

THE NEED OF A PROGRAMME FOR THE PREVENTION OF HEARING IMPAIRMENT IN BENI STATE, BOLIVIA

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Introduction

In the Bolivian Amazonian prairies, Beni State has a surface area of 213,564 km² (approximately half the size of Spain). It has a dispersed population of 406,982 inhabitants, of which 89,613 live in Trinidad, capital of Beni.¹ Bolivia is the poorest country in South America (64% of the people live below the poverty line). In 2004, GNP per capita was \$US 1051 (871€). Direct foreign investment exceeds public investment. \$US 6.5 per person per year is provided for health care.¹

Life expectancy is 62.9 years (men: 61.3 years; women: 64.5 years). Bolivia has the lowest number of deliveries attended by health professionals and the highest maternal mortality in South America: 234 for every 100,000 live births. (In the year 2000, the World Health Organization reported an average of 20 per 100,000 live births in the developed countries). Hospital early neonatal mortality (during first 7 days of life) and infant mortality (under 1 year) are 10 and 54 per 1000 live births, respectively.¹



Justification

1. Absence of programmes for promotion of ear and hearing health

In a preliminary population based survey, out of a sample group of 658 school children (age 7 to 18), 105 presented with ear or hearing problems (16%). Impacted wax in the ear canal was the main finding, followed by chronic otitis media.

2. Absence of programmes for the prevention of hearing impairment

There are no population based studies to determine either incidence or prevalence of hearing impairment in Bolivia, nor is there a register of people with hearing disabilities. The World Health

Organization, based upon investigations carried out in countries with similar characteristics, estimate that 10% of the population suffer some type of disability.² The Japanese International Cooperation Agency (JICA), according to investigations carried out in Bolivia in 1998, established that 9.13% of the people with disability studied suffer a disabling hearing loss according to the WHO definition.³

Correlating those figures to the population in Beni (0.913%), we estimate a prevalence of 3,716 persons with a disabling hearing disability. In 2004, 8,268 births were registered in the State (out of 13,528 expected by the Instituto Nacional

