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Analysis of Dental Management of those with Physical and Mental Disabilities

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Abstract

Those with physical and mental disabilities are at an increased risk of oral complications such as gingivitis and periodontal disease. In comparison with this risk, this population struggles to access appropriate dental care that accommodates those with disabilities. This thesis reviews the demographics of those with special needs, dental education barriers to working with this population and financial barriers that hinder access to care. An overview of the oral health problems of common disabilities is presented as well as behavioral management techniques that could be easily implemented in the dental office. A general review of good oral hygiene for those with special needs is also presented. This dissertation is intended to educate the dental community, parents, caregivers, and the general public of the dental management of those with special needs and to advocate increased access to care for this population.

Methodology

Literature Review

An in-depth review of critical research of dentistry with relation to those with special needs is analyzed in full in this dissertation. As a secondary source, this review reports new or original work in the form of interviews and survey results, but only does so to make formulated opinions of the topic at hand. The research compiled in this dissertation is compiled to shine light on hopeful future research of the topic of dental care management of those with physical and mental disabilities.

Qualitative Methods

A survey was conducted with the utilization of http://www.surveymonkey.com and analyzed in this dissertation. The survey was conducted from March 22nd 2011 to April 2nd 2011 and included nine questions referring to dental visits, finances, feelings about the dentist, and those with special needs. Participants of the study were selected from Facebook (www.facebook.com) and ranged in age from 17 – 50 years of age. The study was a randomized. Of the 1436 Facebook friends invited to take the survey, only about 323 actually chose to participate. The research compiled in the survey was used for the dissertation to shed light on new data and ideas for those with special needs.

This dissertation also utilizes multiple interviews of parents that have children with disabilities and dentists whom have experience in the area of special needs. The interviews conducted further support the need for better access to care of those with disabilities. Those interviewed include:

- Suzanne Paist-Bennett, mother of a son with Autism, Tourette syndrome, and ADHD, from Trevose, Pennsylvania.

Introduction

Imagine a life deprived of performing certain physical activities such as walking, talking, seeing, hearing, or climbing stairs. Imagine a life where you struggle to understand others and are unable to live independently. For those with physical and mental disabilities, these difficulties are faced daily. As of 2008, 52 million people in the United States had some type of disability (an impairment in performing specific functions) while 25 million Americans suffered from a severe disability, or one that makes it very difficult to perform basic activities independently (Guideline on management of dental patients with special health care needs, 2008). These alarming numbers contribute to about 10% of the United States population and are only expected to erupt in future decades. It is believed that the direct correlation between aging and disabilities may contribute to these increasing trends (U.S. Dept. of Commerce, 1997).

In the late 1800s and early 1900s, people with physical or mental disabilities were often placed into mental hospitals or prisons to be cared for if they weren't being cared for at home. Institutions were thus created to educate those with disabilities in hopes they could return to the community with success. In 1876, a humanitarian effort was made to form an organization in the name of mental disability. It was named, "The Association of Medical Officers of American Institutions for Idiots and Feeble-minded Persons," which by today's standards is somewhat shocking. The institutions coordinated by this group were overcrowded and humiliating to those who lived there and little efforts were made to provide superb dental or medical care to these patients. As of the 1960s, laws have been passed to limit over-crowding in state institutions and diverse fields of people now care for those with disabilities. At the break of the 21st century, this population is no longer seen as full of "idiots" or "feeble-minded" individuals but instead as people of disabilities. In fact, in

a recent survey, it was found that almost 54% of people knew of someone with an intellectual, behavioral, or physical disability (Fleck 2011). Of those 54% of people who knew someone with a disability, 57% were unsure as to whether the person with special needs went to the dentist. However, almost 14% claimed a dentist had not treated the individual with special needs regularly (Fleck 2011). To further incorporate these individuals into mainstream society, it is important to grant them equal access to hygiene and care (May 2006).

Oral health and general health are "linked inextricably" because numerous diseases and conditions can manifest in the mouth (Almomani, Brown, and Williams 2006). These conditions include "heart disease, stroke, type II diabetes, pregnancy complications and renal failure" (Moursi et al. 2010). According to the *Psychiatric Rehabilitation Journal,* speech, diet, sleep, communication, education, and self esteem are all affected by one's oral health. Thus, poor oral health significantly impacts the way one's body functions (Almomani, Brown, and Williams 2006). Surprisingly, it is estimated that 96% of Americans suffer from dental disease, which includes tooth decay and gingivitis (Bennett 1999). Those with disabilities are at an increased risk of oral disease and neglected oral care that can have a "devastating impact" on one's health (Guideline on management…2008).

Obstacles for these patients in terms of oral health include fear, dependency, access to care and lack of training of the dental professional with this population (Davis, Bedi, and Scully, 2000). Access to care and lack of training by a dental professional became a mainstream problem when Funice Shriver and Senator Ted Kennedy had trouble finding care for their 62-year-old sister, Rosemary, whom suffered from an intellectual disability in the 1990s (Waldman, Perlman and Cinotti, 2009).

Rosemary was referred to a pediatric dentist whom privately practiced over a thousand miles away, Dr. Steven P. Perlman. Perlman, although a pediatric dentist, was knowledgeable in treating individuals with special needs, and willingly accepted Rosemary as a patient, even though she was not a child. Rosemary received the care she needed under general anesthesia because of the "complexity of care" (Waldman, Perlman, and Cinotti 2009). This famous story alone shed light on the difficulty those with disabilities face in accessing dental care.

Although great strides have been made in the efforts to improve the lives of those with physical and mental disabilities in the United States within the last 40 years, there are still hurdles in health care that this population faces today. The negligence of this population in dental care has necessitated carrying out this study. The principle objective of this study is to not only educate the general public of the dental care needs of people with both physical and mental disabilities but to also highlight the difficulties those with disabilities face in accessing proper dental care. The dissertation also aims to make the dental community and caregivers of those with disabilities aware of the ever-growing debate between general anesthesia and sedation options during dental care. Another aim of the dissertation is to provide recommendations to caregivers and dentists of appropriate ways of helping those with disabilities manage their dental hygiene.

Access to Dental Care

In a survey conducted of 323 people, 77.1% admitted they attend the dentist regularly, every six months (Fleck, 2011). It is of no surprise then that the number of those with a disability that go to the dentist regularly is much less. According to a study in 2004, 14.4% of adults with Intellectual Disability had not had a dental cleaning in the past 5 years, which is significantly higher than the 8% of the general population that had not received a cleaning (Havercamp, Scandlin, and Roth 2004). Furthermore, a recent study found that "with the exception of behavior disabilities" the more disabled someone is, the less likely they are to receive a dental cleaning. Those with behavior disabilities are not included because they typically have more than just one-on-one care. Interestingly enough, those with disabilities living in community settings, such as assisted living facilities (group homes), are less likely to receive dental care than those who live in institutions (Bershadsky and Kane 2010). Both of these studies raised the concern that those with higher levels of disability do not receive preventative oral health care. It is believed that several factors contribute to underrepresented dental care in this population including the abundance of dentists unwilling or having a lack of training in the field, inadequate finances in terms of insurance, and location (Bershadsky and Kane 2010).

Dental Education

The unwillingness of dentists to treat those with disabilities is alarming. Surprisingly, 23% of parents have declared it difficult to find a dentist for their disabled child (Collado, Faulks and Hennequin 2008). The reluctance of dentists to provide dental care is essentially due to education. In many studies, it has been found that dental school graduates have limited preparation in providing services to individuals with special needs.

By the end of the 1990s, it was discovered that "more than half of U.S. dental schools provided fewer than five hours of classroom presentations and about 75% of the schools provide from 0 to 5% of patient care time for the treatment of patients with special needs" according to H. Barry Waldman, Sanford Fenton, Steven P. Perlman, and Debra A. Cinotti, authors of *Preparing Dental Graduates to Provide Care to Individuals with Special Needs.* It should come as no surprise then that only 10% of general dentists are willing to treat children with cerebral palsy, mental retardation, or severe disabilities. Most alarming, 70% of general dentists reported they rarely or never treated those with cerebral palsy in their practice (Waldman, Fenton, Perlman, and Cinotti 2005).

