

LOMA LINDA UNIVERSITY
SCHOOL OF PUBLIC HEALTH

HEALTH EDUCATION FOR WOMEN IN BRAZIL
Focusing on mothers of children with facial clefts

by

Eleuza Alves de Oliveira



0-323-570-2

UFSC-BU

Culminating Activity

Dr. Gordon Buhler

Dr. James Crawford

Dr. Jake Job

Summer 1991

CONSULTA LOCAL

CETD
US
φ 180

SC-00050253-8

172471

ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
DOADO POR _____

2-0 SET. 2000

REGISTRO 0323.570-2

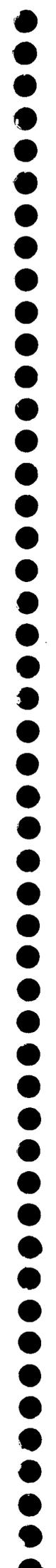
DATA DO REGISTRO 20-9-00

BU/DPΓ

0.323.570-2

ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.

ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.
ΑΔΙΟΤΥΠΟ ΓΕΝ. ΔΙΟΙΚ. ΠΡΟΤ. ΓΡΑΦ.



CULMINATING ACTIVITY REPORT GUIDELINES

The Department of International Health, in determining a culminating activity in lieu of a comprehensive examination, prefers to evaluate the ability of the student to relate academic study to an individual career plan. The Department feels this can best be done by the development of a detailed proposal or plan for a project or program the student plans to implement. In such a paper the student must show himself (herself) knowledgeable of International Health theory, practice, and current issues and able to demonstrate and integrate basic public health principles from biostatistics, environmental health, epidemiology, health administration and health behavior change. This paper must be well organized, typed and in good literary form with adequate footnotes and/or bibliography. Each student must consistently utilize a standard guide for style and organization. Manuals for this are available in the Resource Room.

The student is expected to initiate consideration of this proposal with his (her) academic advisor as early as possible. It must be outlined no later than the beginning of the quarter preceding the quarter of graduation, but the paper cannot be completed until the student has completed the core courses in public health and international health (or is concurrently enrolled). The paper is due in the office of the Department Chairman, having already been evaluated by assigned readers, not later than registration day of the last quarter before graduation. Each paper will be read by at least three persons, the student's academic advisor plus two others chosen to match the interests and needs of the student. The readers are not necessarily from the Department of International Health.

All students will be required to complete this exercise. Students in Program I will complete their paper during the time of their academic study; those in Program II can complete their paper during the time of Field Practicum study. For example, students planning to graduate in June must finalize their proposal topic in consultation with their advisor in early January and must have completed their paper by the beginning of the Spring quarter. Students planning for end-of-Summer graduation must have their topic approved by their advisor at the beginning of the Spring quarter and must have completed their paper by the beginning of the Summer quarter.

TABLE OF CONTENTS

	Page
Summary	1
I. Introduction	2
II. Etiology	3
A. Multifactorial poligenic cause	3
B. Syndromes	4
C. Recurrent genetic factor	4
III. Embriology	5
IV. Classification	6
V. Epidemiology	7
A. Distribution according to kind of deformity	8
B. Distribution according to gender	8
C. Distribution according to ethnic groups	9
VI. Needs assessment	9
A. In developed countries	9
B. In developing countries	10
B.1 Primary health care	11
- Health education	11
a) Breastfeeding	12
b) Nutrition	12
c) Immunization	14
d) Hygiene	15
d.1) Dental hygiene	15
d.2) Facial hygiene	15
e) Family planning	16
B.2 Surgery	17
B.3 Dentistry and orthodontics	17
B.4 Speech therapy	18
VII. Statement of the problem	19
VIII. Program goal	19
IX. Target service population	20
X. Program location	21
XI. Objectives	22
XII. Indicators	22

XIII. Program resources	23
XIV. Program constraints	25
XV. Methods	25
A. Administration	25
B. Staffing, clinetele and services	26
C. Activities and tomeframe	28
D. Actionplan worksheets	31
XVI. Evaluation	35
XVII. Budget	37
- Budget narrative	38
Conclusion	40

SUMMARY

The "Sociedade de Promocao Social do Fissurado Labio-Palatal" (Society of Social Promotion of Cleft Lip and Palate Patients - PROFIS), located in Brazil, has planned a health education program to be brought directly to mothers of children born with facial clefts. Through this program these women will be enabled to meet the primary health needs of their children resulting in a better health status for them.

Health classes will be conducted at the PROFIS facilities where the patients will receive preventive and curative treatments in close cooperation with the Brazilian federal government program called "Comprehensive Health Action". The topics for the classes will be: breastfeeding, nutrition, immunization, hygiene, and family planning. Women from the target population will be trained and will participate in the program as volunteers.

The total cost of this program is US \$ 600,000. Of this, US \$ 370,000 has already been committed by local organizations. This request is for the balance needed of US \$ 230,000.

I. INTRODUCTION

Facial clefts (FC) are considered a very important group of birth defects because of the aesthetic and functional abnormalities that they cause. Around the world the prevalence of babies born with FC varies from 1:2,000 births in South Africa, to 1:600 in the United States, and 1:470 in Japan (HPRLLP, 1986).

The clefts of lip and palate are the third most frequent birth defect in Brazil, occurring with a prevalence of 1:650 births (Nagen, 1968). Considering that there are 4,993,923 children born in Brazil per year (Anuario Estatístico Brasileiro, 1990), it is expected that of these 7,600 will bear FC. Presently it is estimated that there are 200,000 people with FC in the country (HPRLLP, 1986).

This congenital defect is an universal problem and its existence is reported in ancient findings. Some Egyptian mummies and Incas sculptures were identified as having FC, and Greek writings mentioned their occurrence in early times (Rogers, 1971).

Also, since very early, people associated FC with ordinary daily observations. The common designation of a cleft upper lip as a "harelip" is usually a misnomer, for the characteristic cleft in the lip of a hare or a rabbit is in the midline and, except in rare instances, an abnormal cleft in the human lip appears to one side or the other of the midline. Although misused this term is very common, and it is impossible to date when the designations of "harelip" and "throat of wolf" were first employed to describe these abnormalities of lip and palate in human beings.

II. ETIOLOGY

The genesis of FC, and specially the clefts of lip and palate which are the most common in human beings, has been intensively studied. They can be induced in experimental animals by an amazing variety of procedures. But basically there are three different explanations that describe the possible causes of FC.

A. MULTIFACTORIAL POLIGENIC CAUSE

One possible explanation is that the etiology of FC is due to the interaction of genes of low expression that are affected by environmental factors. This is called the multifactorial polygenic cause of FC and explains 70% to 80% of the cases (Israel, 1987). The environmental factors most frequently associated with FC, which may affect the pregnant female specially during the first two months of gestation are (Souza-Freitas, 1974):

- nutritious unbalances: dietary disturbances such as deficiency of vitamin B12, thymine, folic acid; or excess of vitamin A;

- toxic substances: ingestion of alcohol, hydantonades, prymidone, phenobarbital, acetylsalicylic acid, benzodiazepyne;

- hormones: excess of cortisone or testosterone;

- ionizing radiations of parental gonads during gamete production, or irradiation of the growing embryo itself;

- environmental pollution: parental exposure to pesticides and herbicides.

