations in 3 or more of the following areas:*

- Self-care, comprehension and language, skills (receptive and receptive language), learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, ability to function independently without coordinated services (continuous need for individually planned and coordinated services).

# **DEFINITIONS OF INTELLECTUAL/ DEVELOPMENTAL DISABILITY CAN VARY BY STATE**

*Manifested before age 18 instead of age 22*

*Diagnosis of Autism, not ASD*

*Primary diagnosis: intellectual/cognitive disability,  
cerebral palsy, autism or epilepsy, resulting in  
substantial limitations*

*Important to check each state's eligibility*

# SERVICES AND SUPPORTS ARE CHANGING

*Accelerated growth of in-home supports*

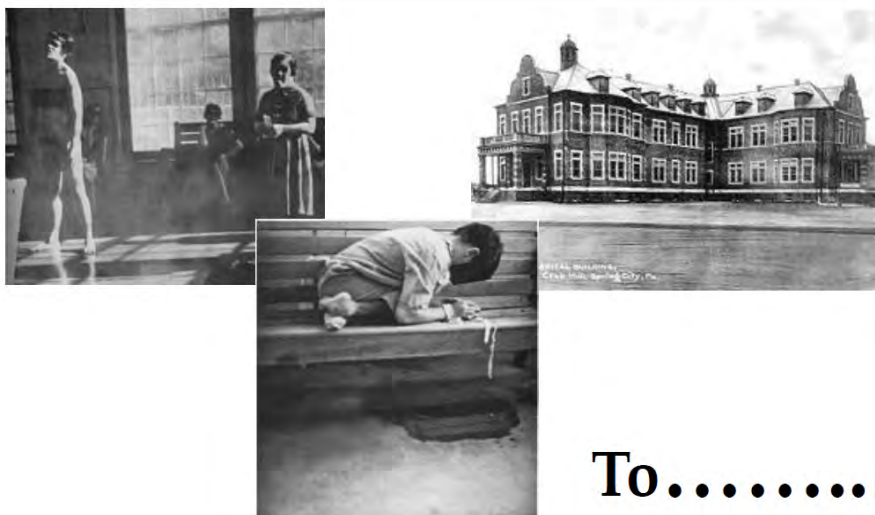
*Out of home settings smaller*

*Increased individual and family voice*

*Emerging services and practices to support individuals with more complex support needs*



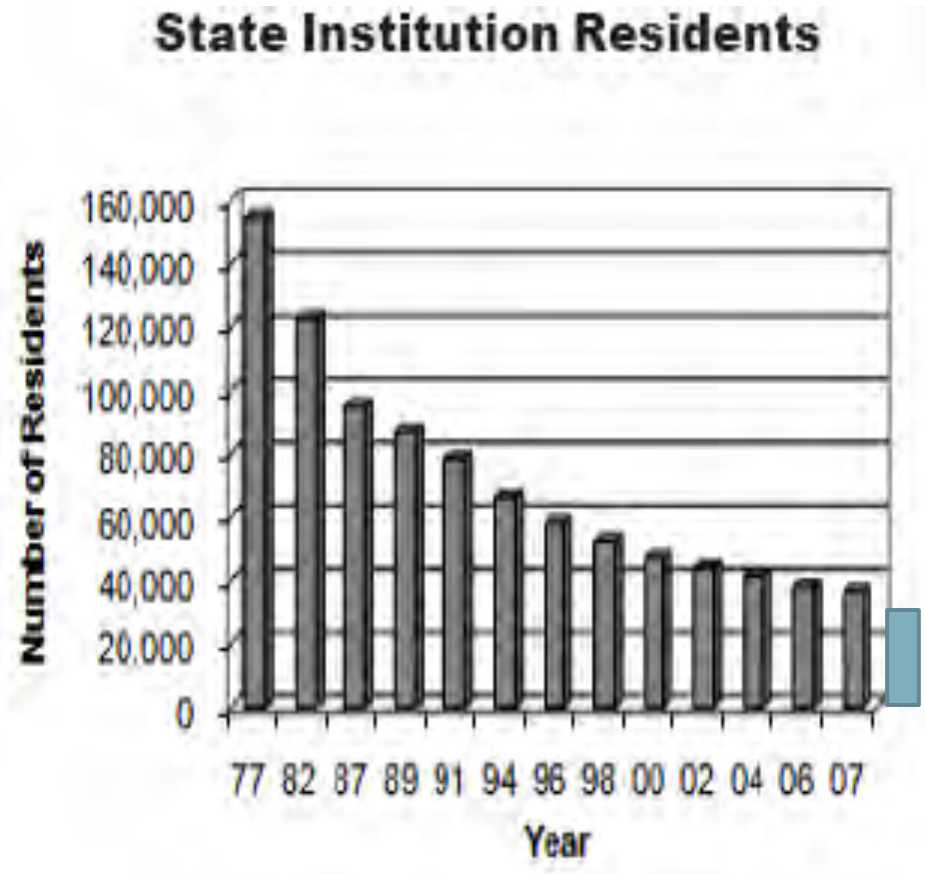
# We Have Made the Leap from



To.....



