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## ARTICLE

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### Providing oral health care to individuals with severe disabilities residing in the community: Alternative care delivery systems

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*For some individuals with disabilities who reside in the community, comprehensive oral health care is inaccessible. This deficiency has been noted by health care professionals and advocacy organizations. For example, most dentists who provide care to people with disabilities who reside in the institutional setting perceive that present resources within the community, both private and public, are generally unprepared to provide comprehensive dental care to the adult with severe disabilities; they also believe that special facilities and programs are needed that will be geographically and financially accessible to these individuals. Fortunately, several "special programs" have been established that successfully provide dental care to this population. This article describes these alternative care delivery systems and discusses their characteristics, advantages, and disadvantages. In addition, given the continuing process of community placement, implications for institutional dental programs are presented.*

Many individuals with mild to moderate physical and/or mental disabilities who previously resided in state institutions have been placed in community residential settings and depend upon the community-based health care system. As a result, dental professionals who provide oral health care in the institutional environment primarily treat persons with severe and/or multiple disabilities which may include: (1) severe or profound mental retardation; (2) chronic, refractory psychiatric disorders; (3) severe neuromuscular disorders; (4) sensory impairments; and (5) orthopedic disorders. Their experience, acquired through years of serving this population, indicates that the difficulties encountered during the provision of treatment are far greater than those met when treating the general population of individuals with mild disabilities, and require special skills, knowledge, and equipment. As the deinstitutionalization process continues, these severely disabled people are also being placed in community settings. Most institutional dentists believe that present resources within the community, both private and public, are generally unprepared to provide care for the adult with severe disabilities. Furthermore, they believe that special facilities and programs are needed that will be geographically and financially accessible to this population.

Conversely, policy-makers responsible for deinstitutionalization have apparently assumed that dental

services for all disabled individuals, regardless of level of disability, can be provided by general dentists practicing in the community.<sup>1-6</sup> This dichotomy in perception of the availability of dental services for the severely disabled is alarming to the institutional dental staff and other interested parties whose experience and commitment to these individuals place them in an advocacy role. This concern, however, should not be equated with an anti-deinstitutionalization attitude.

This article will: (1) review the major factors influencing oral health care for these individuals, (2) highlight the role and limitations of the private sector and public health clinics, and (3) present alternative sources of dental care, including the utilization of institutional dental clinics to serve disabled individuals residing in the community.

#### Major influences on dental services for persons with severe disabilities

##### Deinstitutionalization

The continuing emphasis on noninstitutional placement for individuals with mental retardation has resulted in an institutional population that is overwhelmingly severely or profoundly mentally retarded, many with significant medical complications and physical disabilities.<sup>7</sup> It is these individuals, nearly all adults, who will be transferred to community placements over the next decade. Similarly, deinstitutionalization has had an

impact on mental health facilities, which are now serving fewer chronic, refractive, long-term residents and a larger number of short-term clients who require multiple admissions. It appears that only 1-2 percent of persons with mental retardation, *i.e.*, approximately 90,000 individuals, remain in institutions.<sup>8,9</sup> Since mental illness (MI) is often a sporadic event, the percentage of persons who require long-term institutionalization is unknown.

Aside from responsibility for fewer but more severely disabled patients, the effect of this process on institutional dental programs is not altogether clear. Nationally, information on institutional dental programs is sparse, although the Academy of Dentistry for Persons with Disabilities (ADPD) has developed a directory of these programs. Results indicate that most programs still rely on state-employed dental staff, although contracting of services or direct referral to the private sector is increasing as institutions become smaller.<sup>10</sup>

### **Professional training**

In the mid-1960s, the federal government funded university-affiliated programs (UAP) throughout most states to train professionals in providing services for the disabled population. Most of the people served were children, not adults, and the dental professionals involved were mostly specialists, usually pediatric dental residents; dental students were rarely involved. In the mid-1970s, however, the Robert Wood Johnson Foundation (RWJ) funded dental undergraduate training programs in 11 of the 52 dental schools- The RWJ program is now terminated, with an undetermined amount of training persisting in these dental schools. The UAP programs have experienced reduced funding nationwide, and the effect on developing dental manpower is unknown.

While both of these programs had a positive impact, a recent survey of dental schools revealed a significant lack of didactic and clinical training

for predoctoral dental students in the treatment of people with disabilities.<sup>11</sup> Furthermore, the predoctoral curriculum guidelines of the American Association of Dental Schools state that they apply only to the minimally disabled, not the patient with profound or multiple disabilities.<sup>12</sup>

Most General Practice Residencies (GPR) have clinical curricula related to the disabled person, and some serve people with severe disabilities.<sup>13</sup> Although promising, the ability of these programs to provide an adequate number and geographical distribution of dental professionals with the skills and willingness to treat severely disabled people is in question. In addition, there is a lack of dental hygienists trained to treat people with disabilities, especially those with severe disabilities.

