EVALUATION OF NYIMBWA EPILEPSY OUTREACH CLINIC

DR. MAGDA MCCGREGOR -SCHUERMAN
DEPARTMENT OF PAEDIATRICS
AND CHILD HEALTH
MAKERERE UNIVERSITY

DR. BAINGANA NGANWA
DEPARTMENT OF PAEDIATRICS
AND CHILD HEALTH
MAKERERE UNIVERSITY

MS. SUSAN NANJOBE
CBR CO-ORDINATOR
USDC, LUWERO.

MS. BARBRA KYEYUNE
CBR CO-ORDINATOR
COMBRA, BWAISE
KAMPALA

November 1993

With compliments & best wishes
from Dr Baingana Nganwa
Chairperson
Board of Trustees
COMBRA

TABLE OF CONTENTS

I ACKNOWLEDGEMENT pg. 1

II ABBREVIATIONS pg. 2

III DEFINITION OF TERMS pg. 3

A. INTRODUCTION pg. 5

A.1 Epilepsy in the developing world

A.2 Epilepsy in Uganda

B. NYIMBWA HEALTH CENTRE: pg. 6

B.1 Introduction to Nyimbwa Subcounty

B.2 Nyimbwa Health Centre:

C. INVOLVEMENT OF THE PAEDIATRIC NEURO CLINIC IN NYIMBWA HEALTH CENTRE: pg. 8

C.1. Objectives:

C.2. Structure of the Nyimbwa Epilepsy Clinic:

C.3. Staffing of the clinic:

C.4. Withdrawal of the Paediatric Neuro clinic team from Nyimbwa Health Centre

D. THE EVALUATION: pg. 12

D.1. Justification for the evaluation

D.2. Objectives of Evaluation exercise

D.3. Methodology

a. Type of study
b. Source of data
c. Method of collecting data and evaluation instrument
d. Data collection
e. Data and information analysis

D.4. Limitations of the evaluation exercise

E. RESULTS AND DISCUSSIONS: pg. 15

Section 1 pg. 16

Characteristics of Client

1. Sex

2. Age

3. Tribe

4. Associated Handicaps

Section 2 pg. 18

Control of fits and side effects of drugs

1. Definition

2. Control of fits and drug compliance

2 a. The figures

2 b. The C.B.R.Workers'view

2 c. The Clients' view

2.d. Discussions in the clinic

2 e. Drug Compliance

2.f. Conclusion

3. Side effects of drugs

4. Discussion

5. Recommendations

Section 3 pg. 23

Social/Economic Handicap of clients

1. Introduction

2. Results

2.a. The figures

2.b. The C.B.R.Workers'view

2.c. The client/carers view

2.d. Discussion

2.e. Conclusions

3. Recommendations

Section 4 pg. 28

Drug Procurement

1. Drug Procurement capability of clients

1.a. The Figures

1.b. The CBR workers'view

1.c. The clerical assistant's view

1.d. The medical assistant's view

1.e. Review of records of registered clients

2. Clinic's procurement capability

3. Nyimbwa Health Centre and the Essential Drug Programme

4. User Charges

5. Conclusions

6. Recommendations

Section 5 pg. 34

Human resources

1. Medical Assistant
2. The Staff Nurse
3. The Clerical Assistant
4. Physiotherapist
5. CBR workers
6 Conclusion
7. Recommendations

F. FINAL OBSERVATIONS AND RECOMMENDATIONS pg. 39

G. REFERENCES pg. 41

APPENDICES

I Questionnaire I
II Questionnaire II
III Letter to Medical Assistant
IV Letter to Clerical Officer
V Letter to CBR Workers
VI Essential Drug Kit
VII Map of Nyimbwa subcounty

EXECUTIVE SUMMARY

Mulago paediatric neurology clinic has been conducting out reach services to rural community based rehabilitation programmes. One of the clinics was in Nyimbwa subcounty, Luwero district where epilepsy clinics were conducted every month for 1½ years while preparing the health centre staff in the area to continue the service. Drugs were provided through a drug revolving fund.

This evaluation was done three months after the Nyimbwa Health Centre staff had taken over the running of the epilepsy clinic from Mulago staff. The objectives of the evaluation were to assess seizure control in client; knowledge of clients, carers, CBR workers and health workers concerning epilepsy and its management; and whether Nyimbwa Health Centre is in a position to continue the service.

27 people attending a routine epilepsy clinic were interviewed eleven CBR workers, one medical assistant one nurse and one accounts clerk were also interviewed. Observations were made of the activities in the clinic.

The evaluation revealed there could be a 93% potential of seizure control if: phenobarbitone and phenytoin were available; 10% of clients had stronger purchasing power and another 10% were adequately supervised by their primary carers

Community Based Rehabilitation workers play a prominent role which resulted in the high level of compliance to drugs found among the clients.

A reduced handicap was found among 72% of the clients concerning knowledge about epilepsy, the carers and CBR workers knew more about the emergency management of generalized tonic clonic fits and the importance of taking drugs regularly. The medical assistant lacked adequate knowledge on routine management of epilepsy.

The health centre was found to be in a position to continue the services to people with epilepsy in Nyimbwa if the following recommendations were implemented.

- Health centre staff need to be equipped with more information, on disability and its management through comprehensive inservice training.
- The importance of multidisciplinary approach and referral system needs to be appreciated and utilized especially by the medical workers.
- Phenobarbitone and phenytoin should be made available at health centre level.

The evaluation team also recommends that there is need for further inquiry into the epidemiology of epilepsy and that Health and Educational Services for children with special needs should be developed in at District and National levels.

I. ACKNOWLEDGEMENT

The evaluation team wishes to extend its sincere gratitude to Uganda Society for Disabled Children who provided the team with financial and material support and to Evelyn Kirumira who spent many hours typing and editing this report. Special thanks go to Roy McGregor, Ben Osuga and Dr. Tumwine for technical assistance and moral support.

II. ABBREVIATIONS

CBR	-	Community Based Rehabilitation
IGA	-	Income Generating Activities
DRF	-	Drug Revolving Fund
UEDMP	-	Uganda Essential Drug Management Programme
USDC	-	Uganda Society for Disabled Children
CMS	-	Central Medical Stores
PWD	-	Person With Disability

III. DEFINITION OF TERMS

1. DISABILITY

Disability in the context of health experience is a restriction or lack of ability (resulting from an impairment) to perform an activity in a manner within the range considered normal for a human being. Disability is characterised by excesses or deficiencies of customary expected activities and behaviour. They may be temporary or permanent, reversible or irreversible, progressive or regressive.(1)

2. HANDICAP

Handicap in the context of health experience is a disadvantage for a given individual resulting from impairment or disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that given individual. Handicap represents the socialisation of an impairment or disability and as such reflects the consequences for the individual that stem from the presence of impairment and disability.(1)

3. REHABILITATION

Rehabilitation includes all measures aimed at reducing the impact of disabling conditions and at enabling the disabled and handicapped to achieve social integration.
It aims not only at training disabled persons to adopt to their environment but also at intervening in their immediate environment in order to facilitate their social integration.