B. SYNDROMES

FC can also be associated with syndromes, which are a combination of signs that characterize a disease. Up today there are more than 200 syndromes described in the medical literature that relate with alterations of the genetic material. In these cases, FC appear as one among other defects that occur in the same child. Thus, the genetic pattern of the syndrome is expressed and it includes the FC.

C. RECURRENT GENETIC FACTOR

A third explanation for the etiology of FC is the recurrent pattern of inheritance. This means that different members of the same family are affected because there is a combination of hereditary factors that may cause FC. These are significant findings for family planning because it has been reported that 20% to 25% of patients with FC have two or more family members affected (HPRLLP, 1990).

One or all these explanations may describe why a child is born with his/her face deformed. Normal development is in fact an exceedingly intricate and delicately balanced process which can be easily disturbed while the embryo is formed in the mother's womb.

III. EMBRIOLOGY

In studying the early development of the digestive tract we see that the primitive gut first appears as a cavity which has neither oral or anal opening. But during the fourth week of pregnancy, an opening in the future oral region is established by a depression in the embryo's tissues. This depression is called primitive mouth or stomodeum.

The deep oral cavity characteristic of the adult is formed by the forward growth of structures around the margins of the stomodeum. This cavity is surrounded by five structures (see Appendix 1): the frontal prominence in the midline; two maxillary processes at the extreme lateral angles of the stomodeum; and two mandibular processes which form the mandibular arch and merge with each maxillary process at the angle of the mouth (Patten, 1972).

Between the sixth and the eighth weeks of gestation the median frontal process is divided in four other segments, two nasolateral and two nasomedial processes. When the nasomedial processes are fused with the maxillary processes they form the median part of what will be the baby's upper lip and anterior palate. When the eighth week of pregnancy is being completed, the palatine processes derived from the maxillary processes are fused backwards and towards the midline. An important anatomic point that remains between these processes, since they are completed at different times during gestation, is the incisive foramen behind the teeth 7 and 8 (Pires, 1989).

When the facial processes do not come into contact, or when the embryonic tissues do not fuse with each other, a cleft occurs. Clefts are present as a stage of the embryo's life, and when this particular stage is

paralyzed for any reason, the result will be the birth of a baby with his/her face deformed.

IV. CLASSIFICATION

Considering the importance of the incisive foramen in the embryology of clefts, this anatomical point is used as basis for the classification of the clefts of lip and palate (see Appendix 2). This classification was first suggested by Spina and it has been employed for the purpose of diagnosis, reporting, and research (Spina, 1972).

1. Clefts derived from the primary palate: isolated cleft of the lip or pre-incisive foramen

- 1.1 unilateral left
- 1.2 unilateral right
- 1.3 bilateral
- 1.4 median

2. Clefts derived from the primary and secondary palates: cleft lip and palate or trans-incisive foramen

- 2.1 unilateral left
- 2.2 unilateral right
- 2.3 bilateral
- 2.4 trans-foramen left and pre-foramen right
- 2.5 trans-foramen right and pre-foramen left

3. Clefts derived from the secondary palate: isolated cleft palate or post-incisive foramen

3.1 total

3.2 posterior

3.3 occult or submucous

The clefts of the lip occur in different degrees of severity. A mild form appears to be like a scar on the lip. A severe type affects the alveolar bone and the nasal floor. Most frequently clefts affect the upper lip and very seldom the lower lip and the mouth commissure. When a cleft of the mouth commissure occurs, it is called a transverse cleft or macrostomia.

The clefts of the palate can also show different manifestations. The least severe is the uvula bifida, and the most severe is the total cleft of soft and hard palate. Another mild manifestation is the submucous or occult cleft where there is a discontinuity of the palatal muscles which are only superficially covered by the mucous tissue.

The distribution of these forms of clefts in the population varies according to gender and ethnic groups of people. But according to the literature there is a consistency of findings in this distribution, in spite of the different places where epidemiological studies are conducted.

V. EPIDEMIOLOGY

The epidemiological aspects of patients with FC in Brazil have been studied in the "Hospital de Pesquisa e Reabilitacao de Lesoes Labio-Palatais" (Hospital of Research and Rehabilitation of Patients with Cleft

Lip and Palate - HPRLLP). This is the largest center for treatment of FC in Latin America. It is located in the state of Sao Paulo, Brazil; presently it has a record of 23,000 patients with FC being treated and it receives an average of 10 new patients a day. The epidemiology of FC can be described in terms of their distribution according to the kind of deformity, gender, and ethnic groups.

A. DISTRIBUTION ACCORDING TO KIND OF DEFORMITY

Considering all kinds of clefts registered at the HPRLLP, they are distributed as follows, 25% are pre-foramen, 25% are post-foramen, and 50% are trans-foramen. These results are consistent with most of the clinical findings confirming that the trans-foramen is the most frequent kind of FC (Drillien, 1966).

B. DISTRIBUTION ACCORDING TO GENDER

Sixty percent of the patients registered at the HPRLLP are males. When we separate the different kinds of clefts among the males the most frequent cases are the pre-foramen and trans-foramen. Among the females the post-foramen are the most common ones. These findings are not only peculiar of the HPRLLP, but are corroborated by other researches (Fraser, 1960).

C. DISTRIBUTION ACCORDING TO ETHNIC GROUPS

The records of the HPRLLP show that the ethnic groups that are represented in Brazil follow the same figures of prevalence of FC that is observed in other countries, namely, Asian-Brazilians show an incidence of 1:470, European-Brazilians of 1:600, and African-Brazilians of 1:2,000.

As we consider the variety in which FC occur, it is important to mention that children who are born with these deformities all share common clinical conditions that relate with public health. These will be addressed in the following section as needs to be met in community assessment.

VI. NEEDS ASSESSMENT

A. IN DEVELOPED COUNTRIES

In developed countries where the infant mortality rate due to infectious diseases and malnutrition has decreased, birth defects represent one-fifth of the total deaths in the first year of life (Drillien, 1966). Fifty percent of the children with birth defects who die at this age have other severe deformities associated with FC that cause these deaths. Most of them suffer of abnormalities of the cardiovascular, urogenital, or central nervous systems, which are not compatible with life (Mackeprang, 1972).

B. IN DEVELOPING COUNTRIES

In developing countries, as it is the case of Brazil, the causes of death among children with FC are the same as for all the children, malnutrition and infection. One aspect that relates with this finding is that at the HPRLLP it has long been recognized that the majority of people with FC have low economic status. The data collected at the hospital show that these patients are often lacking in good general health care and nutrition, suffering more from poverty-related illness than from diseases of affluence (HPRLLP, 1986). The social aspects involved with this situation are that they are afforded little political power, they are under-represented by virtue of their economic status, and they find themselves caught between poverty on the one hand and the need of health care on the other.