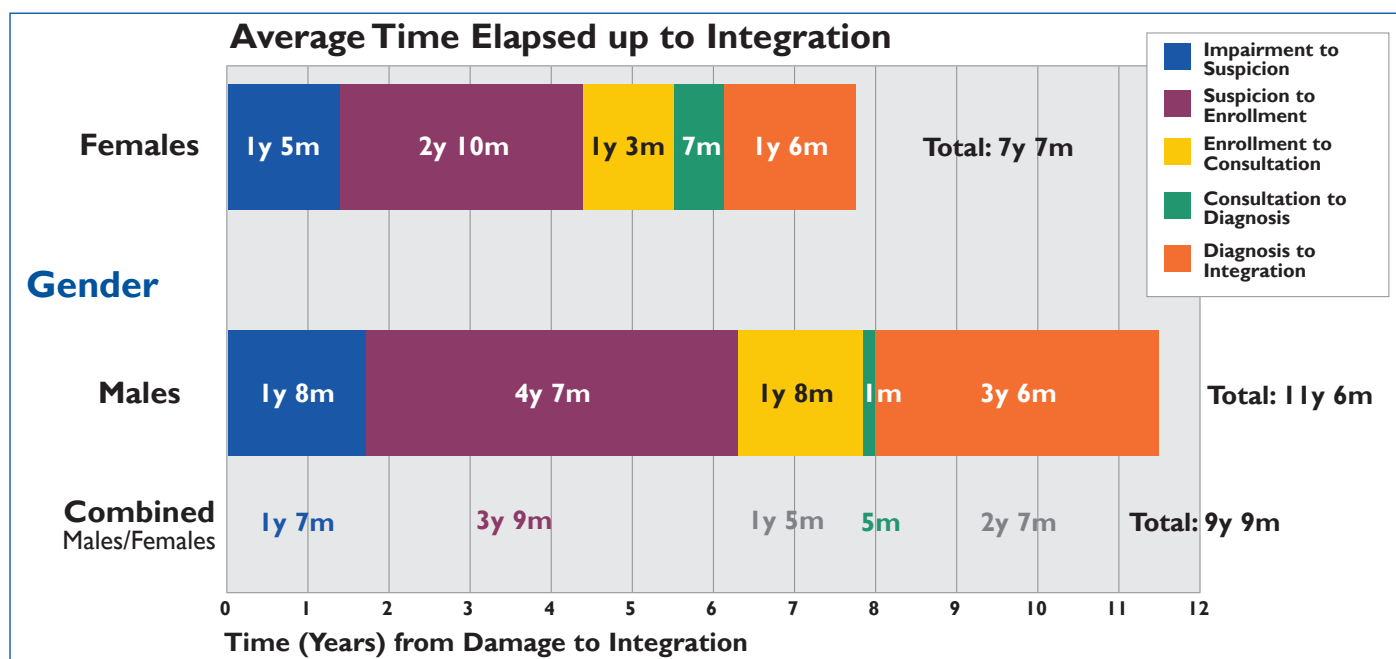


Fig. 1: Representation of the reality of stage sequence in the process of diagnosis and integration



Fig. 2: Community hearing testing in Cobija
Photo: Diego Santana

de Estadística¹), and, of these, 2473 were hospital births in Trinidad alone. Our locally determined aetiology for hearing impairment in Trinidad (under 18 years old) is: 36% acquired, 50% congenital and 14% perinatal. Due to moderate hearing loss being largely undiagnosed in our population of reference, we have been unable to gather enough data to give a realistic estimated incidence for moderate hearing loss.

3. Absence of programmes for early detection of deafness

Early diagnosis of a hearing impairment in Trinidad-Beni (before 2 years) occurs in 7.8% of cases, and late diagnosis in 92.2%. In developed countries, 50% cases of deafness are diagnosed before age 3 years.⁴ Average age at diagnosis in Trinidad is **9 years 1 month (Females: 8 years; Males: 10 years, 4 months)**, children with a profound hearing loss being diagnosed earlier than those whose loss is severe.⁵

Study

A retrospective closed analytical study of 64 students attending the only School for the Deaf in Trinidad was performed, aiming to study the aetiology of hearing impairment and reasons for the delayed diagnosis of deafness. All the students had a chronic hearing impairment greater than 60 dB HL average for the better ear. Both aetiology and the diagnostic process (timing and investigations) were examined. In order to better evaluate such delay in reaching a diagnosis, the period from the moment when hearing impairment occurred until final integration into society took place, was divided into 5 stages:

1. Hearing impairment occurred (day of delivery in congenital cases) to moment when family suspected hearing impairment (HIO-FSHI)
2. Family suspicion of hearing impairment until medical consultation was requested (FSHI-MCR)

3. Medical consultation to definitive diagnosis of hearing impairment (MCR-DDHI)
4. Definitive diagnosis to enrollment in special school (or special support group) (DDHI-ESS)
5. Enrollment in special school to 'integration' into society (ESS-IS)

Findings

The generally accepted aetiological proportions for congenital deafness are: 50% hereditary, 25% non-hereditary and 25% idiopathic.^{6,7} These differ from our study: the hereditary group is relatively smaller (31%); non-hereditary (34%) and idiopathic (34%) are greater. This finding is not unique to our population and is to be expected in an environment with a high prevalence of infectious diseases and limited methods for establishing a diagnosis.⁵

The high proportion of prematurity/ low birth weight and foetal complications such as severe hypoxia in perinatal cases (89% of total), and of meningitis in acquired cases (39% of medical causes), is described by other authors, however, their relative proportion is elevated in our population. The same is true of acquired hearing impairment due to trauma, where 26% of our series contrast with the significantly lower figures of developed countries (not greater than 9%). **Thirty-six percent (36%) of acquired hearing impairment in a mainly infant population, highlights the need to carry out programmes to educate and enable the population to prevent hearing impairment and related systemic illnesses.⁵**

Reality in Beni

In our study, average **total time elapsed** from the moment when hearing damage occurred until 'integration into society' (school or work) of the hearing impaired person took place is: **9 years and 9 months**. A significant difference exists between genders: **males: 11 years 6 months; females: 7 years, 7 months**⁵ (Figure 1).