4. CARER

The person who provides nursing, material and emotional requirements to an individual who through illness or handicap does not have self care capacity (Modified E Debol - Tysk definition) (2).
The carer in this evaluation is often a close relative.

5. COMMUNITY BASED REHABILITATION (CBR)

This term is used for situations where resources for rehabilitation are available in the community. There is a large - scale transfer of knowledge about disabilities and of skills in rehabilitation to the people with disabilities, their families and members of the community. There is also community involvement in the planning, decision-making, and evaluation of the programme. CBR also includes referral services at district, provincial and national levels.(3)

6. CBR WORKER

In the USDC CBR project, Luwero, the CBR worker is the primary cadre (outside the disabled person's immediate family) who is involved in the rehabilitation process. Most CBR workers cover a village of about 30 families, are volunteers and are locally trained.

7. FIT

A sudden, paroxysmal change of consciousness, awareness, movement or sensation arising as a result of a disturbance in the function of the brain.

8. EPILEPSY

A condition in which there is tendency to recurrent fits as a result of an abnormality within the brain.

9. COST SHARING

The setting of user charges at a level which is affordable by the patient. The patient and the service provider (government) "share" the cost of treatment.(4)

10. DRUG REVOLVING FUND

A system of charging patients for their drugs which generates sufficient income to cover the cost of replacing the drugs used. The charges may be set at a level which covers only the basic cost of the drugs or may be applied in such a way that a surplus is generated which pays for distribution/administration etc. A system of cross-subsidisation may also be used such that emergency life-saving drugs are free of charge and are subsidised by a surplus made by charging more for other drugs.(4)

A. INTRODUCTION:

A.1. Epilepsy in the developing world:

The prevalence of epilepsy in developing countries lies between 6-30/1000(5). Between 80 - 98% of people with epilepsy could benefit from modern medical treatment (5). Although in the majority of cases the cause is not known, head injury, birth trauma and cerebral infection including measles, and other viral encephalitis, meningitis and malaria all can cause epilepsy and are more frequent in the developing countries. Epilepsy can be very handicapping for both the affected person and the family and yet it is one of few disabilities amenable to simple treatment with often dramatic response. The challenge in developing countries is not in the clinical aspects of managing the condition but the primary care structures, logistics and trained people to avail treatment and services to the affected population. Coupled with this is the need for social and economic rehabilitation of people with epilepsy and general awareness in the community concerning its cause and management. National level commitment to support district and community level programmes and services is also frequently lacking.

A.2. Epilepsy in Uganda:

In Uganda, management of epilepsy is highly centralised and often hospital based. It is based on drug therapy alone with little involvement of the person's family or community. The doctors or Medical Assistants often have to conduct heavy clinics and may not pay attention to epilepsy-associated handicaps, let alone explain the condition to the patient or carer. The patient may spend hours in the clinic and leave without drugs but with many unanswered questions.

Many patients turn to traditional healers who are nearer home with shorter queues and who offer more comprehensive but often ineffective alternative treatment. Because the condition is highly stigmatized, carers of people with epilepsy have sometimes travelled long distances (over 80 kms) and sold valuable possessions like goats, cows and land in the search for a cure .

B. NYIMBWA HEALTH CENTRE:

B.1. Introduction to Nyimbwa subcounty:

Nyimbwa subcounty is in Luwero district (see appendix VII) and on the periphery of Luwero triangle, the land at the centre of the 1981 - 1986 liberation war. People in this area faced all the brutalities of civil conflict including displacement, loss of property and disruption of social services. Since 1986 recovery programmes have been introduced in the district especially in the areas of agriculture, clean water supply, roads, education, care of orphans and health infrastructure by both government and NGOs. Despite these positive efforts, poverty is still wide spread in the area, and has been aggrevated and perpetuated by low coffee prices and structural adjustment programmes.

Nyimbwa subcounty has two distinct ethnic groups namely the Bantu and Nilotics.
The Bantu are mainly subsistance farmers living in scattered homesteads surrounded by their gardens of beans, sweet potatoes, cassava, bananas and coffee.
The Nilotics are mainly of the Nubian group who settled in the area about 100 years ago but have kept a distinct culture from the Bantu people around them. Their homesteads are grouped together with close relatives living as neighbours, surrounded by gardens of cassava and maize. The women make handcrafts for sale while the men are traders. Their main religion is Islam.

B.2. Nyimbwa Health Centre:

The health centre serves the Nyimbwa county population of 20,271 people (1992 population census). It is situated 1/2 kilometre from the main Kampala - Gulu road and was recently rehabilitated and equipped by the World Bank first health project. The staff at the health centre consists of:

1 Medical Assistant
2 Registered Nurses/Midwives
1 Registered Nurse
1 Registered Midwife
1 Enroled Midwife
1 Enroled Nurse
5 Female Nursing Aides
1 Male Nursing Aide
2 Cleaners

At the time of the evaluation the health centre had no beds.There was an average daily attendance of 50 patients. The health centre has a maternity unit. Like other government health facilities in Uganda the health centre receives a drug kit every three months from the (essential) drug programme.

Cost sharing was introduced early 1993. Although the health centre is directly under the supervision of the DMO's office, it has a local management committee composed of RC officials and other people chosen by the community it serves.

At the time of the evaluation, the health centre staff had not received their salaries for six months.

C. INVOLVEMENT OF THE PAEDIATRIC NEURO CLINIC IN NYIMBWA HEALTH CENTER:

The Mulago Hospital Paediatric Neurology clinic started a pilot outreach clinic in Nyimbwa, Luwero, in November 1991. Uganda Society for Disabled Children (USDC) which runs a CBR project in Luwero identified many people with epilepsy in and around the area of Bombo. Referring people with epilepsy to Mulago for control of seizures was found not to be feasible, USDC therefore approached the Paediatric Neurology clinic of the Department of Paediatrics and Child Health, Makerere Medical School, to extend its services into the community through an outreach strategy, hence the birth of the outreach clinic.

C.1. Objectives of the out reach clinic

1. To control seizures among adults and children with epilepsy within Nyimbwa subcounty.
2. To assess developmental disabilities at secondary health care level. (The primary level was covered by a resident Physiotherapist).
3. To improve knowledge and practices of people with epilepsy and their carers in the management of seizures.
4. To refer people with disabilities needing tertiary assessment and management to Mulago Hospital (only those who required referral).
5. To equip the Medical Assistants with skills to continue running an epilepsy clinic once a month in the health centre.

The identification of clients, developing home programmes and raising awareness in the community and schools concerning disability in general and epilepsy in particular was the task of USDC which was the organisation implementing CBR in the area.

C.2. Structure of the Nyimbwa Epilepsy Clinic:

The clinics were held every last Friday of the month from 10 a.m to 3 p.m. A discussion concerning some aspects of epilepsy opened the clinic. Topics discussed included the following:

1. Causes of epilepsy
2. Management of epilepsy: - First Aid
   - Routine drug therapy
3. Drug storage and administration
4. Attitude towards people with epilepsy
5. Importance of record keeping by family/clients
6. Cost sharing

These discussions took thirty to forty five minutes and often stimulated heated debates especially over controversial issues such as cost sharing and traditional practices towards people with epilepsy.

