SPECIAL NEEDS

The Extraordinary Vulnerability of People with Disabilities: Guidelines for Oral Health Professionals

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ABSTRACT

In the last 40 years, there has been a dramatic shift in living arrangements for people with disabilities from large state institutions to community-based care. This shift has required communities to increase their clinical capacity including oral health care systems. Oral health professionals must be cognizant that the rate of abuse and neglect experienced by people with developmental disabilities and other special needs is at least four times the rate experienced by the general population. These trends have resulted in additional responsibility on community oral health professionals to provide oral health services for many people who formerly lived in state institutions including recognizing and reporting suspected abuse and neglect. Oral health professionals must prepare themselves to successfully carry out these professional responsibilities.

PURPOSE OF PAPER

There is a national trend to normalize and deinstitutionalize people with disabilities and support them in home-like community residential settings.[1] This has resulted in increasing numbers of individuals with special needs seeking oral health care in dental offices. Dental professionals need to be aware of considerations involved in treating this population. Among these is the extraordinary vulnerability of this population to abuse and neglect and the role of the dental professional in recognizing and reporting potential abuse and neglect.

In the last 40 years, the national deinstitutionalization movement has resulted in a dramatic shift from placing people with developmental and other disabilities in large state-operated institutions to moving people with special needs into community living arrangements. In many states there have been significant declines in the institutional population in this time period.[2,3] In Florida, two of six Developmental Services Institutions (DSI); have been closed and the remaining four have been downsized by as much as 65 percent.[1] In California between 1992 and 2002, the population of people being served by the Department of Developmental Services (DDS) who were living in a State Developmental Center decreased by

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45.8 percent while the population being served by DDS who lived in the community increased by 78.2 percent.[4] As of October 2003, 70.3 percent of people with developmental disabilities served by DDS lived in their own home or with a parent or family member; 14.6 percent in a community care setting (group home); 8.5 percent in independent supported living arrangements; 4.7 percent in an intermediate care facility or skilled nursing facility, and only 1.9 percent in a state developmental center.[4]

There are many reasons for this remarkable demographic shift, including parent advocacy for more community-based programs, recognition of the civil rights of people with disabilities to live and participate in society, legislative mandates to downsize institutions, and the establishment of government programs to support community living arrangements.[5] The result of deinstitutionalization, however, is that people with developmental disabilities and other special needs have become increasingly dependent on community-based resources for social services and medical and oral health care. In many cases these resources are not available.[6,7,8] In fact, people with special needs, particularly those with developmental disabilities, have more dental disease, more missing teeth, and more difficulty obtaining dental care than other segments of the population.[9-14]

The Surgeon General's Report on Oral Health points out that populations with mental retardation or other developmental disabilities have significantly higher rates of poor oral hygiene and an increased need for periodontal treatment than the general population.[9] In addition, people with disabilities have a higher rate of dental caries than the general population, and almost two thirds of community-based residential facilities report that inadequate access to dental care is a significant issue.[15-18] Untreated dental disease has been found in at least a quarter of those with cerebral palsy, as well as 30 percent of those with head injuries, and 17 percent of those with hearing impairment.[10] A study commissioned by the Special Olympics concluded that the oral health of individuals with mental retardation is poorer than that of their peers without mental retardation. Individuals with mental retardation have more untreated caries and a higher prevalence of gingivitis and other periodontal diseases than those in the general population.[19]

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Availability of dental providers trained to serve special needs populations and extremely limited third-party support for the delivery of complex services further complicate the issues entailed in addressing the oral health needs of this population.[9] There is even congressional testimony where the opinion has been expressed the health care system in the United States practices active discrimination against people with disabilities for no other reason than the fact they have a disability that makes the health care professional uncomfortable.[20]

Many of the factors that contribute to increased dependence on scarce community resources for special needs populations, such as an increased incidence of oral disease and difficulty accessing oral health services, also contribute to an increased vulnerability to abuse and neglect of these individuals. Oral health professionals can play an important role in providing oral health care for special populations and in recognizing signs of abuse and neglect.

