

THE PROVISION OF DENTAL SERVICES TO DISABLED INDIVIDUALS RESIDING IN THE COMMUNITY

Purpose of this Module

This module is designed to provide the institutional dental staff with an overall view of how dental services are provided to disabled individuals residing in the community and how the institutional dental program interfaces and interacts with these services. The emphasis is on the severely/profoundly disabled mentally ill and mentally retarded individual and reviews the role of the private sector, county/city public health clinics, the institutional dental program, and other sources of dental care.

Learning Objectives

After reviewing the written material, the participant shall be able to:

1. Discuss, in detail, three major influences on how dental services are provided to individuals who are mentally ill/mentally retarded.
2. State the percentage of private dental practitioners willing to accept handicapped patients.
3. Discuss the limitations of the private dentist in treating disabled individuals with moderate to severe behavioral problems, with particular emphasis on the role and limitations of sedation and restraints.
4. List three major medical complications that may present difficulties for the private dental practitioner.
5. Describe the eligibility issues involved in obtaining dental care from a public health clinic.
6. Discuss the advantages and disadvantages of a community hospital-based outpatient dental program.
7. Discuss the advantages and disadvantages of a mobile dental program.
8. Discuss the advantages and disadvantages of an institutional outpatient dental program.
9. Discuss the advantages and disadvantages of the Tufts University model of dental care.
10. List and discuss five major areas that institutional dental staff can participate in to expand services to the community-based MH/MR person.

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INTRODUCTION

The dental professionals who provide oral health care in the institutional environment primarily treat individuals with severe/profound mental retardation and/or severe/chronic mental illness. The experience acquired through years of serving this population indicates that the difficulties encountered are far greater than those met when treating mildly disabled and non-disabled people, and special skills, knowledge and equipment are required. Conversely, many administrators, health planners, and community-based non-dental professionals seem convinced that dental services for *all* mentally disabled individuals, regardless of the level of disability, can be provided in the usual manner through referral to a general dentist practicing in the community. Unfortunately, many of these dentists are unprepared to treat this special population. This dichotomy in perception of the availability of dental services for the severely/ profoundly disabled is alarming to the institutional dental staff whose experience and commitment to these clients place them in an advocacy role. *As the deinstitutionalization process continues, this concern for severely disabled residents being placed in community settings is magnified. This concern, however, should not be equated with an anti-deinstitutionalization attitude.*

MAJOR INFLUENCES ON SERVICES FOR SEVERELY DISABLED PERSONS

O Deinstitutionalization

Clearly, the continuing emphasis on community placement for mentally retarded/developmentally disabled (MR/DD) individuals has resulted in an institutionalized population that is overwhelmingly severely/profoundly mentally retarded, many with significant medical complications and physical disabilities.¹ Similarly, deinstitutionalization has created mental health facilities which are serving

fewer chronic, refractive, long-term residents and a larger number of short-term, often multiple admission, clients. Although no firm data exists, it appears that only 1-2% of mentally retarded (MR) clients remain in institutions. Since mental illness (MI) is often a sporadic event, the percentage of clients who still require long-term institutionalization is unknown. It is also apparent that the vast majority of clients transferred from an institution to a community placement today are adults, not children.

Aside from responsibility for fewer, but more severely disabled clients, 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 the Handicapped (ADH) is undertaking the development of a directory of these programs. Preliminary 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. Several states have completely closed all institutions.

O Professional Training

In the mid-sixties, the federal government funded university affiliated facilities (UAF) or programs (UAP) throughout most states to train professionals in providing services for the disabled population. Most of the individuals served were children, not adults, and the dental professionals involved were mostly specialists, usually pedodontists. Undergraduate dental students were rarely involved. In the mid-seventies the Robert Wood Johnson Foundation (RWJ) funded dental undergraduate training programs in eleven of the 52 dental schools (20%). The RWJ program is now terminated with an undetermined amount of training persisting in these dental schools. The UAF programs have experienced reduced funding nationwide and the effects on developing dental manpower is unknown.