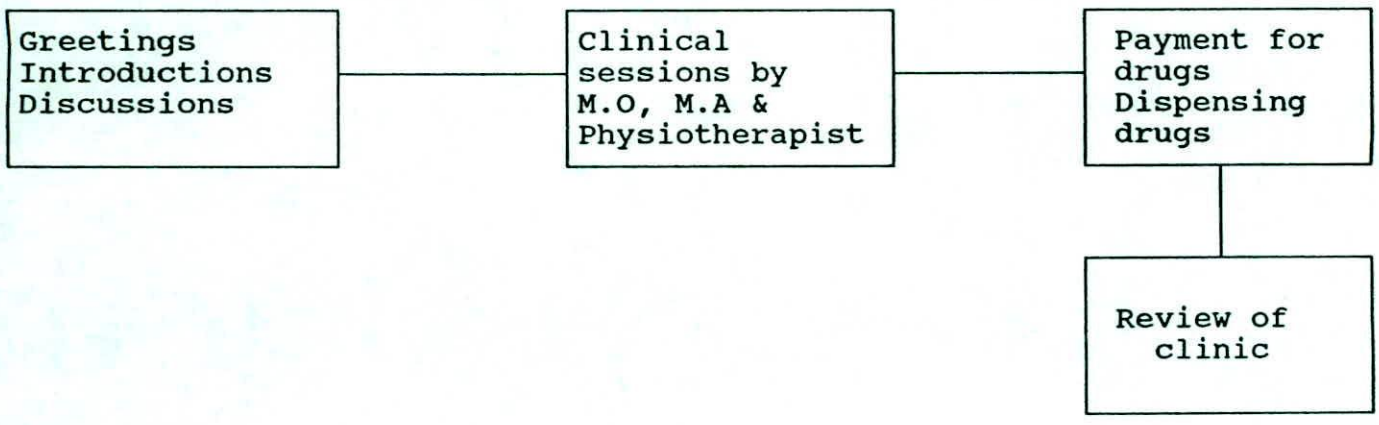
The clinical sessions followed. The clients were reviewed by the Medical Officer and Medical Assistant who also carried out assessment, and counselling. Clients were encouraged to participate in home chores, Income generating activities and school depending on the individuals potential. The CBR workers and/or carers were present during the clinical session. Three sets of records are kept;

1. File kept in the health centre with details of the clients progress and drugs prescribed.
2. An exercise book kept by the client showing drugs given by the clinic and any other medical visits in between clinics.
3. At the back of this exercise book, a record of fits was kept by the carer and a background to these fits: association with flu, fever, the rising of the moon, measles etc.

The client was then given drugs. The drugs were charged at cost price initially supported by a revolving fund provided by USDC. A clerk at the health centre received and recorded money. Receipts were issued.

At the end of the clinic, the health workers including the CBR workers had a short informal discussion to evaluate that day's clinic and suggest remedies for weaknesses identified.

Flow Chart showing outreach clinic activities



C.3. Staffing of the clinic:

Mulago hospital
- Doctor
- Nurse

Uganda Society for Disabled Children
- Field Co-ordinator
- Driver

District hospital
- Physiotherapist

Nyimbwa health centre
- Medical Assistant
- Nurse
- Clerk

Community
- CBR workers

As far as was possible, the outreach clinic integrated into the existing health service using staff from district hospital, health centre and Nyimbwa Community. This was to ensure continuity once the Mulago hospital staff withdrew.

C.4. Withdrawal of the Paediatric Neuro clinic team from Nyimbwa H.C.:

The outreach clinic withdrew from Nyimbwa in June 1993 after conducting 17 clinics.

103 clients had been registered.

Adults - 11 males
- 8 female

Children - 49 males
- 34 female

Almost all the clients were on phenobarbitone alone with a few exceptions on phenytoin or phenobabitone/phenytoin combination therapy, carbamezapine or nitrazepam. Approximately 35 clients were seen each visit.

It was decided to phase out the involvement of the Paediatric Neurology clinic because;

1. Two clinics had been conducted consecutively with no new clients being registered.

2. Approximately 80% of the clients were visiting the clinic every two months due to adequate control of seizures.

3. The health centre staff were in a position (subjective observation) to continue the clinic every last Friday of the month.

D. THE EVALUATION:

D.1. Justification for the evaluation

So far outreach clinics have been accepted as successful (a subjective opinion of staff and clients). As a result similar clinics have been started by Mulago Paediatric Neurology Clinic in Bwaise, Kampala and Kayunga, Mukono.

A more objective assessment was necessary so that valuable resources can be directed appropriately. The purpose of this rapid evaluation exercise was to assess the successes and failures of the outreach clinic for better planning and implementation of future clinics in Luwero and elsewhere. The exercise seeks for qualitative rather than quantitative achievements.

D.2. Objectives of the evaluation exercise

The evaluation set out to answer the following questions:

1. How successful is seizure control in individual clients?

   a) reduction of seizures
   b) side effects of drugs
   c) reduced handicap (socio/economic and social integration of clients)

   It should be noted that no concrete baseline data/information exists concerning this area.

2. What is the knowledge of clients, carers, CBR workers, Nyimbwa clinic health workers concerning epilepsy and its management?
   Attitudes and practices were not evaluated as these required a more in-depth study.

3. Is the health centre in a position to continue the epilepsy clinics once a month?

   a) financial and drug procurement capability
   b) staff availability
   c) client acceptance of Nyimbwa health centre.

D.3. Methodology

a. Type of study:

This is a cross sectional descriptive study.

b. Source of data:

Data and information is collected from the following:

- client's records
- clients and their carers. New clients who registered on the data collection days were excluded.
- Medical Assistant, Nurse and Clerk working with the clinic
- CBR workers
- USDC staff

c. Method of collecting data and evaluation instrument
(Appendix I, II, III)

As far as was practical, a participatory approach was used.

1. Observations were made of the clinic activities and interaction between medical workers and clients.

2. The CBR workers, Medical Assistant and Clerk answered self reporting (open ended) questionnaires 1 week before the day of the evaluation. The questionnaires were prepared by the evaluation team and were in English except for 7 out of the 11 questionnaires sent to CBR workers which were translated to Luganda.

3. Focus group discussions for CBR workers, USDC and Mulago staff were conducted.

4. Interviews of the Medical Assistant, Nurse, and Clerk were conducted. Luganda was used in the interviews with clients/carers but translation from the Nubian language to Luganda was necessary in 4 interviews. Responses were recorded in English. Focus group discussion with CBR workers was in Luganda while discussions with the USDC staff and Mulago staff was in English. Discussions/interviews with the health centre staff were conducted in English.

d. Data collection

A Paediatrician, Medical Officer and CBR Co-ordinator collected the data in one day at Nyimbwa Health Centre during a routine epilepsy clinic (last Friday of October, 1993).

e. Data and information analysis

This was done manually.