Abuse and Neglect in People with Special Needs

There is extensive literature that demonstrates that people with developmental disabilities experience abuse at least four times the rate experienced in the general population and possibly as much as ten times.[21,22] There is also a very high probability of repeat victimization prior to the abuse being reported or investigated. Further, the perpetrator is usually someone well known and trusted by the victim and his or her caregivers.[21,23-29] This literature indicates that:

- There are 5 million crimes against people with developmental disabilities each year in the U.S. compared with 8,000 hate crimes, 1 million incidents of elder abuse, and 1 million incidents of spousal abuse.
- More than 70 percent of women with developmental disabilities are sexually assaulted in their lifetime.
- Thirty-nine percent to 68 percent of girls and 16 percent to 30 percent of boys with intellectual disabilities will be sexually abused before age of 18.
- The rate of robbery against persons with intellectual disabilities is 12.8 times higher than against the general population.
- Offenders are often caregivers providing services related to the disability.
- Offenders often seek out persons with disabilities because they are considered to be vulnerable and unable to seek help or report the crime.
- Forty-four percent of violent crime in the general population is

reported nationally compared with 4.3 percent of violent crime reported against people with disabilities.

There are many factors that contribute to the vulnerability of persons with developmental disabilities. These include:

- Their physical and mental impairments are apparent and thus perceived as "easy targets" who are unable to defend themselves.
- Their multiple service needs require them to access many different service delivery systems and thus expose them to many different types of providers.
- Their limited problem-solving capacity leaves them vulnerable to persuasion by others and less cognizant of warning signs of dangerous persons or places.
- Training on safety and sexuality is often lacking.
- They often believe that if they report abuse, no one will believe them.
- They are often segregated and very dependent on their caregivers.
- Residential care providers often hire unskilled care staff at minimum wage and experience a high attrition rate.

People with Disabilities and the Dental Office Environment

Oral health professionals can be in a better position to provide dental treatment for people with special needs and to recognize signs of abuse or neglect if they consider some of the challenges the dental office environment can present. The dental office can be perceived quite differently compared to the physician's office, particularly for a patient with developmental disabilities. When seeking medical care, the patient is often much more aware of his symptoms and the need for treatment. Except for cases of dental pain, even persons needing significant restorative work may not experience limitations in their daily functioning. Conversely, persons accessing medical care typically present with specific injuries or illness-related symptoms. A person with cognitive limitations may thus be confused or reluctant to agree to dental care.

Second, the array of equipment immediately present for even a dental exam can be foreboding and confusing. Conversely, a medical exam room is more simply furnished with the examination table, blood pressure apparatus, and a few containers of swabs, tongue depressors, etc.

Ensure that a caregiver who knows the patient and their current health information and who the patient trusts will be accompanying the patient.

Third, patients sitting in the dental reception room are often cognizant of the distinctive shrill sounds of dental "drills" and polishing equipment. Fourth, patients in dental offices are typically asked to assume a much more vulnerable position than patients in medical offices who are asked to sit on the exam table. Finally, the medical exam typically begins with some mildly invasive procedures (blood pressure, temperature, stethoscope, etc.) compared to the course of the oral examination and treatment. Procedures in the mouth can be perceived as very invasive even if they are not painful.

There are a number of strategies that can be employed to increase the likelihood of having a successful dental visit with a patient with special needs. It is helpful for dental professionals to recognize that persons with developmental or other disabilities have a dramatically higher incidence of abuse; the dental office can be a strange and confusing place; the patient is asked to assume a physical position that is very vulnerable; prior dental treatments themselves may have involved pain or trauma, particularly if oral health had been neglected for many years; the cognitive processing of many persons with developmental disabilities in particular, varies from less sophisticated to significantly impaired; and caregiver follow through to maintain oral health may be less than optimal. Given these realities, it is important to prepare for the dental visit.

Pre-visit strategies that individuals in the dental office can follow include gathering information about previous dental care. It is important to understand not only what was done, but how the care was delivered and which techniques helped to make the treatment go smoothly and which did not. Some people with developmental disabilities may have received their oral healthcare under general anesthesia in the past, particularly if they have a long history of institutionalization. In considering the best approach to ensure success, the practitioner must take into account any previous trauma or pain history associated with oral health care. The pre-visit information that is obtained should also address whether pre-visit medication (e.g. sedative) has been routinely given in the past. Lastly, but perhaps most importantly, ensure that a caregiver who knows the patient and their current health information and who the patient trusts will be accompanying the patient and be available during the visit.

An excellent technique that also has proven successful to prepare and help to "de-sensitize" anxious patients has been the pre-visit binder. This binder is a collection of photos of the outside of the

office building, reception desk, waiting room, exam/treatment rooms (including the exam light as the primary object in the field of vision during treatment), staff likely to be encountered (both with and without masks), particular cleaning instruments likely to be used, and any "freebie" packs to be given and the end of the visit. An office would be well advised to keep several of these binders available for "check-out" several days prior to the visit. The primary caregiver should review the binder with the patient at least daily for three to four days immediately prior to the visit.