# Institutional Census Decline



**32,900  
'09**

Source: UMN RTC/ICI





# DRAMATIC INCREASE IN THE NUMBER OF COMMUNITY SETTINGS



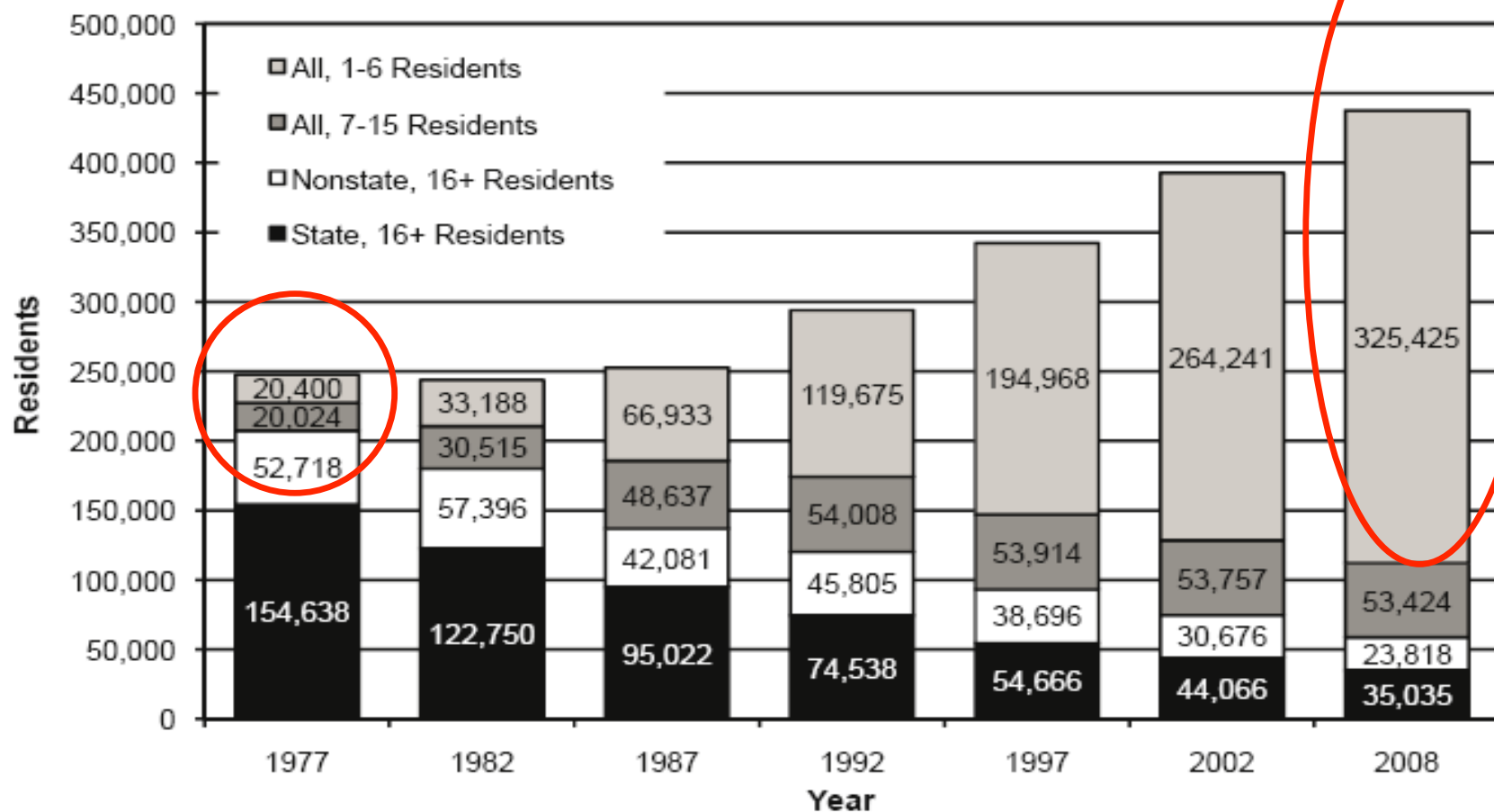
**11,008  
1977**



**173,042  
2009**

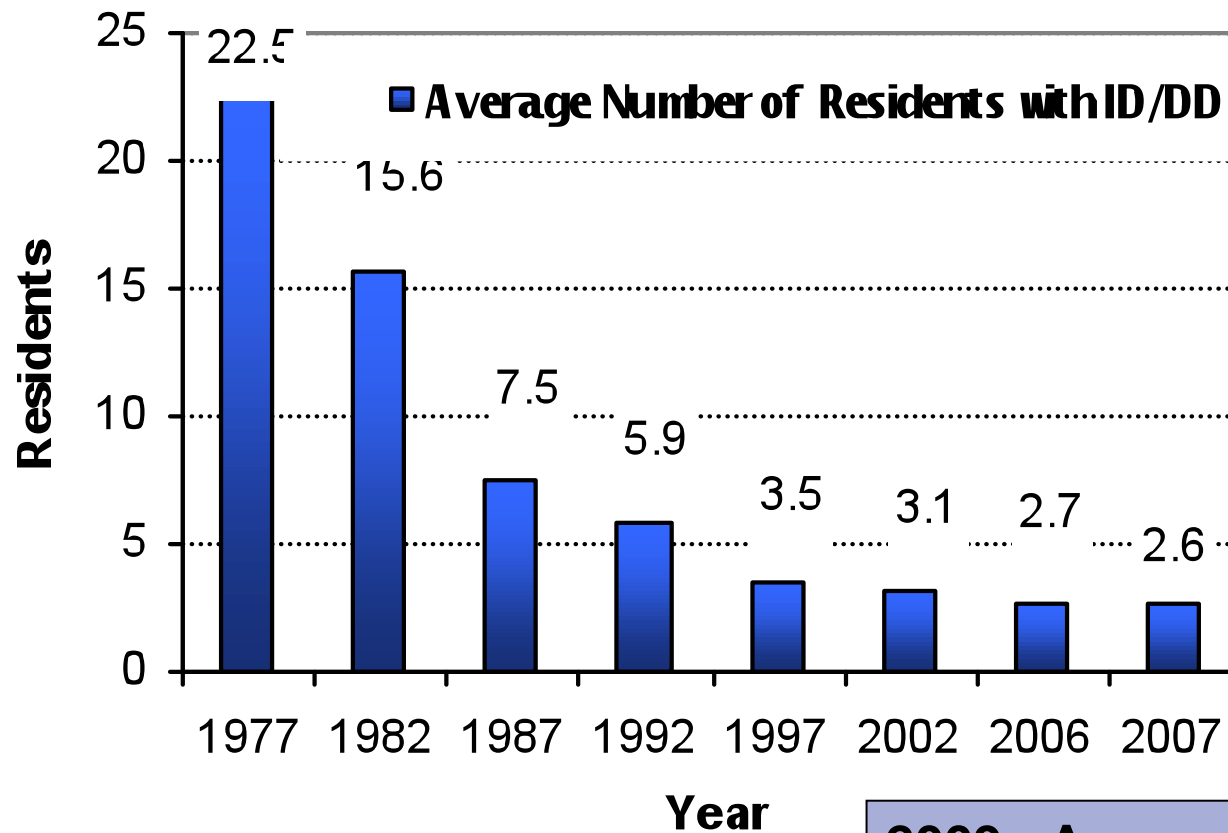
# INCREASING RELIANCE ON SMALL SETTINGS

## Persons with IDD in State and Nonstate Residential Settings 1977-2008





# AVERAGE NUMBER OF PERSONS PER RESIDENTIAL SETTING 1977-2009



**2009 - Average 2.5 persons/  
setting**

Source: UMN RTC/ICI

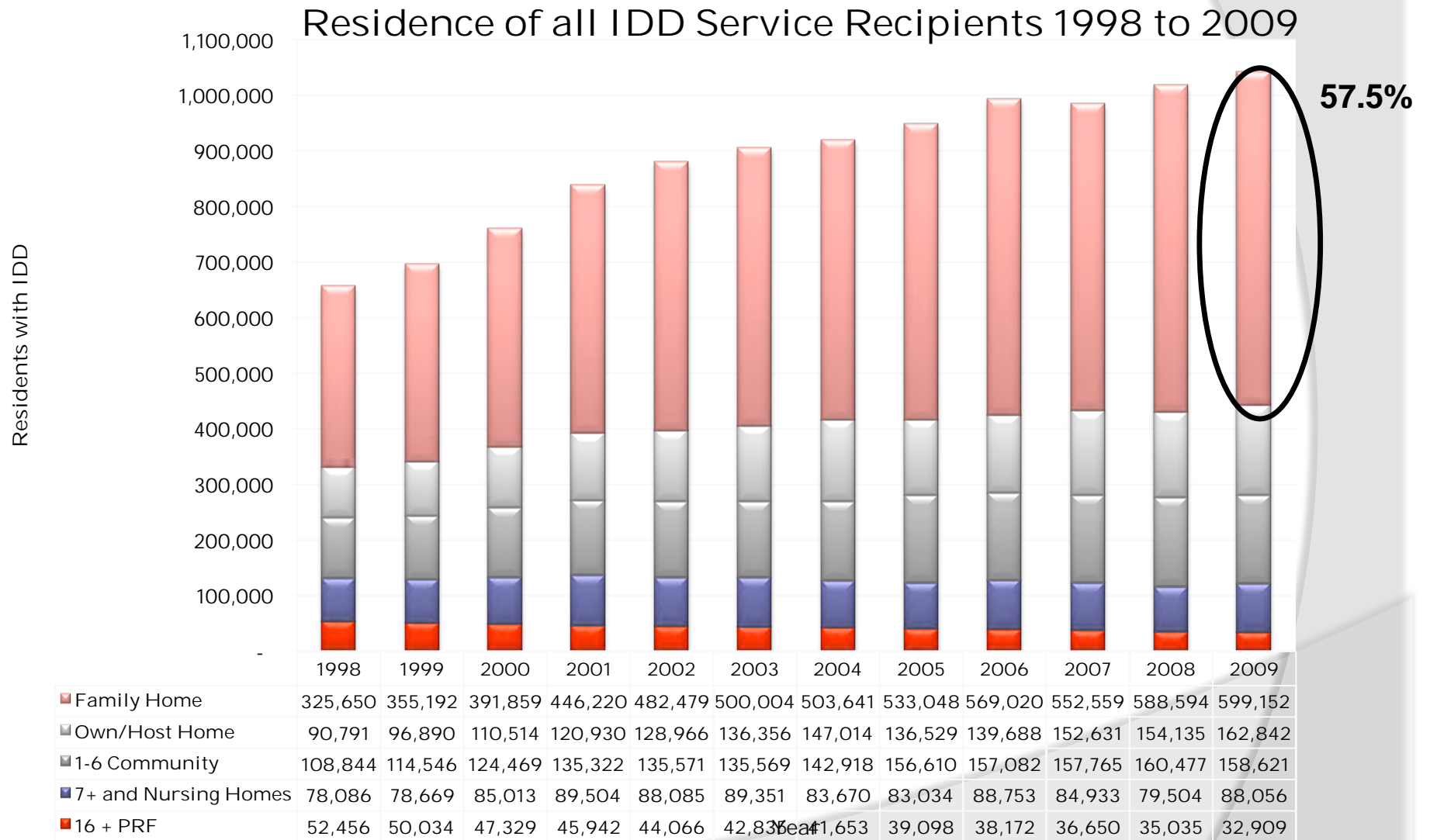
# THE MAJORITY OF ADULTS WITH ID/DD LIVE WITH FAMILIES

- ◎ The number of adults receiving services and supports in the family home is growing
    - 51% in June 2000, 57.7 in 2009
    - 6 states more than 70%
- (Lakin et al, 2009)

What are some of the factors leading to change?



# More People are Living with Family



# FACTORS CONTRIBUTING TO POSITIVE CHANGE:

- ⦿ New options available through Federal initiatives
- ⦿ People with disabilities and family members seeking a typical life in the community with desire to have family members with disabilities live close to home
- ⦿ Dynamic expectations of people's possibilities who have benefited from the Right to Education
- ⦿ ADA and Olmstead obligates states to make services available in the most integrated setting



# EXAMPLES OF FEDERAL INITIATIVES

- ⦿ Medicaid Waiver and Medicaid State Plan options focus on full community inclusion and employment
  - Services such as job coaching, in home assistance, assistive technology, respite care, habilitative therapies, behavior support, home health, attendant care, in-home nursing, intermittent or hourly, family support and support brokers.
- ⦿ Consumer/family directed control through fiscal intermediaries and support brokers
- ⦿ Federal incentives: Money Follows the Person (MFP) and The Balancing Incentive Program (BIP)
- ⦿ Managed care, bundling acute and long term care

# OUTCOMES



- People with developmental disabilities live positive, inclusive lives in communities across the country
- Most people with the most complex health needs reside in community, rather than ICFs/ID or nursing homes