There are many difficulties in expanding educational programs to treat those with special needs. These include costs, unfilled faculty positions on the subject, and limited numbers of trained or prepared practitioners on the topic. As of the early 2000s, the only dental schools that advocated special needs programs included Stony Brook University of Dental Medicine, West Virginia University School of Dentistry, University of Washington, University of Louisville, Ohio State University, University of Florida, and the University of Medicine and Dentistry of New Jersey (Waldman et al 2005). However, these twelve schools definitely don't encompass all 61 dental schools. According to the *Journal of Dental Education*, "in July 2004, the American Dental Association's Commission on Dental Accreditation (CODA) adopted a statement (Standard 2-26) requiring U.S. dental students to prove competency in assessing the treatment needs of patients with special needs" (Schwenk, Stoeckel, and Rieken 2007). However, there is much controversy around the word "assessing" and it is believed by some that assessing is much different than actually providing treatment to those with disabilities. Although the Standard 2-26 will hopefully increase "positive attitudes" in the dental community of treating those with special health

care needs, these attitudes cannot be fully interpreted for a few more years. It is essential that dental school educators advocate for competency in full treatment of patients with special needs whom are at increasing risk of oral disease. We need to be more willing to work with this population (Waldman et al 2005). It has also been noted that continuing education and post-doctoral degrees in dental education "rarely provides additional training on vulnerable and special-needs populations" in which training is needed especially (Waldman et al 2009).

Although general dentistry post-doctoral programs haven't always placed emphasis on the need for special needs education, post-doctoral pediatric dentistry education has played what some may say the only significant role in caring for special-needs patients of all ages, even those typically not seen as 'pediatric' (Waldman et al 2009). Thus, as exemplified in the Rosemary case described in the **Introduction**, many disabled adults must see a pediatric dentist willing to treat them, at sometimes thousands of miles away (Waldman et al 2009).

It is uncertain whether in the past, pediatric dentists were the only ones trained to work with those with special needs because of their previous life expectancy. What is known, however, is that the number of adults with disabilities has increased in the United States as a result of "higher initial survival rates, improved medical management resulting in increased life expectancies, and the increased likelihood of acquiring chronic disabilities later in life." This has ultimately led to controversy over the appropriate age range of patients cared for by pediatric dentists at the expense of desperately overlooked and needed oral health care of those with disabilities (Waldman et al 2009).

Financial Barriers to Dental Care

Aside from education and willingness of dentists to treat those with disabilities, a large barrier to oral health care is the struggle of financing in terms of lack of insurance, Medicaid, and the overall financial burden of having a disability. While the cost of raising a child continues to increase averaging $191,000 per child in 2008, the cost of raising a child with an intellectual disability over a lifetime is more than one million dollars (Waldman and Perlman 2008). The table below describes the lifetime costs for specific developmental disabilities.

Table 1. Lifetime Costs of Individuals Born in 2000 with Intellectual Disabilities

Table 1.

Estimate prevalence and lifetime economic costs (in 2003 dollars) for individuals born in 2000 with intellectual disabilities, cerebral palsy, hearing loss, and vision impairment by cost category: 2000 [3]

	DEVELOPMENTAL DISABILITY			
	Intellectual disability	Cerebral palsy	Hearing loss	Vision impairment
Rate per 1,000 children 5-10 yrs	12.0	3.0	1.2	1.1
Average cost per person	$1,014,000	$921,000	$417,000	$566,000
	All individuals (In billions)			
Direct medical costs *	$7.1	$1.2	$.1	$.2
Direct non-medical costs	$5.2	$1.1	$.6	$.4
Indirect costs**	$38.9	$9.2	$1.3	$1.9
Total costs	$51.2	$11.5	$2.2	$2.5

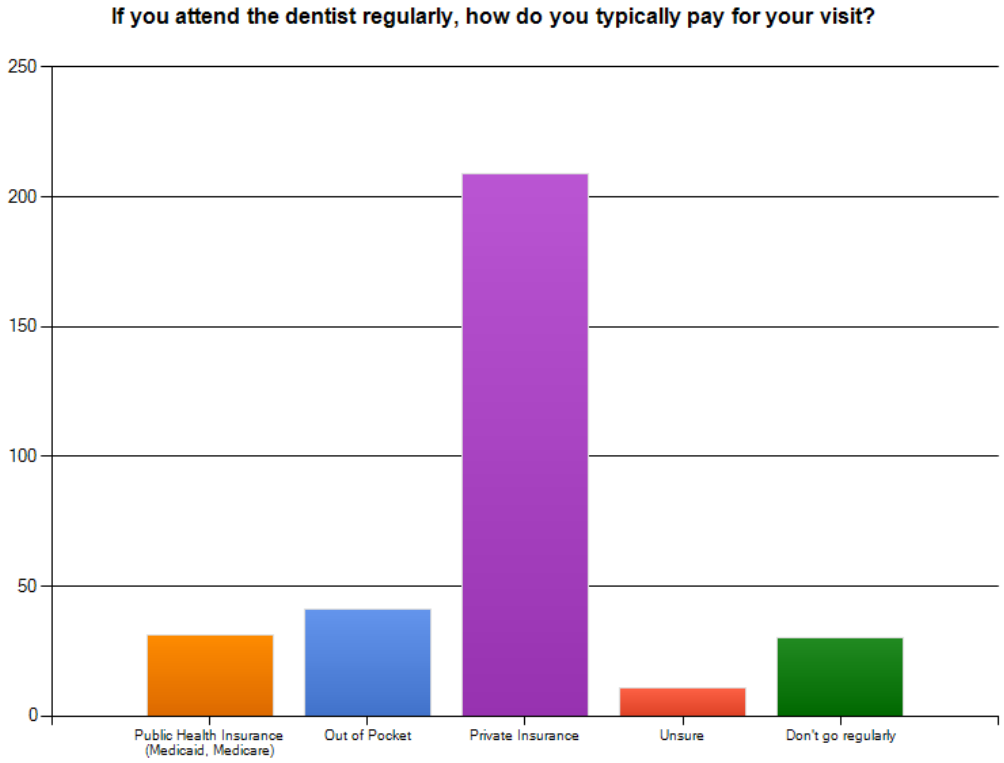
Note: Numbers have been rounded * Does include dental services ** Includes productivity losses from increased morbidity

(Waldman and Perlman 2008 p. 72)

As shown in Table 1, a person with intellectual disability, on average, has medical/dental costs of $7.1 billion dollars over a lifetime. Thus it is not surprising that many patients cannot afford care. While it is known that over 40 million Americans lack health insurance, more than 100 million lack dental insurance. Table 2, below, shows the financial options for people without a disability, taken from the survey, *Special Needs and*

Dentistry. It can be inferred from this data, that although much of this subset pays for dental care with private insurance, those with special needs that have a $7.1 billion need for medical/health care may not be able to afford the insurance needed.

Figure 1. Financing Oral Health: General Population



(Fleck 2011, #8)

Ironically, the service reported as needed yet not received among those with special needs is dental care, because insurance companies, as predicted, cannot pay billion dollar costs for medical and dental care (Waldman and Perlman 2008). The Medicaid dental program, which was established to ensure that poor children and adults received dental services, provides coverage for 22% of children with special health care needs (Waldman and Perlman 2008) and 530,000 individuals with mental retardation and other developmental disabilities. However, only seven states actual cover adult dental care in the Medicaid program as of 2005 (Waldman et al 2009).

But even with Medicaid, those with disabilities may not receive the preventative care they need because of unwillingness of dentists to provide that care to Medicaid patients. Dentists are typically unwilling because of inadequate finances, too much paperwork, and missed appointments. Dentists are also unwilling to care for those with special needs because as a private practitioner, they maximize their income by completing as many treatments as possible per day. Caring for those with special needs or challenging behaviors could take multiple visits for longer periods of time, decreasing the amount of profit (Newton 2009). C. Richard Bennett states, "It is not difficult to understand why dentists refuse to participate in programs that pay 48% of the usual and customary fee when the cost of overhead in a dental office is approximately 65%" (Bennett 1999). Because of this, however, "fewer than one-third of children covered by Medicaid receive any dental treatment at all" (Waldman et al 2009). Most of those children lose dental coverage by the Medicaid program at the age of 21 further increasing the obstacle in receiving dental care.

Most third party insurance companies also refuse to pay for conscious sedation in the dental office, which means that the patient must be treated with conscious sedation in a hospital setting or not at all (Bennett 1999). In a hospital setting, conscious sedation costs about $1500 while in a dental office it costs approximately $300- $500. When these patients are treated in a hospital setting, the training and special skills of dentists in terms of oral health care is held at a substandard level in terms of meeting the oral needs of the population (Bennett 1999).

