

Recognising Impairments at Birth

FACT SHEET

Part of the CBM Prevention Toolkit on "Recognising Impairments at Birth"

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1. Strategies in Prevention of Disability from Birth Impairments

Children and young adults experiencing the disabling effects of birth impairments are commonly seen in CBM supported projects.

CBM's initiative on prevention of disability from birth impairments will adopt two strategies:

- i. Primary prevention through effective maternal care
- ii. Early identification and referral for structural birth impairments

Birth impairments (commonly referred to as "birth defects") are a common cause of mortality and disability in children, yet there is little recognition or profile.

Each year at least 7 million children are born with serious birth impairments.

The incidence of impairments is between 40 and 60 per thousand live births (4-6%), with a higher incidence in lower and middle income countries.

2. Categories of impairments at birth

Birth impairments can broadly be categorized into:

- Congenital malformations (structural birth impairments)
- Chromosomal disorders (e.g. Down syndrome)
- Single gene defects (mainly cause enzyme defects, or inborn errors of metabolism such as hemophilia and thalassemia)

Our early identification program will focus specifically on **structural impairments**, also called congenital abnormalities, which can be identified easily at birth by observation and basic physical examination. We will not focus on impairments which require sophisticated laboratory or other investigations to diagnose.

3. Can birth impairments be prevented?

At least 8 conditions may lead to a higher incidence of birth impairments:

- 1. Inadequate pre-conception intake of folic acid
- 2. Iodine deficiency in the mother's diet
- 3. Lack of vaccination against rubella
- 4. Women giving birth after 35 years of age
- 5. Consanguineous marriages
- 6. Alcohol consumption during pregnancy
- 7. The use of teratogenic¹ medications and environmental pollutants
- 8. Lack of prenatal genetic counseling

These then become the basis of a prevention policy.

¹ Interrupting or altering the normal development of a foetus with evident results at birth

4. Pre-conception prevention of birth impairments

The most effective prevention strategy starts **before conception**.

<u>Strategy</u>: Effective preconception prevention of birth impairments is accomplished through a **primary health care** approach.

Community programs are encouraged to engage the community, primary health facilities, and maternity units with the following information:

- 1. Basic reproductive health services.
- 2. Close relatives should not marry.
- 3. Inform women about the risks of giving birth after the age of 35
- 4. Take 400 micrograms folic acid per day peri-conception
- 5. Use iodized salt
- 6. Women should be vaccinated against Rubella before reproductive age
- 7. Avoid alcohol, illicit drugs and smoking
- 8. Avoid medications during pregnancy where possible. Medications during pregnancy should only be taken on a qualified doctors advice
- 9. Know HIV, hepatitis and syphilis status and get treatment if positive
- 10. Get medical advice and control for chronic diseases, notably anaemia diabetes, obesity and hypertension.

The information community rehabilitation workers should know and teach regarding prevention of birth impairments is contained in the CBM Primary Health Manual and flip chart entitled "*How to Improve the Health and Development of your Child; Preventing Impairment and Disability*".

5. Post-conception and prenatal care

- 1. All of the above should continue to be encouraged.
- 2. Mothers should attend prenatal care at least 4 times during pregnancy.
- 3. Encourage good nutrition, including adequate iron intake.
- 4. Mothers should be encouraged to give birth in the company of a skilled birth attendant.

Good pre-conception and perinatal care reduces the risk of pre-term birth (prematurity), which has a significant impact on preventing birth impairments in babies and pregnancy related impairment in mothers.

6. Incidence of Structural Birth Impairments

Structural birth impairments occur in approximately 30 per 1000 live births (WHO).

- About 25% are very severe resulting in early death.
- About 50% are treatable or correctable.
- About 25% result in long-term disabling impairment despite the best of treatment.

Prevalence statistics from Africa indicate that 25% of all musculoskeletal impairments in children are due to structural birth impairments.

Many structural birth impairments cannot be prevented! The **strategy** then becomes early identification, treatment and rehabilitation. Prevention, treatment and rehabilitation is possible for 70% of birth impairments.

7. Early identification and referral

<u>Strategy</u>: Awareness, early identification and referral targeting maternity workers, birthing units and medical education schools.

- A flip chart and manual have been developed with visuals to educate maternity workers to identify and refer babies with common structural birth impairments (see *Recognising Impairments at Birth*)
- The standard of care is that birth attendants examine carefully all newborns before discharge to identify structural birth impairments.
- The flip chart aids birth attendants and maternity workers to identify the common structural birth impairments.
- The flip chart may also be used to educate and create awareness in the community as deemed appropriate

Congenital conditions seen in CBM medical projects and covered in the package include:

- Occulo-cutaneous Albinism
- Hydrocephalus
- Oro-facial clefts (cleft lip and palate)
- Brachial plexus injury
- Congenital cataract
- Polydactyly and syndactyly (extra digits or joined digits)
- Limb reduction deformities (absent, shortened, or malformed limbs)
- Clubfoot
- Congenital Dislocation of the Hip
- Neural tube defects (Spina bifida)
- Genital malformations

8. Early Intervention for Structural Birth Impairments

Structural birth impairments almost invariably require surgery or surgical expertise for treatment. Where that surgical expertise is not available, as is the case in most resource poor countries, lifelong disability can be expected.

Early intervention is crucial to prevent permanent disability from many birth impairments.

- If congenital cataract is treated early, normal vision is possible. If delayed, permanent blindness results.
- If shunting is delayed for hydrocephalus then this can result in permanent brain damage
- If clubfoot is identified early, it can be treated in the community with good results. If identified late, complex reconstructive surgery is required and the result is not as good.
- If cleft lip and palate is not treated by surgery early, death from malnutrition is common.

The CBM strategy should therefore involve support for service delivery programs for these impairments.

Clubfoot programmes, implementing the Ponseti technique, have been very successful and are now identified as a "core programme" within CBM projects.

9. Curriculum saturation

The Uganda Sustainable Clubfoot Care Project (USCCP) has shown the effectiveness of curriculum saturation of a specific birth impairment. The USCCP developed a curriculum and training module that could be applied to every level of healthcare education in the entire country including physicians, specialists, medical assistants, midwives, and primary health personnel. Thus all health-care personnel at every level of service delivery are aware of clubfoot deformity and the appropriate referral and treatment pathways.

This successful model has potential to be expanded to other areas of curriculum development for early identification and referral of birth impairments, as well as prevention strategies for other disabilities. CBM projects are encouraged to disseminate the prevention toolkit education materials as widely as possible within training institutions.

10. References:

- 1. March of Dimes Global report on Birth Defects. The hidden toll of dying and disabled children. 2006
- 2. Reducing Birth Defects. Meeting the challenge in the Developing World. Institute of Medicine. 2003
- 3. Ponseti Clubfoot Management, a manual for Healthcare providers in Uganda. Global-help.org