Malnutrition and infectious diseases have been targeted by the Brazilian government through the program called "Comprehensive Health Action" that provides the preventive services to combat those maladies. But unfortunately, in many cases people do not use these services because there is a lack of health education among the public who need them; they do not know where to go to, what services to ask for, or even what healthier behaviors to adopt in order to promote their health.

Generally mothers of children with FC look primarily for surgical treatment. But the treatment for those patients is not only a matter of having a surgery performed. First of all the child has to be physically prepared to receive the rehabilitation and afterwards the results of the treatment have to be maintained through healthy behaviors. So, to provide health education and primary health care for these mothers and their

children is the only way to guarantee that further investments in rehabilitation will be well employed.

B. 1 PRIMARY HEALTH CARE

Delivering primary health care for patients with FC involves protection and promotion of the health of individuals as close as possible to where they live, for optimal personal and social fulfillment (Basch, 1990). This strategy involves health education as a priority. On the other hand, to complement these services, rehabilitation is needed to reconstruct facial structures in such a way that the functional impairment and discomfort experienced by the patient are minimized.

- HEALTH EDUCATION

Even before a patient starts the treatment with surgeries, the investment in health education for the mothers cannot be underestimated. Topics like breast-feeding, nutrition, immunization, hygiene, and family planning are to be emphasized as procedures of health promotion and prevention for their children and their families. These topics which are considered so important for mothers of normal children gain a special value when public health workers are dealing with children with FC because these kids will demand special care since early childhood.

a) BREASTFEEDING

In the Department of Public Health of the HPRLLP it has been observed that babies between 1 to 30 days of life are usually brought to the hospital wearing naso-gastrical probes, or they are fed by droppers or syringes. The only case when the probe has to be maintained is when the patient has problems to swallow, which are usually associated with neuropathologies (Claren, 1987). In all other cases, that are the great majority, the probe can be removed and breast-feeding or bottle feeding can start.

Breast-feeding is possible for patients with FC and it has to be encouraged by the health workers who assist them. Some of the advantages of breastmilk that have to be constantly reminded for the mothers are that it is more easily digested by the child than any other kind of milk; it is more hygienic and does not demand preparation, what prevents against diarrhea; it is in the ideal temperature for the baby; it has antibodies that protect the child against enfermities; and it is more economic.

b) NUTRITION

According to the type of cleft there are patients with different levels of problems to be fed. These problems seem to be lighter for those with cleft lip and harder for the patients with cleft palate (Paradise, 1974).

The mouth, as the initial segment of the digestive tract, serves as the primary organ for nutrition sustenance (Pipes, 1989). But the

nutritional intake ability is severely compromised as a result of FC; thus the patient's metabolism is negatively impacted, and one of the major consequences of this is growth deficiency. Especially when the cleft of the palate is present, there is no vacuum formed during the process of suction and thus the act of feeding becomes laborious and weary (Bueno, 1980).

The patients who arrive at the age of 31 days up to 1 year old at the HPRLLP usually show severe malnutrition. It is frequent the case of families who live in the rural areas who feed their children in the first year of life only with a mixture of water and manioc flour. At first, these children look fat, but when they are touched their flesh shows to be really soft and in fact they are only swollen up by the unbalanced diet.

Patients with FC present patterns of inadequate suction and ingestion of food. The anatomic deformity frequently leads to escape of food by the nose, excessive ingestion of air, and nasal obstruction. As a result of this, the patient chocks, coughs, and vomits very easily. Another consequence is that the upper respiratory system becomes easily infected favoring pneumonia and medium otitis, and finally leading to inadequate weigh gain and malnutrition.

The anatomical conditions may deprive the children with FC of an adequate nutrition in many cases. But most frequently this happens because the family members and/or professionals who assist them do not know how to manage the children's actual capacity to suck, and to enable them to breast-feed and to enjoy good nutritional patterns. Usually a wrong technique to feed the child with FC is what causes nasal escape, crises of cyanosis, choking, and vomiting (Avedian, 1980 and Claren, 1987). Such considerations lead us to the conclusion that in order to

improve the nutritional status of patients with FC, intervention has to take place.

c) IMMUNIZATION

There are patients brought to the HPRLLP at one year of age still without any kind of immunization. These babies frequently suffer of diseases which could be prevented by vaccines. When these events occur in children with FC they are exacerbated because the anatomical deformity keeps mouth and nose constantly open to the air contaminants.

When these babies without immunization survive, between 1 and 4 years old they show a delay in their growth (weigh and height), language acquisition, and socialization when compared with other children with FC who were vaccinated (HPRLLP, 1986). Since they suffer of frequent infections with diarrhea, acute respiratory infections, and vaccine preventable diseases, these events contribute to a general deficiency in their development. On the other hand, this is a period of their lives when the patients are specially desired to be in good clinical conditions because it coincides with the time when the surgeries for reconstruction of lip and palate are recommended.

d) HYGIENE

d.1) DENTAL HYGIENE

A research done in 1989 in the HPRLLP showed that 50% of the patients who arrived at the hospital and who were between 4 and 12 years of age did not receive any previous dental care (HPRLLP, 1990). One reason for this is that most of the people have a generalized misconception that since the baby teeth will be replaced, they do not need to be treated. Besides, the majority of dentists in general practices are scared to treat children with FC because of the unusual appearance of the patients' mouth and the anticipation of a complicated treatment. Frequently these dentists give excuses and deny treatment for patients with FC.

Having many teeth loss and several cavities are factors that contribute for malnutrition. If these patients do not receive adequate education on dental hygiene, and services of preventive dentistry, they cannot chew and swallow any food properly. Another great importance of the presence of teeth is that with them the alveolar bone is present, providing the hard structure necessary to rebuild the face aesthetically through plastic surgery.

d.2) FACIAL HYGIENE

The hygiene of the nose and ears is also extremely important for patients with FC. About 60% of the children under 12 years of age at the HPRLLP show a certain degree of hearing impairment (HPRLLP, 1986). This is due to frequent infections, which could be, in many cases, avoided

or even reduced in their severity by adequate hygiene of the facial structures.

e) FAMILY PLANNING

When a baby is born with FC there is a frustration of all family expectations about having an ideal child. The mothers' attitude is frequently of insecurity and fear. Her reaction consists in a sequence of feelings that start with shock, denying, rejection, anger, sadness, and guilt (Irvin, 1978).

The mothers frequently struggle with the reality of preventing a further risky pregnancy. The possibility of choosing an abortion may be higher when the parents are not informed about the methods to control child spacing and avoiding an undesirable pregnancy.

Situations of distress may be common for mothers with children born with FC. In such situations the health professional has to be really cautious not to exacerbate the negative feelings. The child's defect cannot be under or overestimated. The health professional has to show a balanced attitude, honest and understandable. The mothers need practical counsels explaining the procedures to be taken and the alternatives for treatment (Brown, 1984).

Genetic counseling is recommended for the mothers as part of family planning when it is a case of syndrome or when there is a pattern of genetic inheritance involved. On the other hand, normal parents without a recurrent factor in their families should be informed that the occurrence of FC is of 4% for each pregnancy in the total population (HPRLLP, 1986).