This concern is highly debated among aging adults with disabilities. Who cares for disabled adults once Medicaid is no longer available and a pediatric dentist is not willing to treat them? Those practicing dentists who treat disabled children are "those who are older, who accept Medicaid, and who practice in small towns" (Waldman et al. 2009). Currently,

there is no information regarding how many pediatric dentists are actually willing to treat adults with disabilities when Medicaid is no longer available.

On the other side of public insurance, the Medicare program covers a few services for qualified adults with disabilities not including preventative care or the filling of teeth and replacing of prosthodontics. However, the program does cover, according to Waldman and Perlman, "a) extraction of a tooth as part of a repair of a fractured jaw, b) maxillofacial surgery for pathological or traumatic medical conditions, c) prosthetic rehabilitation to replace or treat certain oral and/or facial structures related to covered medical and surgical interventions (e.g. cancer surgery), d) extraction of teeth prior to radiation treatment of the jaw, e) oral examination prior to kidney transplantation and f) certain medical procedures that dentists are licensed to perform," in other words, a small array of services (Waldman and Perlman 2008). The list does not highlight preventative dental care, important to one's overall health.

Although Medicare may cover important surgeries for disabled children and adults, they are typically forced to wait several months for dental treatment or surgery with general anesthesia. Without general anesthesia, John Khalaf, a dental anesthesiologist in West Covina, California, said, "…they have to be tied down, screaming and fighting. They can end up scarred for life" in terms of caring for those with disabilities. Khalaf built a $1 million surgery center for children from low-income families with autism, Down syndrome, and other developmental disabilities in West Covina, California. He did so even though as an anesthesiologist, the state government low-income health-care provider would reimburse him at a low rate. Khalaf realized the need for care among those with disabilities and used his dental education to help regardless of the profit (Abendschein 2007).

Khalaf's efforts serve as an example across the nation. Maybe with the help of a dentist like Khalaf, a twelve-year-old boy from Maryland would have lived to see another day. A tragic story described in the *Journal of Health Politics, Policy, and Law* talks of how expenses in dental care bills and lack of Medicaid coverage led to the boy's premature death in 2007. The boy's abscessed tooth had infected his brain and after two operations and more than six weeks of care, the boy's medical bills were more than $250,000. If a dentist had treated the boy routinely, an extracted tooth would have only cost $80 and would not have affected the brain or have caused his death (Mitchell and Gaskin 2008).

While it is known that few dentists accept Medicaid patients, it is assumed that even less accept Medicaid patients with disabilities (Mitchell and Gaskin). An effort to expand the dental network covered by Medicaid and Medicare programs needs to be considered for special needs patients to receive needed care and to not wait until close to death, as the boy in Maryland had to, to do so. Aside from expanding Medicare plans, many ideas have been proposed by dentists and members of Congress to increase the level of access those with disabilities have in terms of dental care. It has been suggested that more access be available for community-based care in different parts of the nation for those with disabilities (Bershadsky and Kane 2010).

However, the success of these community-based dental programs depends on the ability to maintain health records and services, as well as the ability for the program to consult other medical practitioners while providing and recognizing the need for preventative and restorative oral health care (Waldman and Perlman 2002). Others believe that because education requirements in both dental and dental hygiene schools have been established to allow for competency, future graduates will make an impact on access to

care. However, the nation must wait to see any potential changes until those dental students graduate in what is expected to be a few more years (Waldman et al 2009).

In the survey, entitled, *Special Needs and Dentistry,* participants were asked ideas on how to increase access to care to individuals with special needs. Figure 1 shows ideas prompted in this survey by the general public in changing access to oral health care for this population.

Figure 2. Ideas to Change Special Needs' Access to Oral Health Care

"Training and Understanding from the Dentist and their Hygienists in various/common disabilities so that they can cater and better treat those with disabilities and their families." - #34

"When the dentist or other health care providers are still in school, they should learn how to deal with and treat those with special needs so that will be more willing to work with them having the proper training." - #38

"Provide similar service to everyone, regardless of their needs. If anything, pay extra attention to those who really need it." - #39

"As an incentive for dentists to work with these patients, there could be a tax incentive for their business practice." - #41

"Special needs alone puts a huge financial burden on families, so they may put regular dental visits on the back burner. I believe there should be some sort of government grant to help with such procedures or the dentist should take the hit. I've known quite a few dentists who would be willing to do such a thing and cover any of the costs in order to help the less fortunate." - # 48

"More handicap accessible dental chairs, more space to move around in the exam room, accept more insurance types." - #53

"The dentist must make a willing and conscious effort to understand that his degree was obtained in order to aid others, and not for personal financial gain." - #70

"Mandated training sessions for Dentists to attend on a yearly basis, teaching them how to work with such patients. Also, some type of fund/scholarship available for these patients to cover expenses." - #163

(Fleck 2011, question #7)

As shown in Figure 1, many people believe that dentists and hygienists should receive more education or training in treating those with special needs for greater access to care. Space in the dental office was a large concern as well as financial plans that could be adopted by federal and state governments. Other studies have

suggested linking general health and dental health, such as in the article in 2002 in *Physician Assistant.*

In the article in 2002, Waldman and Perlman suggested that because oral health's relation to general health is overlooked, physician assistants (PAs) should act as a gateway to oral health to increase the access of care to those patients with disabilities. Typically physicians hardly pay attention to dentition of their patients, especially those with special needs. In the article, Waldman and Perlman suggest that PAs could not only refer patients with disabilities to a dentist that would be willing to treat them but they could also:

"(1) Perform a general examination of the dentition and oral cavity, and (2) reconsider some of the seemingly harmless actions of healthy practitioners, their patients, and some parents and guardians" (Waldman and Perlman 2002).

Among those seemingly harmless actions include tooth decay from a baby bottle, advising against prescription medications that induce decay and examining the sugar intake of patients. These small efforts made by PAs could help decrease unmet dental care service for those with special needs (Waldman and Perlman 2002). Waldman and Perlman thus suggest that medical and social history obtained by physicians should expand beyond their specialty fields in an effort to collaborate oral health care and general health.

General Anesthesia and Sedation Concerns

Another option to improve the quality of care of those with disabilities is the use of general anesthesia and conscious sedation to ease the patient as well as the dentist during treatment. Those dentists that do offer care to those with special needs more than likely provide some form of general anesthesia or sedation when dental treatments cannot be tolerated. The application of these two techniques varies depending on the knowledge and

training of the dentist, the equipment available in the office, the patient's tolerability and even financial obstacles (Maeda, Kita, Miyawaki, Takeuchi, Ishida, Egusa, and Shimada, 2005).

For over 150 years, dentists have been able to utilize the techniques of sedation or general anesthesia to patients (Caputo 2009). Sedation is defined as when a patient receives medication either orally or intravenously with a needle or by inhaling through a mask that allows them to relax and become more cooperative while keeping the patient awake (Plaza 2008). General anesthesia on the other hand can be defined as a "drug-induced loss of consciousness during which patients are not arousable, even by painful stimulation" by the American Society of Anesthesiologists (Dougherty 2008). The use of local anesthesia, however, was not condoned by the public until the late 1930s and did not gain full acceptance in dentistry until the late 1940s (Bennett 1999).

There are many benefits to the dentist and to the patient in using general anesthesia (GA), including patient cooperation, unconsciousness, no feeling of pain and rapid onset of delivery (Dougherty 2008). However, even with the general population, GA has some disadvantages to its use including patient protective reflex and vital sign depression, administration by a team, the need of special equipment, and required preoperative evaluations and testing (Dougherty 2008).

According to behavior assessment and evaluation by the dentist, reasoning for GA treatment in a study of 265 cases included 30.2% with intellectual impairment and Autism, 24.0% for multiple handicaps, and 24.4% of cases for physical handicaps and noncooperation. The remaining 21.4% was administered GA for dental phobia (Dougherty

2008). However, treatment under GA is only considered as a last resort after alternative behavior management techniques are attempted in patients mentioned.