D.4. Limitations of the evaluation exercise

- Pretesting of the instruments was not done due to the size of the exercise, time and financial constraints. However, little difficulties were encountered. The only problems occured in 3 clients with mild mental handicap who were not accompanied by carers. In these three interviews the CBR worker concerned assisted with some of the questions.

- The double translation from Nubian language to Luganda, then into English could have been a source of error (interviewers of CBR workers and clients were fluent in both Luganda and English).

- Money and time constraints limited the depth of the study and data analysis.

- The information was mainly based on interviews at the clinic site rather than in people's homes

E. RESULTS AND DISCUSSIONS:

Introduction:

The results are presented in 5 sections

1. Characteristics of clients
2. Control of fits and side effects of drugs
3. Socio Economic handicaps of clients
4. Drug procurement
5. Human resources

There is overlap among the different sections as different aspects of the service are closely interrelated. Percentages have been rounded to the nearest whole number.

SECTION 1

Characteristics of clients

1. Sex

Of the 27 clients 18 were male
9 were female

Male/Female ratio: 2/1

This is not in line with the male/female ratio of all registered clients in the Nyimbwa outreach epilepsy clinic where we see the M/F ratio is 3:2 To know if this in line with the M/F ratio for epilepsy in the area a more in depth evaluation is needed.

2. Age:

Table 1

Age in years	No	Percentage
0 - 3	4	15%
4 - 7	7	26%
8 - 12	5	18%
13 - 15	2	8%
16 - 18	3	11%
18+	6	22%
Total	27	100%

59% of the clients were below the age of 12 years while 19% were between 13 - 18 years and 22% were above the age of 18.

3. Tribe

Table II

Tribe	No	Percentage
Gganda	10	37%
Nubian	9	33%
Other	8	30%
TOTAL	27	100%

As information on the tribal distribution in Nyimbwa subcounty is not readily available it is difficult to comment on these figures.
However, it seems there is a relatively high number of epileptic clients from the Nubian tribe attending the clinic.

4. Associated Handicaps

11 out of 27 clients on the clinic evaluation day had associated handicaps: i.e. Cerebral Palsy, Mental Retardation.

SECTION 2

Control of fits and side effects of drugs

1. Definition:

Definition of "Well controlled epilepsy" as used for this evaluation.

By well controlled epilepsy we mean:
1. Complete seizure control (could be achieved in 16 clients)
2. Reduction of the seizures to once a month or less (could be achieved (in 4 clients).

2. Control of fits and drug compliance:

2 a. The figures:

67% (18/27) clients have their fits well controlled with regular intake of phenobarbitone.

33% (9) are insufficiently controlled.

Of the 9 clients with insufficient control,
- 3 need phenytoin
- 2 took the phenobarb sporadically due to poor supervision by carer
- 2 had been doing well on phenobarbitone till they stopped taking it because of financial constraints.
- 1 may not have achieved control due to underlying suspected pulmonary tuberculosis
- 1 has severe spastic cerebral palsy and epilepsy is a secondary problem, the primary problem being severe extensor spasms.

81% (22) clients can be well controlled with regular intake of phenobarbitone.

93% (25) can be well controlled if both phenobarbitone and phenytoin were available in the health centre. Of the 27 clients seen on the evaluation day none were on other anti epileptic drugs or drug combinations other than phenobarbitone.

2 b. The CBR Worker's view:

CBR workers mentioned that during follow up of clients they did their best to encourage compliance to drugs. During the focus group discussion a number of CBR workers expressed fears that some clients had dropped out because they believed they were cured of epilepsy.

2 c. The Client's view:

Clients/carers also reported that during the CBR workers' visit, regular intake of drugs was always encouraged as shown in the following table

Advice to carers/clients given during home visit by CBR worker (as reported by the carer/client):

Table III

Advice given	No	Percentage
Drug compliance Regular clinic attendace The date of next clinic day	14	52%
Drug compliance Emergency management of fit	2	8%
Date of next clinic day	5	18%
No advice given	6	22%
Total	27	100%

Of the 6 carers/clients who received no advice from CBR workers, 5 had no CBR worker in their area as they were outside the CBR defined area and they were informed about the clinic by friends or relatives from the CBR area. 60% of clients/carers were encouraged by CBR workers to take drugs regularly.

2.d. *Discussions in the clinic:*

Discussions on the clinic days always emphasised regular taking of drugs and this was further stressed during the clinical sessions.

2.e. *Drug compliance:*

The findings described under b, c and d probably contribute to the level of epilepsy control achieved by 2/3 of clients attending the clinic. We can compare the compliance to phenobarbitone in the Nyimbwa epilepsy clinic with compliance to drugs in other chronic diseases e.g.

1. INH used in prevention of Tuberculosis:
   Reports on this issue from studies done in Kenya give figures in the 38-50% range (6)

2. Drug compliance in asthmatic children, as studied in the U.S.A is as low as 12% (7)

3. Only 55% of juvenile rheumatoid arthritis children are compliant with salicylate therapy in the U.S (8).

Among strategies that can be used to maximise compliance with long-term drug regimens are increased supervision and the use of written records on drug intake and disease symptoms (9)

2 f. *Conclusion:*

i) The Nyimbwa clinic has a 93% potential of seizure control in its clients if all the clients on phenobarbitone were adequately supervised, had stronger purchasing power for regular supply and if phenytoin was available for 11% of clients who need it.

ii) The remaining 2 clients could have benefited from referral. Although a referral system does exist within Luwero CBR structure it was not actively utilized.

iii) In general, a good drug compliance has been achieved in Nyimbwa.

3. Side effects of drugs

This aspect of therapy was studied from the point of view of the carer/client and from that of the evaluating paediatrician (clinical examination)

. No signs of side effects or overdose were reported by the paediatrician
. In 14% of clients (4/27) drowsiness was reported by the carers. All 4 clients were below the age of 12 years. In 3 of these the drowsiness was attributable to high dosage of phenobarbitone. In all 4 the drowsiness was not handicapping the child. The dose of phenobarbitone was calculated by weight (4 - 5 mg/kg). The weight was either estimated or calculated using the age of the child.

4. *Discussion*

About 23% of children in Uganda are wasted (10). Children with developmental disabilities are even more likely to be stunted and wasted than their able bodied counterparts (11). Parents also rarely can recall their children's ages. This is especially so in the rural semi literate/illiterate parent.

For the above reasons, it is suggested that drug dosage be calculated using the child's actual weight and not the deduced weight in order to avoid problems related to overdose. Fortunately the health centre has a beam bar as well as a salter scale for this purpose.

Side effects of Phenobarbitone are reported in paediatric literature to occur in 25% of children on this drug (12). The reported side effects are hyperactivity, irritability, short attention span and reduced cognitive functioning affecting learning. The first 2 side effects mentioned above were not noted during the evaluation visit to Nyimbwa Epilepsy clinic. As this evaluation did not set out to look into the later two side effects of Phenobarbitone we cannot answer the question whether these occured or not in the children attending Nyimbwa Epilepsy clinic.

