A thesis submitted in partial requirement for the degree of MASTER OF DENTAL SCIENCE [Public Health Dentistry]
SUMMARY

Down Syndrome is a genetic condition caused by the presence of an extra chromosome which can result in intellectual and physical delay.

Down Syndrome is the most common classifiable category of mental subnormality. The incidence at birth is about 1 in 700, and therefore it is likely that most dental practitioners will encounter the condition at some time during their professional lives.

At present there is no known factor to explain the chromosomal fault which causes Down Syndrome. It is neither racial, geographical, social, economic nor environmental. In about 1% of cases there can be a hereditary factor, but this is most unusual. The child with Down Syndrome has 47 chromosomes instead of the usual 46. The extra chromosome is number 21. This condition called Trisomy 21. Trisomy is the result of chromosomal nondisjunction either in meiosis or in mitosis. In any such case the total somatic chromosome number is 47 instead of 46.

There are three types of Down Syndrome: Standard Trisomy 21, Translocation, and Mosaic Down Syndrome.

It is most common among first born infants of women over 35 years of age.

Clinical findings include mental retardation and a characteristic facies; with slanted palpebral fissures, prominent epicanthic folds, and a small brachycephalic head. The hands are broad, with a short, incurved fifth finger and a rudimentary second phalanx. The space between the first and second toes is wide, and there is increased mobility of the joints.

Other findings present in most patients with Down Syndrome include:

* Significantly higher incidence of congenitally missing primary and permanent teeth.
* Significantly delayed eruption of primary and permanent teeth.
* Reduced salivary flow.
* Underdevelopment of the maxilla and mid-face region.
* Flat or prognathic facial profile.
* Relative tongue enlargement.
* Small nose and low nasal bridge.
* Shortened and narrowed palate with thickened lateral processes.
* Prominent anterior rugae.
* Higher incidence of over-retained primary teeth.
* Orthodontic problems involving anterior and/or posterior teeth.
* A typical patterns of eruption, especially of the primary teeth.
* Unusual shape and form of both the primary and permanent teeth.
* Enamel defects.
* Higher incidence of supernumerary teeth.
* Lower incidence of decay (but probably only slightly).
* Significantly higher and earlier incidence of destructive periodontal disease with early tooth loss.
* Higher incidence of bruxism (night grinding).
* Thick furrowed tongue.
* Hypotonicity, hyperflexibility and ligament laxity.
* Imprecise and slowed volitional tongue movement.

There is much that has been written and described in reference to Down Syndrome since John Langdon Down in 1866. Yet, there is much that is still unknown, especially in the area of clinical treatment.

Most studies of children with Down Syndrome show that the prevalence of dental caries is lower than in children with mental retardation of other etiologies and in normal children. For many years it has been widely believed that individuals with Down Syndrome are inherently resistant toward caries. However, a number of studies have failed to demonstrate any difference in caries prevalence between persons with Down Syndrome and others.

Several reports have dealt with the periodontal conditions in persons with Down Syndrome, and although the studies were carried out within different age groups and employed different oral health scoring criteria, it has generally been agreed that persons with Down Syndrome are characterised by a marked, rapid and early onset of severe periodontal disease.

Based on this information then, dental care should begin early for the child with Down Syndrome, usually at about the time the first teeth erupt. The aim of dental intervention at this point is primary prevention.

Prevention is of paramount importance, especially as the occurrence of dental disease may affect the general health of the children with Down Syndrome.

Oral hygiene is the most important aspect. The standard in general is very poor, because of both the mental and physical retardation.

In the home environment good oral hygiene is possible, but the understaffing of many institution often precludes adequate supervision of oral hygiene, except in the minority who are capable of effectively cleaning their own mouths. In these circumstances staff education is surely more effective than patient education.

Useful aids to prophylaxis include the use of chlorhexidine mouth rinses, automatic tooth brushes, fluoride pastes and a detergent non-cariogenic diet. Regular scaling is of great benefit, the ultrasonic scaler being a useful and well-received adjunct. Due consideration must, however, be given to the possibility of the occurrence of subacute bacterial endocarditis, as many children with Down Syndrome have congenital cardiac lesions, and adequate precautions must be undertaken.

Frequent dental inspections are necessary for children with Down Syndrome since they may lack the ability to communicate that they have pain or other symptoms. Regular inspections have the obvious advantage of acclimatising the patient to dentistry.
A visit to the dentist often then becomes a social highlight of the week rather than an unpleasant encounter.

Cooperation may be very good, but there are times when children with Down Syndrome cannot or will not maintain their attention for an adequate length of time. The use of a McKesson mouth prop or other simple device to steady the mandible is then helpful. Restraint is not indicated: patience is more effective in both the short and especially the long term care. Diazepam orally or by intravenous injection, preferably via an antecubital fossa vein, is a useful drug for sedation on the few occasions that this is required.

General Anaesthesia should be avoided whenever possible in view of the general medical conditions which may be present and the complications that may follow. If general anaesthesia is contemplated, and this is usually when prolonged treatment is necessary, then it is imperative that fitness for anaesthesia be assessed by a physician, and the anaesthetic be administered by the proper authorities under suitable conditions.

Two types of general anaesthetic can be planned. For the children who only require simple tooth extraction or whose examination must be performed under general anaesthesia because of inability to cooperate, a short anaesthesia without intubation may suffice. Those children who require comprehensive operative care, including scaling, restorations and extractions, require a long general anaesthetic with nasotracheal intubation. The latter may be admitted for one or more nights or may be treated as a day-case depending on the local hospital practice.

To present a timetable for dental intervention, the following is offered:

**AGE: 0-6 Years.**

* Referral to paediatric dentist when first teeth erupt.
* Development of a preventive oral hygiene program at home including brushing with fluoridated toothpaste.
* Determination of need for fluoride supplementation.
* Assessment of dietary habits.

**AGE: 6-15 Years.**

* Expansion of preventive oral hygiene program to incorporate flossing.
* Continued fluoride supplementation, if needed.
* Periodontal therapy, if needed.
* Assessment of need and placement of sealants, as determined.
* Evaluation of developing occlusion and orthodontic referral/treatment, as deemed appropriate.

**AGE: 15 Through Adulthood.**

* Regular dental care at intervals determined by the needs of the patient.
* Aggressive periodontal therapy, as included.
* Prosthetic replacement of missing teeth, as deemed appropriate.
Australian Government Dental Services are funded by the Commonwealth Government to serve disadvantaged people and children, who are not able to utilise the private dental service sector.

Dental Services in New South Wales are regulated by Public Health Act 1991, the Area Health Services Act 1986, the Dentists Act 1989, the Dental Technician Registration Act 1975, and the Fluoridation of Public Water Supplies Act 1957.

Public Dental Services in NSW provide a base level of services for eligible adults and school children up to 14 years of age (in some areas up to 16 years of age). Eligible means a holder of the pensioner health benefit card, a health benefit card or health care card issued by the Department of Social Security or their dependants. They are not necessarily referred by any one, and do not necessarily have any dental cover.

The full range of dental services for all children eligible for school dental services (SDS) are available for children with Down Syndrome. These children are eligible for SDS care at any of the fixed clinics and also at the mobile clinics which are used in some country areas. There is no discrimination nor restriction on the type and quality of dental treatment these children may receive.

This care includes treatment provided by teams of dentists and dental therapists and, based on the needs of the individual, includes routine examination, preventive and restorative care. The SDS does not provide specialist orthodontic care, but where clients are eligible for orthodontic care at the United Dental Hospital and Westmead Hospital this service is available for those requiring care.

Dental treatment offered to Down Syndrome patients depending on the severity of their handicap, a great many of them are "ideal" patients and are most co-operative, they are treated on the dental chair by either dental officer or dental therapist, if unco-operative they are treated under general anaesthetic in the day surgical unit.

Statistics are not kept on the numbers of children with Down Syndrome treated in School Dental Service or other public dental clinic even for the last two years, because all the dental clinics do not register or separate Down Syndrome patients from their clientele, so without going through thousands of patients cards individually we can only guess. Except Westmead Hospital which established a record system called Parado X Dental System in 1993. This system can recall individual records by separating them under codes.

A questionnaire was sent to the Directors of Dental Services in NSW to estimate the use of Government Dental Services by children with Down Syndrome, also the Writer did telephone review.

Using the ratio 1/700 the Writer estimates approximately 1800 children with Down Syndrome in New South Wales according to the estimated population for the age group (1-14) in 1993 (Australian Demographic Statistics March Quarter 1994).

Estimates from the NSW Down Syndrome Association indicate approximately 650 Down Syndrome children (age 1 to 14) registered with them.
There is a need for specialised facilities and personnel. This means either in-house training or continuing education programs to deal with this specific disability.

Professionals and Auxiliaries must be trained. There is little doubt that the key to successful dentistry for the handicapped lies in the establishment of a successful child/dentist/parent relationship.

There is a need for adequate coding in every hospital and clinic to keep records for all children with Down Syndrome in NSW.

There is a need for national register, so that co-ordination and planning of treatments will receive the appropriate recognition.
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Mr DC Neesham, Director Dental Services, Western Australia.
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Mr Faye Lamberton, Dental Therapist, Camden Hospital.
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Dr Peter Hill, Principal Dental Officer, North Coast Region.
Dr M Syme, A/Principal Dental Officer, North Coast Region.
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Mr John Ryan and Dr Schawarz Wo, Dental Officer, Maclean District Hospital and Community Health Services.
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Mr Abeyseker, Information Systems Manager.
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Dr Nicolo Bone, Dental Officer, Acting for Dr Peter Roche, Principal Dental Officer, Macquarie Health Service.
Mrs Anglea Copp, Dental Therapist, Central Coast Area Health Service.
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Secretary, Down Syndrome Association of the Northern Territory Inc.
Secretary, Down Syndrome Association of the South Australia.
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Ms Les Mayne, Secretary/Information Officer, Down Syndrome Association of South Africa.
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DEDICATION

TO

MY PARENTS

WAJEH ALMASRI

AND

FATIMA RASHWANI

FOR THEIR GREAT GUIDANCE AND ADVICE ALWAYS THROUGH MY LIFE

DR AKRAM ALMASRI
1. INTRODUCTION

The genetic material, DNA, that controls the production of a single protein (or polypeptide chain) is called a "gene". There are thousands and thousands of human genes, each one regulating the production of a specific polypeptide. These genes are grouped in units called "chromosomes". Such a packaging arrangement has great advantage to the cell when it divides, since it is much simpler for the cell to equally partition a few chromosomes into two daughter cells than it would be to similarly sort out thousands of genes.

Man has forty-six chromosomes, and each chromosome has a paired mate that is referred to as "the homolog". Genes on homologs control the same genetic trait, and, with the single exception of those genes on the sex chromosomes, there are at least two genes that control each inherited trait. Thus, man's chromosome complement actually consists of twenty-three pairs of chromosomes. Twenty-two of these pairs are designated the "auto-somes", the remaining pair, the X and the Y chromosomes, are named the "sex chromosomes".

Since 1959, several disease states in man have been specifically ascribed to alteration in chromosome number. But this quickly proved to be only one aspect of chromosomal alteration in man. Refined karyotyping techniques revealed that the structure of chromosomes, as well as their number, could be altered. These various structural alterations have been given the following descriptive classifications.

**Deletions:** The absence of a piece of chromosome.

**Duplication:** The insertion of an extra fragment into a chromosome from its homolog.

**Inversion:** The breaking of a chromosome in two places and subsequent rejoining with the middle piece inverted.

**Translocation:** The attachment of a broken piece from one chromosome to another, but nonhomologous, chromosome.

With the identification of all these alterations in both chromosome number and structure, a nomenclature system for the various chromosomes based upon their morphology became a necessity. The currently accepted system is called the "Denver Nomenclature" and is primarily based upon chromosome identification by overall size and individual anatomic characteristics. Each chromosome consists of thousands of genes, and it is easy to see how an extra piece or a missing piece of a chromosome could involve many cell functions and hence result in a clinically identifiable disease state.

As might be expected, disease states resulting from gross chromosomal alterations have a complicated clinical picture involving multiple organ systems. This is readily apparent in Down Syndrome.
There have been enormous changes for people with Down Syndrome over the past two decades. Children with the syndrome now usually live at home and enjoy the love and stimulation they receive from their families. They benefit from early teaching and special help through the school years. Included in everyday activities, they are socially more competent, and their needs for recreation and friendship are increasingly being catered for, with improved health care, they are living healthier lives.

Down syndrome is a congenital chromosomal abnormality which results in intellectual and physical retardation. It received its name from Dr. Langdon Down who, in 1866, first described the group of symptoms and signs that pertain to the syndrome.

Although many factors have been proposed as to what causes Down Syndrome, it has now been established that people born with this disorder have 47 instead of the normal 46 chromosomes in each cell of their body. In a normal cell there are 46 chromosomes or 23 pairs. A person with Down Syndrome has an extra chromosome added to the normal number 21 chromosome pair.

Some of the most common physical characteristics include: Eyes which slant upward, ears which are smaller than average that are often low-set, a smaller nose, with a low or flat nasal bridge, a profile that tends to be rather flat, hands and feet that tend to be short and broad, and a tongue which may protrude as a result of a smaller mouth and reduced muscle tone.

In many articles and texts, reference is made to the decreased incidence of dental caries in children with Down Syndrome. This is based on early research data gathered from studies conducted in institutional setting. With deinstitutionalization and more people with Down Syndrome never entering institutions, the finding of reduced caries rate is not nearly as significant as it was. If there is any reduction in decay rate, it is very slight (Ulseth, 1991).

The aim and objectives of this thesis will be to review literature and to:

1. **Update existing data on dental services to children with Down Syndrome in NSW.** To obtain this information from a number of Directors of Dental Services in NSW, and Dental Officers in some hospitals and school dental clinics and from Down Syndrome Associations in Australia and other Countries.

2. **To determine the type of services provided to them.**

3. **To gather data for future requirements for dental services.**
2. DOWN SYNDROME

Down Syndrome is a congenital chromosomal abnormality caused by the presence of an extra chromosome which can result in intellectual and physical delay. It received its name from Dr Langdon Down, who in 1986, first described the group of symptoms and signs that pertain to the Syndrome. It occurs more frequently than any other specific kind of intellectual disability, and occurs in one in every 700 babies born in Australia.

Babies with Down Syndrome do not look just each other. They are individual, with an individual appearance and will resemble their parents, like other children. When they grow up they will still have the typical features of Down Syndrome but will also look just like them selves, marked as every person is with lines of their own experience, good and bad. Down Syndrome knows no barriers to race, creed or colour.

**Syndrome:** Is a condition distinguished by a cluster of features occurring together. (Selikowitz, 1992).

**Syndrome:** A group of signs and symptoms that occur together and characterise a particular abnormality. (Definition from Webster’s Dictionary).

2.1 HISTORICAL BACKGROUND

The condition known as Down Syndrome is certainly not a new phenomena which has surfaced over the past few years, but is probably as old as history itself.

Archaeological shows records of skulls which appear to have the structural idiosyncrasies of Down Syndrome.

Children with Down Syndrome are also depicted in many works of art (mainly religious paintings). The earliest recorded representation to an altar-piece in Aachen, Germany, painted in about 1505.

It was not until the 19th Century that the Syndrome became well documented, and in 1866 Dr. Langdon Down an English doctor working in Surry, first described the characteristic features of the Syndrome. Down did not understand the cause of the condition he had described, his suggestion that Down Syndrome was a reversion to a primitive Mongolian ethnic stock, was soon repudiated by his son Reginald, who was also a doctor.

Although De Waardenburg had suggested in 1932 that Down Syndrome might be caused by a chromosomal abnormality, it was some time before this was confirmed. In 1959, ninety-three years after Down’s original description, Lejeume and his colleagues in Paris demonstrated that Down Syndrome was associated with an extra chromosome.
2.2 CAUSE OF DOWN SYNDROME

At present there is no known factor to explain the chromosomal fault which causes Down Syndrome. It is neither racial, geographical, social, economic nor environmental. In about 1% of cases there can be a hereditary factor, but this is most unusual. The child with Down Syndrome has 47 chromosomes instead of the usual 46. The extra chromosome is number 21. This condition called Trisomy 21. Trisomy is the result of chromosomal nondisjunction either in meiosis or in mitosis. In any such case the total somatic chromosome number is 47 instead of 46.

The reason why the cells divide inaccurately is not known, but it is known that this happens increasingly as the mother grows older (Table 1). It is possible that as the female ages, her ovaries are increasingly subject to environmental hazards. However, mothers of any age can have infants with Down Syndrome and as few women over the age of 40 years have babies, the majority of affected infants are born to younger women and non disjunction is the usual cause. The reason for the correlation between late maternal age and nondisjunction is still a matter of debate. Several environmental factors, in addition to maternal age, have been suspected of playing contributory parts in the origin of the syndrome, they include X-ray irradiation and virus infections, but these have not been proven.

