



# CALIFORNIA COMMUNITY RESIDENTIAL FACILITIES FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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## Abstract

Evolving residential requirements for individuals with mild and moderate intellectual disabilities and related developmental disabilities increasingly place these people in community settings. The increasing numbers of these individuals are dependent upon local practitioners for needed health services. National and California data are reviewed in an effort to provide a general awareness of these community living arrangements, which in turn may assist in the delivery and the follow-up of oral health services.

In 2003, there were an estimated 145,580 residential settings in the United States in which those with intellectual disabilities and related developmental disabilities, ID/DD, received services. These settings exclude psychiatric facilities, nursing homes and private homes in which people received services while living with family members. In 2003, approximately 35,000 people with ID/DD were residents of nursing homes. These facilities were state-operated or state-licensed residential service providers. In the past 25 years, the number of these residential settings has grown more than 11-fold.<sup>1</sup>

The dramatic increase in the number of smaller residential settings for care (99 percent had 15 or fewer residents, 94 percent had six or fewer residents, and more than 95 percent of nonstate-operated settings had six or fewer residents) is a consequence of the deinstitutionalization of individuals with ID/DD. In 1967, there were more than a quarter of a million U.S. individuals with ID/DD in large state institutions. Changing social policies, favorable legislation for individuals with disabilities, and class-action legal decisions, which delineated the rights of individuals with ID/DD, have led to deinstitutionalization (i.e.

“mainstreaming,” establishment of community-oriented group residences and enhanced personal family residential settings) and closure of many state-run large facilities. For example:

■ In 1977, there were about 54,100 child and youth residents with ID in these large state facilities. By 2000, the number of these young residents in the remaining 189 large facilities had decreased to 2,100 individuals.

■ The total number of individuals of all ages in these locations had decreased from 151,100 (in the mid-1970s) to 47,300 by the beginning of the new century.<sup>2,3</sup>

■ By 2003, nationally, almost one-third of a million individuals with ID/DD, including 44,500 California residents, lived in facilities with fewer than 16 residents (Table 1).



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## Residential



## Facilities

**Table 1**

**Number of California and U.S. residents (in thousands) with intellectual disabilities and related developmental disabilities living in small and large residential facilities: 1977, 1991, 2003<sup>1</sup>**

Year	California			Rate per 100,000 pop.	United States			Rate per 100,000 pop.
	< 16	16+ (in 000s)	Total		<16	16+ (in 000s)	Total	
1977	8.9	17.3	26.1	120	40.4	207.4	247.8	115
1991	20.1	12.3	32.5	107	161.9	125.3	287.2	114
2003	44.5	6.4	50.9	153	329.8*	72.5*	402.3	143

\* Estimated

In the past, the residents with ID/DD in the state institutions received needed dental and medical services from health practitioners in the clinical facilities of these large residential institutions. But, most of the community residential facilities are too small in size to provide needed dental services. As a consequence, individuals with ID/DD who reside in our communities are dependent upon local practitioners for needed oral health services. There is the added reality that many of these individuals with special needs, who now reside in our communities, are members of families that already are patients of record of most local dental practitioners. See a previous presentation in the *Journal of the California Dental Association* for an extended review of the geographic distribution of the almost 300,000 children with disabilities in the state.<sup>4</sup>

When community dental practitioners are called upon to provide the needed care for individuals with ID/DD, as with the care of most patients, a general awareness of living arrangements may assist in the delivery and the follow-up of oral health services.

**Table 2**

**U.S. residential facilities for individuals with intellectual disabilities by employment size of enterprise: 2001<sup>5</sup>**

Number of employees per firm	Firms	Establishments	Total number of employees (in 000s)	Avg. salary per employee (in 000s)
<20	1,839	1,883	12.4	\$16.4
20-99	1,093	2,353	48.7	\$17.4
100+	1,219	12,279	232.2	\$18.9
Total	4,151	16,515	293.3	\$18.6

### Firms, Establishments and Residences

In 2001, the Census Bureau reported that for nonstate enterprises with employees, there were more than 293,000 individuals employed by 4,151 commercial firms that maintained 16,515 establishments for residents with ID/DD. An establishment is a single physical location where services are performed. It is not necessarily identical to a firm, company or enterprise, which may consist of one or more establishments. The average annual salary for an employee, including full- and part-time employees, was \$18,600, with employ-

ees of smaller firms averaging \$16,400 (Table 2). For the most part, residency personnel tend to receive wages at the lower end of the salary scale.<sup>1</sup>

■ Only Mississippi reported that a majority of individuals with ID/DD who were receiving residential services lived in larger facilities, 16-plus residents.