Since the demands of raising a child with birth defect are greater than for a normal child, and the mothers may be scared to have another baby with birth defect, they have to be educated about the appropriate methods of family planning. Alternatives are to be explained for each case and access to contraceptives has to be assured for them.

B. 2 SURGERY

In each phase of the treatment of patients with FC, different professionals of the health team may have a more important role. The time for surgeries is generally well defined, but depending on the kind of FC a different number of surgeries may be necessary for the same patient. The essential criteria to perform a surgery in patients with FC are good clinical conditions and minimum age of 10 weeks.

The surgery of the lip is suggested to be performed in the third month of life; if a child is being breast-fed this is indicated to be when s/he is six months old. The surgery of palate is indicated to be between 18 and 24 months of life. After each surgery the patient cannot suck for a period of 10 to 20 days when s/he is fed by spoon with liquid food.

B. 3 DENTISTRY AND ORTHODONTICS

Surgeries for children with FC have only a relative advantage if they are not followed by other kinds of treatment. As the child grows there are great alterations in her/his face and skull. The scar left by the surgery

on the upper lip causes a constant pressure on the bones and thus the patient develops a clinical condition that is called "false prognatism", that means the advancement of the jaw in relation to the whole face. Besides, as the patient's teeth are generally crowded, s/he has problems with her/his gums, difficulty to chew and to clean the teeth.

Thus, orthodontics is a must for almost all patients with FC. The orthodontist is the professional who monitors the child's growth because s/he sees the patient more frequently than any other member of the health team. It is also during the phase of orthodontics treatment that the patient has to be more aware of the importance of dental hygiene because having the braces in place increases the retention of dental plaque and its consequences, gum problems and dental cavities.

B. 4 SPEECH THERAPY

Language acquisition is a complex mechanism that demands the integrity of structures of the mouth, clarity in perceiving sounds, and mental ability to articulate sounds. A child with FC has to adapt the function of her/his mouth to produce sounds and to eat. S/he is also vulnerable to get many infections which reduce her/his capacity to hear.

Speech disturbances related to articulation and voice quality compromise the patient's processes of learning, socializing, and professionalizing (Wo, 1990). The mouth, as the primary organ of vocal speech generates effective communication between fellow humans, therefore disturbs in this process may lead to problems of social adjustment.

and the early intervention in these cases can result in a more successful rehabilitation.

If there is no integration between primary health care, time and technique of surgery, dental rehabilitation, and speech therapy, to treat babies with FC, the child may be unable to produce some sounds for her/his whole life. The speech therapy is a treatment that demands a lot of time but that offers very rewarding results (Souza-Freitas, 1974).

There are serious consequences that affect individuals and communities when health services are not available or when they are not used by the clientele. Since this situation is seen in Brazil, the need of health education for mothers of children with FC has been recognized as urgent in the country.

VII. STATEMENT OF THE PROBLEM

A lack of health education for mothers of children born with FC in Brazil results in less than an optimal health status for them, reducing their effective performance in societal roles.

VIII. PROGRAM GOAL

By the end of the one year program people with FC in Brazil will improve their health status.

IX. TARGET SERVICE POPULATION

The needs assessment presented above were identified at the HPRLLP which is an institution that exists for more than 20 years and offers specialized services for people with FC. The greatest problem for most of its patients is to cope with the distances from the place where they live (the patients are spread over the 8,542,000 sq. km. of the Brazilian territory) to go to the hospital, that is located in the west of Sao Paulo State.

Therefore, the Ministry of Health, recognizing the need to treat people as close as possible to where they live established a Health Center (HC) for Patients with FC in the city of Curitiba, State of Parana, specially to serve the population in the south of Brazil. Curitiba is a city with 1,500,000 people where a prevalence of 1:569 children with FC was found among first grade students (Oliveira, 1986).

A health education program targeting women in the south of Brazil is proposed. The focusing in women is because they serve as primary health nurtures for family members through such duties as selection and preparation of foods, direct care of children, and caring for family hygiene needs. Women also function as family care planners, making decisions of when to seek medical care, scheduling medical appointments, and assuming responsibilities such as seeing that their children are immunized. So, decisions women make materially affect the health, nutrition, attire, cleanliness, and emotional equanimity of all family members. Failure to develop women's resources and skills undermines community development as a whole.

In the south of Brazil there are 568,199 children born per year (Anuario Estatistico Brasileiro, 1990). Considering the prevalence of FC for

the country being 1:650 births gives an incidence of 874 children born with FC per year in the south. Preventive treatment of the "Comprehensive Health Action" target children under five years old; an estimate of the total number of children that will be demanding services during the program year can be made by taking the incidence of 874 children born with FC/year times five years, what will result in 4,370 children with FC under 5 years old at the moment. So, the target service population for this program is estimated to be 80% of this total, the approximately 3,500 mothers of children under five years of age with FC living in the south of Brazil.

X. PROGRAM LOCATION

The "Sociedade de Promocao Social do Fissurado Labio-Palatal" (PROFIS - Society of Social Promotion of Cleft Lip and Plate Patients) is a non-profit organization founded in 1983 in the city of Curitiba, Brazil. Its founders were the parents of children with FC and some health professionals who were treating them. Ninety-five percent of these parents are poor people, with a family income less than US \$ 250 per month.

The PROFIS' purpose is to provide health care for patients with FC, and this is the only organization of this nature in the city of Curitiba. Its associates are the patients with FC, their parents, and community members who have interest in assisting people with these deformities.

The facilities of the PROFIS are located in the following address:

Rua do Rosario 144

80020 - Curitiba, Parana - Brazil

Telephone: (041) 234-7575

XI. OBJECTIVES

By December, 1992 the program will improve the health status of people with FC who attend PROFIS Clinics in the following areas:

1. the mothers of 780 newborn babies with FC will breast-feed their children at least for three months;
2. 820 newborn babies with FC will be immunized for measles, tuberculosis, poliomyelitis, pertussis, diphtheria, and tetanus in their first year of life;
3. 3,200 children with FC between 3 and 12 years old will acquire control of dental plaque through dental hygiene;
4. 2,700 mothers of children with FC will have access to contraceptive devices.

*numbers
parents.*

XII. INDICATORS

The program will increase the health knowledge of mothers with children born with FC who attend PROFIS clinics in the importance of breast-feeding, nutrition, immunization and hygiene in disease prevention, and family planning.

1. Five curricula which provide opportunity for personal interaction between health educators and the target population will be developed. The curricula content will cover the indicators of the program goal.

2. 52 health education classes based upon the curricula will be conducted by a social worker on a weekly basis. 3,500 mothers from the target population will attend these classes during the program year.

3. Five rotating bulletin boards will be utilized at each meeting.

4. Within the first year program the following materials will be operating:

- 5,000 pamphlets and leaflets

- 40 posters

- 5 bulletin boards

5. Four women from the target population will be functioning as trained volunteers in health education to teach breast-feeding for mothers of children with FC.

6. Four women with leadership ability will be identified from the target group for the purpose of community input into the operation of the health education program. They will be trained to function as integral components of the PROFIS team.