However, not all infants with trisomy 21 are a consequence of non disjunction, about 6 percent are associated with chromosomal re-arrangement, so called Translocation, and approximately 2 percent with Mosaicism.

<table>
<thead>
<tr>
<th>Mother's Age</th>
<th>Number of Down Syndrome births</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20 years</td>
<td>Less than 1 in 2000</td>
</tr>
<tr>
<td>20 - 30 years</td>
<td>Less than 1 in 1500</td>
</tr>
<tr>
<td>30 - 34 years</td>
<td>About 1 in 750 to 880</td>
</tr>
<tr>
<td>35 - 40 years</td>
<td>About 1 in 280 to 290</td>
</tr>
<tr>
<td>40 - 44 years</td>
<td>About 1 in 130 to 150</td>
</tr>
<tr>
<td>Over 45 years</td>
<td>Between 1 in 20 to 65</td>
</tr>
</tbody>
</table>

Source: McDonald T (1990), Down syndrome - What do you know?
2.3 TYPES OF DOWN SYNDROME

There are three types of Down Syndrome: Standard Trisomy 21, Translocation, and Mosaic Down Syndrome.

Standard Trisomy 21

This is the commonest format of Down Syndrome in children born to mothers of any age. 95 percent have an extra whole chromosome 21 in every cell of their body (Fig 1). Which is not hereditary. This can happen when either the egg from the mother (about 77%) or the sperm from the father about (23%) carries an extra chromosome prior to conception or, if there was a faulty distribution of chromosomes in the first division of the fertilised egg. The chance of having a second child with trisomy 21 is about 1 in 100.

Figure 1: Standard Trisomy.

Source: Australian Down Syndrome Association Inc.
Translocation

In about 4 percent of cases, Down Syndrome is due to the presence of an extra part, rather than the whole, of chromosome 21 (Fig 2). This occurs when the small top portions of chromosome 21 and another chromosome break off, and the two remaining portions stick to one another at their exposed ends. This process of one chromosome sticking on to another is called 'Translocation'. Only certain chromosomes become involved in this sort of translocation with chromosome 21. They are chromosomes 13, 14, 15, or 22, or another chromosome 21, (14 is the most common).

Figure 2: Translocation.

![Figure 2: Origin of a translocation](image)

Chromosome number

14

21

Fragment lost

Source: Down Syndrome - What do you know? A.C.T. Down Syndrome Association Inc.
Mosaic Down Syndrome

A person with Mosaic Down Syndrome starts with 23 pairs of chromosomes in each cell, but an error is made in an early division of cells. When an infant is conceived, the original cell is perfect containing 46 chromosomes and perhaps the first or second divisions of the cell are also perfect. However, some where later along the way a mistake occurs when one cell divides abnormally, and again we have 47 chromosomes in one cell and 45 in the other. The cell containing 45 chromosomes does not survive whilst the cell with 47 chromosome continues to multiply (Fig 3).

Babies with Down Syndrome due to mosaicism usually do not differ from those with the full trisomy 21 abnormality, but some may be less obviously unusual either in their physical appearance or intellectual ability.

Figure 3: Mosaic Syndrome.
2.4 CHARACTERISTICS OF THE PERSON WITH DOWN SYNDROME

There are over 50 physical characteristics which can be found in people who have Down Syndrome.

(a) The eyes can have an upward and outward slant with an exaggerated fold of skin on the inner side of the eye (the epicanthal fold).

(b) Small white patches (Brush field spots) can sometimes be seen on the edge of the iris of the eye.

(c) The face can have flat appearance because the bridge of the nose tends to be low and the nose short and flat.

(d) The back of the head may appear less prominent and the head tends to be slightly smaller than average.

(e) Often the neck is short, and babies tend to have a loose fold of skin across the back of the neck which disappears as the child grows.

(f) Ears tend to be small and lowset.

(g) The nasal bone can be underdeveloped and the jaw bone small.

(h) The legs and arms are often short in relation to the torso.

(i) Hands are often short and stubby.

(J) Sometimes there may be a cleft between the first and second toes.

(k) Genitals may be small.

(l) Skin may have a mottled appearance and may become dry and less elastic as the child grows older.

(m) Hair is sometimes fine and straight.

Down Syndrome children also may have other disease entities. They are, in fact, more likely to have additional malformations to be the body and the central nervous system.

However, the features of Down Syndrome are usually evident at birth. At that time behaviour is generally similar to that of a normal infant but as the child grows older the associated mental retardation begins to reveal itself. The physical features of the disorder also become more evident.
3. FACIAL AND ORAL MANIFESTATIONS OF DOWN SYNDROME

The oral cavity is one of the complex systems of the human body.

3.1 CRANIAL MORPHOLOGY

The facial features of Down Syndrome (trisomy 21) are numerous and for this genetic disorder, have been considered to be pathognomonic. The skull can be noted to be small, brachycephalic, or rounded and often with an open metopic suture. Thinness of the cranial bones has been reported, with almost an absence of diploe formation. The present sinuses of the frontal area are often missing and when they are present, they are very minute in their formation. The supraorbital ridges may appear small because of this lack of development of the frontal sinuses.

The nasal bridge has been described as flattened and broad, with the nose being both small and short. Absent, or malformed, nasal bones have been reported and this would account for the flattening of the nasal bridge. The length of the nasal bones, if they are present, is generally shorter than normal and the angle formed with the nasal complex more acute. The paranasal sinuses have a marked tendency to be underdeveloped, or missing entirely. The length of the anterior cranial base is markedly less than normal in all ages. This anterior cranial base structure is also flatter than normal.

Many persons with Down Syndrome have the slanting, almondshaped eyes with epicanthal folds and the oblique palpebral fissures. Speckling of the iris or "Brushed Spots" can be seen in many patients. Also quite common is ocular and bony orbital hypotelorism, which is probably a manifestation due to the lack of development of the frontal and nasal complex.

The maxilla and the mandible are considerably smaller in persons with Down Syndrome than in the general population (Frostad, Cleall & Melosky, 1971; Kisling, 1966) and the width, length, and height of the palate are also less. The lower jaw is more often larger in relation to the underdeveloped upper jaw thereby causing an oral occlusion whereby the lower teeth close to the outside rather than the inside of the upper teeth.

3.2 ORAL CAVITY

The oral cavity is one of the complex systems of the human body. The oral anomalies associated with Down Syndrome affect the jaws, the tongue, teeth, and the gingival and mucosal structures. As a consequence of the small oral cavity, the tongue appears to be larger than normal which may protrude beyond lip thereby causing the situation where there is a space between upper and lower front teeth when the back teeth are meeting. This is referred to as an anterior open bite.
The tongue position is probably the main cause of the enlarged freeway space in persons with Down syndrome, but other important factors such as specific malocclusions, the skeletal development, malfunction of the masticatory apparatus, and the shape of the lower face also may be explanatory factors for the enlargement of the freeway space (Kisling, 1966). Because of the narrow palate and very poor muscle tone that the tongue just does not fit in and leads to the problems of tongue thrust posterior.

Bruxism has been reported as being a frequent finding, in some cases it begins as early as two years of age. The traumatic and abnormal occlusal forces of bruxism can further precipitate periodontal destruction.

Finally, it has been reported that the prevalence of bifid uvula and cleft palate is increased in persons with Down syndrome. The prevalence of soft cleft palate has been found to be 0.7%, compared to 0.04% among the general population (Schendel & Gorlin, 1974).

3.3 DENTITION

AGE: 0-6 Years

Infants with Down Syndrome often present with hypoplasia of the dentition which can be either localised or generalised (Kamen, 1976). Given the range of congenital malformations described in Down Syndrome, it would not be surprising to see more generalised rather than localised defects in the tooth structure. These defects can range from intrinsic discolorations which are smooth to the touch of instruments to overt defects which can easily detected with dental instruments. Especially the defects which occur as roughened irregularities lend themselves to an easier onset of decay. The irregularities act as natural harbor for food material to collect and dental decay to begin.

Delayed eruption of the primary teeth is very common. In the general population, eruption of the primary teeth begins at about 6 months of age. In children with Down Syndrome, it is not uncommon for eruption to begin at 12-14 months of age. Clinically, the latest eruption time for a first tooth is 24 months of age. The prevalence of congenitally missing teeth is much higher among individuals with Down Syndrome than in the general population (Troutman, 1982). Missing teeth occur in about 50% of individuals with Down Syndrome compared to approximately 2% in the general population.

The primary teeth of children with Down Syndrome are usually more conical in shape and the clinical crowns are frequently shorter and smaller than the general population. Clinical crowding of the teeth is not uncommon and usually effects the maxillary arch more than the mandibular arch (Troutman, 1982).

In children with Down Syndrome, not only is the eruption delayed, the sequence can be quite irregular. The central incisors still erupt first and the second molars usually erupt lastly, but between the beginning and the end, there is a great deal of variation.
AGE: 6-15 Years

Above or below each primary tooth there is most often a permanent tooth developing. Since dental eruption is so delayed for children with Down Syndrome, it is reasonable to conclude that virtually all development of the permanent dentition occurs postnatally in children with Down Syndrome. Therefore, hypoblastic defects noted involving the permanent dentition are of postnatal origin. Isolated, localised hypoblastic defects are frequently the result of significant illnesses or prolonged fevers.

Similar to the eruption of the primary teeth, the eruption of the permanent teeth in children with Down Syndrome is significantly delayed, also whereas eruption of permanent teeth generally begins at age 6 with the emergence of the "6 year molar" or a mandibular central incisor, these same teeth may not become clinically visible until age 8 or 9. The sequence of eruption of the permanent teeth does follow a more usual pattern in children with Down Syndrome.

The permanent teeth erupt generally without any accompanying fevers or discomforts one associates with the primary dentition. In children with Down Syndrome it is not uncommon for the succedaneous tooth to erupt without the primary tooth being shed. The permanent teeth of children with Down Syndrome like their primary predecessors, are frequently smaller, and more conical in shape. The roots of the teeth, likewise, are shorter and thinner (Kamen, 1976).

Similar to the primary dentition, children with Down Syndrome have a much higher incidence of congenitally missing permanent teeth. The most common teeth to be missing are the maxillary lateral incisors, mandibular lateral incisors and second bicuspid.

The joining together or fusion of teeth is limited to the lower jaw only and occurs at a rate of one in sixty-six Down's Syndrome children.

3.4 MALOCCLUSIONS

One of the characteristics of persons with Down Syndrome is the high prevalence of malocclusions. Almost 100% have one or more occlusal anomalies (Kisling, 1966). Several reports have dealt with the prevalence of various types of malocclusions in persons with Down Syndrome (Swallow, 1964). All have agreed that mandibular overjet, mesial molar occlusion, and crossbite occur far more frequently in persons with Down Syndrome than among persons with mental retardation of other etiologies and normal individuals.

A study of 6 to 19 year-olds with Down Syndrome showed that 41% had mandibular overjet, 54% had mesial molar occlusion, 38% had frontal open bite, and 65% had a crossbite. Because of the longer growth period of the mandible compared to other facial bone structures, the prevalence of mandibular overjet can be expected to increase with age.

It can be concluded that individuals with Down Syndrome have frequencies of mandibular overjet, frontal inversion, frontal open bite, and crossbite that are significantly higher than observed in the general population.
3.5 PERIODONTAL CONDITIONS

Periodontal disease is defined as gingivitis with loss of attachment and loss of alveolar bone. This condition appears in practically all persons with Down Syndrome, depending mainly on the age of the individuals and the level of their oral hygiene. Several reports have dealt with the periodontal conditions in persons with Down Syndrome, and although the studies were carried out within different age groups and employed different oral health scoring criteria, it has generally been agreed that persons with Down Syndrome are characterized by a marked, rapid and early onset of severe periodontal disease (Modeer, Barr & Dahllof, 1990; Orner, 1976; Reuland-Bosma & Van Dijk, 1986; Ulseth, Hestnes, Stovnør & Storhaug, 1991).

The prevalence of periodontal disease is highest in the older age groups, but the incidence is highest among the younger. The most frequently affected teeth are the mandibular incisors and the maxillary molars (Modeer et al, 1990; Reuland-Bosma & Van Dijk, 1986; Saxen & Aula, 1982).

Studies have suggested that institutionalized children with Down Syndrome suffer more from severe periodontal disease than those who live at home (Johnson & Young, 1963; Swallow, 1964). According to these studies, the reason is that the institutionalized individuals have more deposits, probably due to environmental differences in diet or in oral hygiene.

Studies of children with mental retardation have shown that children with Down Syndrome have less plaque and calculus than individuals with mental retardation of other etiologies (Reuland-Bosma & Van Dijk, 1986; Shaw MJ, Shaw L & Foster, 1990; Vigild, 1985).

It seems surprising that children with Down Syndrome have better oral hygiene than other mentally retarded children. The explanation could well be that parents are informed about the high susceptibility to periodontal disease related to Down Syndrome and therefore are particularly careful with daily oral hygiene for their children. In spite of this, children with Down Syndrome often have more gingivitis than other children.

A number of reports exist on the occurrence of acute necrotizing ulcerative gingivitis in children with Down Syndrome (Reuland-Bosma & Van Dijk, 1986). Today, this type of gingivitis is rare in the Western world and is almost never seen prior to puberty. However, among persons with Down Syndrome, necrotizing gingivitis has been reported to occur quite frequently, with a prevalence up to 84% (Reuland-Bosma & Van Dijk, 1986), some studies even found the highest prevalence among 15 to 19 year-olds.

Some studies, however, have failed to demonstrate necrotizing ulcerative gingivitis among persons with Down Syndrome (Barnett, Press, Friedman & Sonnenberg, 1986; Vigild, 1985). This apparent discrepancy is probably due to generally improved oral hygiene among persons with Down Syndrome.

It has been suggested that local factors such as true or false macroglossia, tooth morphology, habits such as bruxism and tongue thrusting, lack of lip seal, and lack of masticatory functions are etiologic factors for the onset of periodontal disease among persons with Down Syndrome (Reuland-Bosma & Van Dijk, 1986; Shaw & Saxby, 1986).
These factors are important because they may affect oral hygiene, but the effect on the periodontal tissues is indirect (Reuland-Bosma & Van Dijk, 1986).

Studies on oral bacteria in persons with Down Syndrome are scarce and generally there is no difference in the plaque flora between persons with Down Syndrome and "normal" individuals within the same environments. There is a tendency for institutionalized individuals with Down Syndrome to have higher levels of aerobic bacteria and streptococci (Reuland-Bosma & Van Dijk).

There have been several attempts to identify systemic etiologic factors and pathogenetic mechanism that may explain the high susceptibility toward periodontal disease among persons with Down Syndrome. The factors suggested include: poor blood circulation and differences in connective tissue (Reuland-Bosma & Van Dijk, 1986) elevated blood levels of citric acid metabolic blocks in the collagen maturation vitamin A malabsorption or malnutrition and a three times higher concentration of cyclic amino-monophosphate, which has been demonstrated in inflamed gingival tissue from persons with Down Syndrome.

However, there seems to be agreement that the main reason for the high prevalence and the severity of periodontal disease in persons with Down Syndrome is a general low resistance caused by immunodeficiency (Reuland-Bosma & Van Dijk, 1986; Shaw & Saxby, 1986; Ugazio et al, 1978).

The main immunologic defect occurs in the thymus-dependent system, which may result in a reduced number of mature T cells and a relatively large proportion of immature cells. According to Whittingham, Pitt, Sharma, and Mackay (1977) the immune system is under stress.

The antigenic stimulus is so heavy that the system becomes overloaded. Together with the larger amount of calculus and of soft deposits and bacteria in the plaque among institutionalized individuals, this may explain some of previously reported differences in the severity of periodontitis between persons living in institutions and those living in the community (Reuland-Bosma & Van Dijk, 1986).

It can be concluded that persons with Down Syndrome constitute a special risk group with respect to periodontal disease.

A number of studies have shown a relationship between emotional disturbances and periodontal disease. It has been suggested that stress affects periodontal tissues in one or more of the following ways:

* Increasing habits such as tooth grinding.
* Changing salivary secretion or vascularity of the periodontium.
* Altering dietary habits e.g., to soft foods,.
* Endocrine dysfunction.
* Neglect in oral care. It used to be thought people with Down Syndrome were completely free of stress but this is not so, patients who are now going into group homes out of institutions are showing all these signs and they could be evident in children under stress at school.
3.6 DENTAL CARIES

Most studies of children with Down Syndrome show that the prevalence of dental caries is lower than in children with mental retardation of other etiologies and in normal children. (Barnett et al, 1986 and for many years it has been widely believed that individuals with Down Syndrome are inherently resistant toward caries. However, a number of studies have failed to demonstrate any difference in caries prevalence between persons with Down Syndrome and others (Shaw et al, 1990; Ulseth et al, 1991).