Significantly, the 1986 curriculum guidelines of the American Association of Dental Schools clearly state that they apply only to the minimally disabled, not the multiply or profoundly handicapped.²

The recent proliferation of General Practices Residencies (GPR) and similar programs in Advanced Education in General Dentistry (AEGD) has made an indeterminate impact on dental manpower. Most of these programs have clinical curriculum interfacing the handicapped person, many serving the severely disabled individual.³ Although promising, the ability of these programs to supply dental professionals adequate in number, skills, and geographical distribution to meet the needs of the severely/profoundly disabled on a national basis is in question.

Regarding professional training, one glaring deficiency is the lack of dental hygienists taught to treat the handicapped individual, especially those who are severely disabled. The UAF, RWJ or GPR/AEGD programs rarely involve dental hygiene trainees.

O Medicaid

Financial resources have historically been a barrier to dental services for the handicapped. Medicaid funding for dental services for eligible individuals has reduced this barrier to some extent. The American Dental Association (ADA) does not have an available profile of dental services available to Medicaid recipients. In the authors' opinion, however, less than twenty percent of the states offer basic restorative and prosthetic services to adult Medicaid recipients. Even in the few states that do offer comprehensive services to adults under this program, the unrealistic reimbursement level and time commitment necessary renders access to dental care problematical.⁴ The concept that deinstitutionalized adults can access adequate dental services through Medicaid reimbursement appears unfounded.

O Public Law 94-142

PL 94-142 enacted in 1978, places all school-aged MR/DD individuals, regardless of cognitive functioning level, in special education programs within the school system. Remaining in community training centers are adults with a similar range of disability. Training centers routinely transport disabled persons to services such as dental or medical clinics. School systems rarely do this. Thus, client grouping by age may act as a help or as a hindrance in accessing dental services.

ROLE AND LIMITATION OF THE PRIVATE SECTOR

O Availability of Services

Survey information presently available indicates approximately 20 percent of private practicing dentists are willing to accept handicapped persons into their practice.⁵ With only 10 percent of the population designated as handicapped, superficially, it would appear that adequate dental manpower is available.⁶⁻⁹ This data is distorted by the fact that specialists, especially pedodontists and oral surgeons, are proportionately over-represented in the survey. Also, the availability of accepting dentists varies among the states, as well as within each state. Since training for dental and dental hygiene students in treating the severely handicapped is rare, the availability of private practicing dental manpower to meet the needs of severe/profoundly disabled adults is clearly questionable. Even if adequate dental services were available, the lack of comprehensive referral directories in many states continues as a barrier to care.

O Behavioral Problems

The presentation of maladaptive dental behaviors by most severely/profoundly mentally disabled people renders comprehensive treatment in a private practice setting problematical. First, these individuals often present disruptive behaviors in the reception areas of a dental office. These behaviors are looked upon with disfavor by many dental staff and by other patients. Secondly, many, if not the majority, of these individuals require some sort of dental restraint or protective device in order to provide comprehensive care in the least restrictive manner. Although some dentists have acquired skills in dental restraint use, many are reluctant to utilize this needed treatment modality. This reluctance has been magnified by recent events concerning the use of restraints. Thirdly, a number of these patients require the use of dental sedation to provide care. Most states now require additional permits or licenses to utilize sedation, especially parenteral sedation. In addition, malpractice premiums rise abruptly for dentists utilizing sedation in their dental practices. For example, for a general dentist in practice for five years in Georgia, the premium for the minimal professional insurance coverage is approximately \$1,000. This premium rises to \$2,500 if the dentist

treats any patient under general anesthesia in a hospital with an anesthesiologist and rises to \$6,500 if the dentist utilizes parenteral sedation in his/her private office. Clearly, these barriers to managing maladaptive dental behaviors lessen the private practicing dentist as a treatment resource for the severely disabled MR or MI person.

O Medical Problems

Many of the severely/profoundly disabled people presently residing in institutions have severe accompanying medical complications. For example, of the 226 MR residents in skilled nursing units in MR institutions in Georgia, 116 (51 percent) are fed by nasogastric or gastrostomy tubes. As these individuals are transferred to community placement, these medical conditions become a barrier to care. Most private dental practices are reluctant to accept patients with poorly controlled seizure problems, tracheostomies, gastrostomies and other severe medical conditions.