Most dentists, however, cannot implement this last alternative of general anesthesia alone. Although different levels of education and training are offered to dentists to employ different anesthesia and sedation techniques, most dentists need post doctorate training to provide this vast array of anesthesia. Included in that category are dentist anesthesiologists (DA), whom are formally trained to provide a large array of anesthetic needs for dentists and their patients (Caputo 2009).

Dentist anesthesiologists are dentists whom receive a postdoctoral degree after two or more years in an anesthesiology program after dental school. They are considered to be professionals in managing pain and fear. While many dentists may not be familiar with working with those with developmental or acquired disabilities out of dental school, DAs are required to provide anesthesia to this population to receive certification. Although DAs are not used in all dental offices today, they are becoming increasingly popular in offices where dentists treat patients with behavior management needs. Those with intellectual and physical disabilities may not respond to low levels of anesthesia by a dentist and thus, DAs can compensate and provide more sedation or anesthesia as needed (Caputo 2009).

In May 2009's, *Exceptional Parent* magazine, Caputo writes, "Often when the dentist attempts to provide care with a failed sedation, the dental treatment is negatively impacted because the patient has not been successfully managed with the sedation approach." Thus, during treatment some sedation attempts are rendered unsuccessful and the dental treatment is affected in a negative light. DAs are better trained to focus on the "physical

and mental conditions" that may contribute to a disability and they can safely comfort these patients through anesthesia or sedation techniques (Caputo 2009).

Sedation techniques can be used effectively with patients of special needs with heightened anxiety. Sedation may also be considered more appropriate and more readily available than general anesthesia (Miyawaki, Kohjitani, Maeda, Egusa, Mori, Higuchi, Kita and Shimada, 2004). The only complications that are known to occur with sedation include vomiting and airway obstruction (Miyawaki et al. 2004).

The benefits of sedation use outweigh the risks. A study in 2008 confirmed that the use of inhalation sedation during dental care showed a reduction in future anxiety cases compared to general anesthesia in those with disabilities or special needs (Collado et al. 2008). Furthermore, "conscious sedation" eliminates fear and anxiety in a conscious patient by the use of a variety of drugs, intravenously, for relaxation. Conscious sedation typically allows the patient to tolerate dental procedures a bit better than without (Bennett 1999).

However, conscious-sedation techniques pose many obstacles in terms of delivery, similarly to general anesthesia. First, at the pre-doctorate level most dental schools in the United States do not teach the use of conscious-sedation. It is believed that conscious-sedation isn't taught because educators don't believe it should be, and instead teach the advanced technique in post-doctorate programs or continued education courses. However, C. Richard Bennett believes otherwise, and claims that to be proficient in the technique only about 100 hours or less is required. Most students that want to be proficient in this technique resort to residency programs and become DAs, but only ten programs of over 50 American dental schools actually exist in regards to this topic (Bennett 1999).

Another obstacle in terms of sedation for those with disabilities includes the controversy over the dose of intravenous sedation required for a successful level of sedation. It is very difficult to access effects of sedation in this population, thus it has been difficult to establish an appropriate sedative dose for dental patients with intellectual disabilities (Miyawaki et al. 2004). Because complications can occur with intravenous sedation as previously discussed, it is important that a correct dose is administered to the patient as to not enhance the sedation more so than expected. In a study conducted by Miyawaki et al. in 2004, it was found that of those with intellectual disabilities, the median dose of propofol (a common intravenous chemical for sedation) required for effective sedation was 4.74 mg/kg/h, much higher than the 3.31 mg/kg/h median that the general population is administered during dental procedures. This group also found that of common sedatives, midazolam and propofol were most useful for dental patients with intellectual disabilities (Miyawaki et al. 2004).

Although Miyawaki et al. 2004 discovered that those with intellectual disabilities require a higher dose of sedation than the general population, it is unclear why. Surprisingly, those with epilepsy require a significantly higher dose in sedative than those without. Because of these differences, studies need to be administered to test a wide range of intellectual and physical disabilities in terms of intravenous sedation to better cater to the needs of those with disabilities (Miyawaki et al. 2004).

A group in 2005 attempted to do just that, by using the International Classification of Functioning, Disability and Health (ICF), typically used in rehabilitation centers, to make better decisions in determining the application of both sedation and general anesthesia during dental treatments (Maeda et al. 2005). This standard, the ICF, describes a patient's condition with an intellectual disability in relation to dental problems and was

approved by the World Health Organization in 2001. “It allows us to describe a patient’s condition in the following ways: ‘Body Functions,” ‘Body Structures,’ ‘Activities & Participation,’ and ‘Environmental Factors’”, states the 2005 article in the *Journal of Intellectual Disability Research* (Maeda et al. 2005). The table below describes the codes involved in the ICF and the data found in the study.

Table 2. Codes from the ICF and Data of Participants in JIDR Study 2005

Table 1 [illegible]

		Rating				
		0	1	2	3	4
Body Function						
b117	Intellectual Function	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
b510	Digestion Function	Normal	Bite-sized pieces	Small pieces	Liquid food	Tubing
Body Structure						
s320	Oral Structure (number of teeth)	25	20–24	15–19	10–14	0–9
Activities & Participation						
d110	Watching	No problem	Almost	Only for favourites	In short time	Impossible
d310	Communicating	No problem	Intimate	Simple order	Own name	Impossible
d330	Speaking	No problem	Almost	More than 2 words	One word	Impossible
d510	Washing Oneself	No problem	Almost	Like playing	Impossible	Refusing
d5201	Caring for teeth	No problem	Almost	Like playing	Impossible	Refusing
d530	Toileting	No problem	Wiping oneself	Dressing to [illegible]	Necessary for bad	Complete help
d540	Dressing	No problem	Taking out of shelf	Putting on oneself	Cooperating with help	Complete help
d550	Eating	Politely	Eating independently	Unstable in volume	Help necessary	Complete help
d560	Drinking	No problem	Spilling sometimes	Spilling often	Help necessary	Complete help
d710	Personal interaction	Conversation	Good feeling	Handshaking	Refusing	Impossible
Environmental Factors						
e310	Immediate Family	Staying at home once a month	Staying at home several times a year	Only for events	No cooperation	Disturbing
e340	Personal Care Provider	A caregiver for 2	A caregiver for 3	A caregiver for 4	A caregiver for 5	Unstable
e355	Health Professionals	Absolute	Relieving	Regular	A bit unsatisfied	Unsatisfied

[illegible]

Table 2 [illegible]

	Epileptic	Emotionally disabled	Autistic	Total (male/female)	Age (mean ± SD)
Intolerable group	10 (43%)	4 (15%)	3 (12%)	26 (17/9)	36.5 ± 6.5
Tolerable group	14 (53%)	5 (19%)	8 (31%)	23 (15/8)	37.4 ± 7.35
Total	24 (49%)	9 (18%)	11 (22%)	49 (32/17)	–

[illegible]

(Maeda et al. 2005)

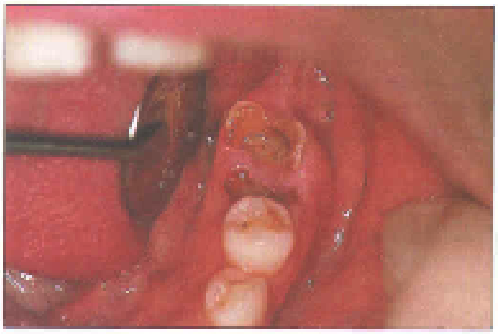
From Table 2, it can be interpreted that the ICF codes can help dentists and caregivers evaluate the tolerability of those with disabilities to dental treatments. It helps dentists assess the need of general anesthesia and sedation. Maeda et al. notes, however, that although the ICF acts as a great resource, dental treatments range in variety of "stresses." For example, some patients with a serious disability may be able to tolerate an extraction while not being able to handle a thorough teeth cleaning, thus a dentist should make the final decision on use of anesthesia or sedation in terms of not only the ICF but also on stress level (Maeda et. al, 2005).

Changes to the ICF may need to be made to better cater to the dental needs of all disabilities. However, Maeda et al. has shown that the system may be a step in the right direction to allow for better understanding among dental professionals in terms of tolerability of treatment of those with disabilities.

While general anesthesia and sedation have proven to be effective in terms of managing pain and anxiety in not only the general population but also among those with disabilities, controversy still stands in the way of the administration of these techniques in a dental setting on those with disabilities. Access to care for this population is severely hindered then because of education, training, financial issues and lack of knowledge.