Many factors must be taken into consideration when the results from different studies are compared. First of all, the living conditions are important. It has been shown that children with Down Syndrome residing in institutions have very little dental caries, but this is probably because they have a lower consumption of sweets and more regular meals than children living at home. Second, the number of teeth is important, and also the time these teeth have been erupted and thus exposed to decay. Third, it is important to take into account whether the decay is scored as the number of decayed, missing, and filled teeth or as the number of decayed, missing, and filled tooth surfaces. Both these indices express the caries experience, which is the sum of untreated and treated decay. When the tooth is used as the unit of measurement, a tooth is scored as decayed or filled regardless of the number of surfaces involved, whereas when the surface is used as the scoring unit, all of the numerous affected surfaces are identified. In other words, when the number of surfaces is used, the seriousness of the decay is taken into account in particular, whether or not the approximal surfaces are involved.

Some authors have considered the late eruption of the permanent teeth (Swallow, 1964) while other studies focused on the higher frequency of missing teeth in children with Down Syndrome (Creighton & Wells, 1966; Cutress, 1971; Orner, 1975; Vigild, 1986). Vigild (1986) took into consideration the living conditions at home or in institution the number of erupted teeth and tooth surfaces, and the time these teeth (surfaces) have been erupted.

The study by Vigild (1986) shows that youngsters with Down Syndrome residing in institutions have a significantly lower caries prevalence than those living at home. Among the 6 to 12 year-olds with Down Syndrome, however, there was no significant difference between institutionalized children and non institutionalized children either with respect to the number of caries-free individuals or to the distribution of caries. This was probably due to the overall low caries prevalence in both groups of youngsters. However, in 13 to 19 year olds with Down Syndrome, 71% of the institutionalized Danish individuals were caries free compared to only 22% of those who were not institutionalized. This illustrates that the caries experience among children and young adults with Down Syndrome is affected by environmental factors just as it is in other individuals.

It has been demonstrated that interdental spacing in persons with Down Syndrome increases with age, even when there is no hypodontia. Contrary to this, there is an overall decrease of the interdental space with age in "normal" controls (Jensen et al, 1973).

The morphologic deviations in the dentition in persons with Down Syndrome (e.g the peg-shaped front teeth) may also play a role when their caries pattern is compared to that of others.
It has been suggested that the high concentration of cyclic adenosine monophosphate in the saliva of persons with Down Syndrome and the increased pH and sodium level in the saliva may be of importance for the susceptibility to dental caries. It has been noted that the decreased flow from the parotid gland, and the habit of mouth breathing causes mouth dryness, which normally results in more decay due to the low level of natural self-rinsing.

It can be concluded that individuals with Down Syndrome are not resistant to dental caries although they have a low frequency of approximal caries. Therefore, caries-preventive measures should not be neglected. This is particularly important for individuals living in the community.

3.7 GENERAL MEDICAL PROBLEMS INFLUENCING DENTAL MANAGEMENT

A number of systemic problems influence dental care.

Mental subnormality

The majority of children with Down Syndrome are mentally subnormal (an IQ of below 70). A small number are at the lower end of the normal range and may be independent. Their intellectual capabilities appear to be higher if they are cared for at home rather than in institutions (Stedman and Eichorn, 1964; Francis, 1970). The average maximum mental age attained is about 8 years. They are often friendly and helpful individuals, but this is not invariable, and communication problems may exist owing to the coexistence of other defects such as deafness or blindness.

Cardiovascular disease

The incidence of congenital cardiac defects in children with Down Syndrome may be up to 50 percent. In the early years the ostium premium defect (a form of atrial septal defect) is the prevalent lesion, whilst the ventricular septal defect predominates in later life. Atherosclerotic lesions occur at an earlier age than normal.

Cardiovascular disease can lead to several problems, which may warrant inpatient management. The major problems are: Congenital heart abnormalities, mainly ostium premium, in 40%.

Many are inoperable, with early pulmonary hypertensive changes and intractable heart failure. Also subacute bacterial endocarditis, polycythaemia and its sequelae, heart block and failure to thrive. There is a high mortality in the early years of life.

Infections

The lower standard of all aspects of hygiene in the mentally subnormal and living in institutions increase the exposure to infections and infestations. The exanthema, especially meals, carry a high risk to children with Down Syndrome.
One of the most important infections occurring in persons with Down Syndrome is infective hepatitis.

1. Virus A (infectious or short incubation) Hepatitis

Type A hepatitis is transmitted almost exclusively by faecal contamination of food or water. Because the reservoir for infection is frequently a common food or water source, hepatitis A often occurs as an epidemic.

Transmission is also enhanced by poor personal hygiene, in general, hepatitis A tends to be of mild severity, has an incubation period of from 15 to 50 days, no vaccine is currently available, and recovery usually conveys immunity against reinfection.

2. Virus B (serum or long incubation) Hepatitis

Has an incubation period of from 15 to 108 days. In this disease a viraemia persists for weeks or months before the clinical illness and for some weeks after. In those with immune defects, as children with Down Syndrome, the hepatitis-associated antigen (HAA, HbAg, Serum hepatitis antigen) persist for much longer.

Hepatitis B may be transmitted in a number of ways including:

1. Direct percutaneous inoculation of infected serum or plasma by needle or transfusion of infective blood or blood products.
2. Indirect percutaneous introduction of infective serum or plasma, such as through minute skin cuts or abrasions.
3. Absorption of infective serum or plasma, such as through mucosal surfaces of the mouth or eye.
4. Transfer of infective serum or plasma via inanimate environmental surfaces or possibly vectors.

Experimental data indicate that faecal transmission of HBV does not occur and airborne spread is not epidemiologically important (Little et al, 1993).

The incidence of hepatitis is very high in institutionalised patients with Down Syndrome, but only slightly increased in those resident at home (Blumberg et al, 1970). However, the patient and dentist are at risk from infective hepatitis. It has been known that as little as 0.0001 ml of blood can produce the disease, and there are obviously numerous potential sources of infection in the dental surgery.

It has been strongly recommended, therefore, that hospital personnel should not work until they are HbAg negative. This recommendation should also include dental surgeons.
4. DENTAL MANAGEMENT OF CHILDREN WITH DOWN CHILDREN

4.1 THE DENTAL TEAM CONCEPT

During the last decade significant changes have also occurred in the education and utilisation of dental auxiliaries. With the emphasis in the 1970s on expanded duties, the team approach, and preventive dentistry, dental hygienists, dental assistants, and expanded function dental auxiliaries have assumed increasing responsibilities for direct patient care, dental health education, and program planning. The expanded responsibilities have also increased the variety of settings in which dental auxiliaries may engage in practice. These settings include, but are not limited to hospitals, solo and group practices, public clinics, schools, universities, residential care facilities, and industry.

The role of auxiliaries will vary depending on the environment (i.e., hospital, school, solo practice) the goals of the team, and the management style of the team leader. Part of what unifies a team is working together to identify and adjust the individual roles each team member will fulfil. The dental hygienist and dental assistant often find themselves in a pivotal role when interacting with patients. In many instances, they set the tone for the dental experience and establish the first line of communication in the dental setting. This tone and line of communication take on a new meaning when the patient has a handicap, the condition may often go unattended. It becomes critical for all members of the team to understand the causes of, and problems related to, children with Down Syndrome in order to plan and conduct a rewarding dental experience for the patient.

4.2 PATIENT MANAGEMENT STRATEGIES

Integrating the concept of normalisation of Down Syndrome patients into a regular dental practice requires that allowances be made only for the limitations that the handicapping condition places upon the individual. In preparing for and treating children with Down Syndrome, members of the dental health team must employ problem-solving/awareness strategies in relation to the patient and the handicapping condition if interaction and dental care are to be effective and satisfying for both patient and the team members.

These problem-solving/awareness strategies can be developed in four ways:

1. Development of a patient condition profile.
3. Use of the anecdotal record.
4. Practice with simulated patient scenarios.
Development of a patient condition profile

When gathering information about the child with Down Syndrome in preparing for the first appointment, the following data will allow you to establish a base for problem assessment:

1. The patient's age.
2. The dental problem.
3. The patient's dental experience.
4. The patient's handicapping condition, degree of impairment, and the patient's capacity for interaction.
5. The patient's method and level of communication.

The assessment of the patient may be made at the clinic or practice, or at a domiciliary visit. There may be an advantage in having interview facilities separately situated away from the clinical area where the dentist can meet the patient and relatives in a neutral environment. The assessment aims to find the current level of dental health of the patient, the probable standard of self-care or home care that can be achieved, whether treatment can be provided under outpatient conditions, or whether specialised facilities will be required to provide treatment under general anaesthesia, either as a day case patient or as an inpatient.

Making the assessment is most easily achieved by adopting a routine that is in two parts, an interview followed by a clinical examination. The interview can have several parts. First, enquiries into the patient's social background may be made. Answers to questions about the patient's next of kin, residence, employment or school, transport, mobility and communication skill should be elicited. The intelligence of the patient and those caring for him or her will have been indicated, and will show what degree of cooperation may be expected in attending for appointments and in following instructions for improving home care.

It is essential to obtain details of the patient's past medical history. The past dental history will indicate whether the patient can be treated easily as a conscious outpatient or whether specialised facilities will be required. If previous outpatient treatment was limited to removal of plaque and calculus with restorations and extractions provided under general anaesthesia, it may be necessary to refer the patient to a specialised centre.

The final part of the interview seeks to find out why the patient presented for advice and treatment. It may be for routine check or because the patient has pain. Often the accompanying person will comment about the real reason for taking the patient to a dentist.

The second part of the assessment is the clinical examination. In addition to the information gathered during the examination of a patient, special attention should be paid to indications of ease of operating. These include where the examination was made (if the patient refuses to leave the car and the dentist makes the clinical examination in the car in a car park adjacent to the practice, it is unlikely that the patient will be suitable for outpatient care), what degree of restraint was needed, what posture was the patient in, did uncontrolled head movements, pronounced biting, retching, tongue thrusting or sucking reflexes impede the examination of the mouth. The successful use of diagnostic tests and aids such as radiographs, if necessary, will also help in assessing how to treat the patient.
It is helpful to have a pro forma on which individual answers given during the interview and the findings of the clinical examination can be recorded. The overall assessment of answers and the ease of examination recorded will help the dentist to decide whether to treat the handicapped patient with his or her available skills and facilities or whether the patient should be referred elsewhere.

**HISTORY**

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<tr>
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**Past Medical History**

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**General Medical Practitioner**

**Hospital Consultants**

**Past Dental History**

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**Presenting complaint**

**EXAMINATION**

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19
DENTAL CHART

Right

| 8 | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |

Left

DMF = D/DF
Plaque Score (site prevalence)
Gingivitis Score
Periodontal Pockets

Radiographic examination

Problems in conducting examination

Diagnosis

Treatment plan

Information by telephone or during the initial interview will enable the dental team to better plan for the first and subsequent appointments. Consultation with the patient’s physicians and other professionals involved may also provide valuable data or assistance with financial, transportation, or home care problems.
Application of a problem-solving assessment technique

Decisions about handling patient problems can be reached through a systematic pattern of evaluating the problem parameters and determining alternative approaches for management.

The systematic pattern includes

1. Identifying the problem
2. Collecting the relevant information or data.
3. Assessing the problem parameters.
4. Anticipating the patient's need(s).
5. Determining approaches to solving the problem.
6. Evaluating the results (successful, unresolved, change, discuss).

Use of the anecdotal record

The anecdotal record is simply a note of any significant fact that will help you maintain effective, positive interaction with the patient or improve a negative interaction. These notes can easily be kept on 3 x 5 or 4 x 6 cards in the patient's record and should be available for all staff members to use or review before subsequent visits. Two different coloured cards or pens used to distinguish positive versus negative behaviours and actions.

The anecdotal records become important when developing the problem-solving techniques previously described. They can include statements made by the patient or caretaker, or observations or perceptions made by an member of the dental team. Notes should also include changes in approach they proved to be effective or personalization of standard treatment plans for a particular patients. Approaches that are successful with one patient may not be successful with another who has the same condition.

Practice with simulated patient scenarios

The scenarios are intended to sharpen your awareness in analysing patient problems and needs. Each scenario consists of a brief description of the patient or problem, some of the anticipated patient need, and a set of questions that form the nucleus of awareness strategies related to the patient condition.
5. PREVENTION OF DENTAL DISEASES FOR DOWN SYNDROME

5.1 PREVENTION OF PERIODONTAL DISEASE

Prevention is of paramount importance, especially as the occurrence of dental disease may affect the general health of the children with Down Syndrome.

The overall greatest threat to the dental health a child with Down Syndrome is periodontal disease. Generally periodontal disease is viewed as an adult phenomenon, however, children with Down Syndrome seem to be particularly prone to this disease.

Oral hygiene is the most important aspect. The standard in general is very poor, because of both the mental and physical retardation. In the home environment good oral hygiene is possible, but the understaffing of many institution often precludes adequate supervision of oral hygiene, except in the minority who are capable of effectively cleaning their own mouths. In these circumstances staff education is surely more effective than patient education.

Useful aids to prophylaxis include the use of chlorhexidine mouth rinses, automatic tooth brushes, fluoride pastes and a detergent non-cariogenic diet. Regular scaling is of great benefit, the ultrasonic scaler being a useful and well-received adjunct. Due consideration must, however, be given to the possibility of the occurrence of subacute bacterial endocarditis, as many children with Down Syndrome have congenital cardiac lesions, and adequate precautions must be undertaken.

Mechanical oral hygiene aids

It is now almost unanimous that children with Down Syndrome have a poorer standard of oral hygiene, together with a higher prevalence of periodontal disease, compared with normal individuals.

The prevention of periodontal disease centres on the regular removal of bacterial plaque by the individual. Plaque must be removed as thoroughly as possible without damaging either the hard or soft tissues (Loe, 1979). Tooth brushing and mechanical cleaning procedures, for example flossing, are the most readily available and effective ways of controlling dental plaque, provided these aids are used correctly and regularly.

The most important factor in assessing any tooth brushing method is that plaque should be removed as thoroughly as possible without damaging either the hard or soft tissues.

Many techniques have been advocated for brushing teeth, but in general none has been found to be better or worse than any of the others. The roll method has been advocated most frequently even though there is little evidence to support its superiority over other brushing techniques.
Effective plaque control using a toothbrush requires practice, technical skill, time, effort and perseverance. A number of studies have shown that comprehensive preventive programs can result in a substantial decrease in gingivitis, periodontal disease and caries (Horowitz et al, 1984).

Removing plaque from the teeth is a skill that can only be mastered when an individual has the manual dexterity to use a toothbrush and understands the objectives of the brushing exercise (Pinkham, 1975). Where severe psychomotor handicaps or mental subnormalities exist, individuals may be unable to achieve adequate standards of plaque control.

Dental floss is the cleaning aid that is most frequently recommended for removing bacterial plaque from aaroximal tooth surfaces. Studies to evaluate the usefulness of dental floss for this purpose, particularly in the mouths of young children, are sparse. The results of a dental flossing study reported by Wright and co-workers indicate that daily flossing of posterior teeth of first grade children by trained assistants significantly reduced dental caries after eight and 20 months. Their study, however, included only a few participants (44) and the teeth were flossed by trained assistants.

Many kinds of dental floss or tape are commercially available: waxed, unwaxed, semi-waxed, shred resistant, minted and plain, and some floss is impregnated with fluoride. To date, there are no definitive studies indicating that one type is superior to another.

Flossing, if the spaces between the teeth are closed, is recommended. However, if parents or care givers are experiencing difficulty with tooth brushing, adding flossing to the list of jobs to do will merely increase the sense of frustration and failure. Flossing can be approached once tooth brushing practices have been established by the adults and accepted (or at least tolerated) by the child.

The maintenance of a high standard of oral hygiene and gingival health in children with Down Syndrome is extremely difficult because of the problems of motivation, manual dexterity and the provision of care at home. Nevertheless it has been suggested that severely handicapped children with Down Syndrome can be taught oral hygiene practices and can carry out the procedures for themselves.

Controlling dental plaque in children with Down Syndrome presents a major challenge, not only to patients and their relatives, but also to the dentist. Where oral appliances are worn, oral hygiene standards must be immaculate. A number of oral hygiene aids have been suggested. These are mainly modifications of the standard toothbrush.

