Section 3:
Developmental Disabilities

Introduction

Developmental disabilities are a number of disorders related to an impairment in physical, or mental functions including motor function, learning, language, or behavior areas. They adversely impact day-to-day function and usually are not curable. They may begin anytime during the developmental period, (up to age 22), and have a lasting effect throughout the life of the affected individual. The majority of these disabilities begin during fetal development, but a few may develop after birth due to injury, infection or other causes [1].

A complex mix of factors are usually involved in the etiology of developmental disabilities including genetics, maternal health and behavior during pregnancy, complications during labor and delivery, infections sustained by the mother during pregnancy or the baby in early life and exposure of mother or baby to environmental toxins. Often the etiology of developmental disabilities is idiopathic.

Recent estimates in the United States show that about one in six, or about 17%, of children aged 3 through 17 years have one or more developmental disabilities [2].

The developmental disabilities that will be covered in this section include:

1. **Down Syndrome (DS)**
2. **Autism**
3. **Cerebral Palsy (CP)**

Causes and manifestations of common developmental disabilities

Developmental Disability	Cause / Biologic mechanism	Systemic manifestations	Dental manifestations
1. Down Syndrome (DS)	- Genetic disorder, trisomy 21 (abnormal cell division resulting in presence of an extra full or partial copy of chromosome 21) - Genotype 14-21 translocation and mosaicism in some cases - Intrinsic immune system defects (increased migration of T cells, increased oxidative bursts of granulocytes and monocytes, impaired neutrophil chemotaxis and monocyte phagocytosis) [3,4,5,6,7,8]	- Characteristic physical appearance (slanted eyes, large anterior fontanelle, short stature) - Obesity - Gastrointestinal issues such as GERD - Normal to marked delay in intellect - Variable degree of low muscle tone and range of physical disorders - Heart abnormalities - Respiratory conditions - Early onset dementia	- 90% have gingivitis / periodontitis / premature loss of teeth [7,1,9,10] - Hypodontia, abnormal teeth anatomy - Hypoplastic midfacial third - High arched palate - Macroglossia - Altered salivary flow [4] - Erosion of teeth
2. Autism	- Unclear etiology - Possible etiologies and /or correlations to *de novo* genetic mutations, brain biological factors, coexisting medical conditions, mitochondrial defects, increased level of inflammatory cytokines, maternal bleeding during pregnancy, metabolic syndromes and advanced maternal age [11]	- Usually diagnosed at age 3 and lasts for persons life - Heterogenous disorder characterized by impairments in communication, social relationships and restricted, repetitive and stereotypes behaviors and interests *(American Psychiatric Association 2000)*	- No peculiar oral characteristics - High caries and periodontal disease risk due to communication limitation, limitations in personal hygiene measures, eating habits, side effects of drugs and resistance to dental care. [11]
3. Cerebral Palsy (CP)	- Caused by brain injury, primarily in regions that correspond to motor function, during or shortly after birth - Injury can be caused because of premature birth, low birth weight or infection of mother early in pregnancy by viral diseases. [12]	- Cognitive impairment in 50% of CP patients - Seizure disorders - Exaggerated reflexes, floppy or rigid limbs with altered muscle tone, involuntary motions - Impairment in functional mobility, upper extremity performance and communication to varying degrees [13]	- Periodontal disease due to difficulty in oral hygiene [13] - Enamel defects and dental caries [13] - TMJ disorders [13] - Difficulty in chewing, altered movements of masticatory muscles and tongue further contribute to bacterial plaque accumulation [14] - Malocclusion, lip incompetence moth breathing, hypotonia and orofacial muscles [13] - Bruxism and teeth abrasion [13]