Oral Care Strategies and Concerns

To further educate the public on the needs of those with disabilities in terms of oral health care, one must understand the prevalence of oral disease and the strategies for care in each population. Typically, those with mental disabilities have poor oral health, which "worsens their struggle for social acceptance" as shown in the image to the right (Davies, Bedi, and Scully 2000). The poor oral health issues of those with Autism and cognitive disabilities differ from those with Down syndrome, from those with seizure disorders and from those with Cerebral Palsy and other neuromuscular disorders.



Poor oral condition in a mentally challenged person

(Davies et. al 2000 p. 497)

Aside from poor oral health issues, the dental community must be advised that those with disabilities may be more fearful than the general public during dental visits. In a recent survey, almost 16% of the general public admitted they were somewhat fearful or anxious during dental visits (Fleck 2011). Because those with disabilities may lack the senses to understand dental procedures, they may be more fearful or anxious during dental visits than the general public. In working with individuals that have cognitive, communication and social disabilities, which include those with mental impairment of any kind, dentists and caregivers must be careful to speak to the individual at a level they can understand while keeping appointments short (Davies et. al 2000). Those with disabilities usually have noncompliance issues and speaking in a friendly explanatory tone may deter these issues.

Autism

The spectrum disorder, autism, can be considered a cognitive, communication, and social disability. Autism is a lifelong neurodevelopment disorder in which a patient could display a variety of different behaviors that can pose potential challenges to care. The prevalence of autism has been reported as 570 per 100,000 by the Centers for Disease Control and Prevention with a male to female ratio of 3.7:1.0 (Loo, Graham, and Hughes, 2008). Those with autism may be uncooperative in the dental office due to severely impaired social and communication skills. According to recent studies, 50 - 65% of children with autism are fearful and inattentive during their first dental visit. Furthermore, those with autism spectrum disorder can display aggression and other psychiatric symptoms that could conflict dental care. In 1999, a study showed that 37% of patients with the spectrum disorder needed to receive care under general anesthesia (Loo et. al 2008).

According to a study in 2007 pursued by Valerie Collado, Denise Faulks and Martine Hennequin in France, dental treatment was more difficult for autistic patients then administering of blood tests or vaccines and was most difficult for patients with autism as compared to those with Down syndrome and cerebral palsy (Collado, Faulks, Hennequin, 2008). Difficulty of dental treatment in those with autism may be due to lack of cooperation of these patients. In a recent study in 2008, 55.2% of patients with autism were uncooperative compared with only 25% from the group without the disorder (Loo et al. 2008).

In addition to these findings, some people with autism have violent tempers and instruments that could lead to injury or danger should be placed out of site in a dental care setting. Although Suzanne Bennett says her son with Autism is “very high functioning”, she

admits, “He covers his ears during treatment because of the loud noises in the office… I have to stand in the room because he likes to touch everything” (S. Bennett, personal communication, March 22, 2011).

To help those with this disorder understand dental processes, a dentist should begin an oral exam with fingers only to show the individual what will take place without arousing any fear. Because those with autism respond inappropriately to overstimulation, dentists must keep the light out of the patient’s eyes and turn down any music or intercom systems as to not confuse or anger the patient. For those with autism especially, dentists and staff must allow time for the patient to adjust to their surroundings before starting any treatment (Plaza 2008).

Although treating those with autism may seem difficult to both caregiver and dentist, studies have shown that those with autism have poorer hygiene and increased periodontal disease compared to those of other disabilities (Pilebro and Backman 2005). Even though those with autism do not have a high level of hygiene, Loo, Graham, and Hughes found in a 2008 study that the prevalence of caries among autism was lower than the rest of the population. In fact, patients with autism were 70.5% less likely to have dental caries. However, patients with autism required more restorative dental treatment than those unaffected by autism (Loo et al. 2008). “My son with autism had his first and only cavity at four years old, much sooner than any of my other children,” Bennett stated, which may be contributed to plaque, claims one study (S. Bennett, personal communication, March 22, 2011). The study found that children with autism have an increased amount of plaque on their front teeth than the general population, probably due to poor brushing skills (Pilebro and Backman 2005).

When working with patients with autism, it is important to note that the medications those with autism take to control symptoms of irritability and hallucinations can cause orofacial adverse effects such as xerostomia (dry mouth due to lack of saliva), sialorrhea (excessive excretion of saliva), difficulty swallowing, infections in the salivary glands, gingivitis (inflammation of the gums), and even teeth grinding (bruxism) (Loo et. al 2008).

Down Syndrome

Down Syndrome, a lifelong chromosomal condition, which can range in complexity and severity, occurs in about one in 700 to 800 births (Sung, Sakurai 2004). Those with Down syndrome (DS) have many distinct oral health care concerns including oral ulcers and infections, ulcerative gingivitis, increased periodontal disease, dental caries and malocclusion (crooked bite). To provide the best oral care, dentists and caregivers should understand strategies for care to combat physical and behavioral concerns of those with Down syndrome, shown in Table 3.

Table 3. Down Syndrome and other Genetic Conditions

Physical/Behavioral Concerns	Strategies for Care
Conical teeth, shallow roots Malocclusion (crooked bite)	• Orthodontia should be carefully thought out • Consult with an orthodontic specialist
Atlantoaxial instability	• Use great care in moving the spine and neck • Consult with primary physician • Use pillows and/or pads for support
Periodontal disease Dental caries	• Avoid sugar in foods, snacks, and treats • Frequent rinsing & twice daily home oral care • Consider topical fluoride, fluoride varnish and sealants • Frequent cleanings

	• Consider Chlorhexidine • Ensure home oral care is properly done
Gingival lesions, prolonged wound healing or bleeding	• Consult with primary physician about the possibility of underlying medical conditions
Cardiac disorders Compromised immune system	• Antibiotics before appointments may be needed • Consult with primary physician • Treat infections aggressively • Perform twice daily home oral care
Delayed eruption Congenitally missing teeth	• Oral exams should begin by the first birthday • Use panoramic X-rays to look for missing teeth • Maintain primary teeth as long as possible • Consider using spacers where teeth are missing

(Plaza 2008 pg. 16)

In *Table 2*, Plaza highlights the need for antibiotics before appointments to avoid cardiac disorders for some DS patients. Because about 40 to 50% of people with DS have some form of congenital heart disease, it has been found that all DS patients are at risk for cardiac abnormalities and must take antibiotics to avoid the risk of infection (Chung et al 2004). The standard regimen for adults is two grams of Amoxicillin taken orally one hour before the dental procedure. It is believed that this population is more susceptible to infection because of defective and somewhat short-lived neutrophil leukocytes, or white blood cells, which are important in combating infection in the immune system (Chung et. al 2004).

Along with a low count of white blood cells, common cardiac abnormalities those with DS may have include Tetralogy of Fallot, patent ductus arteriosus, and septal defects. Patients with these heart defects require special precautions before oral care or anesthesia due to their susceptibility to serious infection. Dentists should also be aware that DS patients may suffer from bleeding disorders, gout, arrhythmias, valve regurgitation, right

sided heart failure, and brain abscesses and that special care must be taken in treating these patients (Chung et. al 2004).

It is suggested that oral providers do a complete review of the patient's medical history, laboratory and clinical data and are in constant communication with a cardiologist to prevent complications in those with Down syndrome during routine dental care. Although the extent of complications in those with Down syndrome may be complex, oral health care should not be avoided, as it may be important to the overall health of these patients (Chung et. al 2004).

Seizure Disorders

Many patients with developmental disabilities also have frequent seizures. Seizures can arise spontaneously due to enhanced stimuli such as sounds or movements. As a dentist or caregiver, understanding the patient's seizure triggers pre-appointment is essentially important. If a patient is prone to seizures, dentists are advised to as Plaza describes, "attach dental floss to instruments before dental treatment begins" for quick removal if needed. It is also important for dentists to make sure that anti-seizure medications are taken prior to appointments. In terms of oral health care, those patients with frequent seizures typically show oral trauma as well as gingival overgrowth, or enlarged gums. To combat these oral effects, these patients must frequently visit the dentist and proficiently manage good oral hygiene at home (Plaza 2008).