### **Medicaid**

Historically, a lack of financial resources has been a major barrier to accessing oral health care for disabled people. Medicaid funding for dental services for eligible individuals has reduced this barrier to some extent; however, only a small percentage of states provide funding for preventive, restorative, and prosthodontic services for adults. In the few states that do offer comprehensive services to adults within this program, the inadequate level of reimbursement serves as a financial disincentive to the care provider.<sup>14</sup> The concept that deinstitutionalized adults can access adequate dental services through Medicaid reimbursement appears unfounded.

### **Role and limitations of the private sector**

#### **Availability of services**

Survey information presently available indicates that approximately 20% of private practicing dentists are willing to accept persons with disabilities into their practices.<sup>15</sup> With an estimated 43 million Americans who have disabilities, it appears that adequate

dental manpower is available.<sup>11,16-19</sup> The data, however, are distorted by the fact that specialists, especially pediatric dentists and oral surgeons, are proportionately over-represented in the survey. Also, the availability of accepting dentists varies among the states, as well as geographically within each state. In addition, since training of dental and dental hygiene students in the treatment of people with severe disabilities is rare, the future production of adequate dental manpower prepared to meet the needs of this population is questionable.

### **Behavior management concerns**

The resistant and maladaptive behavior displayed by most individuals with severe or profound mental disabilities makes the provision of comprehensive treatment in a private-practice setting problematical. These patients often present disruptive behaviors in the reception area of a dental office, and many, if not the majority, require dental restraints or positioning devices so that care may be provided in a safe manner. Although some dentists have acquired skills in the use of dental restraints, many are reluctant to use this behavioral management technique. This reluctance has been magnified by recent legal concerns regarding the use of physical restraints. Moreover, some of these patients require dental sedation to receive care, and most states now require additional permits or licenses for dentists to utilize sedation, especially parenteral sedation. In addition, malpractice premiums rise abruptly for dentists utilizing sedation in their dental practices. These behavior management concerns serve as a disincentive to the general private practitioner.

### **Medical and financial issues**

Many of the persons presently residing in institutions have severe medical problems. As these people are transferred to the community, these medical conditions may become a barrier to care. Most private

dental practices are reluctant to accept clients with poorly controlled seizure problems, trachiestomies, gastrostomies, and other severe medical conditions.

Since most deinstitutionalized adults have no income, and many are from low-income families, and without Medicaid dental benefits, it is not surprising that financial issues remain a serious obstacle to obtaining dental services from the private sector.

### **Role and limitations of the public health sector**

When dental care is not available from the private sector, a possible resource is the county and city public health department dental programs. Most states have some public health dentistry available to eligible residents; however, there are serious limitations in the availability of care for the person with severe disabilities.

### **Availability of care**

During the past decade, there has been a precipitous decline in the availability of dental treatment services in public health clinics nationwide." One reason is the presumption that Medicaid covers dental services for the indigent person. For adults in most states, this is largely unfounded. Furthermore, most public health dental programs place an emphasis on prevention rather than treatment programs. Also, it has become economically infeasible to maintain modern well-equipped clinical facilities throughout most states. Consequently, public health facilities are concentrated in urban areas. Treatment services in remote areas, where available, are usually arranged through the private sector on a contractual basis, with the limitations for the severely disabled person previously described.

### **Eligibility issues**

Many public health dental programs limit eligibility to children and, therefore, are not a resource for the deinstitutionalized adult.<sup>20</sup> Even if eligibility were expanded to adults,

two distinct barriers to comprehensive services would remain. First, there is a lack of funding for laboratory fees for prosthetic services (a common need of adult patients), and second, since these clinics primarily serve children, the clinicians' skills in providing adult care, especially prosthetic services, would have to be addressed. The difficulties related to managing the resistant/maladaptive dental behavior and medical complications experienced in private-practice settings would also apply to public clinics.

### **Special oral health care models**

The inaccessibility of oral health care to the disabled person residing in the community has been noted by health care professionals and advocacy organizations. Consequently, a number of "special programs" have been established to provide dental care to this population. The following describes several special programs and discusses their characteristics, advantages, and disadvantages. It is noteworthy that all of these special programs of dental care delivery depend upon financial support from government agencies or private charitable sources. In fact, none of these programs is self-supporting through the collection of fees for services.