7. Seven women from the target population will be functioning as trained volunteers in health education to teach toothbrushing and flossing for children with FC.

XIII. PROGRAM RESOURCES

The resources and community linkages available for the health education program are:

1. PROFIS officers will provide information, feedback and suggestions about the program.

2. PROFIS associates will work as volunteers to teach breast-feeding for the mothers, and toothbrushing and flossing for the children with FC.

3. Local school districts will be a resource for identification of health education needs and coordination with existing community health education efforts.

4. "Comprehensive Health Action" offices will be a resource for patients' referral for immunization for measles, tuberculosis, poliomyelitis, pertussis, diphtheria, and tetanus.

5. State Health Department will supply materials for health education.

6. HPRLLP will supply data, educational materials and take referrals of patients.

7. The Ministry of Agriculture will supply nutrition education materials, coordinate teaching efforts, and take referrals of families for supplemental foods.

8. The Association of Family Well-Being will provide educational materials on family planning and contraceptive devices.

9. Community leaders will assist in ensuring integration of the program into the community.

10. Community volunteers will help fill staffing needs and provide program input, increasing community ownership of the clinics.

XIV. PROGRAM CONSTRAINTS

1. Lack of provision in PROFIS general operating budget for health education, necessitating additional funding.
2. Lack of continuity and stability with volunteers personnel.

XV. METHODS

A. ADMINISTRATION

PROFIS will provide health education, social, medical and dental care to patients with FC through regular clinics from Monday through Friday. These clinics will be operated daily on appointment basis ranging from 8 am to 6 pm.

Through the affiliation with the "Comprehensive Health Action" that is an interministerial program of the Brazilian federal government, PROFIS will operate its services. In this partnership the government provides the facilities and the wages for professionals who deliver health care to patients with FC. On the other hand, PROFIS will provide the volunteers to participate in the health education program.

The clientele of PROFIS are people of any age who were born with FC. Since health care is socialized in Brazil anybody is eligible to get the treatment with no cost at the Public Health Department. PROFIS, as a non-profit organization, may collect donations for the services delivered.

B. STAFFING, CLIENTELE AND SERVICES

Four PROFIS associates will work as volunteers visiting the hospitals in their own neighborhood where babies with FC are delivered. In these hospitals they will teach breast-feeding to the mothers of babies with FC. Other seven volunteers from the target population will teach toothbrushing and flossing for children at the PROFIS clinics.

The other personnel involved in the program are 7 full-time government officers, namely, a program director, a social worker, a physician, a pedodontist, a speech therapist, a dentist, and an orthodontist. When a patient starts the treatment, the first appointment is with the program director who diagnoses the condition, plans for the follow-up treatment, and refers the case to the other professionals in the team. Once a new case starts the treatment, the patient and her/his mothers are immediately enrolled in the health education program.

The professionals will meet weekly in order to plan for the patients' treatments according to a team orientation, meaning that a multidisciplinary approach to treatment will be observed. At least once a month the team will meet with the PROFIS associates in a general ordinary assembly (see Appendix 3).

TABLE 1. Description of the clientele, staffing and services

CLIENTELE	STAFFING	SERVICES
Mothers of newborn babies with FC	PROFIS volunteers	Orientation on breast-feeding
PROFIS associates	Program Director and Social Worker	Health education on: - immunization - breast-feeding - nutrition - hygiene - family planning
Patients under 15 years of age	Physician	Preventive medicine Pediatrics
	Pedodontist PROFIS volunteers	Preventive dentistry Orientation on dental hygiene
	Speech therapist	Speech therapy
Patients over 15 years of age	Dentist	Oral rehabilitation: - restorative dentistry - prosthodontics
	Orthodontist	Orthodontics

C. ACTIVITIES AND TIMEFRAME

The activities that will be developed during the one-year program are:

1. Health information system (HIS) data collection (Months 1 through 12)

The HIS will give us process data/Tier 1 and impact data/Tier 2. Tier 1 data will be the number of children born with FC. Tier 2 data will be the number of children seen in the PROFIS clinics over the total number of newborn babies with FC in the population.

Other data will include:

- Weekly attendance records in program activities including records of target population attending and records of volunteer personnel
- Monthly expense records

In addition to providing this much needed services, PROFIS will also be a center for health-related research. The HIS generated by the notification of birth defects and the patients' records will supply information for studying the causes of FC in the population, planning better approaches in management the services delivery, and stimulating scientific inquiry.

2. Acquisition of equipment and materials (Months 1 through 3), including:

- office supplies
- posters
- pamphlets and leaflets
- 2 bulletin boards
- 2 flip-charts
- Equipment and materials for the clinics

3. Personnel recruitment, training, and allocating (Months 1 and 2)

4. Curricula development (Month 1)

Five health education curricula will be developed for presentation on a weekly rotating basis. Each of the five curricula will comprise of formats for health education class and discussion, a bulletin board display, educational handouts and leaflets.

5. Health education (Months 2 through 12)

- Class education, 5 rotating presentations
- Bulletin boards, 5 rotating displays
- Consultation, 1 volunteer per city district to teach breast-feeding and educate on a one-to-one basis
- Distribution of educational pamphlets and leaflets

6. Monitoring (Months 2 through 12)

7. Identification and training of volunteers from the target population (Months 3 through 6)

8. Process evaluation (Month 6)

9. Summative evaluation (Month 12)

D. ACTIONPLAN WORKSHEETS

Indicator 1: Five curricula which provide opportunity for personal interaction between health educators and the target population will be developed. The curricula content will cover the indicators of the program goal.

Activities	Completion date	Manpower needed	Materials needed	Cost manpower and materials	Person responsible
Curriculum development	Month 1	1 social worker 1 program coordinator	Literature review	\$ 800	Program coordinator
Presentation development	Month 1	1 social worker	Paper, photocopies, pamphlets, leaflets, handouts	\$ 1,100	Social worker

Indicator 2: 52 health education classes based upon the curricula will be conducted by a social worker during each weekly meeting of the PROFIS associates. 3,500 mothers from the target population will attend these classes during the program year.

Activities	Completion date	Manpower needed	Materials needed	Cost manpower and materials	Person responsible
Presentation	Months 2 through 12	1 social worker	Handout, leaflets, pamphlets	\$ 800	Social worker

Indicator 3: Five rotating bulletin boards will be utilized at each meeting.

Activities	Completion date	Manpower needed	Materials needed	Cost manpower and materials	Person responsible
Information gathering	Month 1	1 social worker	- Literature	\$ 30	Social worker
Bulletin board display development	Month 2	1 social worker	- Visual aids	\$ 100	Social worker
Bulletin board display set up	Months 3 - 12	1 Social worker	- Bulletin board sets	\$ 15	Social worker

Biblioteca Universitária
UFSC

0.323-570-2

Indicator 4: Within the first year program the following materials will be operating: 5,000 pamphlets and leaflets, 40 posters, 5 bulletin boards.