O Financial Problems

With overhead costs at \$100-200 per hour in most dental practices, charitable dentistry is fast becoming a thing of the past. Since most MR/MI individuals have no income, and many are from low income families, and as previously discussed, without dental services covered by Medicaid, it is not surprising that financial issues remain a serious barrier to obtaining dental services from the private sector.

ROLES AND LIMITATIONS OF THE GENERAL PUBLIC HEALTH SECTOR

When dental care is not available from the private sector, a possible resource is the public health department dental program. Most states provide public health dental services to eligible persons, typically, however, the care provided to severely disabled persons is very limited.

O Availability of Care

There has been a precipitous decline in the availability of dental treatment services in public health clinics nationwide over the past decade. One reason is the presumption that Medicaid now covers dental services for the indigent person. As previously stated, a majority of states do not provide Medicaid payment for the routine treatment of adults. Also, it

is not economically feasible to maintain modern well equipped clinical facilities in all geographical regions of most states. Consequently, public health treatment facilities tend to be concentrated in urban areas. Treatment services in the more remote areas of states, where available, are usually arranged through the private sector, on a contract basis, with clear limitations for severely disabled people described above. One positive note is that since public health dental clinics provide services mostly to school aged children, mandated school attendance for MR/DD children (PL 94-142) increases accessibility to this resource for care.

O Eligibility Issues

Nearly all public health dental programs limit eligibility to children and therefore, are not a resource for the deinstitutionalized adult. Even if eligibility were expanded to adults, there would remain two distinct barriers to comprehensive services. First, usually no budget exists to reimburse laboratory fees for prosthetic services (a common need of adult disabled persons, especially mentally ill individuals), and secondly, since these clinics primarily serve only children, the clinician's skills in providing adult care, especially prosthetic services, may not be sufficient to meet the need.

O Behavioral and Medical Issues

The same difficulties experienced in private practice settings exist in most public clinics in managing the maladaptive dental behavior and medical complications common to many severely mentally disabled persons.

SPECIAL ORAL HEALTH CARE MODELS

For a variety of reasons, primary and secondary sources of oral health care may not be accessible by all developmentally disabled individuals residing in the community setting, especially the more severely affected. The resulting lack of dental care 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 or private charitable sources. In fact, none of these programs are self-supporting through the collection of fees for services.

(Note that listed advantages and disadvantages may apply to more than one model.)

O University-provided Dental Care

An 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 institutionalized and community-based developmentally disabled persons throughout the state of Massachusetts at eleven separate locations. It was begun in the mid 1970's as a result of a mandated court decree. Funds are provided through a contract with the Department of Public Health of the Commonwealth of Massachusetts.^{10,11}

Advantages of this program are: 1) patients can be referred to the main facility, Fernald State School, for IV sedation or general anesthesia, 2) each staff dentist is a faculty member of Tufts University School of Dental Medicine and participates in one or more educational components of the program, 3) education of graduate and undergraduate students occurs, 4) all undergraduates are assigned to six week externships, 5) there is an active research component, 6) the presence of eleven locations improves convenience and serves the entire state, and 7) this program serves as a referral resource for private practitioners.

Disadvantages of this program include: 1) this is not true normalization, 2) the cost of building separate locations may be expensive 3) only 17 percent of services are provided to individuals residing in the community, and 4) services are not provided to mentally ill individuals.

The State University of New York at Stony Brook, University of Florida, University of North Carolina, and University of Washington also provide dental services to developmentally disabled individuals on a limited basis.

O Institution-provided Dental Care

An example of dental care provided by a state operated institutional facilities is the Georgia Department of Human Resources. In the early 1970's the Georgia Department of Human Resources redirected its institutional dental programs to extend

the provision of dental services to developmentally disabled individuals residing in the community. As of 1991, eight of ten institutions provide services to developmentally disabled people and three of the ten facilities offer services to mentally ill persons residing in the community. Funding is provided entirely by Georgia Department of Human Resources.