Cerebral Palsy

Seizures, as well as other uncontrolled body movements and sensory problems can be observed in those with cerebral palsy, a condition in which muscle control and coordination are functionally impaired and motor abnormalities are complex. Cerebral

palsy is caused by brain damage of part of the brain and can occur during pregnancy of a child, meningitis, child abuse, stroke, and car crash, according to the Center for Disease Control and Prevention. Annually, about 2.5 births per 1,000 are diagnosed with cerebral palsy (Prevalence and Incidence of Cerebral Palsy - WrongDiagnosis.com). Those with this disability have an increased risk of dental caries, periodontal disease, and enamel hypoplasia (defective tooth enamel). This group also has an increased risk of oral trauma and injury due to uncontrolled body movements (University of Washington 2010).

To combat uncontrolled body movements, dentists should allow the patient to settle comfortably without attempting to stop their uncontrolled movements. Lights should be turned down and breaks should be frequent as to prevent increase in movements. Those with cerebral palsy are also prone to having hyperactive bite and gag reflexes. Dentists should slowly place dental instruments into a patient's mouth and place the patient's chin in a downward position to maintain safety. Dentists should also rinse the mouths of those with cerebral palsy frequently to remove food particles, while using suction frequently and keeping the airway open. These strategies would accommodate the difficulty these patients have in swallowing, or dysphasia (Plaza 2008).

Uncontrolled movements in those with seizures or cerebral palsy can contribute to damages to the oral cavity. Damages to the oral cavity can also occur in different behavioral aspects of disabilities or restrained movements (Plaza 2008). To provide the best oral care, a dentist and caregiver should be proactive when it comes to these concerns as shown in Table 4.

Table 4. Damaging Oral Habits, Oral Defects, Tracheostomy, and Trauma

Physical/Behavioral Concerns	Strategies for Care
Trauma Tooth loss	• Helmets and/or mouth guard • Expect oral aversion • Tooth saving kits
Picking at teeth or gums	• Soft gloves • Keep hands clean and nails trimmed
Mouth breathing Pouching (storing food in the mouth) Tongue thrusting	• Frequent rinsing with water to reduce dry mouth and prevent damage to tongue and lips • Lip balm to soothe dry lips • Thorough inspection of mouth after meals/snacks • Avoid sugary snacks • Rinse after sugary medicines. Use sugar free medicines • More frequent brushing/flossing and dental visits
Bruxism (grinding teeth)	• Mouth guards
Pica (eating non-food items, such as gravel)	• Mouth guards • Frequent oral inspection • Prevention
Reflux (Stomach acid that splashes back up) Rumination (throwing up food to re-chew it)	• Rinse mouth frequently • Place child in a more upright position to keep acid down • Sealants • More frequent brushing/flossing and dental visits
Cleft Lip Cleft Palate	• Expect aversions • Keep feeding bridges clean • Modify rubber dams to fit and use suction frequently
Tracheostomy	• Expect aversions and a hypersensitive gag reflex • More frequent brushings and dental cleanings • Use a rubber dam if tolerated • Do not block or cover an uncapped tracheostomy as this may cause CO_2 build-up or suffocation

(Plaza 2008 pg. 12)

Medications and Oral Care

While damaging oral habits of all disabilities are a large concern to oral health, dentists and caregivers should also be aware of the drugs those with disabilities typically take. Drugs that contribute to xerostomia, or dry mouth, include muscle relaxants, anticholinergics, and anticonvulsants (prescribed to manage seizures) (University of Washington 2010). These drugs can increase plaque and tarter build up which can contribute to a patient's risk of periodontal disease and caries (Plaza 2008). Sugary liquid medicines taken by those with disabilities can contribute to increased dental caries and periodontal disease and patients should rinse their mouth and brush frequently after their use. Alternative methods include combining these medicines with water to dilute the sugar content or to speak to a pharmacist about sugar free versions to eliminate prevalence of caries (Plaza 2008). Medicine use can also contribute to gingival hyperplasia, where gums enlarge and are overgrown. Anticonvulsants, immunosuppressants, and calcium channel blockers (used to treat high blood pressure) can all contribute to gingival hyperplasia. Anticonvulsants can also contribute to distortion of taste (dysgeusia) while anticholinergics can enhance grinding of teeth (University of Washington 2010).

Dentists should also be aware of any contradictions or problems that those with mental or physical disabilities may have to post-operative medications (Trapp 1995). It has been observed that when the patient has a physical disability, contradictions with oral medications are not observed. However, many of those with physical ailments are addicted to narcotics because of heightened use. Thus, if a dentist plans to prescribe a narcotic to one with a physical disability, they should contact the patient's physician. Furthermore, it has been observed that in many mental disorders such as autism, severe mental retardation, and schizophrenia, oral medications are difficult to take. Thus, this group may need to take

their medications crushed in liquid foods, as a liquid dosage, or suppository/rectal dosage (Trapp 1995).

Visual Impairments, Hearing Impairments, and Noncompliance

Understanding the effects of these medications and strategies to comfort a patient with mobile or physical disabilities can contribute to the effectiveness of oral health care. In some cases, a dentist may have to maneuver himself/herself in a different position than seated to provide care (Plaza 2008). For those with visual impairments, it is important that the dentist, dental staff, and caregiver are able to help the patient maneuver around in an oral health care setting by using their other sense. A dentist may have to come up with creative ways of communicating to the patient with a visual impairment to make sure needs are met and the process is understood fully. It is important for a dentist or caregiver to remember to face the patient while speaking for location of sound without fear.

Furthermore, in working with patients with hearing impairments, hearing aids or cochlear implants may need to be removed prior to dental treatment due to excessive "loud noises and vibration." In *Oral Health Care for Children with Special Health Care Needs*, Plaza suggests creative communication such as, "tap once before putting something in their mouth, tap twice before starting the suction" of all patients with disabilities. Dentists should remember to eliminate background noise when talking such as background music and suction (Plaza 2008).

Because many patients with disabilities have noncompliance issues, speaking in a friendly tone may deter these issues. While it may seem impossible to know just how much individuals with these types of disorders understand in terms of dental care, using a 'tell,

show, do approach' ensures that the individual is treated with respect even if they are unable to communicate back (Plaza 2008).

Educational training of common disabilities, such as Autism, Down syndrome, and Cerebral Palsy, could potentially increase the willingness of dentists to care for those with special needs. Each disability has unique oral concerns and strategies for care, essential for dentists to learn to become more willing to care for those with special needs. To reduce the need of invasive dental treatment of those with physical and mental disabilities, preventative dental treatment must begin early in life. We need to be knowledgeable of the prevalence of these disabilities in the population and their oral health concerns to provide better access to care.

Behavior Management Concerns Relating to Oral Health

As discussed in previous sections, it is difficult to care for those with disabilities if one is not educated on the subject or aware of their needs and oral concerns. While many strategies to administer dental care to those with special needs have been suggested, not all of the suggestions can manage people with intellectual disabilities that have challenging behaviors such as unwillingness to cooperate with dental care. Efforts made to reduce pain or stress of the patient include general anesthesia and sedation, nitrous oxide, anti-anxiety medications and restraint (Plaza 2008).

General anesthesia and sedation serve as viable behavior management options to patients with dentists whom are trained and willing. While nitrous oxide can be effective in relaxing a patient, it may be useless in patients that are extremely fearful or pose challenging behaviors. Comparably, anti-anxiety medications can be helpful in reducing stress of the patient during treatment, however, many people with intellectual disabilities

are already on psychotic medications that may reduce the effectiveness of anti-anxiety medications (Dougherty 2009). Frequently, then, during routine dental visits and daily oral hygiene tasks, those with behavioral disabilities are subject to restraint (Newton 2009).

It has been reported that 68% of individuals with intellectual disability in a mental institution in Louisiana required restraint during dental treatment and even "physical holding during tooth brushing" (Newton 2009). The American Academy of Pediatric Dentists condones restraint as a management technique during oral health care procedures as well as hand-over-mouth technique (HOM) and hand-over-mouth with airway restriction (HOMAR). Restraint techniques include holding of the patient or the use of special restraint devices. During HOM, "a hand is gently placed over the child's mouth, and behavioral expectations are calmly explained." The HOMAR technique is refined in which the dentist places a hand over the mouth and nose, restricting the patient's ability to breathe (Newton 2009).

Therapeutic restraint methods such as these can become more difficult to use with larger and stronger patients with mental disabilities. Furthermore, if the patient fights back against the restraint, it may be hard to complete treatment in the dental chair (Dougherty 2009). Because these techniques are invasive and could harm or injure not only the patient but also the dental stuff if not done properly (Dougherty 2009), both dental and public acceptance of these procedures have been quite low (Newton 2009).