Barriers to dental care

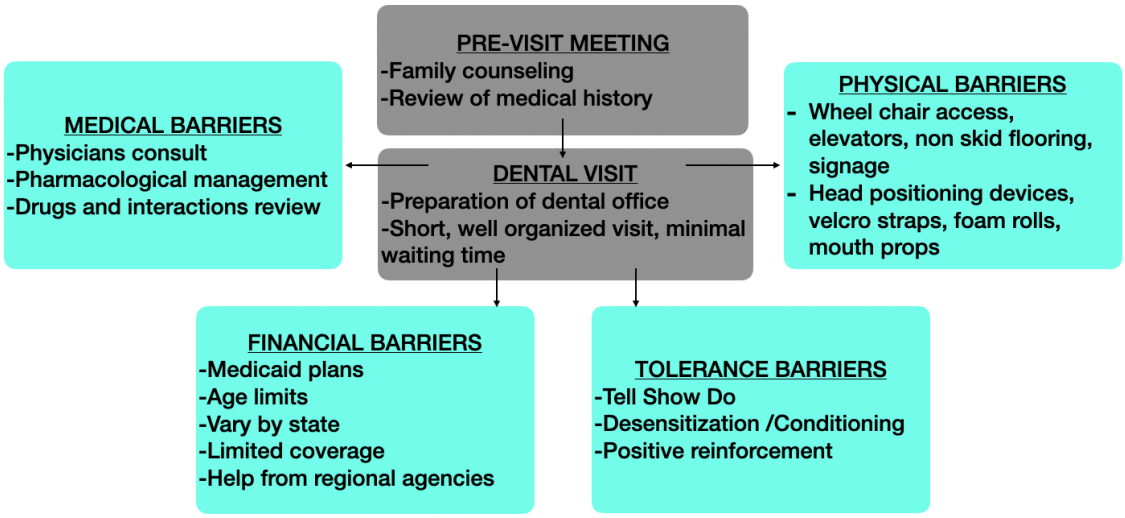
The risk for caries, periodontal disease and tooth loss in all of the above-mentioned developmental disabilities necessitates a stringent dental regimen to ensure maintenance of oral function and esthetics. *Nelson et al* based on his survey, estimates that at a national level nearly a million children with significant special needs suffer because of limitations in dental care system and have unmet dental needs due to environmental and non-environmental dental barriers [15]

Environmental barriers such as cost of care, getting appointments and accessibility have a high impact on dental care for these individuals. Unmet dental needs due to expense of dental treatment, difficulty in finding a dentist willing to treat these patients and medical conditions complicating dental appointments was found to be a major barrier, as shown in a survey conducted by *Nelson et al* [15].
Anxiety, fear of dentists and behavioral challenges are examples of **non-environmental barriers** commonly seen in DS and patients with autism [15]. Communication issues such as language delay and impairment, language deficits, poor speech intelligibility are shown to pose challenges in DS patients [7]. Lack of motor skills and dexterity in patients to perform oral hygiene measures can further complicate dental health in these individuals.

Most of these barriers, in fact, are a result of health care workers being unable to accommodate the needs of patients with developmental disabilities. The sections below describe these barriers in detail and how we, as dentists, can address the individual needs of these patients in our practice to better serve them.

Dental management of patients with developmental disabilities

A basic workflow for successful dental management of patients with developmental disabilities is presented below. Though these disabilities are all "developmental" in nature, each one of them presents with unique barriers, which are discussed in the following section.



Pre-visit meeting with caregiver or parents can be beneficial in family counseling to prepare the parent / guardian for dental treatment needs. It also gives the team an opportunity to discuss previous dental experiences, identify challenges to care, co-occurring medical issues and current oral hygiene regimen of the patient [17].

Medical clearance or physicians consult is an extremely important part of team approach towards managing these patients. A thorough medical history during the pre- visit meeting, can offer valuable clues to help successfully manage their dental treatment. Treating dentist should be aware of common medical

conditions seen in these individuals such as congenital heart defects, apnea, respiratory infections and gastro esophageal reflux. Once these are identified, medical clearance can be obtained from their physicians prior to the dental visit [16].

Once a panoramic view of the patient's needs, medical conditions, medications, previous dental experience and medical clearance is obtained, the patient can be scheduled for their first dental visit. Each one of these developmental disabilities presents with unique barriers and hence, the specifics of their management is discussed in detail in the following sections.

1. Down Syndrome and dental management

Individuals with DS have considerable need for oral health care. However, due to the various barriers stated above, DS individuals may have difficulty receiving the appropriate oral care they need.

Communication - DS intellectual disability and language deficits may significantly impede communication. It is helpful to assess the communication skills of DS individuals to customize the interaction approach. Effective communication will build rapport and trust. Use of short phrases that require simple answers is recommended. If the response is unintelligible, ask the individual to repeat it again. Exercise patience, communicate slowly and clearly, avoid correcting the individual and allow them time to express themselves. The majority of individuals with DS are able to tolerate and follow instructions for care and will require traditional techniques used for pediatric patients, as Tell, Show and Do [7]. Some with difficulty may need treatment under sedation. However, upper-airway obstruction in IV sedated individuals could be problematic due to macroglossia and hypoplastic mid face [18].