Advantages of this delivery system are: 1) services are provided by an experienced staff in a facility equipped to treat the severely disabled, 2) the program utilizes resources that may have been lost during the deinstitutionalization process, 3) general anesthesia is available at two facilities, 4) the institutional dental programs serve as a referral and consultative resource for the private practitioner, who may then be more inclined to treat these special patients, 5) graduate and undergraduate dental students, dental hygiene students, private dental practitioners, and public health dental professionals participate in the educational program, 6) there is an active research component, 7) some of the staff dentists have adjunct faculty status (one institution is a former University Affiliated Facility) which promotes continued professional development, 8) the program enhances the institution's public image as an integral part of the continuum of care, 9) it serves the entire state and no patients are more than two hours from services (except for one small area of the state).

Disadvantages of this program include: 1) this is not true normalization, 2) the provision of comprehensive care may be limited by budgetary constraints, 3) dental clinics may experience efficiency problems caused by increased broken appointments and late arrivals, 4) single-dentist clinics may be limited in their ability to treat patients with severe behavioral or medical problems, 5) the increased roles of patient treatment, research, training, and community/parent involvement can place a strain on the dental staff.

Other examples of this mode of care delivery include Gulf Coast Center, Ft. Myers, Florida, and Western Carolina Center, Morganton, North Carolina.

O Hospital-provided Dental Care

An example of dental care provided by a hospital is Morristown Memorial Hospital Dental Program for Developmentally Disabled People, Morristown, New Jersey. This program was started in 1983. It is staffed by a pediatric dentist with expertise in developmental disabilities, one dental assistant, one

hygienist, a secretary, and a program director with education in periodontics and oral medicine. The program functions in conjunction with the Developmental Disabilities Center in the Department of Pediatrics. It functions under a contract with the Division of Developmental Disabilities of the New Jersey Department of Human Services.^{12,13} Another example of this mode of care delivery is Mt. Zion Hospital, San Francisco, California.

Advantages of this delivery system are: 1) it offers a full range of health services for people with developmental disabilities including adults and children, 2) it operates in conjunction with the Developmental Disabilities Center located in the Department of Pediatrics at the hospital, 3) medical consultations are readily available and routine echocardiograms indicated previously undetected structural defects requiring antibiotic prophylaxis, 4) all dental patients are prescreened by the physicians in the Developmental Disabilities Center, 5) general anesthesia is available for dental treatment, 6) all patients are prescreened for HBsAg, 7) behavioral disorders are detected at prescreening which aids in behavioral management decisions, e.g. sedation, general anesthesia, 8) most patients are treated on an outpatient basis, 9) there is an educational component (general practice resident training), 10) there is a research program.

Disadvantages of this program include: 1) the program operates only one day per week, 2) it does not serve a wide geographic area.

O Donated Dental Care

An example of this type of dental care delivery is the Missouri Elks Mobile Dental Program, "Dental Care for the Disabled Person". This program was established in the early 1970's. The original idea was developed by the Missouri Elks. The Missouri Department of Health, through its Bureau of Dental Health, contracts with Truman Medical Center, a hospital in Kansas City, to operate the program. The department of Dentistry at Truman Medical Center administers the program's activities. The program operates three self-propelled dental units, and serves the disabled population in all areas of Missouri. Each unit is staffed by one dentist and one dental assistant. Mentally retarded individuals are given a prescreening examination by the program's dental hygienist. This has increased the utilization of the program.

Referrals are received from Regional Centers for the Developmentally Disabled, the Missouri Crippled Children's Service, and local agencies that serve the developmentally disabled. Funding is provided through two sources: 1) the Maternal and Child Health funds from the Missouri Department of Health, and 2) the Missouri Elks Benevolent Trust Association, which includes current contributions and a perpetual fund which is derived from the interest earned on an \$850,000 benevolent trust account.¹⁴

Advantages of this delivery system are: 1) it serves a large geographical area, and yearly schedules of the mobile units' locations are mailed, in advance, to agencies serving the developmentally disabled, and eligible individuals, 2) the program serves rural areas, 3) private practitioners can attend a short course and gain clinical experience in the mobile units.