5 *Recommendations*

i) As 81% of clients can be well controlled with phenobarbitone alone, it is highly recommended that phenobarbitone is made available as priority antiepileptic drug at Health Centre level.

ii) Phenytoin needs to be included in the clinic drugs for better control of fits of 11% of clients.

iii) Increased purchasing power of carers/clients through a loan system or income generating activities could further enhance control of fits.

iv) The health workers at the Health Centre need to be encouraged to use the existing referral system.

v) The positive role of CBR workers in increasing compliance to therapy has been noted. CBR workers need to be recruited in those areas that do not have them. Carers of clients from these areas could be the first recruits.

vi) Children should be weighed for :
- Calculation of phenobarbitone using 3 - 5 mg/kg to avoid wrong dosage.
- Growth monitoring to detect early faltering due to disease, poor nutrition or increase in disability. Parents should be encouraged to bring growth charts for follow up.

vii) Better supervision of drug intake especially by carers of children and adults with mental handicap should be advised.

viii) CBR workers need to be commended for the role they play in achieving the level of drug compliance reached by the clinic.

SECTION 3

Social/Economic Handicap of clients

1. *Introduction*

Besides reduction of fits, a person with epilepsy needs to be socially integrated into his family and community and contribute to the economic activities in the home. Control of fits assists this integration process but is not the sole factor at work. Understanding the cause of epilepsy, the emotional needs of people with epilepsy and change of attitude towards the disabled in general by the family and community is important in enhancing socio-economic integration.

Due to resource constraints a detailed study of reduced handicap as a result of the service was not done. However, concrete achievements such as increased participation in home chores/family economy, schooling etc. were used. To clarify this further we give some common responses which indicated a reduction in handicap given.

' He is now able to pick coffee and dig.
' Her speech has improved, she can follow instructions and is less absent minded (okuwugulala)'
' He has started school'
' He is waiting to start school next year'.

2. *Results:*

2 a. *The Figures:*

Among the 0 - 12 year old clients, 47% (7/15) had started schooling since commencing antiepileptic drugs or were able to do more home chores while 2 of them who were under 3 years of age had made marked improvement in their developmental milestones. 53% (8) did not show any obvious reduction in handicap since starting drugs. 2 of the 8 children had severe cerebral palsy, 2 others were already in school before commencing drugs.

Although the sample size is small and handicap much more difficult to assess in children, there is a positive trend in social integration in about half of the paediatric clients.

It would have been interesting to study this further to see if there is a correlation between regular intake of drugs and increased social integration.

Among the clients over 12 years of age, 36% 4/11 showed dramatic improvement especially in their economic independence. One started earning money by pushing a wheelbarrow, another started making and selling handcrafts (and was even able to clear drug debts she had at the clinic), while another with associated mental handicap increased in the variety of home chores and even started carrying bricks for a brick maker in the neighbourhood. The fourth who had dropped out of school sat for his O'level in 1992 and is presently in S5.

Some improvement in socio-economic independence was shown in another 36% (4/11) while 19% (2/11) showed no improvement. One client's handicap had in fact increased. His seizure control was poor, he had lost his job due to the seizures and at the time of the evaluation was coughing blood and was suspected to have pulmonary tuberculosis.

A positive trend in socio-economic integration (reduced handicap) was shown in 72%(8/11) of clients above 13 years of age and in 47% (7/15) below the age of 12 years.

2 b. *The C.B.R Workers view:*

CBR workers have the impression that since the service started, immediate family members are more positive and supportive to the person with epilepsy. However the community at large is still negative and is reluctant to have a person with epilepsy share their crockery or attend gatherings such as village meetings, church services.

One CBR worker out of the 11 reported that both the families and community in his area are still negative. However it was noted that he was the least active of the CBR workers and never attended CBR training courses, or the clinic or followed up his clients.

2 c. *The Clients/Carers view:*

Beside the occupational handicap discussed above the clients/carers were asked whether they experienced hostility or were feared by people outside their immediate family. They were also asked whether they discuss their condition or child's condition outside the family.

The following tables show the responses to these questions.

Table IV: How many people in the community know you have epilepsy?

Answer:	< 8 years	8-18 years	> 18 years	TOTAL
All	9 (100%)	8 (66%)	5 (83%)	22 (82%)
Some	-	2 (17%)	1 (17%)	3 (11%)
None	-	2 (17%)	-	2 (7%)
Total	[9] (100%)	[12] (100%)	[6] (100%)	27 (100)

Table V: Do you speak about your condition to people outside your family and the clinic?

Answer:	< 8 years	8 - 13 years	> 18 years	TOTAL
Yes	9 (100%)	8 (66%)	5 (83%)	22 (82%)
No	-	4 (34%)	1 (17%)	5 (18%)
Total	9 (100%)	12 100%	6 (100%)	27 (100%)

Table VI shows Clients who faced fear or hostility from neighbours

	0 - 12 years	> 13 years	TOTAL
Fear/hostility	5 31%	3 30%	8 (31%)
No. fear/hostility	11 69%	7 70%	18 (69%)
Total	16 100%	10 100%	26(100%)

2 d. *Discussion:*

It is interesting to note that the response 'all neighbours know about the condition' comes from the extreme ages - either from carers of young children or from adults. Older children and teenagers seem to keep the condition within the family. One 12 year old boy in primary five said the only person who knows about his condition outside the family is the headmaster of his school. Studies about chronically ill children and teenagers show that older children and teenagers find their disabilities most handicapping during this period. Teenagers with B thalassesmia and sickle cell anaemia become rebellious to their drug regimens, those with cerebral palsy and spina bifida develop rebellious behaviour and depression as they become more aware of the image reflected back to them by society(13).

Eight children and adults face fear and hostility from the community. Two of the four children face hostility from fellow children but these two children have associated mental handicap and behaviour problems.

Epilepsy is a highly stigmatized condition because of its bizarre presentation. The impaired consciousness, associated movements, body discharges (urine, faeces, frothing) and sudden fits are difficult to understand. The condition was therefore elevated to an infectious spiritual disease. While collecting baseline information from carers in Kasana (15 km from Nyimbwa) it was found that persons with epilepsy have separate crockery and often sleep alone. It was believed that touching his urine or saliva after a fit would definitely lead to transfer of the condition.

Tables IV to VI however show a more positive attitude than expected. 82% of clients or carers have neighbours who know about their condition and they can speak to neighbours about their condition. Most important of all is that 69% of clients do not face hostility or fear from neighbours. Unfortunately no baseline data exist in Nyimbwa on this aspect so it is difficult to conclude that the service started in 1991 and the efforts of the CBR workers resulted in the positive attitude towards clients.

2 e. *Conclusions:*

A few conclusions emerge from this review

1. The younger the child, the more likely it is that the community knows about the child's condition and the easier it is for the carer to speak about it.

2. The older the adult the more likely it is that the community knows about the condition of the client and the easier it is to speak about it.

3. The teenagers found it more difficult to speak about their condition outside the family.

4. Hostility is about the same for adults and children (faced by 31% of clients) and is much less than expected although this may not be solely attributable to the service.