Preventive Measures - Due to compromised immunity, DS individuals are at greater risk for infections [19]. Prophylactic precautions and preventive measures, such as fluorides, may be needed for individuals with DS with compromised medical health for safe delivery of dental care [20]. A prevention strategy should be developed and customized for each DS individual including parent/caregiver education, early intervention, oral hygiene motivation, prophylaxis and caries prevention [21].

Tooth Decay - Although scientific evidence suggests that DS children are less susceptible to caries than children without DS [22], caries prevention should not be relaxed. Adult DS individuals are at increased risk for caries due to decreased salivary flow, sugary diet and hypotonia. Oral hygiene awareness, decreased intake of sweets and periodic dental visits are recommended. Effort should be made to prevent progression of caries into the pulp. Root canal therapy in DS individuals could be challenging due to altered root anatomy [23]. Furthermore some individuals with DS with congenital cardiac defect, are at increased risk for infective endocarditis following root canal therapy [24]. Up to date information about antibiotic prophylaxis can be obtained from American Heart Association website (https://www.heart.org/en/health-topics/infective-endocarditis)

Periodontal Disease - DS individuals have an increased risk for periodontitis independent of oral hygiene [5]. Periodontitis typically starts much earlier in this population than the general population. Periodontitis can progress much faster. Fast disease progression in conjunction with the sometimes-short root anatomy in this population, can lead to early tooth loss. Pediatric providers should be aware of the early onset of periodontal disease in this population. Periodontal assessments should be performed and counseling on periodontal management provided. Conventional preventive therapy failed to control progression of periodontitis in DS individuals and poor oral hygiene played a minor role in the pathogenesis of periodontal disease [25]. Management of periodontal disease in DS individuals requires active periodontal therapy focused on professional plaque control and management of gingival inflammation. In spite of compromised immunity, DS individuals respond favorably to both non-surgical and surgical periodontal therapies [26]. A diligent periodontal maintenance program should be implemented following completion of initial periodontal therapies [7]. Use of antimicrobial therapy may further assist with periodontal disease control in DS individuals [27]. Involving parents/caregivers in plaque control at home is critical in improving periodontal health in DS affected individuals [28]

Malocclusion and Missing Teeth - Congenitally missing teeth, delayed and abnormal sequence of tooth eruption, tooth size discrepancy, macroglossia and tongue thrust all contribute to malocclusion in DS individuals. Occlusal abnormalities in DS individuals may impede vital functions such as speaking and chewing. Orthodontic treatment could be attempted in an interdisciplinary approach to correct occlusal issues and improve function [29,30].

Orthodontic treatment also requires good case selection in this population. If the patient doesn't understand why they are receiving orthodontic treatment, it could lead to distressed behaviors including the individual pulling off the orthodontic brackets/wires at home.

Replacement of missing teeth in Individuals with DS with removable dentures is not recommended because of adjustment difficulties [7]. Furthermore, removable partial dentures will contribute to occlusal stress, plaque buildup and increased risk for caries and periodontal disease. Removable partial dentures can be helpful in some situations and are often the only option for tooth replacement in this population. Again, case selection is important, some individuals are able to tolerate removable appliances better than others. Often, we will want to save periodontally compromised teeth longer than we normally would due to limited ability to tolerate dentures and the risk of tooth loss with no replacement options.

Tooth wear - Bruxism and associated tooth wear are common in DS individuals. Bruxism in DS individuals is induced by mental health issues such as general anxiety and obsessive-compulsive behavior [31]. Occlusal abnormalities further contribute to bruxism in DS individuals [31]. Behavioral intervention and psychiatric pharmacotherapy might be needed to manage bruxism in DS individuals [32]. Correction of occlusal abnormalities might help [33]. Traditional preventive techniques, such as occlusal guards, are often not tolerated in this population, and could pose the risk of choking if the patient has poor oral neuromuscular control.

2. Autism and dental management

The tone for the dental appointment is set for a patient with Autism even before they enter the dental operatory.