Disadvantages of this program include: 1) the basic dental care provided in the mobile units involves no dental laboratory procedures or extensive visits, and treatment is designed to not interfere with efforts to provide care in the private sector, 2) no general anesthesia is provided by mobile clinics, however, patients are referred to other facilities for treatment under general anesthesia. In these cases, the dental care is paid for by the Elks, and hospital costs are provided on a sliding fee scale, 3) the requirement to obtain informed consent to use restraints can delay treatment, and sometimes patients occasionally have to be reappointed, 4) the jostling and vibration of the equipment caused by transportation over long distances increase service requirements, 5) Missouri temperatures range from over 100 degrees above to 10 degrees below Fahrenheit, and the mobile units are inadequately insulated, requiring special precautions in winter and summer, 6) the mobile units are dependent on a sponsoring institution for electricity.

Another example of donated care is the "Donated Dental Services Program" (DDS) of the National Foundation of Dentistry for the Handicapped which uses funding from private and corporate donations.

CHARACTERISTICS OF AN EFFECTIVE TERTIARY PROGRAM

Since demographics and geography vary from state to state, clearly no one system is appropriate for all. For example, the institution based model would be a poor choice in those smaller states that are closing all institutions or in those states in which the

quality of institutional dental programs is poor. Similarly, the university based model would be relatively ineffective where the university is remotely located and where funds are not available for satellite clinics. It appears that the most effective action would be for most states to adapt portions of each model that best fits its circumstances. Although each model of care offers advantages and disadvantages, several components appear vital to the success of any regional resource for dental care for severely/profoundly disabled.

First, medical support is vital since many referred individuals will have severe medical complications and some will need parenteral sedation, therefore, the availability of qualified physicians to aid in diagnostic and/or emergency procedures is important.

Secondly, a source of care under general anesthesia is vital. This source may be physically removed from the tertiary clinic, but an effective referral mechanism should be available. Services under general anesthesia should include endodontic and restorative, not just surgical.

Third, a liaison with referral sources is important. 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 severely disabled persons is important. One brief review of outpatient services in a mental health facility revealed a broken appointment rate of 22 percent for mentally retarded clients, 33 percent for mental health clients and 62 percent for substance abuse clients. An understanding of the difference between serving MR versus MI outpatients (e.g., demand for prosthetic services) should also be understood.

Finally, successful programs usually have multiple objectives (e.g. university training and research) in addition to providing clinical services. Although it may be helpful to obtain support from state administrative directors, programs often originate from local groups such as parent groups, institutional dentists, and others.

IMPLICATIONS FOR INSTITUTIONAL DENTAL PROGRAMS

It is extremely important that institutional dental staff, in describing the need for tertiary treatment resources, do not appear to be unsupportive of the continued deinstitutionalization process. The concern for continued comprehensive dental services should be the advocacy role of the institutional dental staff.

Although some institutional dental programs presently maintain a training role through a university affiliation, many other institutional dental programs could function as a training site for dental students and especially for dental hygiene students who attend community colleges. The initiation of these training commitments can be provided by a proactive institutional dental staff.

A review of the literature revealed inadequate clinical information related to the particular needs of profoundly disabled individuals. Institutional dental programs can become a research as well as a training site. Academic staff from dental schools and dental hygiene schools could be attracted to an environment with easy access to appropriate subjects and a dental staff available for support.

Continuing Education courses offering clinical experience in providing dental care for the handicapped, especially the severely disabled, are few in number. A one-on-one clinical experience could be arranged with private practicing dentists and dental hygienists desiring training in this area. Similarly, providing an educational clinical experience to public health dentists and dental hygienists to increase their ability and willingness to provide care to this population should not be problematic. It is particularly important to involve the public health dental hygienists in preventive programs involving community-based MR/DD clients residing in group homes and other community placements.

Institutional dental staff can be instrumental in initiating and 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(ARC), organized dentistry and dental boards is helpful in this regard.

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 a Down Syndrome parent group to consulting with the State Dental Director on possible impact of proposed legislation.

A most important activity for institutional dental professionals is to become organized on a state level. Particularly in the large states, an effort should be made 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.

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