5. A positive trend in socio-economic integration (reduced handicap) as a result of the service was seen in 3/4 of adults and in 1/2 of children.

6. Immediate family members were more positive towards the person with epilepsy than the larger community.

The service under evaluation has therefore had a positive impact on clients (and families) by reducing handicap and enhancing socio-economic integration.

3. *Recommendations*

1. Older children and teenagers need much more attention and support from both the health workers, their families and CBR workers to cope with a chronic disease like epilepsy.

2. During the next phase of the service, the raising of community awareness (beyond the family) needs to be emphasised by the CBR workers and USDC. This should be systematically planned and implemented with all parties concerned participating fully.

3. The Health Workers involved in the clinic could play a bigger role in the social integration of clients especially in specific problem areas like schools, places of work and social activities, by direct advocacy for people with epilepsy.

SECTION 4

Drug procurement

1. *Drug Procurement capability of clients and Drug Revolving Fund*

When the epilepsy clinic was started, free antiepileptic drugs were provided by USDC in order to attract clients to the service and demonstrate to the families and community that epilepsy is amendable to modern treatment. After 12 months, when the clinic was fully established the idea of drug revolving fund was introduced to the clients and carers, first for discussion and later as a necessity if the service was to continue. The charge for a 30 mg phenobarbitone tablet was Ug Shs.5/=(1 US $ = Ug.Shs.1120/=)

1 a. *The figures:*

During the evaluation exercise acceptability and procurement power of clients was inquired into with the following findings:

- 82% (22/27) of clients said that the price of phenobarbitone was fair while two clients felt it was rather high. Two were not sure and 1 client throught the price was low (and thus affecting the general service).

- Money spent on drugs on the evaluation day ranged between U.Shs. 150/= and U.Shs.1200/= with an average expenditure of U.Shs.720.

- 4 clients out of 27 (15%) had debts at the clinic. The debts ranged from U.Shs.300 to U.Shs.2070 with an average of U.Shs.1200.

- 2 clients had stopped buying drugs due to financial constraints and therefore had no debts.

- Therefore 6 out of 27 (22%) clients interviewed had insufficient purchasing capacity.

- 2 of the clients supplement their source of drugs with other health facilities (Nsambya hospital and private pharmacies). This is especially so in the case of phenytoin which is not available at Nyimbwa Health Centre.

1 b. *The CBR workers view:*

CBR workers had the following comments on cost sharing in the clinic. This was not a direct question put to them but they mentioned it either as a problem faced by clients or by themselves during the course of their work.

- Among the 12 problems faced by clients which were sited by CBR workers are the following:

  - Poverty
  - Cost sharing
  - Difficulties in paying for drugs

- Among the 7 problems faced by CBR workers, they mentioned that

  - Carers expect free things from the service
  - Carers do not want to spend money on drugs for clients. There are more urgent needs in the home.

- During the focus group discussion CBR workers said that cost sharing was unpopular with some clients because:-

  - they lacked confidence in the Health Centre accounting and procurement capabilities
  - initial free drugs made cost sharing difficult to accept.

Confidence of clients in the accounting system was enquired into with the following responses:-

22 (80%) expressed satisfaction with the accounting system while 5 (18%) were not sure.

1 c. *The Clerical Assistant's view:*

- The Clerical assistant was worried about clients inability to pay for drugs. He wanted a clear policy on the issue especially for clients whose debts continue mounting.

- It was observed during the evaluation that all drugs on that day were paid for and a number of clients cleared their debts.

- Some clients took fewer tablets than prescribed and requested if they could collect the remaining tablets during the course of the month.

1 d. *The Medical Assistant's view:*

The Medical Assistant mentioned the client's drug procurement power as a constraint both in his questionnaire and interview.

1 e. Review of records of registered clients

Review of records showed that the clinic had 103 registered clients by the time of evaluation. About 35 clients turned up for the evaluation although only 27 were reviewed and interviewed (the remainder became impatient and left after buying drugs). Some of the clients who did not attend the clinic receive drugs on a two monthly basis.

Two clients transferred to Kasana clinic because it is nearer.
Some questions that arise are:-

i) What is the drop out rate at Nyimbwa Epilepsy Clinic?

ii) Could the major reason for dropping out be the issue of cost sharing (as mentioned by CBR workers)

iii) Could the evaluation (hence the clinic) have seen only those clients with less problems?

2. *Clinic's Procurement Capability*

One of the objectives of the evaluation was to find out if the health centre is in a position to continue the epilepsy clinic by enquiring into its financial and drug management capability.

The Medical Assistant has been procuring phenobarbitone from a local pharmacy on a monthly basis using the money collected from the previous clinic. The cost price at whole sale was Shs.5/= per tablet. Clients/carers pay for drugs to the clerical officer who issues a receipt. A nurse then dispenses the drugs prescribed. If drugs other than phenorbarb are needed, the client/carer collects these from the dispensary (where cost sharing is also practiced).

Money from the epilepsy clinic is handled then banked together with money collected from cost sharing of ordinary drugs from the dispensary. Although careful records were seen to be kept, these were not studied as this was beyond the scope of this study. No carer or CBR worker participated in the financial management of the clinic. (it should be noted that over the last three months the price of phenobarbitone has tripled in the wholesale pharmacies). All clients/carers also reported that the clinic had never run short of phenobarbitone since they started attending although some wished other antiepileptic drugs could also be supplied.

3. *Nyimbwa Health Centre and the Essential Drug Programme*

Before any conclusions or recommendations can be made about the health centre's financial and drug procurement capability it is important to discuss how the Essential Drug Programme operates in Nyimbwa Health Centre. The only drugs from the "Essential drug Programme", available in Nyimbwa Health Centre, are the drugs from the Essential drug kit. Nyimbwa Health Centre receives 1 Essential drug kit every 3 months. The content of the Essential drug kit is given in appendix VI. Phenobarbitone is not available in this kit. The essential drug programme in Uganda has phenobarbitone on its list of drugs available for the health centres but due to financial constraints of the Ministry of Local Government and the district Medical Officers and the huge debts they have incurred with the Ministry of Health no drugs have been supplied to health centres in many districts including Luwero.

Another practical constraint has been the absence of many drugs in the Central Medical Stores (CMS). Even if the Health Centres is in a position to purchase drugs like phenobarbitone, this drug has not been available in the CMS for many months.

With the reorganisation of CMS we hope phenobarbitone can be made available and affordable at the Health centre in the near future.

4. *User charges*

The introduction of user charges for government health services in Uganda has been under consideration for a number of years. It is hoped that Uganda Essential Drug Management Programme (UEDMP) will continue to supply kits of essential drugs at subsidised cost. The Central Medical Stores will become National Medical Stores and will operate on a commercial basis. It is also assumed that decentralisation will take place in the health care field devolving overall responsibility to the districts with further devolution to health unit level(4).

Tentative steps have been taken in Mulago hospital and in pilot districts at introducing user charges. Unfortunately the scheme has not been as successful as expected due to insufficient preparation and sensitisation. In Kenya, the introduction of service charges at rural health facilities had the following effects:

- User charge was acceptable to most clients and patients but after introduction many people turned to traditional herbs and drug shops. Transport plus user charge was found to be beyond means of the poor.