Activities	Completion date	Manpower needed	Materials needed	Cost manpower and materials	Person responsible
Information gathering	Month 1	1 social worker	- Pamphlets and leaflets - Posters - Bulletin boards	\$ 40	Social worker
Materials buying	Month 1	1 social worker		\$ 150	Social worker

Indicator 5: Four women from the target population will be functioning as trained volunteers in health education to teach breast-feeding for mothers of children with FC.

Indicator 6: Four women with leadership ability will be identified from the target group for the purpose of community input into the operation of the health education program. They will be trained to function as integral components of the PROFIS team.

Indicator 7: Seven women from the target population will be functioning as trained volunteers in health education to teach toothbrushing and flossing for children with FC.

Activities	Completion date	Manpower needed	Materials needed	Cost manpower and materials	Person responsible
Leadership criteria development	Months 1-2	1 program director 1 social worker	- Literature	\$ 200	Social worker
Volunteer selection	Month 2	1 social worker			Social worker
Volunteer training	Months 3 - 6	1 social worker	- Training manual	\$ 800	Social worker

XVI. EVALUATION

Internal evaluations will be conducted during the 6th and 12th months of the program (see Appendix 4).

Process evaluation: The evaluation team will comprise the program director, one government officer appointed by the PROFIS board, and two PROFIS associates members of the board. The evaluation criteria will be based on the assessment of HIS. The evaluation team will generate reports outlining each objective, the data and specific measures employed, and their evaluation of the results. These reports will be presented to the Board of Directors of the "Comprehensive Health Action" of the Ministry of Health, and the Thrasher Research Fund.

~~The key questions to be answered in the process evaluation are:~~

1. Are program activities acceptable and well-received by the target population?
2. Has the health education curricula been developed?
3. Have the health education classes been presented every week?
4. Have eleven women from the target population been trained for volunteer staff positions?

Summative evaluation: The evaluation team will comprise the program director, one PROFIS associate, and the regional director of the "Comprehensive Health Action". They will generate reports analyzing each indicator, tier 1 and tier 2 data, and matching expenses with the budget.

The key questions to be answered in the summative evaluation are:

- Presently*
1. Did mothers of children with FC breast-feed their children for at least 3 months?
 2. Were children with FC immunized in their first year of life?
 3. Are eleven women from the target population effectively functioning as volunteers in health education at the PROFIS clinics?

A positive answer to these questions will demonstrate program effectiveness.

*Objectives
3, 4*

XVII. BUDGET

BUDGET SUMMARY	
EXPENSES	US \$
RECURRENT EXPENSES:	
PERSONNEL	
A. SALARIES AND BENEFITS	
- Program director	21,400
- Physician	20,300
- Orthodontist	20,300
- Pedodontist	17,000
- Dentist	16,500
- Social worker	14,400
- Speech therapist	14,400
- Volunteers	11,000
B. STAFF TRAINING	4,700
EQUIPMENT, EXPENDABLE MATERIALS AND SUPPLIES	
A. ADMINISTRATIVE	
- Computers	11,000
- Office supplies	4,000
B. HEALTH EDUCATION	
- Teaching materials	20,000
C. PRIMARY HEALTH CARE	
- Vaccines	50,000
- Contraceptive devices	20,000
FACILITIES	180,000
TRAVEL AND TRANSPORT	15,000
INDIRECT COSTS	20,000

BUDGET SUMMARY (cont.)	
EXPENSES	US \$
CAPITAL EXPENSES:	
PROFIS Clinics	
- Preventive medicine	50,000
- Dentistry	70,000
- Speech therapy	20,000
TOTAL EXPENSES	600,000
INCOME	
- Brazilian Government	340,000
- PROFIS	30,000
REQUESTED FUNDS	
- Thrasher Research Fund	230,000

- BUDGET NARRATIVE

1. Personnel

The salary figures are yearly salaries based on full-time employment at normal rates for responsibility, education and experience, including the respective social benefits. Eleven volunteers will participate in the program. As community members they will be paid per hour of work. Staff training will be conducted by the Ministry of Health and it will be designed to assure the desired outcomes. The wages of all personnel are donated in kind by the Brazilian Government and sum a total of US \$ 140,000.

2. Equipment, expendable materials and supplies

The expenses with computers and office supplies for one year program will be paid by PROFIS and sum US \$ 15,000.

The expenses with teaching materials for health education; vaccines and contraceptive devices for primary health care are requested from the Thrasher Research Fund and sum US \$ 90,000.

3. Facilities

Costs with facilities are covered by the Brazilian Government through the Ministry of Health and sum US \$ 180,000.

4. Travel, transportation

Participation in seminars and conferences as well as in government business will depend on traveling by the staff. PROFIS will cover these expenses up to US \$ 15,000 during the program year.

5. Capital expenses

Costs with drugs, medicines, and supplies for clinical treatment will sum US \$ 140,000 and are requested from the Thrasher Research Fund.

6. Indirect Costs

From the budget of the Brazilian Government, through the Ministry of Health, an amount of US \$ 20,000 will be provided for indirect costs.

7. Sustainability

This program has been designed as a pioneer project. The successful component parts will integrate the regular assistance provided by PROFIS to patients with FC. It is intended that this program will be continued and funded through the Ministry of Health, the Parana State Health Department, the Ministry of Agriculture, the Association of Family Well-Being, and PROFIS.