### **University-contracted dental care**

One example of dental care provided by a university is Tufts Dental Facilities in Massachusetts. The program is administered by the Tufts University School of Dental Medicine and provides comprehensive dental services to all institutionalized and some community-based developmentally disabled persons throughout the Commonwealth of Massachusetts at 11 separate locations. Begun in the mid-1970s, the program is the result of a mandated court decree. Funds are provided through a contract with the Department of Public Health of the Commonwealth of Massachusetts.<sup>21</sup> The presence of multiple, geographically distributed clinic

locations improves access to care statewide. Those individuals, particularly severely disabled adults, requiring IV sedation or general anesthesia are referred to a central facility. Each staff dentist is a faculty member of the dental school and, in that capacity, provides training to predoctoral and graduate students and participates in related research activity. Unfortunately, only 17% of services are provided to individuals residing in the community, and no services are provided to mental health clients.

This type of program may be less desirable in a large and sparsely populated state or one in which the dental school is not centrally located. The cost of building and equipping multiple clinics may also serve as a major barrier.

### **Hospital outpatient dental programs**

One example of dental care provided by a hospital outpatient program is Morristown Memorial Hospital Dental Program for Developmentally Disabled People, in Morristown, New Jersey. This program began in 1983, is staffed by a pediatric dentist and other dental professionals with expertise in developmental disabilities, and functions in conjunction with the Developmental Disabilities Center in the Department of Pediatrics. Funding is provided via contract with the Division of Developmental Disabilities of the New Jersey Department of Human Services.<sup>1,5</sup>

One major advantage of an outpatient program within a community hospital is the ready availability of medical consultation and evaluation, and general anesthesia. Dental patients are screened by physicians knowledgeable about the special problems common to people with disabilities, who can provide behavior management assistance, e.g., IV sedation or general anesthesia. A full range of health services for people with developmental disabilities, including adults and children, is available on both an inpatient and an outpatient basis.

The program operates only one day *per week* and serves a small geographical area which limits access. In addition, a fee-for-service reimbursement system will not finance such a program; therefore, public and private support is essential. Consequently, funding for similar programs may not be available in all communities where services are needed.

### **Mobile dental programs**

One example of this type of dental care delivery is the Missouri Elks Mobile Dental Program, entitled "Dental Care for the Disabled Person." The program, conceived by the Missouri Elks, was established in the early 1970s. The Missouri Department of Health, through its Bureau of Dental Health, contracts with the Truman Medical Center Department of Dentistry in Kansas City to administer the program. The program operates three mobile dental units and serves the disabled population in all areas of Missouri.

Referrals are received from Regional Centers for the Developmentally Disabled, the Missouri Crippled Children's Service, and local agencies that serve individuals with developmental disabilities. Funding is provided through Maternal and Child Health funds from the Missouri Department of Health, and the Missouri Elks Benevolent Trust Association.<sup>22</sup>

The chief advantage of this type of program is that it serves a large geographical area, thereby increasing access to residents in rural and urban areas. Only basic dental care which involves no dental laboratory procedures or extensive appointments is provided. Patients requiring more extensive procedures or general anesthesia are referred to other facilities. Private practitioners can attend a short course and gain clinical experience in the mobile units.

A major disadvantage is the physical demand placed on the equipment caused by the jostling and vibration, during transportation over long distances, which increase service

requirements. While this type of program has certain advantages, availability of care to the more severely disabled and medically compromised patient is limited.

### **Institutional outpatient dental programs**

A recent survey of institutional dental programs indicates that only three states offer extensive dental services on an outpatient basis to people with disabilities residing in the community: Georgia, Texas, and New York.<sup>9</sup> One example of dental care provided by state-operated institutional facilities is the Georgia Department of Human Resources. In the early 1970s, this agency redirected its institutional dental programs to extend the provision of dental services to individuals with developmental disabilities residing in the community. As of 1994, seven of ten institutions provided outpatient dental services to developmentally disabled people, and three of the ten facilities offer services to individuals who are mentally ill. Funding is provided entirely by the Georgia Department of Human Resources, and services are available throughout the state.

As the institutional population is being reduced, the redirection of dental programs to serve people in the community preserves resources that would otherwise be lost. The utilization of specially equipped facilities and professional staff experienced in and capable of treating the individual with severe disabilities, including behavioral and medical complications, becomes a valuable resource for the community. Most of these facilities provide services using sedation, and some are equipped to provide general anesthesia. The wide geographical distribution of institutions in most states would enhance access to dental care for this special population.

A major concern related to this type of program is that it is not true "normalization," *i.e.*, returning to the institutional environment for health services may create a negative image for some individuals. In addition,

providing services to people residing in the community may cause financial difficulty for some agencies.

