

CHILDREN AND YOUTH IN STATE INSTITUTIONS

<u>Year</u>	<u>% of Total Residents in State Institutions</u>	<u>Est. Number</u>
1950	38.9%	48,354
1965	48.9%	91,592
1977	53.8%	54,130
1982	22.0%	26,254
1987	12.7%	12,026
1989	10.6%	9,230
1991	8.7%	6,944

Lakin, C, Blake, E., Prouty, R.W., Managan, T. & Bruininks, R.H. (January 1993). Residential services for persons with developmental disabilities: Status and trends through 1991 (Report #38). Minneapolis: University of Minnesota, Institute on Community Integration.

National Survey of Public Residential Facilities June 30, 1994

As of June 30, 1994, 1.5% of the residents of large facilities (16 or more residents) were ages 0-14; and 4.6% of the residents of large facilities (16 or more residents) were ages 15-21; total of 6.1% of residents of large facilities were ages 0-21.

NOTE: This survey has not been completed; data are still being collected and analyzed. Any additional or more specific information is not yet available.

CHILDREN IN NURSING HOMES

According to 1987 data:

- * An estimated 3,967 children between the ages of 0-12 lived in nursing homes. Of that total estimated number, approximately 2,797 children had a primary diagnosis of mental retardation or a related condition; and 1,170 children had a medical condition as the primary diagnosis

in addition to mental retardation or a related condition;

- * An estimated 3,817 children/young adults between the ages of 13-21 lived in nursing homes. Of that estimated number, approximately 3,232 children/young adults had a primary diagnosis of mental retardation or a related condition; and 585 children/young adults had a medical condition as the primary diagnosis in addition to mental retardation or a related condition;

Based on a total estimated population (all ages) of 300,000 individuals who lived in nursing homes, the percentage of children/young adults is about 1%.

Lakin, C., Prouty, R.W., White, C.C., Bruininks, R.H., & Hill, B.K. (March 1990). Intermediate care facilities for persons with mental retardation (ICFs-MR): Program utilization and resident characteristics (Report #31). Minneapolis: University of Minnesota, Institute on Community Integration.

**CHILDREN/YOUTH UNDER AGE 22 RECEIVING
HOME AND COMMUNITY BASED SERVICES (HCBS) WHO WERE
ALSO LIVING OUTSIDE OF THE FAMILY HOME**

With 20 states reporting data, a total of 58.2% of children/youth under the age of 22 (1,328 individuals out of a total of 2,280 individuals) were receiving HCBS services and living outside of the family home.

Prouty, R.W. & Lakin, C. (June 1991). A summary of states' efforts to positively affect the quality of Medicaid home and community-based services for persons with mental retardation and related conditions (Report #34). Minneapolis: University of Minnesota, Institute on Community Integration.

Minnesota Data:

As of June 1991, about 24% of children, ages 17 and under, received Medicaid long-term services in ICFs/MR (139 children out of a total of 589 children); 447 children were receiving HCBS in family settings.

Lakin, C, Burwell, B.O., Hayden, M. F., & Jackson, M.E. (March 31, 1992). An independent assessment of Minnesota's Medicaid home and community based services waiver program (Report #37). Minneapolis: University of Minnesota, Institute on Community Integration.

**PROPORTION OF CHILDREN/YOUTH LIVING IN
ICFs/MR BETWEEN 1982 AND 1992**

In 1982, more than 25% of people living in ICF/MR in 18 states were under the age of 22 (approximately 35,269 individuals). In 1992, only three states reported that percentage.

Four states (Alabama, Arizona, New Hampshire, North Dakota) reported increases in the proportion of children and youth in ICFs/MR between 1982 and 1992.

Four states reduced the proportion of children and youth ages 0-21 who lived in ICFs/MR by more than 30 percentage points (Hawaii, Oklahoma, West Virginia, District of Columbia).

Larson, S. & Lakin, C. (March 8, 1995). OSCAR 1992 analysis and report: Changes in the ages of ICF-MR residents between 1982 and 1992. Minneapolis: University of Minnesota, Institute on Community Integration.

**CHILDREN AND YOUTH IN THE RESIDENTIAL SERVICE SYSTEM
JUNE 30, 1977 TO JUNE 30, 1994**

In 1994, a total of 10,427 children and youth lived in residential settings, other than natural/adoptive homes, and made up 10.2% of the total number (102,225) of individuals receiving Medicaid HCBS.

Given the 1992 national average costs of:

Large nonstate ICFs/MR = \$ 36,269, and
Community ICFs/MR = \$ 55,682;

AND:

1993 HCBS service costs (SSI contributing \$ 30,408), and
State financed out-of-home services (SSI contributing
\$ 14,500);

The total costs for residential services for 41,701 children and youth outside of state institutions = \$1.1355 billion

The number of children and youth with developmental disabilities, ages 21 and younger, living in state institutions decreased from 54,095 individuals as of June 30, 1977 to 4,048 individuals as of June 30, 1994;

The average annual per person cost of state institution services in the United States in FY 1994 = \$86,000

The decrease in state institution costs that can be associated with the decrease in the number of children and youth living in state institutions can be directly estimated to be \$4.304 billion.

Approximately 240,000 children and youth receive SSI benefits totaling about \$1 billion. The average benefit is about \$4,000 compared with the average cost of placement which is about \$25,000.

Lakin, C. (March 1995). What has happened with children youth within the residential service system during the period subsequent to the creation of the education entitlement P.L. 94-142 and the development of related supports
Minneapolis: University of Minnesota.

**ILLINOIS EXPERIENCE: COST AND SERVICE COMPARISON FOR
PEOPLE WITH DEVELOPMENTAL DISABILITIES WHO
LIVE AT HOME OR A RESIDENTIAL FACILITY**

In 1988, one in nine individuals with developmental disabilities lived in a residential facility. For each person living in a residential facility, the state spent 16 times the amount that was spent for a person living at home - \$26,570 per year compared with \$1,618 per year;

Illinois maintains 13 facilities that are licensed to provide skilled nursing care to children:

FY 1988 funding:	\$ 26,744,400
Estimated number of children:	1,140
Cost per child:	\$ 23,460

Illinois maintains 11 licensed Child Care Institutions (CCIs)

FY 1988 funding:	\$ 13,835,000
Estimated number of children:	642
Cost per child:	\$ 21,550

The Department of Rehabilitation Services (DORS) operates three residential schools for children:

FY 1988 funding:	\$ 5,006,400
Estimated number of children:	120
Cost per child:	\$ 41,720

* The estimated number of people with developmental disabilities in Illinois is 149,643;

* The estimated number of people with developmental disabilities living in residential settings is 17,147 individuals (represents 11.5% of 149,643);

- * The estimated annual cost to provide services in residential settings for 17,147 individuals is \$ 409,337,000;
- * Approximately 88.5% (132,496) of the total number of people with developmental disabilities live with families or independently;

It is assumed that 10% of the above number of individuals are on waiting lists for services; therefore, the total number of persons living at home who are in contact with the service system is about 88,500;

The total "at home" cost is \$ 214,380,200;

Therefore, the average "at home" cost per person is \$2,422;

(Given all of the above, an estimated annual cost to provide services in residential settings for all people with developmental disabilities would be \$ 3,559,452,100).

Louro, C., Miller, L., Morton, D., & Clucas, C.
Family support: Meeting the challenge in Illinois
Springfield: The Governor's Planning Council on
Developmental Disabilities.