Pre-visit preparation can also include gathering information about the individual's particular medical, psychological, or social situation. There is an excellent Web-based resource available for information about developmental disabilities called the *Developmental Disabilities Digest*. It is a continually updated summary of the latest research on the 50 most common diagnoses and syndromes of developmental disabilities.[30]

During the dental visit, there are also some strategies to ensure success. Given the limited cognitive and perceptual difficulties experienced by some persons with disabilities, a practitioner should be prepared to make some minor but important adjustments in interacting with the patient. First, have the trusted caregiver/parent accompany the patient. This person can continue to reassure the patient during the dental procedures. Second, err on the side of speaking too simply and too slowly. Third, the closer you are to the patient, the more slowly you should move. You will recognize the importance of this strategy especially for those patients with histories of abuse or even bullying at their day programs or workshops. Fourth, display and explain the instruments, as you are about to use them. If the pre-visit binder was done correctly and utilized, there should be no stressful surprises for the patient.

If the techniques described above are combined with a friendly and caring demeanor and a willingness to be flexible about routines normally followed in the dental office, providing treatment for people with special needs can be very rewarding. The rewards include the fact that the treatment experience may very well constitute a life-altering event for the patient. Given the myriad of chronic medical and functional difficulties these patients experience, oral health is too often overlooked or less of a priority. Patients have been literally rescued from locked institutional care and returned to their family homes because someone recognized that behavior problems were resulting from dental pain. Chronic medical conditions have been resolved because remediation of oral cavity issues allowed the patient to eat and receive adequate nutrition. Simply stated, you will have the opportunity to turn around someone's life.

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Some patients will present with unparalleled clinical complexity. These treatment opportunities can provide the oral health professional with fascinating clinical experiences reminding you why you became a clinician. You will also enjoy the camaraderie of being one of several clinicians on a multi-disciplinary treatment team focusing on the health and well-being of the patient. You will enjoy the team mobilizing resources to follow through on your recommendations. In addition, you may have the opportunity to reaffirm the critical role of the oral health practitioner in peoples' general health and well-being. Speech therapists, occupational therapists, nutritionists, the primary care physician, psychologists, and social workers will all be waiting for your essential input before proceeding with their course of treatment to improve the quality of life for the patient.

Finally, you will receive unequaled gratitude on the part of families, caregivers, and social workers. The appreciation expressed by families of patients with special needs is often more profound than with any other treatment population. Just as life has been a terrific struggle for persons with disabilities, their families and caregivers have been alongside them in this effort to live as full a life as possible given their disabilities. Family members have approached many clinicians working with this population with tears in their eyes thanking them profusely for improving the quality of their lives. Other measures of gratitude have included letters to the governor and other elected officials, recognition awards from advocacy groups, and peer recognition awards from professional organizations.

Recognizing Signs of Abuse or Neglect in People with Special Needs

The oral health provider who has taken the time to incorporate people with special needs in their practice may observe signs of abuse or neglect. Clinicians must be alert to unexplained or unusual bruising, any burns or fractures or significant weight loss and other possible physical symptoms of abuse or neglect. Dental practitioners are in a unique position to detect facial injuries consistent with abuse including

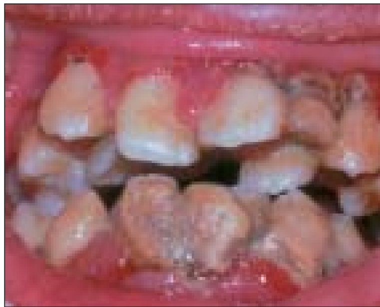

Figure 1. Oral neglect may indicate general neglect or abuse.

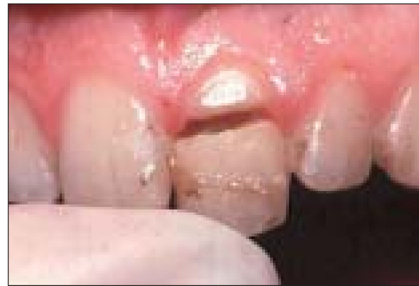

Figure 2. Oral trauma, such as this broken tooth, may be a sign of abuse.

black eyes, bloody or swollen lips, and broken jaw or nose. Dentists may observe a persistent reluctance to remain seated in a standard position in the dental chair (possible reaction to bruises or fractures) or even a vague verbal reference from the patient (**Figures 1 and 2**).