However, as acceptance of restraint techniques decrease, behavioral challenges in the dental chair among those with intellectual disabilities continue to increase. To combat behavior problems in the dental office, 53% of dentists preferred to use restraint instead of sedation to treat a child or patient with disability, with pediatric dentists more likely to do

so than general dentists (Newton 2009). It has been suggested, however, that restraints should not be used on a patient unless all other efforts have failed (Plaza 2008). If a dentist chooses to utilize these restraint techniques, J.T. Newton describes four steps that must be adhered to in the *Journal of Applied Research in Intellectual Disabilities*:

1. Dentists must provide a detailed assessment of why the restraint is being used along with the risks and benefits.
2. The patient must consent to the use of restraint, and if they are unable to give consent, the caregiver must consent on their behalf.
3. Dentists should keep record of when restraint is used, alternative approaches attempted, type of restraint used and length of restraint.
4. Restraint should never be used "as needed" but instead should have specific terms of use (Newton 2009).

While the restraint techniques such as HOM or HOMAR may be useful, especially if the four steps are followed efficiently, there is still a lot of controversy surrounding the topic. As Newton writes, " The use of these techniques may result in… dental fear and unwillingness to return to the dentist later in life" (Newton 2009). What are a dentist's options other than restraint, general anesthesia/sedation or medications in terms of handling a patient with behavior management problems?

Positive approaches to managing challenging behaviors do exist that place emphasis on reinforcement and remodeling without the use of invasive or restrictive techniques. It is expected that with the use of such methods as systematic desensitization, in vivo desensitization, contingent escape, non-contingent escape and differential reinforcement, a

wider acceptance by not only patients and caregivers but also by the dental community would be achieved (Newton 2009).

During the technique of systematic desensitization, frequent exposure of the feared stimulus combined with an object/act of prevention occurs. Typically the feared stimulus by those with any intellectual disability is dental treatment. Dentists might slowly show pictures of treatment to the patient while encouraging muscle relaxation. In a recent study in 2002, "greater improvement in tolerance of dental techniques and the number of treatment steps completed was found in those individuals who were managed with systematic desensitization" (Newton 2009). In terms of *in vivo* desensitization, studies have found that when those with severe intellectual disabilities watch a video of a child undergoing treatment, patients are more willing to behave during the procedure (Newton 2009).

Differential reinforcement is similar to desensitization, but instead the dentist utilizes distraction methods to avoid challenging behaviors. For example, a dentist could show the patient a poster and tell a story about the poster during treatment. After, they would expect the patient to answer questions about the story for rewards such as prizes (Newton 2009).

Both contingent and non-contingent escape techniques provide relaxation or a break for the patient with challenging behaviors. During contingent escape, the patient is praised by the dentist and provided five seconds of break time away from dental treatment if the patient behaves. In previous studies, the use of this technique improved disruptive behavior. On the other hand, non-contingent escape, utilizes break periods at "a fixed interval" regardless of the patient's behavior. In a recent study, the number of restraints

was reduced significantly among patients who were introduced to the technique of non-contingent escape (Newton 2009).

While the five of these alternative methods to restraint have proven to significantly improve the behavior of those with intellectual disabilities, it is unlikely that they will be adopted throughout the field because of little reward to dentists. It is understood that "time is money" and these techniques may take too much of a clinician's time as compared to restraint or medications. Newton suggests that payment to dentists "for the use of non-aversive techniques" is required to seek change in restrictive behavior management techniques (Newton 2009). Dentists need to be educated on behavior management techniques for widespread treatment of those with intellectual disabilities to be effective in the foreseeable future.

Oral Hygiene in the Office and at Home

This section of the dissertation aims to provide tips for caregivers or parents on how to help achieve an excellence in oral health care in regards to a person with physical or mental disabilities. Suggestions on finding a dentist for a child with special needs is discussed as well as dietary management for a healthy mouth and brushing habits and techniques. This section may also serve as a guide to practicing dentists to better facilitate and assess the needs of patients with special needs.

Finding a "Dental Home"

For a parent or caregiver of a child with disabilities, it may be difficult to find a dentist that will suit the needs of your exceptional child because of limited access to care and lack of knowledge. However, both the American Dental Association (ADA) and the American Academy of Pediatric Dentistry (AAPD) have both advocated the need for every

child to have a "dental home" by their first birthday. A "dental home" as Paul Casamassimo defines in the September 2007 issue of *Exceptional Parent*, serves as not only a home for dental care but also a place for a growing relationship. Thus, he suggests that parents of children with disabilities start early in finding a dentist and to come prepared and knowledgeable. Casamassimo explains that dentists learn a lot from their patients and suggests, " a dentist's lack of familiarity should not be a turn-off." Furthermore, it is suggested that parents or caregivers find a clinician who listens attentively and welcomes those with special needs with open arms. For the best comprehensive care, the dentist chosen should be linked to other services (Casamassimo 2007). Table 5 below, taken from the article, explains important features of a dental office for the child with special needs.

Table 5. Finding a Dental Home for Your Child with Special Needs

The Dental Home and Your Exceptional Child

Characteristics	What You Should Expect
Comprehensive dental care, including acute and preventive services	The dentist should be able to provide the same level of care for your child as for any other child, or have relationships with other dental and medical professionals to accomplish needed care
Comprehensive assessment	The dentist should be familiar with the conditions, medications, medical and other therapeutic regimens for your child
Individualized preventive plan of oral diseases and conditions	Your child's individualized preventive plan should be designed so that specific oral health concerns as well as medical, behavioral, and other elements are considered and addressed
Anticipatory guidance	The dentist should provide you with advice for oral health that changes with the changing life needs and abilities of your child
Plan for acute trauma if it occurs	Is he/she available 24-7 in case of trauma or other problem requiring urgent care
Proper home care for a child's teeth	Have you received the education and training necessary for you and/or your child to optimize home preventive care
Dietary counseling	The dentist should be familiar with special dietary needs and their implications for oral health, including things like special diets, gastrostomy, and restricted food choices
Referrals to dental and other professionals	The dentist has an established network of health care professionals to assist you and can work with your current array of professionals to optimize your child's oral health
Transition services for emerging adults	The pediatric dentist anticipates the therapeutic needs of your emerging adult child or is capable of rendering continued care

(Casamassimo 2007)

Upon finding a dental home, the dentist, caregiver, and parent should be familiarized with the patient's medical history and at each visit this

history should be analyzed and updated. Dentists should also complete "comprehensive head, neck, and oral examinations" and a caries-risk assessment of all patients (Guideline on management of dental patients with special needs, 2008). At the completion of these examinations, dentists should offer preventive care strategies and encourage assistance of other community-based resources when appropriate. This may include "groups that advocate" for those with special needs to "help the dentist/patient address language and cultural barriers" (Guideline on management of dental patients with special needs, 2008).

Hygiene at Home

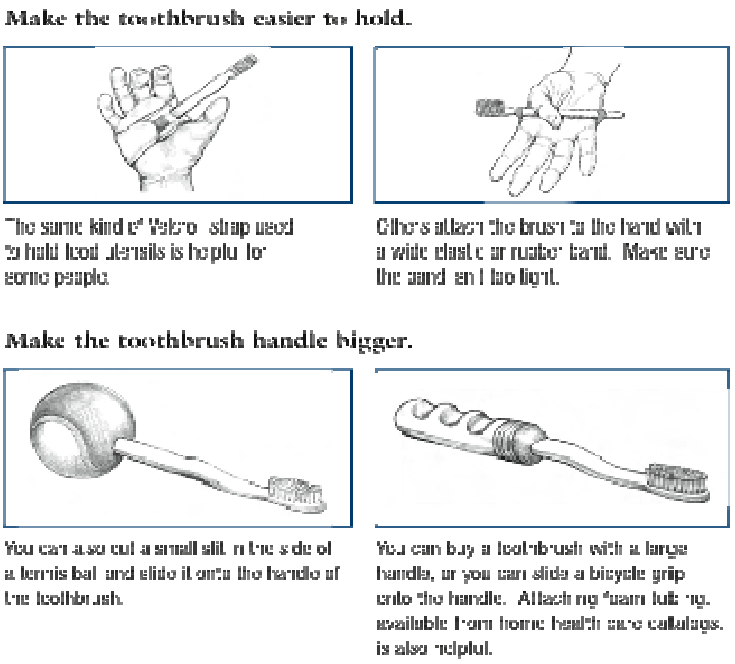
Because dental access is limited for those with special needs, it is essential to start good oral hygiene habits at home. Like everyone else, for a healthy mouth, those with disabilities need to brush every day, floss every day, and visit the dentist regularly. It is recommended that the "2-2-2 rule" be followed as a guide. A toothbrush should be used for 2 minutes, 2 times a day, while waiting 2 hours between brushing and eating or drinking (Moursi et. al 2010). Brushing and flossing every day, however, can be a challenging feat for those with special needs. In fact, in a recent survey, only 55% of people with psychiatric disabilities regularly brushed their teeth (Almomani, Brown, and Williams 2006). Thus, it is essential that brushing teeth begin at home by the time the child is 2-years-old.

