Feature Article

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A survey of the availability of dental services to developmentally disabled persons residing in the community

Public Law 88-164, enacted in 1963, has led to extensive deinstitutionalization of persons with mental retardation from a peak census of 194,650 in 1967 to 91,440 by 1988. This population now depends on the community-based health care system for medical and dental care. A survey conducted to determine the availability of dental care to the developmentally disabled residing in group homes located in north central Florida indicated that 40% of caretakers experienced difficulty in locating dentists willing to provide comprehensive dental services for residents. According to the caretakers, although 75% of the residents were cooperative dental patients, dentists were reluctant to provide services for a variety of reasons, including financial disincentives, inadequate knowledge and preparation, and a lack of proper equipment necessary to treat this group of special patients.

Significant changes in the care of handicapped and mentally retarded individuals occurred during the late 1960s and the 1970s. The President's Panel, established by President Kennedy, made key recommendations that led to the enactment of Public Law 88-164 in 1963. This public law encouraged the states to provide services to individuals with mental retardation residing in community settings, and authorized research centers and facilities to educate additional personnel to work in the field of mental retardation.

One concept that evolved indirectly from PL 88-164 is normalization, an approach that includes providing home-like settings with minimal regimentation, "least restrictive environment," and activities similar to normal family life. The normalization approach contrasts with the more regimented and restrictive environment of state institutions.[1-4]

Normalization has led to deinstitutionalization, which is the integration of institutional residents into the community, or mainstreaming. This movement has caused a depopulation of the large state facilities.[5-10] The number of residents in public facilities for the mentally retarded declined from a peak census of 194,650 in 1967 to 91,440 by 1988.[11] Concurrently, many of the 108 state institutions were closed nationwide.[5] For example, since 1970,32 state operated facilities for the mentally retarded have been closed, and another 11 are scheduled for closure by 1995.[11]

Normalization and deinstitutionalization have placed a large number of individuals who previously resided in institutions into the community. They may reside in foster homes, group homes, or with their own families.[12,13] A foster home is licensed for one to three clients, and provides a supportive family atmosphere with encouragement for social interaction and assistance in improving personal care habits.[14] A group home is licensed for four to 16 clients and provides a family-like situation that allows residents to be integrated into normal neighborhood activities. Various levels of direct care and training are available for all residents of foster homes and group homes with additional homebound intervention services provided as needed.[14]

The integration of developmentally disabled people into the community has made this population dependent on the community-based health care system for their medical and dental care.[6,10,15-17] Obtaining comprehensive health care services for this special patient population may be difficult in some communities because of their many handicapping conditions and an inadequate number of trained and experienced health care providers.[15] Specialty medical services essential to the care of this group may not be available in the community and some health care providers may be reluctant to treat patients with mental retardation.[15] Policies that rely solely on existing community health care services, therefore, may lead to inadequate medical care.

Recently, group home operators, social workers, parents of developmentally disabled individuals, and dentists of north central Florida have expressed concern to the University of Florida about the availability of dental care to the developmentally disabled persons

Table 1. Sample survey questions.

1. Frequency of dental visits: for example, how many of your residents visit the dentist:
   - ☐ Every 3 months?
   - ☐ Every 6 months?
   - ☐ Once a year?
   - ☐ Never?
2. Types of services available: for example, what level of dental care do your residents receive?
   - ☐ No dental treatment
   - ☐ Emergency dental treatment
   - ☐ Periodic examinations
   - ☐ Periodic cleanings
   - ☐ A full range of dental services on a regular basis
   - ☐ Other (please specify)
3. Payment mechanisms: for example, who pays for the dental treatment?
   - ☐ Medicaid
   - ☐ Health and Rehabilitative Services
   - ☐ Resident
   - ☐ Parents
   - ☐ Dental insurance
   - ☐ Other (please specify)
4. Cooperativeness of the residents: for example, how many of your residents are:
   - ☐ Cooperative for dental treatment?
   - ☐ Moderately resistant to dental treatment?
   - ☐ Very resistant to dental treatment?
   - ☐ Unwilling to be treated by a dentist?
5. Reasons for not obtaining care: for example, when a dentist refuses to treat your residents, do you know why?
   - ☐ Yes
   - ☐ No

   If yes, what are the most common reasons?
   - ☐ Medicaid or Health and Rehabilitative Services does not pay enough.
   - ☐ Too busy with other patients.
   - ☐ Dental office not properly equipped.
   - ☐ Dentist not trained to care for the developmentally disabled/mentally retarded patient.
   - ☐ Other (please specify)

Table 2. Frequency of dental visits and cooperativeness of residents (N=362).

Frequency	Number of residents	%	Cooperativeness	Number of residents	%
none	17	4.7	cooperative	267	73.8
annually	247	68.3	moderately resistant	64	17.7
6 months	78	22.5	very resistant	20	5.5
3 months	20	5.5	unwilling to be treated	11	3.0

residing in their communities. Investigators from the College of Dentistry conducted a survey of group homes in the area to determine if and to what degree these concerns were warranted. This report is a summary of that survey, and includes a description of the methods used, a discussion of the data collected, and presentation of recommendations.