- Staff disliked the extra work of financial matters and control.

- New outpatients declined by an average of a third and 6 months after introduction of user charge, stabilised at 1/2 the previous number (4).

Experience in Senegal and Mali (15) is also similar to that in rural Kenya. In principle user charge was generally acceptable but access to health services is constrained by limited income. However, in Mali improved quality of service lead to willingness to spend more of a limited income in government hospitals rather than in drug shops.

The Nyimbwa experience is similar to that of the above mentioned countries. CBR workers reported that the introduction of user charges had driven some clients away. They also reported that the clients/carers lacked confidence in the health centre accounting and procurement capabilities. The clerical officer expressed concern over the client's inability to pay for drugs.

Most worrying however, are the clients who took fewer drugs than prescribed and promised to come back in the course of the month for more. These clients need closer follow up by CBR workers to avoid sudden discontinuation of drugs and precipitating status epileptics.

5. *Conclusions*

i) Clients/carers are satisfied with the price of phenobarbitone and the accounting system.

ii) 1/5 of the carers/clients are unable to pay for phenobarbitone due to financial constraints.

iii) At the time of the evaluation the clinic had a well established procurement and accounting system.

iv) The epilepsy clinic, although conducted at the health centre, is not fully integrated into the health centre organisational structure.

v) Problems faced by cost sharing are universal to all cost sharing schemes. The Nyimbwa experience is not unique.

vi) Nyimbwa clinic is in a position to continue procuring antiepileptic drugs (as long as the market stays stable).

SECTION 5

Human resources

Manpower involved in the running of the epilepsy service in Nyimbwa is from three main sources.

1. The health centre
   - Medical Assistant
   - Staff nurse
   - Clerical Officer

2. Nakaseke Hospital
   - Physiotherapist

3. The community
   - CBR workers

A fourth and fifth source which are more indirect in that they are used as referral centres are Mulago National Hospital, 18 kilometres away and Kiwoko Missionary hospital 20 km away from the Health centre.

USDC and the paediatric neuro clinic which played a prominent role in the genesis of the clinic withdrew four months prior this evaluation exercise.

One of the objectives of the evaluation was to find out if the clinic was adequately staffed to continue the service and if the staff are adequately equipped to provide a comprehensive service.

The following observations were made (some of these rose from the Medical Assistant's self reported questionnare others were observed by the evaluation team):

1. Medical Assistant:

- The workload of conducting the epilepsy clinic plus his routine duties is heavy and thus reduces his efficiency in reviewing clients.

- Some clients have no problems which need the attention of the Medical Assistant but all the same come to see him.

- As this is an epilepsy clinic, he tends to focus on epilepsy alone and other associated disabilities and health conditions are peripheral.

- Has not been able to follow up all clients due to logistical problems. He is involved more with physio carer.

- Has not been able to adequately draw or implement a rehabilitation programme for those with mental handicap. This is beyond his scope of training.

5. CBR Workers

Eleven were present at the evaluation, 10 of whom are very active. One is a Community Development Assistant. They are chosen by the community and are volunteers. Each CBR worker covers a village and has approximately 10 people with disability and their families under her/his care. Her/his role is to identify people with disabilities, follow up home programmes in homes, provide information and general support to the family and raise community awareness on disability issues. A number of the CBR workers play a double role in the community as leaders in church, women's organisations, RC etc. They meet with USDC staff for discussion and training once a month and are very supportive to the epilepsy clinic, its staff and clients.

CBR worker:
- visit their clients regularly as shown in the following response by carers/clients when asked how often do CBR worker visit.

Table VII How often CBR worker visit clients

Frequency	No	Percentage
Daily	3	11%
Weekly	5	18%
Bimonthly	7	26%
Monthly	4	15%
Never	8	30%
TOTAL	27	100%

The CBR Workers appreciate the importance of regular drugs in controlling epilepsy and that epilepsy is not infectious. They can manage an epileptic fit and a febrile seizure and understand the client's need for extra love and support. Their approach to a person with disability is more holistic than that of other clinic facilitators. They however expressed the need for further training so that they can give advice more confidently as they are considered to be 'doctors' in their communities.

6. Conclusion

1 Human resources at the clinic are adequate in terms of numbers but still lack sufficient knowledge to handle client's, carer's and community needs.

2 Each profession is working in isolation from the other.

3 The workload is heavy and reduces the quality of the service

4 Remuneration is not commensurate with effort put in (by parties concerned).

7 Recommendations

1. Further comprehensive inservice training of Medical Assistant and nurse in the care of epilepsy and disability in general is needed.

2. The Epilepsy Clinic should be fully integrated into the health centre activities so that clients come on a daily basis and receive their drugs from the dispenser rather than the nurse.

   or

   The nurse could run the epilepsy clinic (after training) and only refer the difficult clients to the Medical Assistant

3. Teamwork needs to be strengthened especially cross consultations between the different professions (including CBR workers).

4. Greater efforts need to be made in training of "facilitators" at all levels of CBR in the management of clients with mental handicap and associated behavioural problems.

5. Arrangements need to be made urgently for clinic staff to receive their salaries from the Ministry of Local Government.

6. If cheap drugs can be availed on a regular basis, the difference made through cost charing could contribute to snacks for the health centre

staff and CBR workers.

F. FINAL OBSERVATIONS AND RECOMMENDATIONS

The evaluation of Nyimbwa Epilepsy Clinic has been successful in as far as it answered the questions set forward in a qualitative and quantitative way. Recommendations are drawn at the end of each section in chapter E, following the results and discussions. However a few extra general observations and recommendations have been made.

1. Eleven of the 27 clients attending the Nyimbwa Clinic have associated handicaps (41%). Therefore it is recommended not to run an epileptic clinic in separation of a clinic for persons with disabilities but to integrate both in a "clinic for disabled and epileptic persons". The approach to the disabled person and/or person with epilepsy should be a holistic approach and the clinic staff should work as a multi disciplinary team.

2. To organise integrated health care for people with disabilities and people with epilepsy at the community and district level important responsibilities should be put with the district Medical Officer and District Health committee. In the future, with a decentralised Health Programme for the district in Uganda emphasis has to be put on including disability and epilepsy into the district health plan. Affordable anti-epileptic drugs should be available at the primary health care level.

3. The work done by USDC/CBR Programme in Nyimbwa subcounty and the epilepsy clinic could be an important base for further inquiry into the etiology of epilepsy in the area. A good relationship between clinic facilitators, evaluation team and the Nyimbwa communities was observed during the evaluation exercise. Elders from the Nubian Tribe who were present expressed their concern about the high prevalence of epilepsy and disability in their communities and asked the evaluation team if they could further investigate this and give advice on prevention. Such an opportunity should not be missed!
   A clinic for people with disabilities and people with epilepsy, when supported by the community (through a CBR Programme), is an excellent starting point for further inquiry into the epidemiology of epilepsy and disability in general.