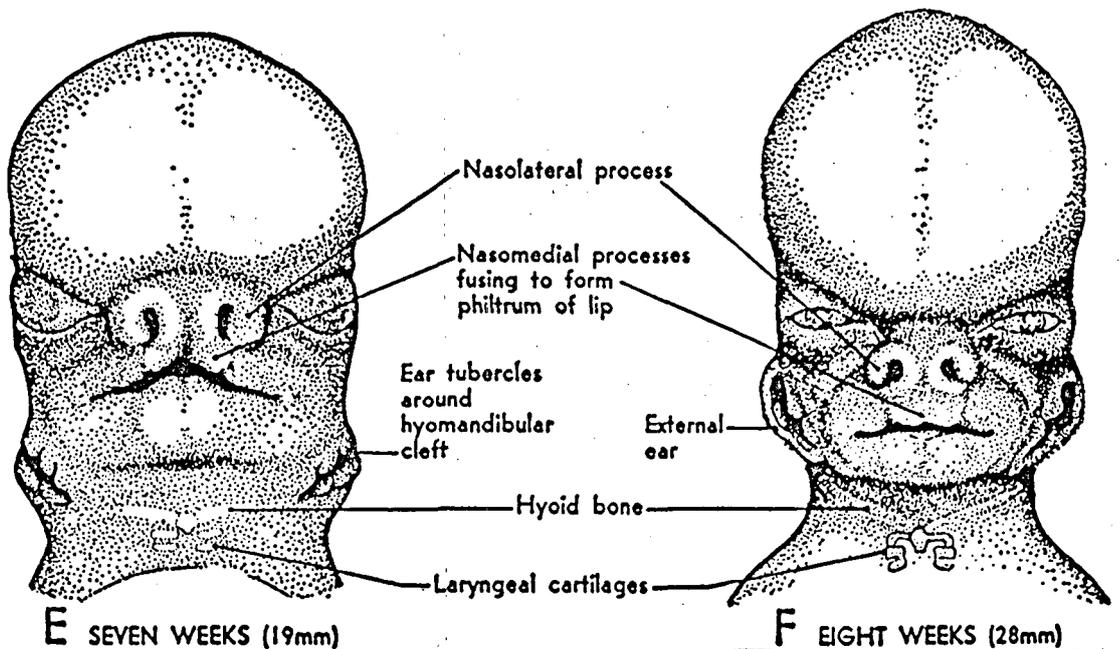
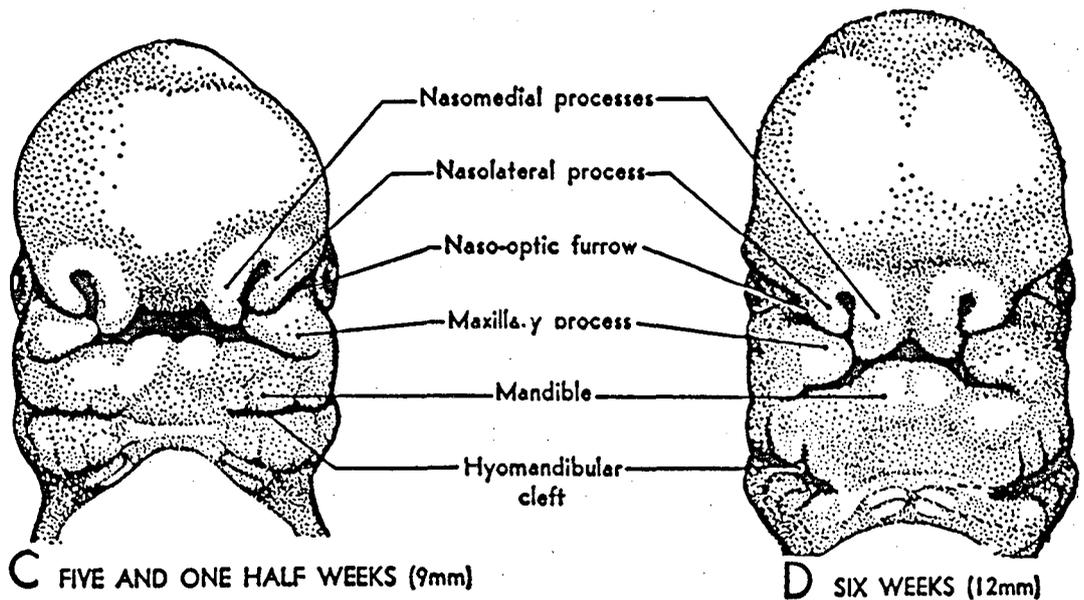
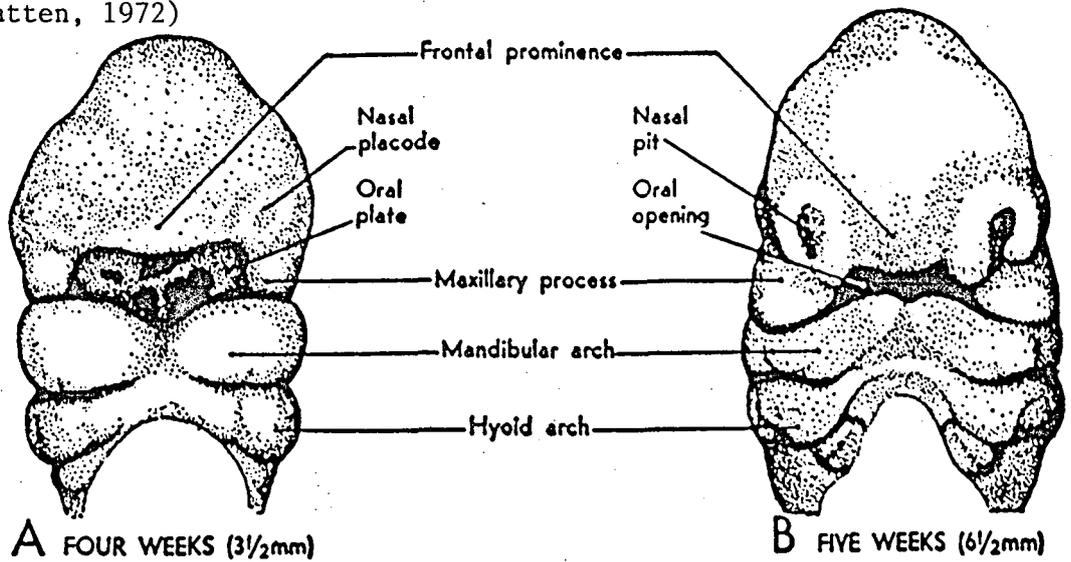
CONCLUSION

To promote education for mothers of children with facial clefts in Brazil is to promote development. Through a program of health education the women's role will be no longer seen as only of passive procreators. They will be challenged and enabled to be the agents of well-being for themselves, their children, other family members, and the society as a whole.

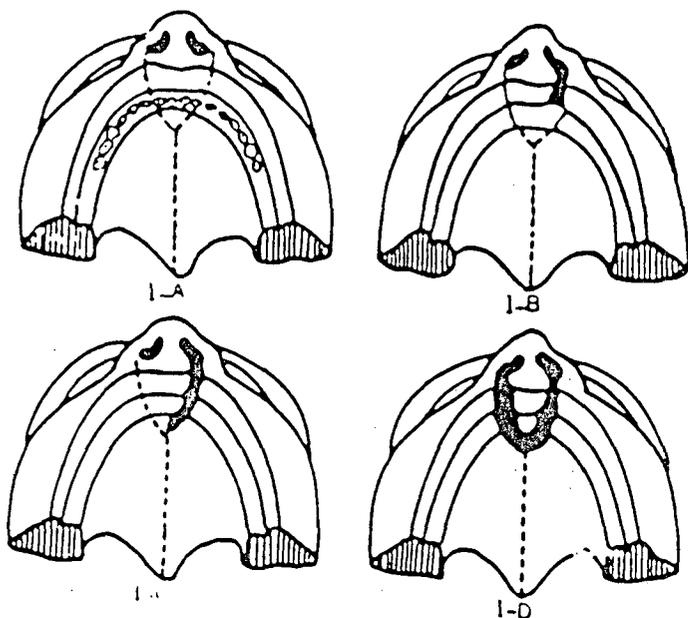
The present program is planned to transform a vision in reality. It represents a first step to implement the quality of physical and social health of thousands of people. The means to achieve this reality is to change the mental attitude of mothers, women in general and agents of development that will result in a better health status for the community.