# DEMOGRAPHIC CHANGES

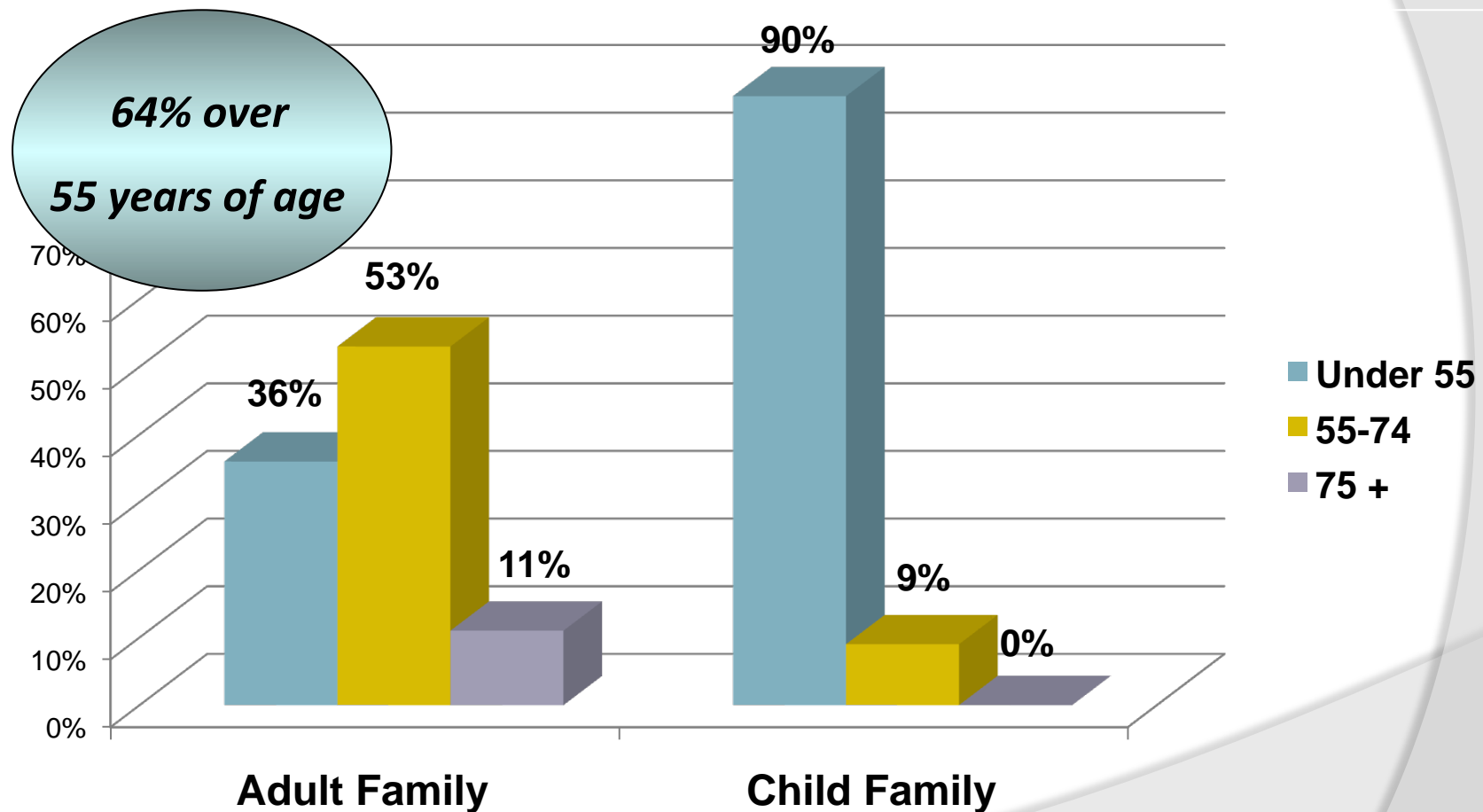


- Many Americans live longer, including people with disabilities, and live with chronic health conditions
- Baby boomers are the talk of health care, social security and other national conversations. Boomers become aging caregivers for a large number of people with developmental disabilities
- Many members of this generation express a desired future to “age in place” and seek models outside of nursing facilities for themselves
- The number of people diagnosed with autism keeps growing

# CHALLENGES IN THE ROAD AHEAD

- ⦿ Waiting lists
- ⦿ Aging caregivers
- ⦿ Economic changes
- ⦿ Keeping abreast of data, research and resource materials regarding Medicare, Medicaid and health care reform when new information is provided frequently

# The Age of Family Caregivers



Source: NASDDDS National Core Indicators

# Challenge

- ⦿ Economic problems have slowed growth in community services resulting in waiting lists

**The Waiting List**

People Waiting	Residential Capacity	Growth Needed
122,870 Lakin 240,000 Kaiser	<b>439,515</b>	<b>28%</b>

- ⦿ With caregivers aging, there is sometimes a desperate search for alternatives

# Response to the Challenge

- ⦿ States are working with families to:
  - Provide robust supports to assist caregivers
  - Engage extended family members
  - Plan earlier for the future
- ⦿ Host homes, developmental homes or shared living with one licensed caregiver, or supported through an agency that can provide nursing services
- ⦿ Improved coordination with acute, long term care and behavioral health

## PASRR PROFESSIONALS PROVIDE A KEY ROLE

- Help others to understand lack of verbal communication is not an indication of person's ability to express themselves. Ask about communication devices and rely on those who know the person best on what is being communicated.
- People with developmental disabilities could temporarily lose daily living skills during an inpatient stay. This can be caused by inability to talk about placement changes and interruptions in routine, but the ADL's can be quickly regained.
- Developmental disabilities are a life-long condition. Recovery models are distinct from progressive learning and support.
- Come visit community programs and become familiar with what is available on a regular basis. PASRR professionals will increase their expertise on referrals, alternatives to nursing homes and outreach to DD agencies.