Electric toothbrushes have been suggested as the solution to plaque control and for children with Down Syndrome they may be more effective than manual toothbrushes (Vowles, 1963;). Yet normal individuals who use a toothbrush correctly and receive adequate oral hygiene instruction are equally effective in removing dental plaque whether using a manual or an electric toothbrush.
A comparison of manual and electric toothbrushes used by intellectually handicapped children showed no improvement in oral hygiene performance with the electric brush. However, in the same study the value of oral hygiene instruction for intellectually handicapped groups was demonstrated whether electric or manual toothbrushes were used (Shaw et al, 1983).

While the traditional mechanical methods of plaque control will continue to form the basis of plaque control for children with down Syndrome, there is a need for a safe, effective and acceptable chemical agent to control dental plaque (Horowitz, 1980). Others have concluded that new aids and methods of antibacterial dental plaque should be investigated in children with Down Syndrome to simplify plaque removal.

**Chemical plaque control**

To prevent or control periodontal disease, dental plaque must be stopped from forming on tooth surfaces or it must be removed before producing inflammatory changes in the gingiva. For most individuals, even a well-performed brushing twice daily may not be sufficient to maintain adequate plaque control in all parts of the mouth (Loe, 1979). In consequence much attention has been focused on the chemical inhibition of plaque formation, particularly the use of chlorhexidine gluconate.

Clinical studies of 1 per cent chlorhexidine gel have shown a significant effect on plaque accumulation, but gingival health showed little improvement. Despite the obvious benefits of mouthrinsing with chlorhexidine gluconate demonstrated by these studies in children with Down Syndrome, there remains a high proportion of children with Down Syndrome who are unable to rinse effectively due to poor oromuscular control or coordination, and other methods of delivery may be of benefit to this group.

Reductions in plaque index values of 80 per cent were recorded when 0.8 per cent gel was applied to the teeth of children with Down Syndrome once every weekday for 3 weeks using cap splints (Flostra et al, 1971), and gingival index values were also reduced. Debris scores were considerably decreased. The use of chlorhexidine solution in an oral irrigate has achieved encouraging results and this may well be the most suitable method of delivery for patients in institutions.

A significant reduction in plaque levels and gingival inflammation occurred following the use of the chlorhexidine spray.

Many children with Down Syndrome suffer from gingivitis, periodontitis and poor oral hygiene either because of their own inability or the failure of those caring for them. Mechanical plaque control methods often fail to achieve the required standard of plaque control. Chemical children with Down Syndrome agents either substituted for, or as an adjunct to mechanical methods may offer some benefit. The benefit may be further enhanced if the delivery method chosen overcomes some of the problems of cooperation often encountered in groups of handicapped children. The most widely used chemical plaque control agent is chlorhexidine gluconate. The benefit that children with Down Syndrome gain from using this agent outweighs its side-effects of tooth staining and temporary taste disturbance.
Plaque removal techniques

Techniques for brushing and flossing are the same regardless of whether it is the child with Down Syndrome himself or someone else performing the tasks. The brushing technique should reflect consideration of the child with Down Syndrome disability. Since there is no evidence that indicates one method is clearly superior the technique used should be the most simple method that is effective in the hands of the individual performing the brushing.

For children with Down Syndrome, the scrub method seems to offer results superior to others. This recommendation is based on clinical experience as well as on several studies of children that indicate a horizontal scrub method is superior to other techniques investigated. Moreover, the scrub method, according to these studies, appears to be used naturally when no brushing instructions are given. In this method the brush is placed horizontally on the facial, lingual, or occlusal planes and is merely scrubbed back and forth in short strokes on all surfaces of the tooth. The present indication is that, properly used, the Bass technique (intracrevicular brushing) may provide superior plaque control for children with Down Syndrome with gingival inflammation. This technique, while being worthwhile may not be as effective as the scrub method in the hands of Down Syndrome patients.
The brush used should be soft multitufted nylon with rounded tips. The size of the brush should be appropriate for the individual’s mouth.

In addition, it has been demonstrated that time of brushing is an important variable in plaque removal. Children who brush for as long as three minutes are more effective in removing plaque than children who brushed for shorter durations (Wessels, 1978).

The electric toothbrush may benefit people who lack the perceptual motor skill to use a manual brush. The use of unwaxed dental floss has a prominent place in an effective plaque control program (Wessels, 1978).

Frequency and Timing

There is support for the position that through teeth cleaning once a day will significantly improve oral health. Timing of the procedure should be determined by the life-style of the child with Down Syndrome and his family or caretaker. In most situations, the preferable time is following the last snack or meal in the evening when adequate time can be devoted to the procedure. In addition, it is particularly important to remove plaque before bedtime because the reduced salivary flow that accompanies sleep appears to contribute further to plaque growth, increasing its detrimental effects. For some people who have greater independence in oral hygiene care, more frequent brushing, especially after meals, is desirable and should be encouraged.

Since dental disease often occurs in very young children it is necessary to start preventive procedures early before disease has had a chance to begin. Therefore, the time to begin oral hygiene procedures is shortly after the first primary teeth erupt. Plaque removal may first be done gently scrubbing the teeth with a clean cloth or gauze pad, but as more teeth erupt it can be removed more effectively with a soft toothbrush.
Beginning oral hygiene procedures in infants has several advantages. First, scrubbing disrupts the plaque and thus contributes to good dental health. More important for the infant, it establishes habits that need to become a part of the family's life, and the child becomes accustomed to the sensation of having his teeth cleaned.

5.2 PREVENTION OF DENTAL CARIES

Studies of patients with Down Syndrome often show a low prevalence of caries. A New Zealand study of over 400 persons with Down Syndrome showed the lower caries experience was not significant when factors of congenitally missing teeth and later eruption of existing teeth were corrected statistically. Other studies have found significantly lower caries rates in these patients, but an explanation of related factors has not been advanced.

Diet

The association between dietary sugar and dental caries is well recognised. Evidence incriminating dietary sugars comes from animal studies, human clinical studies, laboratory studies and epidemiological studies. An important milestone in the investigation of dietary sugar and dental caries was the Vipeholm study (Gustaffson et al, 1954). It has particular relevance to the prevention of dental caries in handicapped groups since the study population consisted of the inmates of the Vipeholm Hospital near Lund in Sweden.

These comprised 964 mentally handicapped patients. 80 per cent of whom were men, housed in 12 independent wards. The study started in 1945 and finished in 1953 and aimed to investigate how the ingestion of non-sticky refined sugar at meals, sticky refined sugar at meals, and sticky refined sugar between meals, would affect dental caries. The sugars were presented as sucrose, bread, chocolate, caramel and toffee, and there was a control group receiving a low carbohydrate, high fat diet virtually free of sugar.

The main conclusion were that consumption of sugar with meals is associated with only a small increase if no sugar is taken between meals. If sugar is consumed both with meals and between meals there is an associated marked increase in dental caries activity. In a review of diet and dental caries Rugg-Gunn (1983) concluded that sugar would appear to be the most important dietary item in the etiology of dental caries and sucrose is likely to be the most cariogenic.

Dental caries is fundamentally a diet bacterial disease (Wessels, 1978). Epidemiologic studies have demonstrated that diet high in sucrose as well as high sucrose snakes between meals increased the incidence of caries. The studies found that the more the tooth surface retains sucrose, the greater the caries susceptibility. In other studies, diet counselling was used to restrict sucrose intake in rampant caries subjects with resulting significant improvement in dental health.

Yet there are strong social, traditional and commercial pressures promoting the use of sugar with foods. For example, sweetened products used with a comforter have been accepted as a method of calming infants by many parents.
It may help to explain the higher caries prevalence found in handicapped individuals living at home compared to those resident in institutions (Forsberg et al., 1985) where diet is likely to be closely controlled with fewer opportunities of eating between meals. There is clearly a major role for dental health education in counselling and convincing parents and relatives of children with Down Syndrome individuals of the need to control dietary sugar intake.

Fluorides

Fluoride is the most effective agent for preventing all dental caries. Recommendations for fluoride use in a preventive dentistry program are based upon conditions related to normal patients, however, research has not specifically resolved the quantitative needs for optimal caries reduction, so it is appropriate initially to prescribe a fluoride program that meets standards set for normal children, then closely to monitor results of that program, and to make necessary changes.

The field of fluoride therapy is continuously changing, but current evidence suggests the following as an initial regimen for children with minimal to moderate caries.

Fluoridated Areas

Children with Down Syndrome exposed to fluoridated community water should follow daily oral hygiene procedures that include brushing with an effective fluoride containing dentifrice.

At semiannual recall appointments patients should receive topical applications of stannous or acidulated phosphate fluoride solution following either a professional prophylaxis using a very fine cleaning agent or supervised self-cleaning.

Techniques of application may have to be altered to fit patient behaviour. If the patient can tolerate only minimal manipulation, only a few teeth may be available for isolation and treatment at one time. In this instance the fluoride would be applied in cements. On patients for whom premedication is indicated for any intraoral procedures, it is appropriate to coordinate fluoride applications with restorative treatment by quadrant or half-mouth.

Non-Fluoridated Areas

If the fluoride level is unknown, secure analysis of the drinking water to determine the fluoride content. Most state health departments maintain laboratories that analyse water samples for fluoride. This is a mandatory first step in establishing a fluoride program when the level of fluoride to which the patient is exposed is unknown. In addition to checking the drinking water, look carefully for other possible sources of fluoride exposure. School mouth-rinse programs and fluoridation of school drinking water are examples of public health programs that are increasing the exposure of patients to fluoride. Once the level of fluoride exposure has been established, the amount and type of supplement can be determined. (table 2).
Table 2: Fluoride Supplement Schedule.

<table>
<thead>
<tr>
<th>Patient’s Age (yr)</th>
<th>0-0.3 ppm</th>
<th>0.3-0.7</th>
<th>0.7 ppm</th>
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</thead>
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<tr>
<td>0-1</td>
<td>0.25 mg</td>
<td>0 mg</td>
<td>0 mg</td>
</tr>
<tr>
<td>1-3</td>
<td>0.50 mg</td>
<td>0.25 mg</td>
<td>0 mg</td>
</tr>
<tr>
<td>3-8</td>
<td>1.00 mg</td>
<td>0.50 mg</td>
<td>0.25 mg</td>
</tr>
<tr>
<td>over 8</td>
<td>1.00 mg</td>
<td>1.00 mg</td>
<td>0.50 mg</td>
</tr>
</tbody>
</table>


Supplement usually are administrated in drops, tablets, or rinses. The form of fluoride supplement will depend upon the patient cooperation, and ability and willingness of parents or guardian to administer the supplement. Drops are incorporated into the patient’s food. Tablets require the most patient cooperation while rinses can be applied either by the patient or brushed on the teeth by parent or guardian.

A fluoride containing dentifrice should be used in conjunction with regular home care. Semiannual professionally applied topical fluoride application should be administered following professional prophylaxis or supervised self-cleaning.

Therapeutic fluoride supplements

The child with Down Syndrome who has rampant caries or one that is not progressing adequately under a basic fluoride program should be placed on a more intensive therapeutic program. This may be indicated for only a short time until oral hygiene and diet improve or may be for an extended period. These regimens are in addition to the basic systemic supplement and are topical in effect, the patient is not to swallow or ingest these doses.

Accepted therapeutic regimes include

1. Daily rinsing with 0.055 NaF solution.
2. Weekly rinsing with 0.1%-0.2% NaF solution.
3. Brushing with either 0.5%-1.23% acidulated phosphate five times a year.

Prescription of these potentially excessive fluoride regimes should be considered carefully in younger patients and monitored closely because of the potential causing fluorosis.
Fluoride Varnishes were developed in an attempt to prolong the exposure of the surface of the tooth to the active agent, thus increasing the amount permanently retained. Varnishes applied directly to the tooth surface without prior etching. Two products are used widely.

Duraphat is a preparation of 5 per cent sodium fluoride in a natural colophonium base that adheres to tooth surfaces even when wet with saliva, and is dispensed in a concentration of 50 mg sodium fluoride per ml yielding 22.6 fluoride per ml. It hardens to a yellow-brown coating.

Fluor-Protector is a polyurethane-based lacquer consisting of 0.7 per cent fluoride ion by weight in a 5 per cent difluorosilane compound. It has a lower pH and fluoride content than Duraphat and is transparent and colourless. Duraphat has been reported to be the quickest and easiest agent to use in a comparison of eight topical fluoride techniques. The recommended dosage for pre-school children is 0.3 ml, and for school children 0.5 ml with repeated applications at 6 monthly intervals.

**Restorative dentistry and occlusal sealants**

Good quality restorative dentistry is an essential component of a preventive program. It is essential that dentists recognise the importance of providing comprehensive restorative dental care to the children with Down Syndrome and that this will do much to maintain the dentition for them.

Occlusal sealants are a valuable adjunct to preventive dentistry for preventing pit and fissure caries. Research indicates that caries reductions do occur when properly placed sealants are used on the occlusal surfaces of posterior teeth. To have a properly placed sealant, one must have a thoroughly dry field which is sometimes difficult to achieve with handicapped patients. To the extent that adequate dryness can be affected in restorative treatment the use of occlusal sealant is strongly advocated.
6. OPERATIVE DENTAL CARE FOR DOWN SYNDROME

The success of operative dental care for children with Down Syndrome depends more on the dentist than on the patient. The attitude of the dentist is all important, a caring, sympathetic and understanding approach being essential. Operative care may be carried out with the patient conscious or sedated or unconscious.

Treating a conscious child with Down Syndrome can be trying and taxing even for the most dedicated and forbearing of dentists. It can also be extremely rewarding, where the quantity of operative work is large it may be kinder to both patient and dentist to arrange for the work to be carried out under general anaesthesia. Subsequently, most children with Down Syndrome can be managed routinely without general anaesthesia.

6.1 THE CONSCIOUS CHILD WITH DOWN SYNDROME

The most important element in success is the confident, sympathetic, caring approach by a dentist. Most children with Down Syndrome tend to be happy, commented individuals, many are cared by devoted relatives. Most can be treated under local anaesthesia, they can take advantage of orthodontic and if necessary prosthodontics care later in life.

Non-surgical procedures such as superficial plaque and calculus removal and the application of fluoride varnishes may be carried out for most children with Down Syndrome, with restraint if required and the patient conscious. Conditional on a periodic preventive maintenance programs, repeated prolonged treatment under general anaesthesia for such children should be rare.

Where treatment is attempted under local anaesthesia it may not be possible to use block injections due to, for example, an exaggerated retching reflex or an excessively large and mobile tongue. In these cases or where cooperation is limited the intraligamentary injection technique may prove invaluable.

Whenever offering treatment to a child with Down Syndrome who is conscious, the dentist is well advised to have a chaperone present. If both the dentist and the dental nurse are female it is essential that a charge nurse or other competent person is present in case the patient should become violent, and forcible restraint is required. Female staff should wear trousers rather than dresses or skirts.

The sedated child with Down Syndrome

Sedation is a technique in which a drug or drugs depress the central nervous system while maintaining verbal contact with the child throughout. Both the drugs and the techniques should make unintended loss of consciousness unlikely (Wylie, 1978; Seward, 1981).
Criteria for a sedation technique include the following: The child should be conscious, cooperative, communicative and calm, the technique must be safe with minimal cardiovascular and respiratory depression and the pharyngeal reflexes must be maintained, induction and recovery should be rapid with no side-effects, the technique should not interfere with the dental procedures, it should be simple and inexpensive.

Before sedating a patient the dentist has certain duties to ensure the safety of the child with Down Syndrome. The principal limitation of sedation are the wide variation of patient reactions to sedative drugs and techniques. The aim of sedation is to overcome fear and anxiety and to reestablish the child's confidence in dental treatment. With care, the need for sedation will decline following several sessions.

Nitrous oxide and oxygen sedation, where the concentration of nitrous oxide is not allowed to exceed 30 per cent, satisfies the criteria outlined above. Two techniques of nitrous oxide and oxygen sedation are available: Relative Analgesia (RA) and Inhalation Sedation (ISH). The principal difference between the two techniques lies in the control of the level of sedation.

The dentist controls the child's level of sedation in relative analgesia by adjusting the gas flows and concentrations according to the child's signs and responses. With concentration of up tp 25 per cent nitrous oxide the patient relaxes, fear diminishes and the pain threshold is raised. Between 20 and 55 per cent nitrous oxide the child becomes very relaxed, responding to commands only sluggishly. With this technique the operator controls the sedation level but must pay constant attention to the controls of the relative analgesia machine at the same time as he or she operates in the child's mouth.

