

**DEMOGRAPHICS**

- Total U.S. Census population 290,286,350 in 2004.
- 18% or 51.2 million people in the U.S. are individuals with disabilities.
- 12% or 32.5 million people in the U.S. are severely disabled.
- 1.58% or 4.618 million people in the U.S. have MR/DD.
- 0.78% or 2.308 million people in the U.S. have MR only.

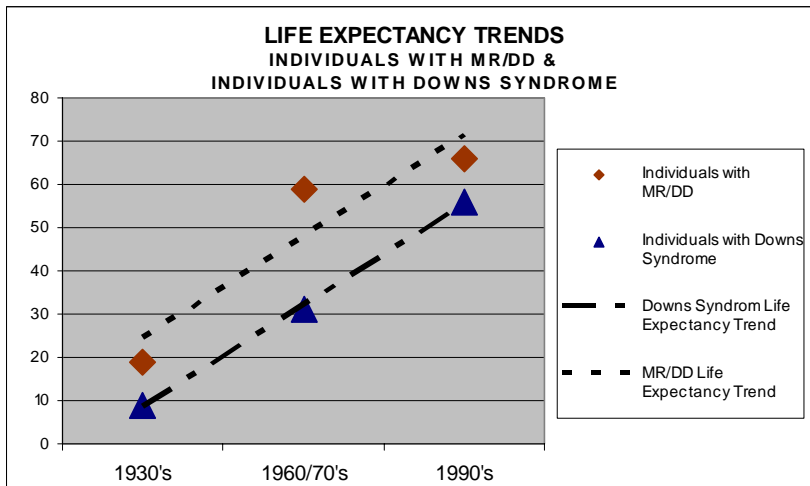
IL total population: 12,562,462.

IL has approximately 198,487 people with MR/DD and 97,987 people with MR (based on 2004 U.S. prevalence rates).

People with MR/DD supported in IL FY05:  
 10,457 persons in HCBS waiver,  
 9,592 persons in ICFs/MR, and  
 635 persons in nursing homes.

**MR/DD TRENDS – UNITED STATES**

- A total of 545,429 people received services from either HCBS waiver or ICFs/MR, a 12.4% average annual increase ('92 - '05).
- 443,608 (81%) of the people were served by HCBS waiver (an increase from the 16.4% in HCBS in 1987) and 101,821 in ICFs/MR.
- 411,215 people lived in residential settings; 291,142 (71%) in settings of 6 or fewer.
- 101,143 people lived in homes they owned or leased, a 5.6% decrease from FY04.
- 35,386 people lived in family/foster care, a decrease of 11.2% from FY04.
- 73,828 on waiting lists (41 states) for residential services.



- In 2004, 641,000 individuals with developmental disabilities were over the age of 60.
- In 2030, 1,242,800 individuals with developmental disabilities will be over the age of 60.
- 35% of people with MR/DD live with caregivers between ages of 40-60.
- 25% live with caregivers over the age of 60.

## MEDICAID FUNDING FACTS

### IL HCBS Waiver Expenditures (FY05):

HCBS Waiver (7 waivers):  
\$825,951,173  
MR/DD (1 waiver):  
\$418,648,223  
Aging/Disabled (2 waivers):  
\$156,677,514  
Physically disabled (1 waiver):  
\$188,207,865  
Additional waivers (3 waivers):  
\$62,417,571

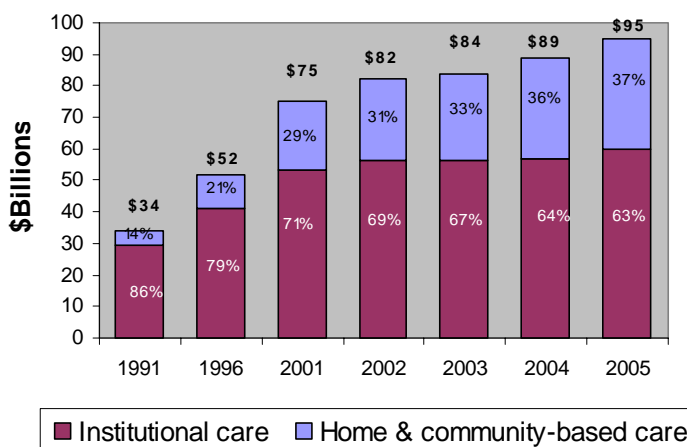
### Illinois

- Medicaid enrollees 2,177,300 residents (17% of population) in FY03.
- Blind or disabled enrollees 265,800 in FY03.
- Total Medicaid spending \$11.2 billion in FY05.
- Nursing home care accounted for 48% of long term care spending in FY04.
- Home/personal care accounted for 27% of long term care spending in FY04.
- IL was 38<sup>th</sup> in fiscal efforts in FY04 for services for individuals with MR/DD, down from 36<sup>th</sup> in 2002.
- 312 ICFs/MR, 9 state serving 2,763 and 303 private serving 6,829. ICF/MR spending is \$328.9 million for public ICFs/MR and \$359.3 million for private, for total of \$688.2 million (FY05).
- Waiting List: Did not furnish number on waiting list as of FY05.

### United States

- All Long Term Care (personal care, home health, HCBS waiver, nursing home, ICF/MR) spending increased 3.8% to \$94.5 billion (expected to increase by 5% after final adjustments) in FY05.
- All Community Based LTC services (HCBS waivers, personal care, home health services) spending increased by 6.1% to \$35.2 billion in FY05.
- MR/DD spending increased 5.7% to \$38.55 billion (FY02 - FY04).
- HCBS waiver spending increased 5.4% to \$22.7 billion (FY05).
- HCBS MR/DD spending increased 5.3% to 17.2 billion, an average of \$38,679 per person (FY05).
- ICF/MR spending increased 0.6% to \$12.1 billion; \$7.5 billion in public and \$4.6 in private settings, an average of \$117,600 per person in FY05.

Growth in Medicaid Long-Term Care Services Expenditures, 1991-2005



## WORK FORCE & FAMILY CAREGIVERS – UNITED STATES

- \$8.86/hr average pay for direct support professionals (majority are women supporting families) yielding an annual income of \$18,054 - below poverty level of \$19,350 for a family of 4.
- Number of people needing Personal Assistance Services (PAS) is expected to double from 2000 to 2050 (13 million to 27 million).
- 55.3% PAS pay increase, \$5.41/hour to \$8.40/hour for '89 – '04; nursing home aide pay increased 79% and food workers 85.5% for same period.
- "Unpaid care" by a relative or friend valued at \$257 billion per year, twice amount on paid care.
- 1 of 6 people in the U.S. (50 million) provides care for a chronically ill, aged or disabled friend or relative without public funds.

**IL: 1,193,025 family caregivers provide 1.3 billion hours of care = 11.3 billion dollars (03).**

## Medicaid Services Are Critical For Our Future

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U.S. Census Bureau, 2004 data & Survey of Income, 2002; Kaiser Comm. Medicaid and Uninsured Fact Sheet, 8/06; *Residential Services for Persons with Developmental Disabilities: Status & Trends 2005* – K.C Lakin et al. (July 2006); *State of the States in Developmental Disabilities*, D. L. Braddock, et al., 2005; Thomson Medstat Medicaid Long-term Care & HCBS Waiver Expenditures July FY 05; Report – Invitational Research Symposium on with Aging DD, 2001; Personal Assistance Workforce, Trends, H. S. Kaye et al. Health Affairs, 2006; Caregiving Statistics, National Family Caregivers Association. Details at [www.ANCOR.org](http://www.ANCOR.org).