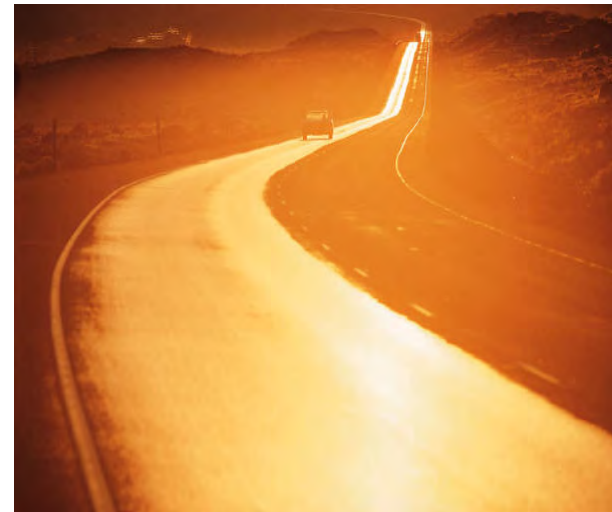


# PASRR PROFESSIONALS PLAY A KEY ROLE

- Support nursing home staff to increase learning about people with developmental disabilities: How people communicate, learning the person's routine before admission (a person may already know how to use the bathroom with prompting and staff need the family/home schedule to maintain the skill).
- Continue to be welcoming to all caregivers; ensuring they are a part of everything possible.
- Be mindful of medication changes. If PRN medications are used for challenging behavior post surgery, note some state's group homes don't allow PRN's to be administered by direct support professionals. Certain medications compromise a person's ability to communicate.

# IN CLOSING

- PASRR work is important and can be a catalyst for change, assuming competence and helping to ensure appropriate placement.
- Thank you for the opportunity to speak today.
- Questions?



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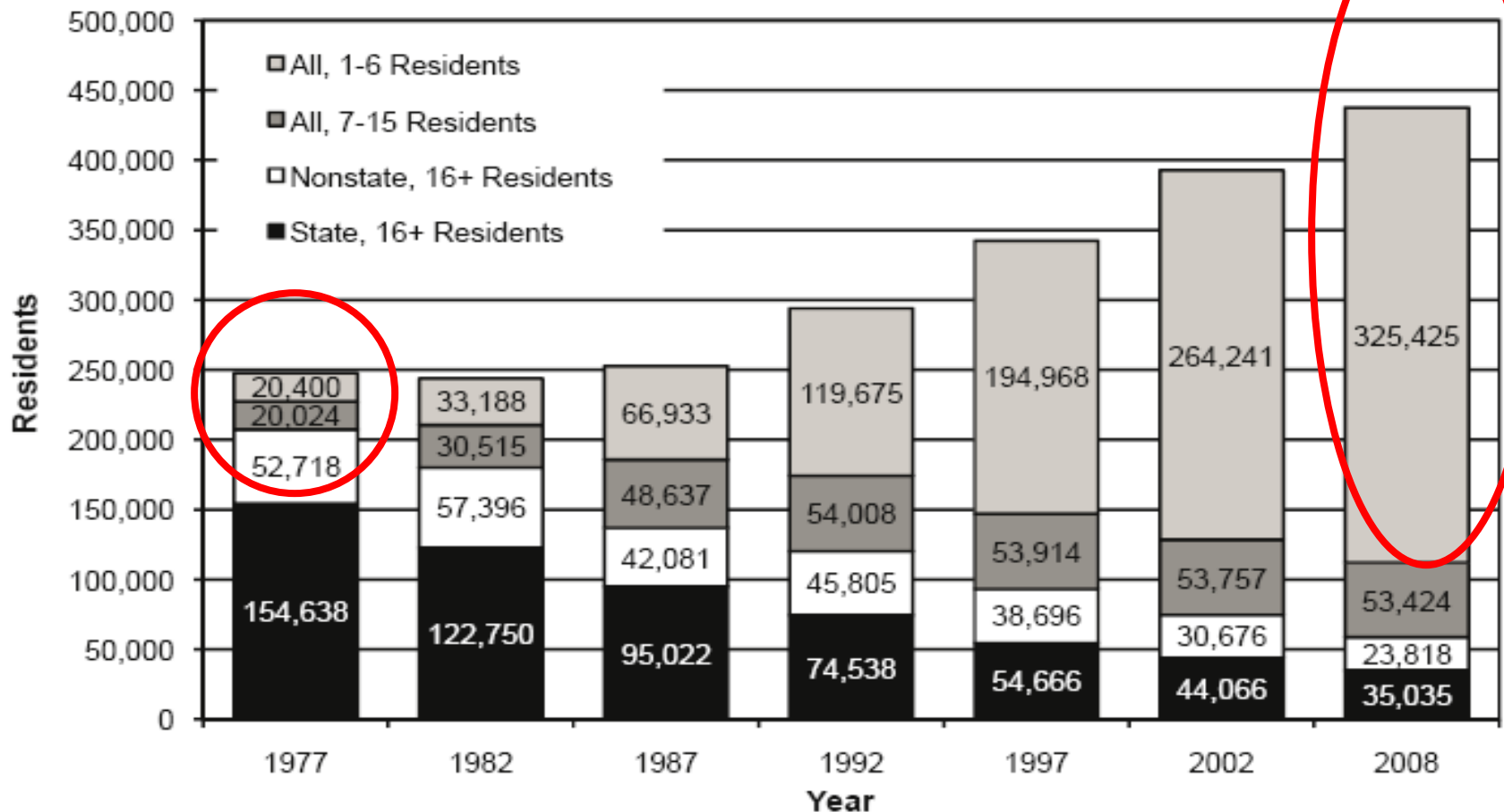