With inhalation sedation the child controls the level of sedation. Unlike relative analgesia machines that can deliver up to 70 per cent nitrous oxide, the inhalation sedation machine delivers a fixed concentration of 25 per cent nitrous oxide. The child with Down Syndrome can breathe entirely through the nose to achieve the full effect or can dilute the effect by mouth breathing.

Sedation is usually well established at nitrous oxide concentrations of around 25-30 per cent. There may be reduction of the awareness of pain but local anaesthesia is required for most dental procedures. Paraesthesia may occur and there is usually variable amnesia. Some patients experience a sense of euphoria at very low concentrations of nitrous oxide and vivid dreams can occur.

This type of sedation is safe but conditions that absolutely contra-indicate its use are: acute or chronic nasal obstruction, upper respiratory tract infection, multiple sclerosis. Patients must be able to understand the procedure, if their understanding is impaired either by illness, sedation should not be attempted without first consulting the child's psychiatrist.

Whenever possible at a preoperative visit the child should be introduced to and familiarised with the equipment and technique. If possible the child should try the sedation method and experience the sensations it induces without any operative procedure.
At the next visit, with constant support and encouragement a short procedure under sedation and under local anaesthesia can be completed many child’s confidence improve so that they can be weaned of the sedation.

In dentistry intravenous sedation achieved prominence with the Jorgensen technique in which increments of pentobarbitone were injected followed by pethidine and hyoscine, through an intravenous cannula. Subsequently, intermittent methohexitone was advocated but the major advance was the use of intravenous diazepam. The oily fluid is injected into a large vein either in the antecubital fossa or the back of the hand at a rate of 5 mg per minute up to a maximum dose of 20 mg.

Slurring of the speech and ptosis indicate satisfactory sedation. Normally the sedation is reliable and the child will not lose consciousness and it usually lasts about 30 minutes. An important feature is amnesia, which peaks 1 minute after injection, and it is at this point potentially distressing procedures like administering local anaesthesia should be performed. Less traumatic procedures such as placing restorations can be carried out after the effect has begun to wear off provided the cavity preparation is completed during the period of maximum sedation. A premedication 1 hour will prolong the period of sedation if required. Recovery is slow and a rebound effect may occur 8 hours later. The optimum time for sedation is therefore in the afternoon.

6.2 THE UNCONSCIOUS CHILD WITH DOWN SYNDROME

Children with Down Syndrome may need to be treated unconscious for many reasons, most of which relate to the degree of handicap, An important group are those who might be able to tolerate short outpatient appointments for treatment consciously, but who require a lot of treatment to be made dentally fit. For these children, an initial session under general anaesthesia when all necessary dental treatment is carried out may be all that is necessary, future care being provided while the child is conscious. Prolonged general anaesthesia should be administered only in a hospital.

Two types of general anaesthetic can be planned. For the children who only require simple tooth extraction or whose examination must be performed under general anaesthesia because of inability to cooperate, a short anaesthesia without intubation may suffice. Those children who require comprehensive operative care, including scaling, restorations and extractions, require a long general anaesthetic with nasotracheal intubation. The latter may be admitted for one or more nights or may be treated as a day-case depending on the local hospital practice.

The procedure can be carried out either in a fully equipped dental surgery theatre or in a general surgery theatre using transportable dental equipment. Before the anaesthetic is administered an assessment of the patient’s suitability must be made by the anaesthetist. Where the medical history is complex or where there may be increased risk due to, for example, cardiac disorder, arrangements should be made for an anaesthetist personally to assess the patient in advance of the appointment for treatment.
Treatment under a short anaesthetic can be arranged for an outpatient session: this is most suited to uncomplicated extractions of teeth or examining the mouth of an uncooperative patient for the purpose of treatment planning. Careful peroperative assessment is essential, including an accurate contemporary medical history, dental treatment plan and consent to treatment signed by the appropriate person. The person signing the consent form must understand that a future additional general anaesthetic may be needed if restorations are found to be necessary. When teeth are to be extracted, the number should be prominently entered on the consent form and clearly stated for the person signing.

The admitted child is usually asked to arrive at the ward in mid-morning starved from breakfast. After clerking in, a suitable premedication may be given. Commonly papaveretum and hyoscine are given. Hyoscine is an antispasmodic and when used with narcotic analgesics produces profound sedation. The procedure is carried out in the early afternoon and some patients may have recovered in time to go home in the early evening.

The usual sequence of treatment under general anaesthesia is, first, removal of plaque and calculus, second, restorative care, and, finally, any surgical procedures and extraction of teeth.

The restorative phase should be planned carefully. Treatment under general anaesthesia may be the only way any dental treatment can be provided. In consequence any treatment that cannot be completed at one visit should be avoided. The use of endodontic treatment techniques is thus severely limited, and restorations needing laboratory work are almost always contra-indicated. Cariously exposed teeth should be extracted unless it will be clinically feasible to complete endodontic treatment at a subsequent visit. Similarly, following surgical procedures resorbable sutures should be used as it may not be possible, without another general anaesthesia, to remove sutures.

In addition to restorations and extractions, children can benefit from fissure sealants.
7. PREVALENCE AND DENTAL TREATMENT NEEDS OF PERSONS WITH DOWN SYNDROME IN N.S.W

7.1 PREVALENCE OF PERSONS WITH DOWN SYNDROME IN N.S.W

Down Syndrome is the most common chromosomal disorder, with an incidence of about 1.2 per 1000 births, in Australia. (National Perinatal Statistics Unit). The prevalence of the disorder continues to mount because medical science can better ensure the survival of the high risk Down's Syndrome infant.

The International Classification of Diseases code for Down Syndrome is 758.0. The 5 digit British Paediatric Association Classification enables separate codes for the different type of chromosomal abnormality (trisomy, translocation, mosaic).

The AIHW National Perinatal Statistics Unit (funded by a grant from the Australian Institute of Health and Welfare to the University of Sydney) aims to monitor trends in the incidence of malformations in Australia and in each state and territory. Data on more than 100 different types of malformations are reviewed each quarter. Copies of perinatal forms, death certificates and other notifications are sent subsequently in regular batches to this unit from around Australia.

The national rate of Down Syndrome varied between 10.1 and 13.5 per 10,000 births in the period from 1982 to 1992 (table 3, figure 4). The reported number of induced abortions performed after prenatal diagnosis of trisomy 21 by amniocentesis or chorionic villus sampling increased substantially during this period, reaching the highest number of 114 in 1992.

The rate of Down Syndrome increased with advancing maternal age, ranging from 6.2 per 10,000 births among teenage mothers to 89.3 per 10,000 births among mothers aged 40 years and over (table 4). This is the basis of current prenatal screening practice for Down's Syndrome in NSW.

Among 3,277 infants with Down Syndrome and known outcome, 6.6 per cent were still born, 4.7 per cent of live born infants died in the neonatal period.

For births in 1990-1992, Victoria (14.1 per 10,000 births) had the highest rate of Down Syndrome, the Northern Territory (10.0 per 10,000 births) had the lowest rate and New South Wales (12.3 per 10,000 births) (table 5, figure 5).

Down Syndrome was slightly less common in twins than in single births (table 4).

The sex ratio of Down Syndrome was 121.9 male births per 100 female births (table 4).

Preterm birth (less than 37 weeks) occurred in 22.3 per cent of infants with Down Syndrome and stated gestational age, 5.9 per cent were born before 28 weeks (table 6).
Low birthweight (less than 2500g) occurred in 22.3 per cent of infants with Down Syndrome and known birthweight, 3.2 per cent were extremely low birthweight (table 6).

Of the 87,587 births in NSW during 1990 an estimated 4,586 (5 percent) were to women aged 37 years or over. Only 35 of the infants born would be expected to have Down Syndrome. Thus, while the risk of Down Syndrome is higher in women aged 37-plus, most Down Syndrome affected pregnancies occur in younger women, because the great majority of pregnancies occur in younger women. Screening by maternal age alone gives a false positive rate of 5 percent, which may be expressed as a specificity of 95 percent.

A screening test which identifies high-risk pregnancies at all ages is needed. Four case-control studies and one prospective trial have shown that a combined screening test, which uses maternal age and three maternal serum markers (alpha-fetoprotein, unconjugated oestriol and human chorionic gonadotrophin) to calculate a woman's individuals risk of having a Down Syndrome pregnancy, is better than maternal age alone (table 7 and 8).

The Down Syndrome Association of NSW Inc, was formed in 1980 to represent the interests of people with Down Syndrome. The Association performs a multi-faceted role in the community for the benefit of people with Down Syndrome. One of its aims is to provide advice and information about medical, social, legal, financial and educational benefits to which they are entitled.

The figures have been supplied by Ms Jill O'Connor, an office staff worker. She said that about 650 to 700 children with Down Syndrome out of 900 persons under 21 years have been registered in the association, It is not compulsory for every family to register their baby.

According to the Table 9 which was published by the Australian Bureau of Statistics the writer has estimated the number of children with Down Syndrome in NSW born since 1988 until December 1993. The total number of live births registered in NSW was 528,352 and we know that the incidence of Down Syndrome to be about 1.2 per 1000. Therefore, about 634 children with Down Syndrome would be expected to be born in NSW from 1988 until December 1993.
Table 3: Trisomy 21 outcome and type of malformation, Australia, 1982-1992.

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<td>Stillbirths</td>
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<td>240</td>
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<td>292</td>
<td>305</td>
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<td>Induced abortions</td>
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Rate per 10,000 births

<table>
<thead>
<tr>
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<th>10.1</th>
<th>12.2</th>
<th>13.5</th>
<th>11.9</th>
<th>12.3</th>
<th>13.0</th>
<th>13.1</th>
<th>12.9</th>
<th>12.0</th>
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<td>327</td>
<td>345</td>
<td>335</td>
<td>318</td>
<td>3,320</td>
</tr>
</tbody>
</table>

Rate per 10,000 births

| Isolated             |      |      |      |      |      |      |      |      |      |      |      |       |
| Associated           |      |      |      |      |      |      |      |      |      |      |      |       |
| Chromosomal          | 11.1 | 11.2 | 10.1 | 12.2 | 13.5 | 11.9 | 12.3 | 13.0 | 13.1 | 12.9 | 12.0 | 12.1   |


Figure 4: Trisomy 21, Australia, 1982-1992.

Table 4: Trisomy 21 by selected characteristics, Australia, 1982-1992.

<table>
<thead>
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<th>Characteristic</th>
<th>Number</th>
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<th>Rate per 10,000 births</th>
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</thead>
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<tr>
<td>25-29</td>
<td>720</td>
<td>1,029,355</td>
<td>7.0</td>
</tr>
<tr>
<td>30-34</td>
<td>927</td>
<td>665,613</td>
<td>13.9</td>
</tr>
<tr>
<td>35-39</td>
<td>875</td>
<td>207,031</td>
<td>32.6</td>
</tr>
<tr>
<td>40 and over</td>
<td>272</td>
<td>30,450</td>
<td>89.3</td>
</tr>
<tr>
<td>Not stated</td>
<td>174</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plurality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Singleton</td>
<td>3,071</td>
<td>2,675,229</td>
<td>11.5</td>
</tr>
<tr>
<td>Twin</td>
<td>66</td>
<td>62,315</td>
<td>10.6</td>
</tr>
<tr>
<td>Other multiple</td>
<td>3</td>
<td>2,438</td>
<td>12.3</td>
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<tr>
<td>Not stated</td>
<td>180</td>
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<tr>
<td>Infant’s sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1,819</td>
<td>1,404,758</td>
<td>12.9</td>
</tr>
<tr>
<td>Female</td>
<td>1,492</td>
<td>1,331,784</td>
<td>11.2</td>
</tr>
<tr>
<td>Indeterminate</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not stated</td>
<td>6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Table 5: Trisomy 21, States and Territories, 1990-1992.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>NSW</th>
<th>Vic</th>
<th>Qld</th>
<th>WA</th>
<th>SA</th>
<th>Tas</th>
<th>ACT</th>
<th>NT</th>
<th>Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Live births</td>
<td>310</td>
<td>254</td>
<td>160</td>
<td>77</td>
<td>47</td>
<td>21</td>
<td>14</td>
<td>9</td>
<td>892</td>
</tr>
<tr>
<td>Stillbirths*</td>
<td>22</td>
<td>22</td>
<td>16</td>
<td>8</td>
<td>13</td>
<td>7</td>
<td>3</td>
<td>2</td>
<td>93</td>
</tr>
<tr>
<td>Total births*</td>
<td>335</td>
<td>281</td>
<td>176</td>
<td>85</td>
<td>64</td>
<td>28</td>
<td>18</td>
<td>11</td>
<td>998</td>
</tr>
<tr>
<td>Induced abortions</td>
<td>122</td>
<td>67</td>
<td>30</td>
<td>27</td>
<td>25</td>
<td>3</td>
<td>5</td>
<td>-</td>
<td>279</td>
</tr>
<tr>
<td>Rate per 10,000 births</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Live births</td>
<td>12.3</td>
<td>14.1</td>
<td>12.9</td>
<td>11.1</td>
<td>10.8</td>
<td>13.3</td>
<td>13.1</td>
<td>10.0</td>
<td>12.3</td>
</tr>
<tr>
<td>Number</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolated</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Associated</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Chromosomal</td>
<td>335</td>
<td>281</td>
<td>176</td>
<td>85</td>
<td>64</td>
<td>28</td>
<td>18</td>
<td>11</td>
<td>998</td>
</tr>
<tr>
<td>Rate per 10,000 births</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolated</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Associated</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Chromosomal</td>
<td>12.3</td>
<td>14.1</td>
<td>12.9</td>
<td>11.1</td>
<td>10.8</td>
<td>13.3</td>
<td>13.1</td>
<td>10.0</td>
<td>12.3</td>
</tr>
</tbody>
</table>

Figure 5: Trisomy 21, States and Territories, 1990-1992.

Figure 48: Trisomy 21, States and Territories, 1990-1992

Australia: 12.8 per 10,000 births (n=998)


Table 6: Proportion of births with trisomy 21 by birthweight and gestational age, Australia, 1982-1992.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birthweight (g)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1000</td>
<td>80</td>
<td>3.2</td>
</tr>
<tr>
<td>1000-2499</td>
<td>481</td>
<td>19.1</td>
</tr>
<tr>
<td>2500 and over</td>
<td>1,960</td>
<td>77.7</td>
</tr>
<tr>
<td>Not stated</td>
<td>799</td>
<td></td>
</tr>
<tr>
<td>Gestational age (weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 28</td>
<td>155</td>
<td>5.9</td>
</tr>
<tr>
<td>28-36</td>
<td>452</td>
<td>17.3</td>
</tr>
<tr>
<td>37 and over</td>
<td>2,002</td>
<td>76.7</td>
</tr>
<tr>
<td>Not stated</td>
<td>711</td>
<td></td>
</tr>
</tbody>
</table>


38
Table 7: Expected number of true positive, false positive and total positives for maternal serum screening using the triple test, assuming 100 percent amniocentesis uptake rate, by risk cut-off level, NSW, 1990.

<table>
<thead>
<tr>
<th>Risk cut-off level</th>
<th>True positive</th>
<th>False positive</th>
<th>Total positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>1:100</td>
<td>55</td>
<td>1,489</td>
<td>1,544</td>
</tr>
<tr>
<td>1:150</td>
<td>65</td>
<td>2,452</td>
<td>2,518</td>
</tr>
<tr>
<td>1:200</td>
<td>71</td>
<td>3,416</td>
<td>3,487</td>
</tr>
<tr>
<td>1:250</td>
<td>77</td>
<td>4,379</td>
<td>4,456</td>
</tr>
<tr>
<td>1:300</td>
<td>80</td>
<td>5,343</td>
<td>5,423</td>
</tr>
<tr>
<td>1:350</td>
<td>84</td>
<td>6,306</td>
<td>6,390</td>
</tr>
</tbody>
</table>

Source: Sensitivities and specificities are taken from Wald et al.
Table 8: Expected number of Down Syndrome cases detected and missed, and expected total number of amniocenteses and fetuses lost for various population-based maternal screening programs, for an amniocentesis uptake rate of 50 percent (a).

<table>
<thead>
<tr>
<th>Screening program (b)</th>
<th>Number of Down pregnancies detected No.</th>
<th>%</th>
<th>Number of Down pregnancies missed No.</th>
<th>%</th>
<th>Number of amniocenteses</th>
<th>Number of foetuses lost (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>18</td>
<td>14</td>
<td>107</td>
<td>86</td>
<td>2,293</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>24</td>
<td>19</td>
<td>101</td>
<td>81</td>
<td>4,642</td>
<td>23</td>
</tr>
<tr>
<td>3</td>
<td>38</td>
<td>30</td>
<td>87</td>
<td>70</td>
<td>2,228</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>42</td>
<td>34</td>
<td>83</td>
<td>66</td>
<td>4,363</td>
<td>32</td>
</tr>
<tr>
<td>5</td>
<td>44</td>
<td>35</td>
<td>81</td>
<td>65</td>
<td>6,405</td>
<td>41</td>
</tr>
</tbody>
</table>

(a) These figures are based on the maternal age distribution for NSW births, January-June 1990.