Dental clinic environment – All staff members of the dental office should be informed of the patients visit since a successful dental visit for a patient with Autism requires a caring and compassionate environment. Some patients are likely to get disturbed by stimuli like texture of gloves or plastic covering on chairs, light, sound and smell. Dimming the lights, rhythmic music, single operatories with reduced decorations or distractions should be reserved to accommodate these patients [17].

Appointment structure – Short**,** well-organized appointments with minimal waiting time are essential. Establishing a routine for these individuals, minimizing movements during the course of the procedure will help get through the appointments seamlessly [17]

Dental examination – Use of dental mouth props can be helpful to aid in dental examination. The presence of bruises, abrasions and traumatic ulcerations should be noted, as these could be related to self-injurious behavior. The dentition should be evaluated for erosion as it is noted that some individuals with Autism, regurgitate their food and acidic stomach contents. If noted, it should be brought to parents notice and appropriate medical attention should be suggested [16]. Antipsychotic drugs such as Resperidone given to patients with Autism can result in orthostatic hypotension and hence, drastic postural changes should be avoided. The dentist should be well versed with other common drug side effects and interactions such as –

1. Risperidone / Olanzapine –
- Can cause motor disturbances affecting speech, swallowing and precludes use of removable dental prosthesis
- Can cause CNS depression, transient sialorrhea and xerostomia
2. Fluoxetine / sertraline –
- Can cause xerostomia, dysgeusia, stomatitis, dyskinesia and glossitis
3. Carbamazapine /Valproate
- Can impair hemostasis with aspirin, NSAID's [16].

Behavior guidance - Goals of behavior guidance is to develop rapport, lessen anxiety and provide quality care while building a trusting and professional environment. Using short, clear and simple sentences can help overcome communication challenges. Some may require assistive communicative devices such as Picture Exchange Communication System (PECS) which consists of a book of pictures to express desires, observations and feelings. Tell – Show -Do is a basic and very effective way to introduce dental instruments, equipment's or procedures. Desensitization or classic conditioning involving dividing dental procedures into smaller steps, though time consuming, may be helpful strategy to accomplish effective care in these individuals. Positive reinforcement, distractions and minimizing exposure of auditory and taste stimuli will enhance acceptance from patients with Autism [16]. Simple rehearsals at home by parents can help prepare the patient for upcoming visits [16].

Pharmacological management–
Conscious sedation has a variable effect on patients with Autism. Besides, commonly used medications for conscious sedation in dental office may interact with the medications taken by the patient. For example, sertraline and fluoxetine which are selective serotonin reuptake inhibitors and commonly prescribed for patients with autism potentiates the effect of sedative benzodiazepines [16]. Medical clearance as deemed necessary and stringent patient monitoring during sedation are paramount for patient safety [17].

3. Dental Management of patient with Cerebral Palsy

Besides behavioral and communication challenges highlighted above, CP may present with unique challenges related to posture, positioning and wheel chair access to a variable degree depending on the level of functional mobility and upper extremity performance.

Wheel chair access in dental office - is a basic necessity to facilitate care for CP patients with higher level of mobility challenges. Parking space, walkway, entry doors, corridors, restrooms and operatory should be designed for smooth movement of the chair following guidelines set by the Department of Public Health. Elevator access should be available if the dental office is located above ground level. Non-skid flooring with no obstructions such as doormats, carpets are preferred [13].

Patient positioning during dental appointment – The dental chair should be adjusted carefully and many of these patients are best treated with the chair tipped well back to give a position of security, especially to those with ataxia. Assistive stabilization and postural maintenance can be achieved through the following techniques:

- Head positioning devices placed in the occipital level
- Velcro straps for upper extremity positioning
- Foam rolls for lower extremity positioning
- Mouth props for mouth opening

Sudden actions and movements should be avoided to prevent precipitations of a startle reflex. [13].

Pharmacological management–

Nitrous oxide and oxygen through the nasal mask are medications that can be employed in patients with mild to moderate disability. However, in a severe disability the patients will be resistant to or will not tolerate the mask on their faces. Jensen et al, found significant reduction in movement when the patient was given nitrous oxide.

Conscious sedation with benzodiazepines, narcotics, propofol and adjunct drugs such as anti-sialogogues can be used with due consideration to maintenance of a patent airway [13].