### **Implications for institutional dental programs**

Institutional dental professionals should work closely with community agencies, community parent organizations, and others in broad planning efforts to ensure access to comprehensive dental care for all persons with disabilities. It is important that institutional dental staff, in promoting the need for outpatient services, not appear to be unsupportive of continued deinstitutionalization. It should be emphasized that the advocacy role of the institutional dental staff relates solely to concerns regarding the limited availability of dental care for individuals being placed in the community, and other models of regional resources should also be supported.

Although some institutional dental programs presently maintain a training role through a University Affiliated Program (UAP), many other institutional dental programs could function as a training site for dental students, dental hygiene students, and dental assisting students. This is particularly advantageous in states where dental hygiene programs are geographically dispersed and not located near a dental school. The appointment of institutional dental staff to adjunct faculty status with dental and dental hygiene schools offers several advantages, including increased access to professional development and to continuing education activities within the schools. Except for some GPR programs, the institutional environment may be the only setting in which professionals can acquire skill and knowledge in treating people with severe disabilities. The initiation of these training activities can be made by a proactive institutional dental staff.

Professional training activities can be expanded to include the practicing dental professional, including dentists, dental hygienists, and

dental assistants. There are very few continuing education opportunities offering clinical experience in treating disabled patients, especially those with severe disabilities accompanied by medical and behavioral complications. This training experience could be individualized for trainees in order to meet the specific needs and schedule constraints of the practitioner. This continuing education activity could be part of the university or dental hygiene school, or arranged through contracts with the state dental or dental hygiene associations.

A continuing education didactic and clinical experience should also include public health dentists and dental hygienists to increase the public health sector's ability and willingness to provide care to the disabled population. It is particularly important to provide training and experience to public health dental hygienists and to encourage them to involve individuals with mental and physical disabilities in their preventive programs.

A review of the literature reveals a paucity of clinical information related to the specific needs of individuals with severe disabilities. Institutional dental programs can become research as well as training sites. Academic staff from dental schools and dental hygiene schools could be attracted to an environment with ready access to appropriate subjects and a dental staff available for support. Similarly, research activities can be initiated by the institutional dental staff, especially with university support. Even limited treatment and prevention evaluation efforts can make valuable contributions to the dental literature.

Institutional dental staff can develop advisory and consultative roles with professional and community groups, including the development of a good working relationship with the state Director of Public Health Dentistry. These activities may range from providing seminars for parent groups to consulting with the State Dental Director on the possible impact of

proposed legislation. Institutional dental staff can also be instrumental in developing referral directories that list all dental resources, public and private, for this population. Development of good working relationships with organizations such as Associations of Retarded Citizens, organized dentistry, and dental boards is helpful in this regard.

A most important activity for institutional dental professionals is to become organized on a state level. A recent survey indicated that only seven states (14%) have a state dental director/coordinator for institutional programs.<sup>19</sup> An effort should be made, particularly in the large states, to develop a position of Director/Coordinator of Institutional Dental Services or have these duties administratively assigned. At a minimal level, institutional dental staff can form a professional group and meet periodically to review and discuss concerns within their areas of responsibility.

## Conclusions

Since funding, demographics, and geography vary from state to state, no one system of oral health care delivery is appropriate for all. For example, the institutional outpatient model would be a poor choice in those states that are closing all institutions or in those states in which the services provided by the institutional dental programs are limited. Similarly, the university contract model would be relatively ineffective where the university is remotely located and where funds are not available for satellite clinics. The most effective action would be for states to adopt portions of each model that best fits its circumstances. Regardless of which model or combination is developed, the existence of a regional dental program serves as a referral and consultative resource for private and public health practitioners, who, consequently, may be more inclined to accept special patients.

Although each model of care delivery offers advantages and disadvantages, several components

appear vital to the success of any regional resource for dental care to individuals with severe disabilities.

First, readily available medical support is vital, since many referred patients will have severe medical complications, and some will need parenteral sedation; the availability of qualified physicians to aid in diagnostic and/or emergency procedures is important. Second, a source of care under general anesthesia is vital. This source may be physically removed from the regional clinic, but an effective referral mechanism should be available. Services under general anesthesia should include diagnostic, radiographic, periodontic, restorative, and endodontic services, not just surgical procedures. Third, a liaison with the referral sources is imperative. Although it is not necessary for each regional clinic to have a social worker, someone with experience and expertise in dealing with community agencies is very important. This may be any professional, such as a nurse, dental hygienist, clerical staff, or other identified position. Fourth, an understanding of the inefficiencies inherent in a public clinic, especially one serving the severely disabled, is important. These inefficiencies include frequent broken appointments, especially with mentally ill patients, and late arrivals, causing treatment delays and limitation of services. Finally, successful programs usually have multiple objectives (e.g., university training and research) in addition to providing clinical services.

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