(b) Screening programs as follows:

1 Maternal age >37 years.
2 Maternal age >35 years.
3 Triple test screening (incorporating age) only.

4 Maternal age > 37 years plus triple test screening of remainder with triple test cut-off of 1:250.
5 Maternal age > 35 years plus triple test screening of remainder with triple test cut-off of 1:250.

(c) Expected number of foetuses lost is estimated at 0.5 percent of total amniocenteses.
Table 9: Live births registered in NSW 1988 to December 1993.

<table>
<thead>
<tr>
<th>Year ended 31 December</th>
<th>Number in NSW</th>
</tr>
</thead>
<tbody>
<tr>
<td>1988</td>
<td>84,268</td>
</tr>
<tr>
<td>1989</td>
<td>85,464</td>
</tr>
<tr>
<td>1990</td>
<td>90,260</td>
</tr>
<tr>
<td>1991</td>
<td>87,047</td>
</tr>
<tr>
<td>1992</td>
<td>92,207</td>
</tr>
<tr>
<td>1993</td>
<td>89,106</td>
</tr>
</tbody>
</table>


7.2 TREATMENT CHILDREN WITH DOWN SYNDROME

Frequent dental inspections are necessary for children with Down Syndrome since they may lack the ability to communicate that they have pain or other symptoms. Regular inspections have the obvious advantage of acclimatising the patient to dentistry. A visit to the dentist often then becomes a social highlight of the week rather than an unpleasant encounter.

Cooperation may be very good, but there are times when children with Down Syndrome cannot or will not maintain their attention for an adequate length of time. The use of a McKesson mouth prop or other simple device to steady the mandible is then helpful. Restraint is not indicated; patience is more effective in both the short and especially the long term care. Diazepam orally or by intravenous injection, preferably via an antecubital fossa vein, is a useful drug for sedation on the few occasions that this is required.

Consultation with the patient's physician is mandatory when any thing but the simplest treatment is envisaged.

General anaesthesia should be avoided whenever possible in view of the general medical conditions which may be present and the complications that may follow (Joyce and Swallow, 1964). If general anaesthesia is contemplated, and this is usually when prolonged treatment is necessary, then it is imperative that fitness for anaesthesia be assessed by a physician.

Full dental care carried out at one visit under general anaesthesia, the staff involved may include one or two dentists, one or more dental surgery assistants, theatre nursing staff, porters, anaesthetists and ward staff.
8. DENTAL SERVICES FOR CHILDREN WITH DOWN SYNDROME IN N.S.W

The state of New South Wales (NSW) occupies most of the south-eastern part of the Australian continent. New South Wales was the first colony established by Britain in Australia, and was named by Lieutenant James Cook on its discovery in August 1770. (Australian Encyclopaedia, 1983: vol, 7:125-141).

Capital: Sydney. Population 3,713.5
(ABS Census 1993).

Area: 801,600 square kilometres, (10.43 percent of the area of the continent).


8.1 GOVERNMENT DENTAL HEALTH SERVICES

Public dental services in NSW provide a base level of services for eligible adults and all school children up to 14 years of age (in some areas up to 16 years of age).

Eligible means a holder of the pensioner health benefit card, a health benefit card or health care card issued by the Department of Social Security or their dependants.

In NSW the number of eligible persons for free dental care is 2,099,470 including 436,497 children up to 4 years of age, 427,291 children age 5 - 9, 420,633 children age 10 - 14. (ABS Census 1993).

The dental health care in NSW is provided through several government agencies.

Community Dental Health Clinics

Community Dental Health Clinics which are an integral part of area health services and health regions, provide dental care for children and eligible persons through dental clinics based in hospitals, community health centres and primary schools. Mobile clinics are used to provide dental care to smaller communities, schools and in remote areas.

Dental Hospitals

The Health Department has two dental teaching hospitals, the United Dental Hospital (UDH), a unit of the Central Sydney Area Health Service, and Westmead Dental Clinical School at the Westmead Hospital located in the Western Sydney Area Health Service.
The dental teaching hospitals house the Faculty of Dentistry of the University of Sydney and provide:

* Teaching for both undergraduate and postgraduate dental students.

* General dental care for eligible persons from their own and neighbouring health areas UDH - Central, Eastern, Southern and South Western Sydney Areas. Westmead Dental Clinical School - Western, South Western and Wentworth Sydney Areas.

* Specialists services on a referral basis from community dental health clinics. Some of these specialist services are provided by the University of Sydney dental academic staff and dental postgraduate students.

* The Royal Newcastle Hospital and the Royal North Shore Hospital provide some specialist services.

* The Institute of Dental Research was established in 1946 and is a Department within the United Dental Hospital.

Domiciliary Care Services

Provide the services by mobile or portable equipment for eligible persons who are homebound or non-ambulatory residents of nursing homes. Domiciliary care units are based at United Dental Hospital, Westmead Dental Clinical School, Port Kembla (Illawarra AHS), Wallsend (Hunter AHS), and Royal North Shore Hospital (Northern Sydney AHS).

Aero Dental Services

Provide dental care to isolated communities in the north west of NSW, south-western Queensland and north-eastern South Australia. They are based with the Royal Flying Doctor Service in Broken Hill.

School Dental Therapy

The school Dental Scheme was initiated in 1973 when agreement was reached between the Commonwealth and States on a Commonwealth Government proposal, to provide assistance for the development of an Australia-wide scheme of dental care.

This scheme was established to provide free dental treatment and care for children in primary schools. In 1973 the program accepted by the States and Territories was, that the service be based on the training and employment of dental therapists, who would work under the direction and control of dentists in government services.
Dental Therapists are qualified to provide restorative, preventive and community dental services for children. The School Dental Service provides general dental care for pre-school and primary school children in Government and non-Government schools.

A unit of Westmead Hospital in the Western Sydney Area Health Service has the responsibility of training dental therapists for employment within the Department of Health, and provides treatment for school children as a part of the training role.

**Institutional Dental Services**

Dental care for inpatients and long time residents in departmental institutions is provided by employed dentists in these institutions, and for prisoners by prison medical services.

The school dental service is run from dental clinics which are located in certain regional schools, community health centres or from a mobile dental caravan which travels to schools.

The dental clinics are staffed by school dental therapists, dental assistants and are advised by supervising dental officers.

Generally speaking dental services available for children with Down Syndrome can be broadly consisted of the following:

1. **Private practicing dentists.**

2. **Institutions caring for handicapped persons.**

3. **Dental and general hospitals.**

4. **Government mobile dental services for rural population and Aboriginals.**

5. **Hospital based community dental program.**

6. **Public fixed dental clinics.**
8.2 PRIVATE PRACTICING DENTISTS

In addition to Departmental resources, dental care is provided to the NSW population by both private dental practitioners and dental prosthetists.

Most dentists which phoned by the writer consider children with Down Syndrome as normal patients, and treat them on the dental chair. But if the child do not respond positively to verbal behavioural management techniques and treatment cannot proceed, the use of premedication, nitrous oxide analgesia, or IV sedation should be considered.

Before prescribing or administering any of these, the patient's physician should be consulted, and the parents or care taker informed of the change in the treatment. There are about 20 dentists in Sydney who provide facilities for general anaesthesia to children with Down Syndrome.

Abnormal behaviours such as self-abuse, excessive masturbation, rocking, head banging, hyper activity, aggression, and destructive outbursts require a consistent, concerted effort to control.

However, regular dental examinations, appropriate dental hygiene, fluoride treatments, restorative care, if needed, and good dietary habits will help prevent dental caries and periodontal disease in children with Down Syndrome.

A questionnaire was sent to the Directors of Dental Services in NSW to estimate the use of Government Dental Services by Children with Down Syndrome.

Also the writer phoned to many Public Hospitals asking what type of Dental Services they provide to children with Down Syndrome.
9. ALLOCATION OF DENTAL SERVICES BY AREAS AND REGIONS


9.1 CENTRAL COAST AREA HEALTH SERVICE

Local Government Areas:

Wyong, Gosford.

Dental services for children are provided at:

* Gosford East School Dental Clinic.
* Kanwal Fixed Mobile Kanwal School Dental Clinics.
* The Entrance School Dental Clinic.
* Toukley School Dental Clinic.
* Woy Woy School Dental Clinic.

Three letters were sent to Dr Brian Redmayne, Director of Dental Services without any response up to date.

Telephone Review carried out with Mrs Sandra, Receptionist Gosford Dental Clinic.

There are two dental clinics in Gosford Hospital and Wyong Hospital, five school dental clinics. Children with Down Syndrome are treated in the dental chair and referral is made to the hospitals if they need treatment under GA. No records are kept.

9.2 CENTRAL SYDNEY AREA HEALTH SERVICE

Local Government Areas:

Ashfield, Burwood, Concord, Drummoyne, Leichhardt, Marrickville, South Sydney City (part), Strathfield, Sydney City (part).

Dental services for children are provided at:

* The Royal Alexandra Hospital for Children.
* School Dental Clinics.
* United Dental Hospital.
Fixed:

Marrickville, Newton and Rozelle.

Mobile:

Mobile 1007 and
Central Sydney School Dental Mobile 100.

Information obtained by courtesy of Mrs Phillpa Davis, Registered Nurse in Concord Repatriation General Hospital. She said they have two dental clinics, one run by UDH Hospital and the second runs by Concord Hospital. Dr Murphy, is Acting Department Head, Community Dental Health, United Dental Hospital. Dr Rathi Selvarajah, Area School Dental Officer, Marrickville School Dental Clinic.

For the last four years only one adult inpatient with Down Syndrome has been treated in Concord Hospital.

Mrs Kathy Barker, Dental Nurse Receptionist in The Royal Alexandra Hospital for Children, said for the last year only 10 children with Down Syndrome had been treated in the dental clinic.

It is impossible to give accurate statistics on Down Syndrome Patients as we do not distinguish between handicapped patients but rather treat them as a group within the community dental health department.

About the type of treatment offered to Down’s Syndrome patients. They, depending on the severity of their handicap, would receive the treatment as is needed but perhaps using a general anaesthesia or relative anaesthesia rather than local anaesthesia, depending on their behavioural problems.

For children with Down Syndrome no treatment under general anaesthesia is available to them in the United Dental Hospital, they are referred to Concord Hospital and the treatment could be done for them there.

Most Down’s Syndrome patients are acceptable for dental treatment under local anaesthesia. For the last year only 8 to 10 children with Down Syndrome had been treated in the United Dental Hospital in the dental chair. Others were sent to Concord Hospital, second floor and treated under general anaesthesia.

Only a very few children with Down Syndrome treated in Marrickville school dental clinic over the years. There is no register or a separate list of Down Syndrome patients.

Treatment offered includes routine dentistry as carried out in the school dental clinic if patients are compliant, if not they are referred to the Westmead Hospital. For specialist services they are referred to the United Dental Hospital on eligibility criteria or treated privately.
9.3  EASTERN SYDNEY AREA HEALTH SERVICE - RANDWICK

Local Government Areas:

Botany, Randwick, South Sydney (part) City (part), Waverley, Woollahra.

Dental services for children are provided at:

* The Prince of Wales Hospital. Inpatients only.
* School Dental Clinics.

Fixed:

Chifley, Daceyville, and Mascot.

Mobile:

Mobile 1008.

Information obtained by courtesy Dr Albert Cusick Dental Officer, Eastern Sydney Area Health Service, Daceyville School Dental Clinic. Dr Gnama Spiale, Dental Officer, The Prince of Wales Children's Hospital.

The children seen by the School Dental Service in our Area afflicted with Down Syndrome are fairly rare. During the past year there would have been approximately seven or eight cases. Most of these are regular patients and are those with mild to moderate symptoms. The more severely affected who require a general anaesthetic are referred privately or to the United Dental Hospital, as we do not have facilities to undertake these procedure.

We have three clinics and two mobile vans in our area and while all would be capable of treatment of the above, most of the work is done at the Daceyville Clinic.

At The Prince of Wales Children's Hospital, children with Down Syndrome have been treated under general anaesthesia within a waiting time for one week, but there are no figures about how many of them have been treated.
9.4 HUNTER AREA HEALTH SERVICE - New Lambton Heights
Adamstown

Local Government Areas:

Cessnock, Dungog, Lake Macquarie, Maitland, Merriwa, Murrurundi, Muswellbrook, Newcastle, Port Stephens, Scone, Singleton.

Dental services for children are provided at:

* School Dental Clinics

Fixed:


Mobile:

1. East Maitland Dental Clinic.
2. Adamstown Dental Clinic.

Information obtained by courtesy Mr Per Holmberg, Stockton Centre. Mrs Sophia Lee, Clinical Team Leader, Hunter Area Dental Health Services. There is no data on how many patients with Down Syndrome been treated in the 17 clinics. However, every one that turns up at school and community dental clinics is treated; if necessary under G.A.

The main institution for mentally disabled is Stockton Centre, There are 54 clients with Down Syndrome out of a total number of 750. All are receiving comprehensive treatment.

9.5 ILLAWARRA AREA HEALTH SERVICE - Port Kembla

Local Government Areas:

Hornsby, Hunters Hill, Ku-ring-gai, Lane Cove, Manly, Mosman, North Sydney, Ryde, Warringah, Willoughby.

Dental services for children are provide at:

* School Dental Clinics

Fixed:

Beecroft, Berowra, Dee Why, Mona Vale, Queenscliff, Ryde East, Stewart House Preventorium Dental Clinic, Willoughby
Mobile:
Lower North Shore Mobile
Ryde Macquarie AHS Mobile

Information obtained by courtesy Dr Gordon Mollar, Dental officer in charge, Special dental and oral surgery service.

There are no statistics available in Illawarra Area Health Service that specifically relate to the number of children with Down Syndrome that have used the service. However, developmentally disabled patients in general share the same facilities available to all other children in the region. Special services are available according to special needs and patients abilities to cooperate, but not specifically according to if they have specific disability such as Down Syndrome.

Treatment available is the same as other children which includes services for special needs. Institutionalised developmentally disabled patients have a priority recall system. This allows them to be seen routinely on a regular basis. Reports are given to the patient's case manager after each visit.

Patients requiring specialised services have a range of services available within the service including.

A
* Special dental service at Shellharbour District Hospital where general dental treatment and minor oral surgery can be carried out under relative analgesia, sedation or general anaesthesia as necessary.

* Domiciliary Service.

* Orthodontic services at Port Kembla Dental Clinic.

* Maxillo-facial Service at Port Kembla District Hospital.

B
* Westmead Hospital Dental Clinical School.

Mrs Lisa Polonis, a Secretary in Children Community Team (Disability Team).

There are currently 58 active clients with Down Syndrome, that is children who are currently receiving some form of therapy or medical service from their team. They receive up to 8 - 10 new referrals of children with Down Syndrome each year. The children's community team see children from 0 - 16. It is difficult to know how many children had registered through their service since its conception

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9.6 SOUTHERN SYDNEY AREA HEALTH SERVICE - Dolls Point

Local Government Areas:

Canterbury, Hurstville, Kogarah, Rockdale, Sutherland.

Dental services for children are provide at:

* School Dental Clinics:

  Fixed:

  Canterbury, Clemton Park, Hurstville, Lugarno, Menai, Rockdale, Sylvania.

  Mobile:

  Mobile 1004
  Mobile 1003

Dr Anna Young, Director of School Dental Service, reported there is no dental services available for children with Down Syndrome.

The dental clinic in Canterbury Hospital treat only adults.
The writer did not receive any other information about the area.

9.7 SOUTH WESTERN SYDNEY AREA HEALTH SERVICE - Liverpool

Local Government Areas:

Bankstown, Camden, Campbelltown, Fairfield, Liverpool, Wollondilly.

Dental services for children are provide at:

* School Dental Clinics:

  Fixed:

  Bankstown North, Mittagong, Camden, Cartwright, Fairfield, Chester Hill, John Warby, Picton.

  Mobile:

  Moss Vale 1000.
Information obtained by courtesy Dr John Sanders, Area Dental Co-ordinator, Narellan Community Health. Dr Helen Tsougrannis, Area Dental Officer, South Western Sydney Area Health Service. Mrs Judith McDonald, Director, Clinical Information Services in The St. George Hospital. Mrs Faye Lamberton, Dental Therapist, Camden Hospital. Mrs Judia Smith, Dental Therapist, John Warby Dental Clinic.