Dental practitioners must also be alert to caregiver behavior for signs of abuse of patients. Note how the patient presents generally. Is the patient dirty or unkempt? Are the clothes in good condition and well fitting? When practitioners observe caregivers relying on physical coercion or threats in a public venue such as a dental office, one must wonder what transpires when no one is observing. One should query further if the caregiver characterizes the patient as "bad" or "evil" or uses other global negative terms or harshly criticizes the patient. Some caregivers who are abusing those entrusted to their care may make offhand remarks about desires to harm the patient or actually mention harsh discipline practices such as belts, sticks or other objects.

Patient behavioral indicators are less definite. Individuals commonly display a wide range of behavior with regard to routine behavior. This is even more true for reactions to high stress circumstances such as abuse and neglect. However, there are situations worth investigating further. Abuse may be suspected when the patient appears anxious or nervous, or readily flinches or recoils when approached by others. Or, the patient may display extreme muscle tenseness while undergoing specific dental procedures. The key distinction here is that with dental phobia, one would expect pervasive tenseness, often from when first entering the office. We would expect tenseness resulting from fear of further abuse will be most manifest when practitioners are in specific positions (e.g. directly over the patient). Further, when the patient demonstrates extreme timidity or appears overly compliant, one may wonder if this behavior is fear driven.

Reporting Abuse or Neglect of Dependent Adults

There are federal and state laws that specifically address the definition and prohibition of abuse and neglect of elders and dependent adults and requirements for reporting. A listing of these laws can be found on the Web site of the Department of Aging, Long Term Care Ombudsman Program.[31] Among these is Section 368 of the California Penal Code which defines "dependent adult" as "any person who is between the ages of 18 and 64, who has physical or mental limitations which restrict his or her ability to carry out normal activities or to protect his or her rights, including, but not limited to, persons who have physical or developmental disabilities or whose physical or mental abilities have diminished because of age." Dependent adults are also defined as "any person between the ages of 18 and 64 who is admitted as an inpatient to a 24-hour health facility." In addition, "caregiver" is defined as "any person who has the care, custody, or control of, or who stands in a position of trust with, an elder or a dependent adult."[32]

In California law, abuse of dependent adults is defined as either physical abuse, neglect, financial abuse, abandonment, isolation, abduction, or other treatment with resulting physical harm or pain or mental suffering or the deprivation by a care custodian of goods or services that are necessary to avoid physical harm or mental suffering.[33] Neglect is defined as "the negligent failure of any person having the care or custody of an elder or a dependent adult to exercise that degree of care that a reasonable person in a like position would exercise or the negligent failure of an elder or dependent adult to exercise that degree of self care that a reasonable person in a like position would exercise." Neglect is considered to include, but not be limited to failure to assist in personal hygiene, or in the provision of food, clothing, or shelter; failure to provide medical care for physical and mental health needs; failure to protect from health and safety hazards; failure to prevent malnutrition or dehydration; and failure of an elder or dependent adult to satisfy the needs described above for himself or herself as a result of poor cognitive functioning, mental limitation, substance abuse, or chronic poor health.[34]

Oral health professionals can play a role in detecting and reporting signs of possible abuse or neglect in their dependent adult patients. In fact, as mandated reporters, oral health professionals are required to do so. Mandated reporters are those groups specifically identified in California law as required to report

suspected abuse or neglect. Licensed dental professionals are among this group and can be found guilty of a crime for not reporting.[35] This law is specific about the reporting requirements. It says that "any mandated reporter who, in his or her professional capacity, or within the scope of his or her employment, has observed or has knowledge of an incident that reasonably appears to be physical abuse, abandonment, abduction, isolation, financial abuse, or neglect, or is told by an elder or dependent adult that he or she has experienced behavior, including an act or omission, constituting physical abuse, abandonment, abduction, isolation, financial abuse, or neglect, or reasonably suspects that abuse, shall report the known or suspected instance of abuse by telephone immediately or as soon as practicably possible, and by written report sent within two working days." The California Department of Social Services form for filing a written report can be downloaded from the Web.[36]

Oral health professionals who suspect abuse or neglect in a dependent adult are required to report these suspicions to different agencies depending on where the abuse or neglect occurred. The California Attorney General's Office launched a "SafeState" Campaign in April 2003.[37] The campaign features a statewide hotline, (888) 436-3600, for reporting of suspected cases of elder or dependent adult abuse. The hotline will directly connect callers wishing to report suspected abuse to the responsible agency including their local Adult Protective Services Agency or the Long-Term Care Ombudsman crisis line (**Figure 3**).