Methods

The survey questionnaire was mailed to 64 group homes in District III of the Florida Department of Health and Rehabilitative Services, which is composed of 16 counties in north central Florida. If a questionnaire was not completed and returned within 2 weeks, a follow-up telephone call was made, and if necessary, another questionnaire sent to the group home operator. Self-addressed stamped envelopes were enclosed in both the initial and follow-up mailings.

The 16-item questionnaire addressed frequency of dental visits, type of services available, payment mechanisms, resident's cooperativeness, and reasons for not obtaining care. A representative sample of questions related to these concerns is presented in Table 1.

Results

Of the 64 group homes queried, 58% responded. The total population of the 37 responding facilities was 362 residents, of which 91% are older than 13 years (Figure). Among those 37 group homes that responded, 15 reported difficulty in locating a dentist to treat their residents, whereas 22 reported no difficulty. Five percent of the residents reportedly visit the dentist every 3 months, 22%, every 6 months, and 68% visit the dentist annually (Table 2). Only 5% of the residents never visit the dentist. The group home operators reported that 33 % of their residents received a full range of dental services, while 57% received periodic examinations and cleanings, and 10% received emergency dental treatment only (Table 3).

The group home operators were asked to indicate the degree of cooperativeness exhibited by the residents while receiving dental care. They reported that 91% of their residents were either cooperative or moderately resistant during dental treatment, while 6% were reportedly very resistant, and 3% were unwilling to be treated by a dentist (Table 2). Moreover, 94% of the group home operators reported that the dentist seldom or never used sedation when treating their residents. Also, only 11 % of the operators observed that the dentist used some form of physical restraint during treatment. Cooperativeness also was reflected by the number of residents who brush their own teeth. A total of 76% brush their own teeth, whereas 18% require assistance with brushing, and 2% refuse to brush their teeth.

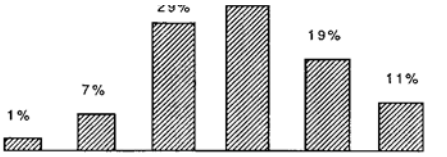
Of the residents, 77% have their dental services paid for by state or federal funds, whereas the remainder pay for their services through insurance or personal funds. In this survey, the main reason given by the dentists who refused to provide treatment to the mentally handicapped is that "Medicaid or Department of Health and Rehabilitative Services does notpay enough." Additional reasons given for refusing to provide dental treatment include: "dentist is not trained to deal with mentally retarded patients," "patient is too uncooperative," "office is not properly equipped," and "dentist is too busy with other patients."

Discussion

The response rate with this survey was nearly 60%. No obvious factors were unique to the nonresponders that could account for their lack of participation.

Clinical management of special patients may require additional staff members, extra time, physical restraint and/or sedation, for which the dentist may

Figure Distribution of group home residents by age (N = 362)



not be reimbursed. This situation creates a financial disincentive for treating this population. Many dentists are unwilling to treat the individual with mental retardation because of an inability to obtain fees commensurate with the time and effort required to treat this group of special patients.[6,18] It has also been reported that many dentists are hesitant to treat this type of patient, due to a lack of knowledge and understanding, and feelings of inadequacy.[12,18-21] The existence of these barriers is supported by the data from this survey. Although 73% of the residents were reportedly cooperative for treatment, 40% of the group home operators experienced difficulty in locating a dentist who would treat their residents, and only 33% of the residents were receiving a full range of dental services.

It is noteworthy that 95% of the residents are seen by a dentist at least annually even though more than 40% of the group home operators reported difficulty in locating a dentist who would treat their residents. The need to fulfill licensure requirements may account for the group home operators persistence in locating a dentist.

Given the difficulty in locating a dentist, it is not surprising that 76% of the group home operators commented that they needed more dentists in the community willing to treat their residents. Moreover, 79% indicated that residents would benefit from a mobile dental unit that would visit the group homes and deliver treatment on site.

Table 3. Type of dental care received by group home residents.

Type of dental care	%
emergency treatment only	9.8
examination and prophylaxis only	57.4
comprehensive services	32.8

This survey addressed only one side of the issue—that of the group home operator. Further studies correlating the caretakers' personal use of dental services with that of the residents' would be useful and a survey of the dentists of record should be conducted to determine their experiences with this population.

It is apparent that the deinstitutionalizaton and normalization processes will continue, leading to a greater number of developmentally disabled individuals who depend on existing community-based health services. If comprehensive dental care is a goal for this special group, education of dental personnel at all levels must be enhanced and the insufficiencies of the reimbursement system must be addressed. Moreover, community networks should be established to facilitate the acquisition of dental services by the developmentally disabled residing in the community.

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