APPENDICES

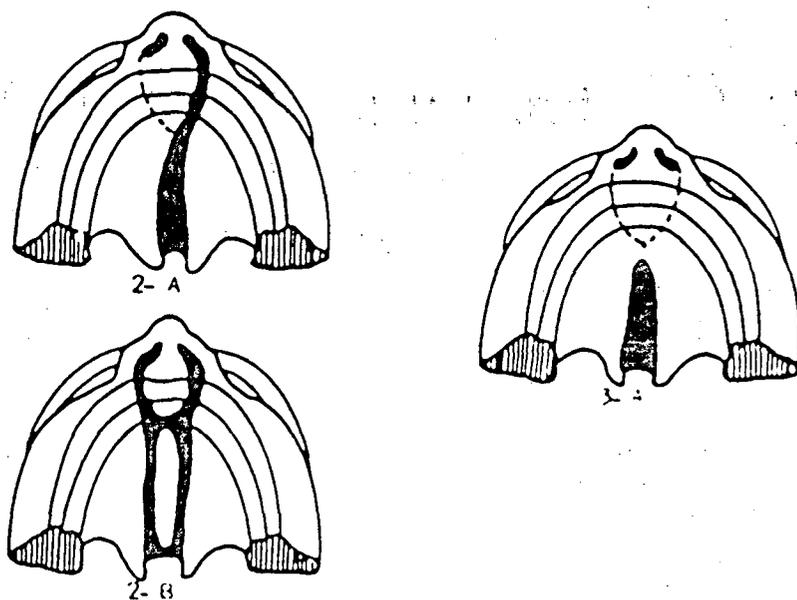
APPENDIX 1 - STEPS IN THE FORMATION OF THE FACE
 (Patten, 1972)



APPENDIX 2 - CLASSIFICATION OF CLAFITS OF LIP AND PALATE



- 1 - A : Normal structures and points of reference
- 1 - B through 1 - D : Clefts derived from the primary palate
- 2 - A and 2 - B : Clefts derived from primary and secondary palate
- 3 - A : Clefts derived from the secondary palate



APPENDIX 3

JOB DESCRIPTION FOR THE PROGRAM DIRECTOR

Job Title:

Director of the Public Health Program for Patients with Facial Clefts

Date:

August, 1990

Salary level:

US \$ 21,400/year

Job summary:

To establish and to coordinate a program in public health for patients with FC and other tasks as assigned by the supervisor.

Duties:

To plan, coordinate, and monitor activities in health promotion and prevention.

Relations:

The program director reports to the central board of the "Comprehensive Health Action" and supervises the team of 7 professionals who are delivering health care to patients with FC.

Qualifications:

Specialist in Oral Rehabilitation (Minimum 3 years experience)

Experience in clinical research (Minimum 2 years)

MPH

Development:

Prospects of promotion to director of the Department of Disease Prevention

Appraisal:

Annual increments based on work performance

APPENDIX 4
LOGICAL FRAMEWORK

Hierarchy of Objectives	Objectively Verifiable Indicators	Means of verification
GOAL Improve health status of children with FC	Mothers of children with FC attending health classes	Program director records
PURPOSE Mothers of children with FC educated on health issues by December, 1992	Health classes conducted at PROFIS clinics	Program director records
OUTPUTS 1. Newborn babies breast-fed at least for 3 months 2. Children immunized in their first year of life 3. Reduction in number of dental cavities 4. Children spaced in at least for 2 years	1.1 780 mothers of newborn babies with FC will breast-feed them at least for 3 months 2.1 820 newborn babies with FC will be immunized for measles, TB, polio, and DPT 3.1 3,200 children with FC between 3 and 12 years old will acquire control of dental plaque 4.1 2,700 mothers of children with FC will have access to contraceptive devices	1.1.1 Clinical records 2.1.1 Records from the Public Health department 3.1.1 Dental plaque control charts 4.1.1 Family planning counseling charts
ACTIVITIES 1. Hire and train personnel 2. Acquire equipment, materials, and supplies	INPUTS US\$ 1. 1 Personnel 140,000 2. 1 Vaccines, equipment for the cold chain, drugs 460,000	1.1.1 Records of the Ministry of Health 2.1.1 PROFIS, TRF records

BIBLIOGRAPHY

1. Anuario Estatístico Brasileiro. IBGE, Rio de Janeiro. 1990
2. AVEDIAN, L. V. & CLAREN, S.K. Impaired weight gain in cleft palate infants. Cleft Palate Journal., 17:24-6. 1980
3. BASCH, J. Textbook in International Health, APHA, Nashville. 1990
4. BROWN, J.T. 7 BERNSTEIN, D.W. Cuidado de enfermagem centrado na família. In: AVERY, C.B.; ed. Neonatologia, MEDSI, Rio de Janeiro. 1984
5. BUENO, A. G. et al. Reabilitação das lesões labio-palatais: uma experiência de enfermagem. Rev. Bras. Enf., 33:242-52. 1980
6. CLAREN, S.K. et al. Feeding infants with cleft lip, cleft palate, or cleft lip and palate. Cleft Palate J., 24:2444-9. 1987
7. DRILLIEN, C.M. et al. The causes and natural history of cleft lip and palate. Baltimore, Williams and Wilkins. 1966
8. FRASER, F.C. Some experimental and clinical studies on the causes of congenital clefts of the palate and the lip. Arch. Pediat., 77:151-6. 1960
9. Hospital de Pesquisa e Reabilitação de Lesões Labio-Palatais. Relatório Anual, FOB, Bauru. 1980
10. Hospital de Pesquisa e Reabilitação de Lesões Labio-Palatais. Relatório Anual, FOB, Bauru. 1990

11. IRVIN, N.A. et al. Assistencia de los padres del nino con malformacion congenita. IN: KLAUS, N.A. & KENNEL, J.H.; ed. Relacion madre-hijo. Panamericana, Buenos Aires. 1978
12. ISRAEL, J. et al. Genetic aspects of cleft palate and cleft lip and palate. In: PIRRUCCELLO, F. W. ed. Cleft Lip and Palate. Charles Thomas, Springfield. 1987
13. NAGEM, H. et al. Contribuicao para o estudo da prevalencia das malformacoes congenitas labio-palatais na populacao escolar de Bauru. Rev. Fac. Odont. Univ. Sao Paulo., 6:111-28. 1968
14. OLIVEIRA, E. A. Ocorrencia de fissuras labio-palatais em Curitiba. Rev. Saude Publica. 1986
15. PARADISE, J. L. Pediatric and otologic aspects of clinical research in cleft palate. Clin Pediat., 13:587-93. 1974
16. PATTEN, Brodley. Foundations of Embriology, McGraw Hill, New York. 1972
17. PIPES, P. Nutrition in infancy and childhood. Mirror/Mosby, St. Louis. 1989
18. PIRES, C. A. et al. Anatomia do labio e palato: embriologia cranio-facial. FOB, Bauru. 1989
19. ROGERS, B. O. History of cleft lip and palate treatment. In: GRABB, W. ed. Cleft Lip and Palate. Little and Brown, Boston. 1971

20. SOUZA-FREITAS, J. A. Centro de Pesquisa e Reabilitacao de Lesoes Labio-Palatais, FOB, Bauru. 1974
21. SPINA, V. et al. Classificacao das fissuras labio-palatinas. Sugestao de modificacao. Rev. Hosp. Fac. Med. Sao Paulo. 27:5-6. 1972