Children with Down Syndrome within South Western Sydney access dental services in public child clinics, or may access private dental services.

In reference to public services for children with Down Syndrome no records are kept separately for them. The treatment offered to them would be of the standard and expertise a dental therapist is capable of providing in conjunction with their supervisory dental officer.

If specialist services were required a referral to Westmead Community Health or Westmead Paediatric Dental Department would be provided.

All South Western Sydney Child Clinics (Thirteen) do provide basic dental services to Down's Syndrome children.

As a general rule South Western Sydney child dental services treat the dental treatment needs of Down Syndrome children in the same way as for all other children. Assessment and treatment is based on dental need, priority is based on clinical situation.

The total number of Down Syndrome patients admitted to St George Hospital in 1992 was 10 and in 1993 was 17.

In Camden Hospital only three children with Down Syndrome have been treated over the last four years.

In John Warby Dental Clinic only two children with Down Syndrome have been treated over the last two years. Others have been referred to Westmead Hospital.
In Liverpool Hospital there is no dental treatment for Down Syndrome children.

9.8 NORTHERN SYDNEY AREA HEALTH SERVICE.

Royal North Shore Hospital.

Local Government Areas:

Hornsby, Hunters Hill, Ku-ring-gai, Lane Cove, Manly, Mosman, North Sydney, Ryde, Warringah, Willoughby,
Dental services for children are provided at:

* School Dental Clinics.

**Fixed:**

Beecroft, Berowra, Dee Why, Mona Vale, Queen cliff, Ryde East, Stewart House, Preventorium Dental Clinic, Willoughby.

**Mobile:**

Lower North Shore Mobile.
Ryde Macquarie AHS Mobile.

Information obtained by courtesy Dr Caroline Hong, Area Coordinator - Dental Services, Northern Sydney Area Health Service. Ms Jane Bell, Dental Health Branch, NSW Health Department. Mrs Moreen, Dental nurse at Developmentally Disabled Clinic in Royal North Shore Hospital.

The Northern Sydney Area Health Service and most Area Health Services have been collecting Dental Management Information System (DMIS) since 1991.

In NSW all children up to 14 years old are eligible for free dental services in the school dental service (SDS). They are not necessarily referred by anyone, and do not necessarily have any dental cover. Also, any children/dependants (still at school) of health card holders are eligible for dental services in the SDS. They may be older than 14 years.

There are only limited data available for children using the school dental service in the Northern Sydney Area (NSA) for 1992 and 1993. It was estimated that in 1992 in NSA, 3.7% of examinations done were reported in the Child Dental Health Survey. In 1993, approximately 4.3% of examinations were reported to the Child Dental Health Survey (CDHS).
Table 10: Children aged 0-14 years, seen in the School Dental Service, and reported to the CDHS, Northern Sydney Area Health Service 1992 and 1993.

<table>
<thead>
<tr>
<th></th>
<th>1992 Northern Sydney Area</th>
<th>1993 Northern Sydney Area</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
</tr>
<tr>
<td>Number new patients</td>
<td>158</td>
<td>166</td>
</tr>
<tr>
<td>Number seen for first time in year</td>
<td>152</td>
<td>146</td>
</tr>
<tr>
<td>Number recall exams (seen &gt; 1) within the year.</td>
<td>37</td>
<td>31</td>
</tr>
</tbody>
</table>

Source: The Writer.

The total number of examinations done in the SDS in NSA in 1992 was 19181. In 1993, 20622 exams were done. These numbers are for all ages, and may include children outside the 0-14 years range. There are no demographic data to go with this count of examinations.

A HEALTH PROMOTION CLINIC FOR THE DEVELOPMENTALLY DISABLED

At Royal North Shore Hospital, there is a clinic specifically for Developmentally Disabled people. The clinic encourages clients to have a healthier lifestyle through a health assessment which includes diet and exercise.

The medical examination

The client is given a medical examination which includes:

* Tests for any diseases and disorders.
* Tests for general health and fitness for exercise.

If any problems are discovered, then referrals to particular specialists may be recommended and organised.

The Government stopped the funds this year for the dental services at the Developmentally Disabled Clinic, therefore no dental treatment been provided this year for children with Down Syndrome.
During 1992 an oral health assessment of 206 children with varying developmental disabilities, 26% (n = 53) have Down Syndrome aged from 5 to 19 years, was undertaken in the North Shore Area of Sydney. The study group was chosen by sending out letters and questionnaires for parents to students in special schools, I.Q. classes in State schools and Catholic schools where children were integrated. The questions covered information about frequency of dental care, services utilised, treatment review, satisfaction with treatment, holding private dental insurance and history of intercurrent medical conditions and treatment.

**Treatment at last visit**

At their last dental visit, 91% (n = 188) of the children received treatment and 45% (n = 93) of the children received more than one treatment.

The treatments included:

Dental examination 72% (n = 149), teeth cleaned or polished 27% (n = 55), fluoride treatment 13% (n = 26), oral hygiene instruction 12% (n = 25), dental filling or crown 11% (n = 23), tooth extracted 9% (n = 18), dental x-ray 5% (n = 11), orthodontic treatment 3% (n = 7), gum treatment 0.4% (n = 1), and other 9% (n = 18).

**Conclusion**

Malocclusion, periodontal disease and oral pathology were more common in the children with developmental disabilities than in the general Australian population. However, there was a significant increase in the perceived need for developmentally disabled children to have bands and gum treatment.

Down Syndrome children like the other Developmentally Disabled children, the DMFT Index was significantly lower than in the general Australian population.

However, the negative comments about treatment included: Lack of feedback from travelling dental clinic, dentist did not want to treat a disabled child and distance involved in travelling to Westmead Hospital Clinics and their comments need to be addressed by the community.
FIGURE 6: NSW AREA HEALTH SERVICE

FIGURE 7: NEW SOUTH WALES HEALTH REGIONS

9.9 NORTH COAST REGION - Lismore.

Local Government Areas:


Dental services for children are provided at:

* School Dental Clinics

Fixed:

Tweed Heads District Hospital, Ballina District Hospital, East Murwillumbah School Dental Clinic, Goonellabah Dental Clinic, Byron Bay Community Health Centre, Casino Memorial Hospital, Nimbin Community Health, Grafton School Dental Clinic, Maclean Hospital, Woolgoolga School Dental Clinic, Tyalla School Dental Clinic, West Kempsey, West Port.

Mobile:

Wauchope School, Bellingen/Nambucca.

Information obtained by courtesy Dr Peter Hill, Principal Dental Officer, North Coast Region. Dr M Syme, A/Principal Dental Officer, North Coast Region. Dr Geoffrey Webster, District Dental Officer, Coffs Harbour Base Hospital, Primary Health Care Services Dental Clinic. Mr John Ryan and Dr Schwarz Wo, Dental Officer, Maclean District Hospital and Community Health Services. Dr NF Cause, Dentist in charge, Casino Dental Clinic. Mrs Elizabeth Power, dental Assistant, Grafton Base Hospital and Health Service Community Health.

Children with Down Syndrome are treated as normal patients and are offered a full range of conservative and prosthetic treatment. Many of them are "ideal" patients and are most co-operative, these are treated in the dental chair by either dental officers or dental therapists dependent on their age. If unco-operative, they are treated under general anaesthetic in the day surgical unit.

There are three dental clinics in North Coast Region, i.e. Ballina, Lismore and Casino, and all offer these services.

The dental clinic in Maclean District Hospital and Community Health Services offer routine dental care to these patients some times; under GA. In the past orthodontic cases have been referred to Newcastle but now there is a visiting orthodontist in the district.
Any oral surgery would be referred to Newcastle (John Hunter Hospital). They do not keep a register of Down Syndrome patients.

Mr John Ryan estimated the number of these patients who use public dental services in Casino Dental Clinic would be:

**Kempsey:** School and adult clinic  6
**Port Macquarie:** School and adult clinic  9

Dr Geoffrey Webster estimated three Down Syndrome children used the public dental service in the last two years. Treatment ranged from conservative/preventive to general anaesthetic. There is no need to refer, and no records are kept.

Five individual children with Down Syndrome treated in the last two years in Ballina dental clinic and if they need specialist service often are referred to specialist in Lismore.

In Casino dental clinic they had only one child with Down Syndrome, the treatment has been carried out by Dental Therapists and the dentist in the clinic over the last six years. The treatment has been offered and carried out is as follows:

* Regular examinations.
* Prophylaxis and scaling.
* Orthodontic assessment.
* Extraction of over-retained deciduous teeth.
* Referral to Royal Children's Hospital in Brisbane after request by mother.

Suggested referral to Royal Far West Clinic, but mother preferred to go to Brisbane for treatment and orthodontic services.

If any specialist treatment is required in the future the staff will make arrangements so the treatment can be carried out within the Richmond Health Service or will be referred to either Royal Far West Clinic or the Royal Children's Hospital in Brisbane as suits the parent.

In Casino dental clinic they do not keep a register of Down Syndrome patients.
9.10 CENTRAL WESTERN REGION - Bathurst

Local Government Areas:

Bathurst, Great lithgow and Orange, Shires of bland, Blayney, Cabonne, Cowra, Evans Forbes, Lachlan, Oberon, Parkes, Rylstone, Weddin.

Dental services for children are provided at:

* School Dental Clinics

Fixed:

Bathurst, Cowra, Forbes, Lithgow, Orange, Parkes, West Wyalong.

Mobile:

Condobolin, Lithgow, Bathurst, Orange.

Information obtained by courtesy Mr Ethel McAlpine, Principal Policy Officer, Service Planning and Development Unit.

All treatment is offered including general dental care, orthodontic and general anaesthetic. If they need specialists, then a referral to private dentist.

9.11 NEW ENGLAND REGION - Tamworth

Local Government Areas:

Armidale, Greater Taree, Tamworth, Municipality of Glen Innes, Shires of Barraba, Bingara, Dumaresq, Gloucester, Great Lakes, Gunnedah, Guyra, Inverell, Manilla, Moree Plains, Narrabri, Nundle, Parry, Quirindi, Severn, Tenterfield, Uralla, Walcha, Yalleroi.

Dental services for children are provided at:

* School Dental Clinics:

Fixed:

Biripi aboriginal medical centre.
Zone 1 Manning river district hospital.
Zone 2 Tamworth, Gunnedah.
Zone 3 Armidale, Glenn Innes, Inverell.
Zone 4 Moree, Narrabri.
Mobile:

Zone 1  Foster.
Zone 2  Manilla.
Zone 4  Wee Waa.

Information obtained by courtesy Dr Dan Naidoo, Principal Dental Officer, Barwon, Lower North Coast, New England and North West Health Districts. Mrs Vanessa Redmond, Coordinator, New England Educational Diagnostic Centre. Mr Lyn Haack, Senior Dental Therapist, Community Dental Service, Tamworth.

There are four children with Down Syndrome had used the public dental service for the last two years.

All treatment is offered including general dental care, orthodontic and general anaesthetic. If they need specialists, then a referral is made to private dentist.

Two Down Syndrome patients were treated in Moree last year and two in Taree.

Taree patients attend regularly. One is easily treated under local anaesthetic, the other has to be treated under a general anaesthetic.

The two Moree patients are under eight years of age and with the cooperation of their parents respond well to oral hygiene instruction etc.

New England Educational Diagnostic Centre provides services to children having learning difficulties. Those children with developmental disabilities are assisted through other agencies.

The community dental service in Tamworth are known to both the home and community care service and the special school in Tamworth who refer patients to it.

For the last year six children with Down Syndrome have been treated in the community dental service in Tamworth.
9.12 WENTWORTH AREA HEALTH SERVICE - Penrith

Local Government Areas:

Blue Mountains, Hawkesbury, Penrith.

Dental services for children are provided at:

* School Dental Clinics:
  Fixed:
  Richmond, Springwood, St.Marys.
  Mobile:
  York Public School, St.Marys Mobile.

Information obtained by courtesy Dr George Terrazzolo, Co-ordinator of Dental Services, Wentworth Area Health Services.

There are no records for children with Down Syndrome, they can be treated on the dental chair or under general anaesthetic dependent on their co-operation.

9.13 ORANA AND FAR WEST REGION - Dubbo

Local Government Areas:

Broken Hill, Dubbo, Shires of Bogan, Bourke, Brewarrina, Central Darling, Cobar, Coolah, Coonabarabran, Coonamble, Gilgandra, Mudgee, Narromine, Walgett, Warren, Wellington, Unincorporated Areas.

Dental services for children are provided at:

* School Dental Clinics:
  Fixed:
  Morgan Street, Nyngan, South Dubbo.
  Mobile:
  Coonabarabran, Dubbo, Mudgees, Bourke, Narromine, Walgett, Broken Hill, Aero-Dental Service.
Information obtained by courtesy Dr Peter Roche, Principal Dental Officer, Orana & Far West Region. Mr Abeyesekera, Information Systems Manager. Mr Keyol, Senior Dental Therapist, South Dubbo Dental Clinic. Dr Nicola Bone, Dental officer; acting for Dr Peter Roche, Principal Dental Officer, Macquarie Health service.

The Dubbo Community Health Centre, especially within the scope of their child adolescent and family health service, do not maintain specific case details relating to Down Syndrome condition. Five children with Down Syndrome attend for regular examination every six month at South Dubbo Dental Clinic and comprehensive restorative treatment is offered to them, or if this is not suitable they are referred to the dental officer who will provide all general dental treatment and where necessary treatment under R.A, or G.A. All treatment where possible is carried out within the service.

9.14 SOUTH EASTERN REGION - Queanbeyan

Local Government Areas:

Goulburn, Queanbeyan, Shires of Bega Valley, Bombala, Boorowa, Cooma-Monaro, Crookwell, Eurobodalla, Gunning, Harden, Mulwaree, Snowy River, Tallanganda, Wingecarribee, Yarrawulumba, Yass, Young.

Dental services for children are provided at:

* School Dental Clinics:

**Fixed:**

Cooma North, Goulburn Queanbeyan, Young.

**Mobile:**

Bega 1002, Boorowa 1004, Bateman's Bay 1003, Yass 1005, Cooma 1001.

Telephone review with Mrs Anglea Copp, Dental Therapist, Central Coast Area Health Service.

Indicated that in the last four years there were only three Down Syndrome children with complications are referred to Dr Peter Wong, Paedodontist in Canberra, ACT. Children are only referred if treatment cannot be undertaken in clinics.
9.15 SOUTH WEST REGION - Albury

Local Government Area:


Dental services for children are provided at:

* **School Dental Clinics:**

  **Fixed:**


  **Mobile:**


Information obtained by courtesy Dr Neville Heer, Acting Principle Dental Officer, Hume Health Service. Ms Joanne Mcelman, Senior Dental Therapist, Griffith Base Hospital. Ms Ane Marrey, Dental Therapist, Deniliquen Dental Clinic.

In the South West Region no specific records are kept on dental services provided for children with Down Syndrome. From 2,106 children registered within Griffith Base Hospital only one children with Down Syndrome have been treated, and three in the Deniliquin Hospital and Community Health Services.

Down’s Syndrome children have full access to school service clinics and adult dental services later on if they are covered by a health care card or pension card.

Where possible, treatment is carried out in a normal dental surgery setting but in some cases treatment is completed under general anaesthetic by a dental officer.

The treatment offered is mainly of a routine conservative nature with a big emphasis on oral hygiene. The standard referrals to oral surgeons, orthodontists and speech pathologists are available if they are required by the patient.
Local Government Areas:

Auburn, Baulkham Hills, Blacktown, Holroyd, Parramatta.

Dental services for children are provided at:

* School Dental Clinics

Fixed:

The Blacktown District Hospital
The Mt Druitt, Community Health Centre
Mt Druitt, Parramatta, Westmead School of Dental Therapy

Mobile:

Auburn Area Mobile, Castle Hill (Fixed Mobile).

Information obtained by courtesy Dr A Vern-Barnett, Consultant Emeritus, Community Dental Health. Mrs Linoa, Booking clerk, Westmead Hospital. Mrs Kate Laughlan, Dental Record Manager, Westmead Hospital.

The Community Dental health Unit (CDH):

It was established in 1986 by the Western Sydney Area Health Service as part of its community health care program. The aim of the unit is to provide dental treatment to special groups of people who cannot get access to normal dental care easily such as aged people, physically handicapped as well as the intellectually handicapped.

The unit is located on level three of the Westmead Hospital-Dental Building and comprises of one consultant dentist, five dentists and five chairside assistants.