The average **time elapsed by stage** is:

1. HIO-FSHI (Impairment to suspicion): **1 year 7 months**
2. FSHI-MCR (Suspicion to consultation): **5 years 2 months**
3. MCR-DDHI (Consultation to diagnosis): **-1 year 10 months**

4. DDHI-ESS (Diagnosis to schooling): **1 year 5 months**
5. ESS-IS (School to integration): **2 years 7 months**.

Interpretation

There is a significant and important delay for congenital hearing impairment in stage 1: an average **2 years 4 months** passed before relatives suspect it (compared to 2 months, 2 weeks in acquired cases). However, the most significant delay in diagnosis happens in stage 2, **from family suspicion to requesting specialist consultation: average 5 years, 2 months**, with a significant difference between genders: males: 6 years 3 months; females: 4 years 1 month. The negative symbol of stage 3 indicates that the norm is to enter special schooling *before* medical or audiological evaluation takes place. For a clearer interpretation of the sequence see Figure 1.

Frequently, the request for consultation takes place at the schools (special or main stream); this fact and eventuality delays definite diagnosis due to lack of referral routes to health services. As defined by Flores and Berruecos,⁸ **It is important to distinguish between identification and diagnosis, the latter being the one which leads to the appropriate therapeutic and rehabilitation programmes.**

We agree with other authors⁹ that the **best solution to reduce time** elapsed from moment of hearing damage to specialist consultation (stages 1 and 2) is to **establish systems of universal screening at the health institutions**. This action is limited in our environment, as the Public Health Insurance, for both the mother throughout pregnancy until 6 months after delivery and for the child up to 5 years of age, is hugely underused and lacks basic provision.



Fig. 3: Donated hearing instrument (Guayaramerín)

Photo: Joanne Santana

Present Setting

Currently there are two special Schools of/for the Deaf in Beni: 'Arca Maranata' in Riberalta and IDEPPSO-Beni, Trinidad. In 2005, the first School enrolled 37 students and the second 50. This highlights the situation of the estimated 1000 children of school age with hearing disability, in the Beni, who are neither identified nor registered.

Seventy-seven percent (77%) of our study group are under 19 years old, comparable to 75% of disabled people attending rehabilitation institutions in Bolivia reported by JICA. According to M. Guevara,¹⁰ in Bolivia, only **1.6% of those with hearing disability are integrated** into education and the labour market, which represents 6% of the total disabled population (or with learning difficulties) successfully integrated in the country.

Programme

The setting of a programme for the prevention of hearing impairment, with activities for primary, secondary and tertiary prevention, seems to be the way forward to alleviate the burden of hearing disability in Beni and Bolivia.

Hope

For such a programme to see the light, it will be necessary to join the efforts of

resident health professionals and external aid agencies. To integrate it into the National Health Service will take some extra help. By their fruit you will recognise them.¹¹

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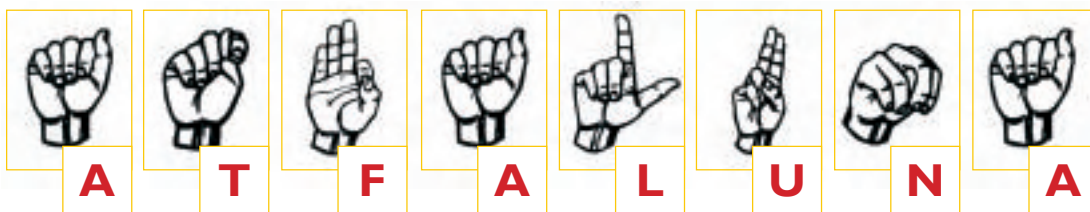
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Atfaluna News Update

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Very Dear Friends

It's a warm and sunny morning here in the Gaza Strip, and already there are subtle signs of spring in the air. The clear blue skies made for a perfect day to be outdoors, but few cars and even fewer

people are on the streets. It's post-election Palestine and the mood is one of uncertainty and apprehension. Years of military occupation and political unrest have instilled in most an uncanny sense of when it's just best to stay indoors and wait it out.

The children are back to school today following their three-week mid-year break. They are clearly happy to be back where their friends, teachers, and staff members 'speak' their native tongue, Palestinian Sign Language. This morning the playground was a sea of hands of

all sizes...hands whose eloquent movements so expressive and so meaningful in context and concept, that stories of thousands of words are expressed in only a few minutes. I watch as two three-year-olds hug each other and say how much they've missed each other and it's clear that they mean it.

How good it feels to see the children hold their heads up high in surroundings where disability has always carried with it social stigma that cannot be erased overnight. I feel proud of the children, their parents, their teachers. I feel proud