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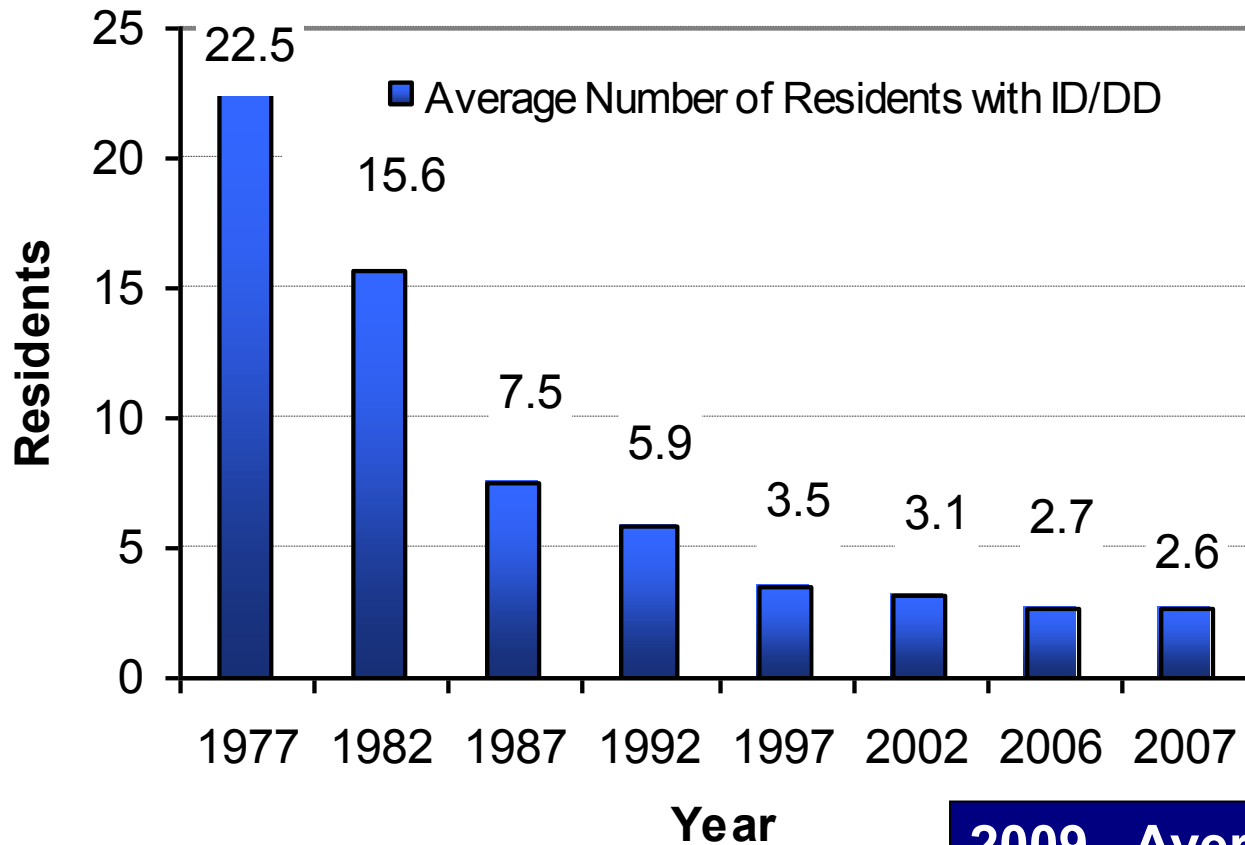
Slide design courtesy of C. Moseley NASDDDS

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# DEMOGRAPHICS

- ◎ Baby boomers are the talk of health care, social security and other national conversations. Boomers are aging caregivers for a large number people with developmental disabilities.
- ◎ Many members of this generation express a desired future to “age in place” and are seeking models outside of nursing facilities for themselves. Conversations include options for family members with disabilities.
- ◎ The number of people diagnosed with autism keeps growing.
- ◎ Many Americans live longer, including people with disabilities, and live with chronic health conditions.