As indicated earlier in this article, few dependent adults with developmental disabilities live in long-term institutional care facilities. However, if a dental professional suspects abuse or neglect for someone in a long-term care facility, they should report this to the local long-term care ombudsman. Information about the state's ombudsman program can be found on the California Department of Aging Web site.[38] There is an Office of the State Long-Term Care Ombudsman (OSLTCO) that develops policy and provides oversight to 35 counties' Long-Term Care Ombudsman Programs. The state also maintains a 24-hour, seven-day-a-week crisis line at (800) 231-4024 to receive complaints from residents. There is also a listing of county Long-Term Care Ombudsman Program contacts available on the Department of Aging Web site.[39] In an emergency, report suspected abuse or neglect to local law enforcement agencies using the 911 system.

Another state agency concerned with abuse of dependent adults is the Bureau of Medi-Cal Fraud and Elder Abuse in the Office of the Attorney General. This agency is concerned with attempts to defraud California's Medi-Cal program, including health care providers and persons involved in the program's administration. They are also concerned with abuse and neglect of patients in Medi-Cal-funded facilities, such as nursing homes, developmental treatment facilities, and hospitals. They can be contacted at the state Attorney General's Bureau of Medi-Cal Fraud and Elder Abuse toll-free hotline at (800)722-0432.[40]

As indicated earlier in this article, the vast majority of dependent adults with developmental and other disabilities live in community care facilities, independent or supportive living arrangements, or in family homes. Suspected abuse or neglect in these individuals should be reported to the local Adult Protective Services (APS) agency or local law enforcement. The California Department of Social Services is responsible for the various counties' Adult Protective Services Program. These agencies provide assistance to elderly and dependent adults who are functionally impaired, unable to meet their own needs, and who are victims of abuse, neglect, or exploitation. The role of the county adult protective services agencies is to investigate reports of abuse of elderly and dependent adults who are living in the community. They provide or coordinate support services, such as counseling, money management, conservatorship, and advocacy. They also provide information and education to other agencies and the public about reporting requirements and other responsibilities under the elder and dependent adult abuse reporting laws.[41] There is a county contact list available on the APS Web site[42] (**Table 1**).

Figure 3. Poster from the California Attorney General's SafeState Campaign. *Used with permission by the California Attorney General's Office.*

Report Follow Up

Confidentiality for the reporter is protected by law. You will provide the name of the person, the current location of the person, and the nature and extent of the suspected abuse or neglect. The phone call must be followed up within 36 hours by a written report to the protective services agency. After the report, the county's social services agency may

Table 1

Contact List

Attorney General's Elder and Dependent Abuse Hotline

- Referral to Ombudsman or Adult Protective Services: (888) 436-3600

Reporting Suspected Abuse in Long-Term Care Facilities

- State Ombudsman 24-hour, seven-days-a-week crisis line (800) 231-4024
- List of Local County Ombudsman Programs: http://www.aging.state.ca.us/html/programs/ombudsman_contacts.html
- California Attorney General's Bureau of Medi-Cal Fraud and Elder Abuse hotline (800) 722-0432
- Local Law Enforcement

Reporting Suspected Abuse outside of Long-Term Care Facilities

- Adult Protective Services County Contact List with 24-hour, seven-days-a-week hotline number: http://www.dss.cahwnet.gov/pdf/apscolist.pdf
- Local Law Enforcement

or may not investigate. Indeed, budget constraints results in varied response from county to county. Some counties have been criticized for investigating only if there is a "gaping wound." Typically, this "triage" approach is the result of budget constraints. Generally, however, the county social service agency will investigate or at least document the report. This becomes valuable data if there are a number of these reports over time regarding a particular individual caregiver.

If your concerns fall short of "reasonable suspicion" of abuse or neglect, yet you are concerned that the person is receiving less than optimal care you have several options. The first would be to contact the patient's service coordinator at the local regional center if they are registered with the regional center system and discuss your observations with him/her. Another option exists in the case of a major wound or bruise but not a reasonable suspicion of abuse or neglect. You may complete a "Special Incident Report" for your local regional center. This documents your observation and assists the regional center in establishing a "paper trail" should other team members make additional observations.

Conclusion

People with special needs including those with developmental and other disabilities are living and seeking dental care in the community in greater numbers than ever before. Dental professionals can prepare themselves to provide oral health services for these individuals and enhance their practices and professional lives in the process. In the course of providing dental care, oral health professionals may encounter signs of abuse or neglect which they are mandated to report. Knowing what, where and how to report suspected abuse and neglect is essential information for every dental practice. CDA

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