Treatments provided for out-reach visits consist of routine dental check-up, construction of partial or full dentures, repair & reline of existing dentures and also simple GIC restorations. More complex treatments are done back in Westmead Hospital. General anaesthesia sessions are also available every Monday morning. The work of the unit covers mainly the Western Sydney Area, looking after about 9,000 patients in 70 nursing homes, 50 workshops and 40 schools. Also, patients referred from other regions can also be seen.

A record system called Parado X Dental System was established in 1993. This system can recall individual records by separating them under different codes.
Records for a 15 month period indicated children with Down Syndrome have been seen by Community Dental Health Unit. There were 86 Children out of 314 patients with this condition.

No specific figures are available for children with Down Syndrome who have been treated by Paediatric Dentistry Unit. The writer knew that 504 children had been treated by Paediatric Dentistry Unit and were coded 1.

**Code 1:**
Medically compromised.
Handicapped.
Syndrome.
Dental Anomaly.

Information requested from Dental Records (Westmead Hospital Dental Clinical School) revealed that 23 children with Down Syndrome been treated in Westmead Dental Clinical School on the dental chair (out patients) since 12/08/1982, and 81 children with Down Syndrome been treated under general anaesthesia (inpatients) since 14/10/1982.

Examinations of the files of these patients by the writer for:

**Reason for asking dental treatment:**  
**Dental treatment services provided to them**

- Interference in occlusion.
- Small early carious lesions on the teeth.
- Tooth erupted palatally.
- Family concerned about chewing all the time.
- Check up.
- Orthodontic consult.
- Delayed eruption of the lower anterior teeth.
- Facial swelling.
- Grinding the teeth down very rapidly.
- Unco-operative patient on the dental chair.

- Basic dental care.
- Oral health education.
- Prevention.
- Restorative dentistry.
- Endodontics treatment.
- Periodontics treatment.
- Emergency treatment.
- X ray.

Telephone review with Ms Michele Burrows, Dental Therapist, Auburn Hospital, she said for the last 12 months no child with Down Syndrome treated in the dental clinic.

Telephone review with Ms Karen Moy, Dental Therapist, Community Dental Service in Mount Druitt, she said children with Down Syndrome are treated as normal patients and are offered routine dental care, if unco-operative, they are treated under general anaesthetic in the day surgical unit in Mount Druitt Hospital.

Telephone review with Ms Gulie Kennedy, Dental Assistant, Blacktown Hospital, she said for the last 12 months no one with Down Syndrome treated in their clinic, and if they need general anaesthetic a referral to Westmead hospital will made.
9.17 NUMBER OF CHILDREN RECEIVING SERVICES

There is no data on how many patients with Down Syndrome had been treated by Government Services (even for the last two years), because all the dental clinics except Westmead Hospital do not register or separate Down Syndrome patients from their other clientele. So without going through thousands of patients cards individually we can only guess.

The writer sent a questionnaire to the Directors of Dental Service in N.S.W. The information received has been listed in the following Table 11.

Table 11: Number of Children received Treatment in the last year by Government Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Treatment details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Coast Area Health Service</td>
<td>No records are kept</td>
</tr>
<tr>
<td>Central Sydney Area Health Service</td>
<td>20 children had been treated</td>
</tr>
<tr>
<td>Eastern Sydney Area Health Service</td>
<td>8 children had been treated</td>
</tr>
<tr>
<td>Hunter Area Health Service</td>
<td>No records are kept</td>
</tr>
<tr>
<td>Illawarra Area Health Service</td>
<td>58 active clients, no records are kept</td>
</tr>
<tr>
<td>Southern Sydney Area Health Service</td>
<td>No records are kept</td>
</tr>
<tr>
<td>South Western Sydney Area Health Service</td>
<td>17 children in 1993 in St George Hospital</td>
</tr>
<tr>
<td></td>
<td>&gt;3 children have been treated last year</td>
</tr>
<tr>
<td></td>
<td>&gt;2 children have been treated last year</td>
</tr>
<tr>
<td>Northern Sydney Area Health Service</td>
<td>No records are kept</td>
</tr>
<tr>
<td>North Coast Region</td>
<td>&gt;24 children with Down Syndrome</td>
</tr>
<tr>
<td>Central Western Region</td>
<td>No records are kept</td>
</tr>
<tr>
<td>New England Region</td>
<td>10 children have been treated</td>
</tr>
<tr>
<td>Wentworth Area Health Service</td>
<td>No records are kept</td>
</tr>
<tr>
<td>Orana and Far West Region</td>
<td>5 children have been treated</td>
</tr>
<tr>
<td>South Eastern Region</td>
<td>&gt;3 children have been treated</td>
</tr>
<tr>
<td>South West Region</td>
<td>4 children have been treated</td>
</tr>
<tr>
<td>Western Sydney Area Health Service</td>
<td>&gt;102 children have been treated</td>
</tr>
</tbody>
</table>

TOTAL > than 170 children have been treated
10. CONCLUSIONS

Down Syndrome is a genetic condition caused by the presence of an extra chromosome which can result in intellectual and physical delay.

Down Syndrome is the most common classifiable category of mental subnormality. The incidence at birth is about 1 in 700, and therefore it is likely that most dental practitioners will encounter the condition at some time during their professional lives.

The overall greatest threat to the dental health of a child with Down Syndrome is periodontal disease. Generally, periodontal disease is viewed as an adult phenomenon, however, children with Down syndrome seem to be particularly prone to this disease (Reuland-Bosma, 1986). Some studies have reported gingival pocket formation in more than 30% of children with Down Syndrome under age 6 years.

Based on this information then, dental care should begin early for the child with Down syndrome, usually at about the time the first teeth erupt. The aim of dental intervention at this point is primary prevention. By working with the parents or primary care givers, the dental health professional is establishing sound preventive practices in the home. These include:

* Tooth brushing with or without toothpaste with a brush of proper size and type.
* Determination of need for fluoride supplementation.
* Dietary habits and recommendation.

It is recommended that a small, paediatric sized toothbrush be used. In doing this so, both the child and the parents are employing an appropriate armamentarium from the outset.

Flossing, if the spaces between the teeth are closed, is recommended. However, if parents or care givers are experiencing difficulty with tooth brushing, adding flossing to the list of jobs to do will merely increase the sense of frustration and failure. Flossing can be approached once tooth brushing practices have been established by the adults and accepted (or at least tolerated) by the child.

When child with Down Syndrome is entering the mixed dentition stage of dental development with a mixture of permanent and primary teeth present in the arches. The aims of dental care at this time are primary and secondary prevention. These are accomplished by:

* Good home care program.
* Regular periodic dental care check-ups at an interval determined by the needs of the child.
* Fluoride supplementations, if needed.
* Early periodontal therapy, if needed.
* Sealants to fill in irregular or deep grooves and fissures on posterior teeth.
* Assessment of the developing occlusion to determine need and/or timing of orthodontic intervention and referral as needed.
Children with Down Syndrome have full access to School Service Clinics, and they can use Adult Dental Services if they are covered by a health care card or pension card.

Where possible, treatment is carried out in a normal dental surgery setting but in some cases treatment is completed under general anaesthetic by a dental officer.

Estimates from the NSW Down Syndrome Association indicate approximately 650 Down Syndrome children (age 1 to 14) have been registered with New South Wales Down Syndrome Association.

Using the ratio 1/700 the writer estimates approximately 1800 children with Down Syndrome in New South Wales according to the estimated population for the age group (1-14) in 1993 (Australian Demographic Statistics March Quarter 1994).

Regular dental examinations, appropriate dental hygiene, fluoride treatments, restorative care, if needed, and good dietary habits will help prevent dental caries and periodontal disease in children with Down Syndrome.

There is a need for specialised facilities and personnel. This means either in-house training or continuing education programs to deal with this specific disability.

Professionals and Auxiliaries must be trained. There is little doubt that the key to successful dentistry for the handicapped lies in the establishment of a successful child/dentist/parent relationship.

There is a need for adequate coding in every hospital and clinic. To keep records for all children with Down Syndrome in NSW.

There is a need for national register, so that co-ordination and planning of treatments will receive the appropriate recognition.

There is a need for a society called The Australian Academy of Dentistry for the Handicapped, having as one of its aims, to encourage and assist dental practitioners to prepare and qualify themselves to treat handicapped persons. No such organisation exists in this country.

Those who have found themselves faced with the difficulties of providing dental care for handicapped children have not had the support of fellow practitioners and so have had to solve them as best they can in isolation—a most unsatisfactory state of affairs.
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Information Systems Manager, Dubbo Community Health Centre.

Baker N
Dentist, Health and Community Services, Victoria.
Letter on 5/05/1995.

Bell J
Dental Health Branch, NSW Health Department, North Sydney.

Bone N
Dental Officer, Macquare Health Service.
11/05/1995.

Brown G
Assistant Manager, Community Services, Woodstock Centre, Lavington.

Cause NF
Dentist in Charge, Casino Dental Clinic
Letter on 31/03/1995.

Cusick A
Area Dental Officer, Daceyville School Dental Clinic.

Fleetwood MJ
Principal Dental Officer, Department of Health, ACT.

Greely JE
Chief Executive, Down's syndrome Association of Ireland.

Haack L
Senior Dental Therapist, Community Dental Service, Tamworth.

Halloran G
Director Statistical Information Section, Department of Social Security, Canberra.
Hassam R  
Chief Executive Officer, SA Dental Services.  

Heer N  
Acting Principle Dental Officer, Hume Health Service, Albury.  

Hill PR  
Principal Dental Officer, Richmond Health Service, Lismore.  

Holmberg P  
Dental Officer, Stockton Centre, Hunter Region Developmental Disability Service Department of Community Services.  
Fax on 19/08/1994.

Homan BT  
Director, Oral Health, Queensland Department of Health.  

Hong C  
Area Coordinator-Dental Services, Northern Sydney Area Health Service.  

Keyal A  
Senior Dental Therapist, School Dental Service Orana Region.  

King A  
A/Manager, Bathurst cluster Community Services Centre.  

Laughlan K  
Dental Record Manager, Westmead Hospital.

Lee S  
Clinical Team Leader, Hunter Area Dental Health services.  
Letter on 28/03/1995.

Mayne L  
Secretary/Information Officer, Down Syndrome Association TVL.  
Letter on 11/05/1995.
McAlpine E  
Principal policy Officer, Service planning and Development Unit, Ashfield.  

McDonald J  
Director, Clinical Information Services, The St. George Hospital, Kogarah.  

Mclennan J  
Senior Dental Therapist, Griffith Base Hospital.  

Moller G  
Dental Officer in charge, Shellharbour Hospital, Llawarra Area Health service.  

Murphy D  
Acting Department Head Community Dental Health, United Dental Hospital.  

Naidoo D  
Principal Dental Officer, Barwon, Lower North Coast, New England and North West Health Districts.  

Neesham DC  
Director Dental Services, Health Department of Western Australia.  
Letter on 11/05/1995.

Polonis L  
Secretary, Children's Community Team ( Disability Services ), Fairy Meadow.  

Power E  
Dental Assistant, Grafton Base Hospital Dental Clinic.  

Redmond V  
Co-ordinator, New England Educational Diagnostic Centre, Armidale.  

Ryan J  
Dentist, Macleay Hastings Health Service.  

Sanders J  
Area Dental Co-ordinator, Narellan Community Health.  
Letter on 2/05/1995.
Schwarz WO
Dental Officer, Maclean District Hospital and Community Health Services.

Searle IM
CDHP, Dental Health Branch, NSW.
Letter on 29/03/1995.

Selvarajah R
Team Leader Dental Services, Central Sydney Area Health Service, Marrickville School Dental Clinic.

Service Director
Northern Metropolitan Sector, Chatswood Assessment Centre.

Shaw D
Secretary, the Down's Association Affiliated with IHC. Auckland.

Syme M
A/Principal Dental Officer, Richmond Health Service, Lismore.

Tsougralis H
Area Dental Co-ordinator, South Western Sydney.

Webster G
District Dental Officer, Mid North Coast Health Service.
Fax on 18/08/1994.

Weidenhofer R
Director of Dental Services, NSW Health Department.

Westwater A
Program Director, Dental, Department of Health and Community Services, Northern Territory.
TELEPHONE REVIEWS

Baker K
Dental Nurse, Children Hospital.

Baxter K
Dental Therapist, Royal South Sydney Hospital.

Burrows M, Dental Therapist, Auburn Hospital.

Copp A
Dental Therapist, South Eastern Region.

Davis P
Registered Nurse, Concord Repatriation General Hospital.

Kennedy G, Dental Assistant, Blacktown Hospital.

Lamberton F
Dental Therapist, Camden Hospital.

Moy K, Dental Therapist, Community Dental Service, Mount Druitt.

Mrs Sandra
Receptionist Gosford Dental Clinic, Central Coast Area Health Service.

O'Connor J
Office Staff, Down Syndrome Association of NSW.

Smith J
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Spaile G
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Warght C
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APPENDIX 1 USEFUL ADDRESSES

AUSTRALIA
Australia Down Syndrome Association Inc;
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Fax: (08) 3376707

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NEW SOUTH WALES
Down Syndrome Association of Tasmania,
p.o. Box 2356,
NORTH PARRAMATTA NSW 2151

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VICTORIA  Down Syndrome Association of Victoria Inc;
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COLLINGWOOD VIC 3066

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Dr Peter Roche
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Orana & Far West Region
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DUBBO 2830
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Overseas Down Syndrome association include

NEW ZEALAND N.Z. Down's Syndrome Association,
P.O. Box 4142,
AUCKLAND

SOUTH AFRICA Down Syndrome Association (TVI),
87 Waterfall Avenue,
CRAIGHALL 2024

UNITED KINGDOM Down Syndrome Association,
12 - 13 Clapham Common South Side,
LONDON SW4 7AA

UNITED STATES National Down Syndrome Society,
141 Fifth Avenue,
NEW YORK NY 10010
### APPENDIX 2

**LIST OF OUT PATIENTS WITH DOWN SYNDROME TREATED IN WESTMEAD HOSPITAL. SYDNEY 14/10/1982 TO 8/08/1995. AGE FROM YEAR 0 TO 14.**

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**Gp:** General practitioner.  
**Ped:** Paediatric Department.  
**P:** Paediatrician.  
**Com:** Community dental health department.  
**E:** Early childhood.  
**Ort:** Orthodontic department.  
**D:** Dentist.  
**S:** Speech department.
APPENDIX 3  

LIST OF IN PATIENTS WITH DOWN SYNDROME TREATED IN WESTMEAD HOSPITAL, SYDNEY 14/10/1982 TO 8/03/1995.

AGE FROM YEAR 0 TO 14.

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**TOTAL NUMBER OF RECORDS EXTRACTED: 99**
APPENDIX 3 LIST OF CODES

D 3068 Other specified psychophysiological malfunction.
D3182 Profound mental retardation.
D319 Unspecified mental retardation.
D3699 Unspecified visual loss--- coded as D3199.
D49390 Asthma. Unspecified type without mention of status asthmatics.
D5200 Anodontia.
D52000 Partial Anodontia. (Syn Hypodontia, Oligodontia).
D5201 Supernumerary Teeth.includes: supplemental teeth.
D5206 Disturbances in tooth eruption.
D52063 No Description in file.
D52066 Dental Caries.
D5210 Unspecified dental caries.
D52109 Habitual.
D52121 Periapical abscess without sinus.
D5225 Radicular Cyst.
D5234 Chronic Periodontitis.
D5236 Accretions on teeth.
D52364 Supragingival Calculus.
D52366 Dental Plaque.
D52369 Unspecified.
D5239 Unspecified gingival and periodontal disease.
D52414 Maxillary retrognathism.
D5243 Anomalies of tooth position.
D52430  Crowding includes: imbrication.
D7450  Common Truncus.
D7452  Tetralogy of fallot.
D7454  Ventricular septal defect.
D7455  Ostium secundum type atrial septal defect.
D7459  Unspecified defect of septal closure.
D7469  Unspecified congenital anomaly of heart.
D7509  Unspecified congenital anomaly of upper alimentary tract.
D7580  Down Syndrome.
D7852  Functional and undiagnosed cardiac murmurs.
D87363  Open wound of tooth (Broken), uncomplicated.
DV548  Other orthopedic after care.
DV722  Dental Examination.
P2301  Extraction of deciduous tooth.
P2309  Extraction of other tooth.
P2311  Removal of residual root.
P2319  Other surgical extraction of tooth.
P232  Restoration of tooth by filling.
P233  Restoration of tooth by inlay.
P2349  Other dental restoration.
P2370  Root Canal, not otherwise specified.
P246  Exposure of tooth.
P8712  Other dental X-ray.
P8931  Dental Examination.
P9355 Dental Wiring.
P9654 Dental Scaling. Polishing. And debridement.
P9788 Removal of external immobilisation device.