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What are some of the factors leading to change?





# EXAMPLES OF FACTORS CONTRIBUTING TO CHANGE: POSITIVE

- ◎ New options available through waivers
- ◎ People with disabilities and family members seeking alternatives to larger settings, with desire to have families members with disabilities live close to home
- ◎ Stakeholders working together
- ◎ Dynamic expectations of people's possibilities
- ◎ Development of more community options through provider and community development
- ◎ Regulatory reform within states
- ◎ ADA and Olmstead



# EXAMPLES OF WAIVER CHANGES

- ◎ Family support, support brokers, multiple waivers targeted for people with different support needs
- ◎ Services available such as in-home nursing, intermittent or hourly, habilitative therapies, behavior support, home health, attendant care. Focus on increasing community inclusion through employment, volunteering and community engagement.
- ◎ Fiscal intermediary to enhance consumer/family directed choice and flexibility.
- ◎ Waiver authorities with incentives; Money Follows the Person
- ◎ Managed care, bundling acute and long term care

# OTHER FACTORS CONTRIBUTING TO MORE PEOPLE SERVED IN FAMILY HOME: REFLECTIONS

- ◎ Waiting lists (Lakin et al. estimate that there are 122,870 people on state waiting lists for DD residential services. The system would need to expand residential services by 28% over the current 439,515 in order to meet the need.)
- ◎ Declining state revenues
- ◎ Enormous pressure on maintaining Medicaid and state services

While Difficult- - -are there opportunities for new models?

# ENGAGE EVERYONE

- ◎ State agencies set policy and are learning/listening organizations.
- ◎ Provider organizations are a resource for service delivery, connecting to community resources, have close relationships with consumers and families and are essential partners at the table for systems improvement ideas and strategies.



# ENGAGE EVERYONE, CONTINUED

- ◎ Family members and self-advocates are the heart of our work. Their voices inform what supports should look like, how services run now from their experiences and assist to identify gaps. From a systems standpoint, their significant involvement is integral to the development all policies, processes and models. Please don't forget the role of siblings, grandparents and extended family as part of the family voice.
- ◎ If not already in the same state agency, ensure acute care and behavioral health have meaningful involvement.
- ◎ Include non-traditional partners in the community such as businesses, community volunteer and service organizations not necessarily tied to disabilities lend expertise and time.

# **MORE STRATEGIES BEING EMPLOYED TO ASSIST PEOPLE TO LIVE IN THE COMMUNITY**

- ◎ Medical group homes for 6 or fewer people
- ◎ Host homes, developmental homes or shared living in which one caregiver is licensed, or supported through an agency provided nursing services
- ◎ Improved coordination with acute, long term care and behavioral health
- ◎ Service approaches with less than 24 hour shift staff

# REMINDER: FOUNDATIONAL WORK

- If a person is most appropriate for a nursing home, begin admission with discharge planning in mind.
- When a person has developmental disabilities, skills in activities of daily living could be interrupted by an inpatient stay. If the person doesn't communicate easily with nursing home staff, include families and residential staff (if person came from group or host home) each step of the way as to person's baseline skills set. Include family members and residential staff anyway!
- The team should meet to discussion discharge planning and support needs. Ideally, the team should meet ahead of any health or behavioral crisis for advance planning, but not all circumstances can be predicted.
- Consumers, families and residential staff can be provided checklists of medical information, signs and symptoms of illness, prevention and when to see a doctor. People are already knowledgeable, but there is so much to gather, quick fact sheets, a medical "passport" and related tools can make it easier.



# REMINDER: FOUNDATIONAL WORK

- ◎ Likewise, nursing home staff benefit from continuing training on how to listen to people with limited verbal communication, reaching out to families, caregivers and those that know the person best to understand what the person is saying (the person hurts, is sad, lonely, doesn't feel well, is happy, wants to eat, etc)
- ◎ Continue to be welcoming to all caregivers; make sure they are a part of everything possible
- ◎ Continue to be mindful of medication changes. If PRN medication was used for challenging behavior to keep a person from taking off O2, for example, note that some state's residential group homes don't allow PRN administration by direct support professionals



# IN CLOSING

- ◎ PASSR work is important and can be a springboard for change, as well as ensuring appropriate placement.
- ◎ Thank you for the opportunity to speak today.
- ◎ Questions?