■ There has been a slow increase in the number of people with ID/DD, 42,300 in 2002, living in host family/foster care settings.

■ About 22 percent of people receiving ID/DD residential services live in their "own home" that they own or lease.

■ Almost an estimated 500,000 individuals with ID/DD reside in their family homes.

## Residents

### National

Large facilities with ID/DD populations are overwhelmingly made up of non-elderly adults and increasingly, middle-aged adults. In 2002, 86 percent of residents in large institutions were between the ages of 22 and 62.

■ Every state, except Alaska and Vermont, operated at least one large state ID/DD facility.

■ The average annual per person cost in a large facility was \$131,000 in 2003.

■ Males remain a substantial majority among residents in large facilities, 63 percent in 2002.

■ Individuals with the most severe and profound cognitive impairment represent an increasing proportion of the residents in large state facilities, almost two-thirds of all residents in 2002. Those with mild or moderate intellectual disabilities increasingly reside in local community facilities.

■ In mid-2002, based on reports from 36 states, an estimated 60,000 individuals with ID/DD were awaiting residential services.<sup>1</sup>

### California

In line with the national transfer of individuals with ID/DD to smaller facilities, more than 87 percent of California residents with ID/DD receiving residential services live in locations with fewer than 16 individuals. Corresponding with national data, residents of these smaller community facilities primarily are people with mild or moderate intellectual disabilities.

**Table 3**

### California and U.S. individuals with intellectual disabilities and related developmental disabilities residing in state and nonstate run institutions: 2002<sup>1</sup>

Residential setting	California Number of residents				United States	
	1-3	4-6	7-15	16+	Total	Total
Nonstate-run		42,053*	1,775	3,007	46,835	336,113
State-run	0	0	0	3,671	3,671	56,627

\* Includes both 1-3 and 4-6 residents.

**Table 4**

### Per diem expenditures for California and U.S. individuals with intellectual disabilities and related developmental disabilities residing in state institutions: 1977, 1991, 2003<sup>1</sup>

Year	California	United States
1977	\$55	\$44
1991	219	206
2003	489	359

**Table 5**

### California and U.S. youngsters (newborn to 21 years) with intellectual disabilities and related developmental disabilities as a proportion of total population with ID/DD living in residential facilities: 1977, 1991, 2002<sup>1</sup>

Year	California	United States
1977	39 percent	36 percent
1991	13	9
2002	6	5

■ In most years since the mid-1970s, California has had a higher ratio of individuals with ID/DD living in residency facilities (153 people per 100,000 state residents in 2003) than the national average (143 individuals per 100,000 of the general population). The highest rate,

in 2002, was reported by North Dakota (319 people per 100,000 state residents); the lowest by Arizona (56 persons per 100,000 state residents) (Table 1).<sup>1</sup>

■ All of the individuals with ID in smaller residential facilities live in non-state-run residences (Table 3).

## Residential



## Facilities

■ Per diem expenditures for California individuals with ID/DD residing in state institutions reached \$489 in 2003. Since the mid-1970s, California per diem expenditures consistently have been higher than the national average (Table 4).

■ In the mid-1970s, youngsters through age 21 represented 39 percent of all California residents with ID/DD residing in large state institutions. By 2002, youngsters who represented 6 percent of residents with ID/DD lived in these institutions (Table 5).

### Significance of Change

Smaller state-operated and state-licensed voluntary and commercial enterprises, family residencies, and just about any combination of community locations now provide the primary setting for the increasing number of individuals with ID/DD who live in our neighborhoods. The perception that somehow these individuals with special health care needs are cared for in some “out of the way” location by government employees no longer rings true.

The facts are:

■ Almost one-third of a million individuals with ID/DD, more than 44,000 in California, live in small residential facilities.

■ In line with the national transfer of individuals with ID/DD to smaller facilities, more than 87 percent of California residents with ID/DD receiving residential services live in locations with fewer than 16 inhabitants.

In many ways, community group homes have become variations of family arrangements for individuals with mild or moderate intellectual disabilities.

The added reality is that these individuals are long-term residents of our communities who require a wide range of services: from employment to recreation, as well as needed social and health services. An increased awareness of the changed residential setting in our communities for individuals with intellectual disabilities and related developmental disabilities can only improve the potential for the delivery of needed care. **CDA**

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