Informed Consent for patients with developmental disabilities

Informed consent requires understanding the recommended treatment and being able to compare the risk versus benefit. Many individuals with developmental disabilities have the capacity to consent [34]. It is recommended to assess the capacity of the individual to consent and get them involved if possible, in the decision-making process [35]. In some cases, an adult with a developmental disability may have a legal guardian. The parent or legal guardian should finalize acceptance of recommended treatment based on the patient's best interest and factoring patient's wishes [36],[37].

Financial barriers to dental care for patients with development disabilities

Many people with developmental disabilities are dual-eligible, meaning that they are insured under both Medicare and Medicaid. But routine dental services are not covered under Medicare, and coverage of dental care under Medicaid is limited for adults. Because states are not required to provide dental coverage to adults under Medicaid, policies vary considerably. Some states cover only emergency services, and others provide limited coverage for dental services, with spending caps and constraints on covered procedures. Fewer than half of the states provide extensive coverage for dental services under their Medicaid program. Even in those states where beneficiaries with disabilities receive coverage, very few providers accept Medicaid patients. It might be beneficial to work with local non-profit organizations such as the Regional Centers Coordinate Services in California run by the Department of Developmental Services that can help by providing individuals with qualifying disabilities, with services that meet their needs in the least restrictive environment possible [37], [38].

As seen above there are multiple barriers to care for individuals with developmental disabilities. As the individual's medical, social or psychological history and condition becomes more complex, there are

additional factors that need to be considered in order to prevent dental disease, deliver the best treatment possible and help that individual obtain a lifetime of oral health.

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Resources

Administration on Intellectual and Developmental Disabilities (AIDD)

American Academy of Pediatrics

American Association on Intellectual and Developmental Disabilities (AAIDD)

American Heart Association

- Infective endocarditis and up to date recommended prophylaxis regimen is listed here for individuals with congenital cardiac defects and history of repair

Association of University Centers on Disabilities (AUCD)

Center for Parent Information and Resources (CPIR)

Department of Education

- The U.S. Department of Education (DOE) has resources to assist with the educational needs of children with developmental disabilities.

DisabilityMeasures.org

- DisabilityMeasures.org is an online resource with measurement tools for assessment, screening, and research concerning individuals with disabilities.

Diagnostic and Statistical Manual of Mental Disorders

- The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, is the standard classification of mental disorders used by mental health professionals in the United States.

Disability.gov

- Disability.gov offers comprehensive information on disability programs and services in communities nationwide.

First Signs

- First Signs is dedicated to educating parents and professionals about early identification and intervention for children at risk for developmental delays and disorders, including autism.

Insure Kids Now!

- Each state provides no-cost or low-cost health insurance coverage for eligible children through Medicaid and the Children's Health Insurance Program. This website has basic facts about these programs.

International Classification of Functioning, Disability, and Health

- The International Classification of Functioning, Disability, and Health provides a unifying framework for classifying the consequences of disease and for measuring health and disability at both individual and population levels.

MedlinePlus

- MedlinePlus, a service of the U.S. National Library of Medicine and the National Institutes of Health, provides information on many different types of developmental disabilities, as well as resources on prevention and screening, research, statistics, law and policy, and more.

My Child Without Limits

- My Child Without Limits provides resources for families of young children from birth through 5 years of age with developmental delays or disabilities, as well as for professionals who work with these individuals.

National Association of Councils on Developmental Disabilities (NACDD)

- The NACDD supports state and territorial councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act and promoting the interests and rights of individuals with disabilities and their families.

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

- NIDILRR is a federal government grants-making agency that sponsors grantees to generate new disability and rehabilitation knowledge and promote its use and adoption.

National Institutes of Health (NIH)

- Several institutes within the NIH conduct and fund research about developmental disabilities. They also offer information to the public and educational programs for health professionals. They include:

The Arc

- The Arc is a national, community-based organization advocating for individuals with intellectual and developmental disabilities and their families through public policy and provision of supports and services.

The International Classification of Diseases

- The International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) is the official system of codes for diagnoses and procedures in the United States. The International Classification of Diseases, Tenth Revision (ICD-10) l icon is used internationally.

The State of the World's Children 2013: Children with Disabilities

- The 2013 edition of this report focuses on the situation of children with disabilities across the world.