If the person with special needs is unable to brush by themselves, it is suggested that parent or caregiver help. In *Dental Care Every Day: A Caregiver's Guide*, steps are suggested in helping a person with special needs to brush effectively. First, the caregiver should wash their hands and wear gloves. The caregiver should also position himself or herself to see all surfaces of the teeth. Next, a pea-size amount of toothpaste or fluoride should be added to a regular or electric toothbrush. If the person with special needs has

swallowing difficulties, it is suggested that only water is used on the brush. If needed, a parent or caregiver should help the person brush from front to back and top to bottom of each tooth. Afterwards, help may be needed in rinsing the mouth with water (Chin, Fenton, Lyons, Miller, Perlman, and Tesini 2009).

If the person with special needs can brush with assistance, there are ways in which the toothbrush can be made easier to hold and in which the handle can be made bigger. The diagrams below show creative ways of solving brushing problems so that those with disabilities can begin to learn to brush on their own (Chin et al. 2009).

Figure 3. Solving Brushing Problems



(Chin et al. 2009)

Another alternative to combat brushing problems is other toothbrush options such as an electric/mechanical toothbrush. A recent study examined the "plaque removal

efficiency" of mechanical toothbrushes in those with mental disabilities. At the conclusion of the study, 95% of the participants stated that their teeth were cleaner because of the mechanical toothbrush and 71.4% thought the mechanical toothbrush made their teeth whiter. Almost 24% of the participants stated that the toothbrush was also much easier to use than a manual toothbrush. In fact, the plaque of each participant was examined over the course of the study and "plaque index scores" did improve (Almomani et al 2006). The American Academy of Pediatric Dentistry has also stated "electric toothbrushes may improve patient compliance" (Guideline on management of dental patients with special needs, 2008). Thus, it can be interpreted that the oral health and hygiene of those with psychiatric disabilities can be improved with the use of a mechanical toothbrush.

Of course, however, many people with disabilities still need dental education or instructions to improve their oral hygiene regardless of the use of a mechanical toothbrush. In the same study, hygienists taught those with psychiatric disabilities how to effectively brush their teeth and gave them reminders of when to do so, which showed significant improvement in their overall oral hygiene (Almomani et al. 2006).

Oral Hygiene and Nutrition

Aside from education and proper instruction, parents and caregivers should be aware that those with mental or physical disabilities should follow a strict dietary regimen to also improve their overall health and oral hygiene. It is estimated that over 40% of children with special needs are at risk for nutritional problems that can affect not only growth and development but also dental malformations, according to *Pediatric Dentistry* (Moursi et al. 2010). Those with special needs are subject to decreased appetite, infrequent food intake or parental overindulgence that can lead to poor oral hygiene. In a recent study,

"parents of children with chronic illnesses have been shown to experience more stress… than parents of healthy children." Thus, these parents tend to be overprotective and overindulgent. Furthermore, because those with a chronic illness have an abundance medical problems, oral health seems to be less of a priority.

It is recommended then that parents or caregivers discuss "dietary counseling" with their dentists to prevent oral disease. Because many disorders require restricted diets, it is important that parent/caregiver discuss this with the dentist to understand oral effects of this diet. According to AAPD, "dentists should encourage a non-cariogenic diet and advise patients/parents about the high cariogenic potential of… dietary supplements rich in carboydrates" (Guideline on management of dental patients with special needs, 2008).

There are recommendations available to manage "poor appetite or nutritional density" of those with special health needs and an oral health team should be able to help accommodate. Even for those with restricted diets, the Food Guide Pyramid should act as a guide to general health. It is essential that those with special needs eat high-density foods "that can increase energy and other nutrient levels of the diet" to improve overall health (Moursi et al. 2010). Dietary management can also control xerostomia. Sugarless candy, gum, medications and even ice chips can be helpful. Healthy vegetables such as carrots or celery can also manage xerostomia, by creating more residual saliva (Moursi et al. 2010).

According to the AAPD, patients with special health care needs should highly consider sealants, which seal the posterior teeth, to reduce the risk of carries (Guideline on management of dental patients with special needs, 2008). Dentists may also recommend topical fluorides to reduce this risk as well. If a patient seems at risk for gingivitis and periodontal disease, a dentist may suggest chlorohexidine mouth rinses.

Overall, it is very important for parents/caregivers to be heavily involved in the oral hygiene of their child with special needs. By finding an appropriate "dental home" for the person with special needs, starting good oral hygiene habits or education at home, and communicating with a dentist about nutrition needs, parents/caregivers serve as a push in the right direction in improving the oral health care of those with disabilities. We need parents and caregivers to help change oral hygiene among those with physical and mental disabilities to not only improve this population's oral health but to also improve their overall general health.

Conclusion

Although those with mental and physical disabilities have made great strides in the past 40 years in terms of assimilating with the general public, dental care accessibility for this population is still a challenge. Those with special needs are denied care because of untrained dentists, an uninformed general public, financial barriers, and geographical obstacles. Because the health of one's oral cavity can greatly influence general, psychological, and emotional health, everyone deserves equal access to care, including those with special needs. According to the AAPD, "dentists have an obligation to act in an ethical manner in the care of patients" (Guideline on management of dental patients with special needs, 2008). Thus, no patient should be turned away from oral health care.

It is the responsibility of dental educators, students, and dentists to see that those with disabilities receive fair assessment and treatment in the field of dentistry. Although the Standard 2-26 in 2004 was implemented to require dental students to be competent in assessing those with special needs, it is important that we actually implement the *treatment* of these individuals as well. To implement treatment in general dentistry, dental

schools, congress and the voices of those with special needs, must advocate for handicapped accessible dental offices, education, and financial assistance for this population.

Over 52 million people in the United States have some type of disability and change must occur in the field of oral health to accommodate their needs (Guideline on management of dental patients with special needs, 2008). Those with disabilities can live long lives just as the general population can. Pediatric dentists should not be the only ones trained in working with this population.

Thus, dental schools should advocate for the special needs of these patients in their general dentistry clinics. Classes should be taught to educate students of the assessment and treatment of those with varying disabilities (including behavioral management techniques and general anesthesia/sedation training) at not only the post-doctorate level but also at the doctorate level. Continued-education courses should be held to address special needs care to those dentists already in practice. Mandated yearly training sessions for all American Dental Association dentists should exist to inform the field of the need to provide care to those with disabilities. Dentists should also consider carrying the weight of the financial burden families of those with special needs have and offer discounted payment plans out of the goodness of their hearts and their oath to provide dental care to all in need. Furthermore, dentists should be required to be in constant communication with general health practitioners as a gateway to oral health care for those with special needs.

These proposals, I suspect, will be challenging to implement. Currently, the general public and some dentists are uninformed and unwilling to advocate for oral health care needs of those with disabilities. However, solving this crisis of care by changing the face of general dental education to advocate the treatment of those with special needs is a rational

solution. It's been almost 20 years since Rosemary, Funice Shriver and Ted Kennedy's sister, had difficulty in accessing care. She found care miles away from her home at the age of 62, in a pediatric dentist who managed her behaviors with general anesthesia (Waldman, Perlman, and Cinotti 2009). The time is now to make a change in the oral health of those with disabilities. With the support of educators, parents, caregivers, congress, and the dental community, those with special health care needs will receive dental treatment from their neighborhood general dentist knowledgeable of various behavioral management techniques —a privilege that all Americans deserve to have.

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