4. The majority of clients in Nyimbwa Epilepsy Clinic were under 18 years of age (see table I). Schooling in Uganda is recommended up to the age of 18 years. As 41% of clients at the clinic have associated handicaps the integration of these "handicapped children" in the normal educational system may pause considerable problems. It is therefore recommended that the Health Services and Educational Services for children with special needs be developed in close cooperation with each other at National and District Level

in Uganda. Again, interdisciplinary consultation and collaboration is essential for the optimal utilisation of scarce resources in the country.

5. During this evaluation the team was in a position to observe the influence at a National Level, of people with epilepsy. It is clear that people with other chronic diseases have organised themselves into Organisations (e.g. The Diabetic Association, The Sickle Cell Association) which empower them to lobby for resources for their condition at a national level. Although Uganda has an estimated 400,000 people with epilepsy, these people are by the nature of their disease and the associated handicaps not vocal or influential. There is need for a "Ugandan body of people with epilepsy" to lobby for their rights at a national level.

6. The notions of "Interdisciplinary refferal" and "Multidisciplinary team work" are not yet emphasised enough in the curriculum of medical, paramedical students and teachers.
Also at this level some steps should be taken to include these principles into the curricula for medical students, nurses, paramedical students and teachers.

Nyimbwa community represents thousands of similar communities in Uganda. The disabled, their caring families, concerned individuals willing to work as volunteers as well as under equipped health centres are present in each subcounty. The results of this evaluation therefore describe similar situations where CBR has been attempted. The evaluation team sincerely hopes that the results, and conclusions in this report are taken seriously both at the district and national level, and the recommendations translated into practical plans and action.

G. REFERENCES

1. Wood, P H. Appreciating the consequences of disease: the international classification of impairment, disability and handicaps. WHO chron 1980; 34(10):376-80

2. Debol - Tysk, E. Careload Analysis of severely Motor and Mentally Handicapped children. Investigations in Spastic Tetraplegic Cerebral Palsy. Department of Paediatrics, East Hospital, Gothenburg, Sweden 1986.

3. Helander, E; Mendis, E; Nelson, P; Goerdt, A; Training in the community for people with disabilities: United Nations centre for Social Development and Humanitarian Affairs ISBN 924 1544015 (1989)

4. Osmond, B F. Principles and Policies for the introduction of user charges for drugs. U.E.D.M.P. P.O. Box 8, Entebbe, Uganda, May 1993 (unpublished).

5. Van Ardel, F G; Ellison, R H; Better Docter - Patient interaction through appropriate training. Health Horisons 1989 ;12-14.

6. Egmose, T; Angawa, J O W; Poti, S J. The use of Isoniazid among Household Contacts of open cases of Pulmonary Tuberculosis. Bull World Health Organisation 1965; 33:419-433

7. Eney, R D; Goldstein, E O. Compliance of chronic asthmatics with oral administration of theophyline as measured by serum and salivary levels. Paediatrics 1976; 57:513-517.

8. Litt, I F; Cuskey W R. Compliance with salicylate therapy in adolescents with Juvenile rheumatoid arthritis. Am.J.Dis.Child 1981: 135:434-436.

9. Raposs, M A. and Christophersen E.R. Improving compliance in Paediatrict Practice: Paediatric Clinics of North America April 1982; 339 - 357

10. Demogrophic and Health Survey 1988/1989, Ministry of Health, Uganda.

11. Kiguli S. Nutrition in Cerebral Palsy children. Department of Paediatrics and Child Health 1991 (unpublished).

12. Nelson - Text book of Paediatrics, 14th edition, 1992 editor R.E

Behrman, W.B Saunders company.

13. Hirst, M. Patterns of impairment and disability related to social handicap in young people with Cerebral Palsy and Spina Bifida Ibiosoc Sci 1989; 21:1-12.

14. Osuga, B; Nordberg, E. Effects of New Service charges on Attendance at rural health facilities in Kenya, East African Medical Journal; October 1993, 627-631.

15. Vogel, R A. Descriptive analysis of the evolution and current practice of user charges in Senegal. Cost Recovery Policy in Mali. Cost Recovery in the Health Care Sector. Selected Country studies in West Africa, World Bank Technical paper No. 82 ISSN 0253-7494: 34-84.

QUESTIONNAIRE I

Nyimbwa Evaluation

Client and Client's file

Name: ..... Sex: ..... Age: .....

No. ..... Ethnic group:..... Village: .....

CBR Worker: ..... Type of seizure: .....

Mental handicap: ..... Physical handicap: .....

Physical disability: ..... Medication: .....

Dose: .....

Seizures/week or/month prior to treatment:

.....

Seizures/week now:.....

No. of visits to clinic: .....

Associated handicap: .....

What has been done about it? .....

.....

If irregular attendance (more than 2 months gap) - Reason:

.....

.....

Side effects of drugs (as noted by doctor)

.....

.....

Is patient on correct anti epileptic medication? .....

Was patient ever referred for treatment of his seizures? .....

What was the result of the referral?

.....

Other general comments/observations:

.....

.....

.....

QUESTIONNAIRE II

Nyimbwa Evaluation

Carers and Clients

Name: ..... Relation to client: ..... No: .....

What condition are you suffering from? .....

Have drugs helped your condition? ..... If yes in what way?

.....

Have you ever run short of drugs? ..... What did you do .....

.....

Why is it important to take drugs regularly?

.....

.....

Have you ever had to increase/reduce the dose of drugs?.....

Reasons: .....

.....

Do drugs cure epilepsy?.....

Occupation prior onset of treatment: .....

Occupation since onset of drugs: .....

Side effects of drugs (as noted by patient/carer)

.....

How often does the CBR worker visit you? .....

What advice does he give you?.....

.....

In between clinics; Have you had problems? ..... What did you do?

.....

Did you receive help? .....

.../2

APPENDIX VI

List of drugs in the essential drug kit

Acetyl Salicylic acid (asprin) tablets
Benzoic Acid/Salicylic acid ointment
Benzyl Benzoate, saponated conc
Chlorphenamine Maleate tablets
Chlorhexidine conc solution
Chloroquine tablets/inj
Chlorpromazine tablets
Diazepam rectal tubes
Epinephrine (adrenaline) inj
Ergometrine Maleate inj
Ferrous sulphate tables
Folic Acid tables
Gentian Violet powder
Lidocaine Hydrochloride inj.
Magnesium trisilicate tablets
Mebendazole tablets
Metronidazole tablets
Oral Rehydration salts
Paracetamol tablets
Penicillin Benzyl injections
Phenoxymethyl Penicillin tablets
Penicillin Procaine Forte (PPF) Injections
Probenicid tablets
Salbutamol tablets
Tetracycline tablets
Tetracycline eye ointments

Dr. Baingana Nganwa,
Mulago Hospital,
P.O. Box 7051,
KAMPALA.

10-10-1993

The Clerical Officer,
Nyimbwa Health Centre,
Luwero.

Dear Sir,

A participatory evaluation has been planned for Nyimbwa Epilepsy clinic, Luwero on 29.10.93. The purpose of the evaluation is to assess the successes the clinic has scored, problems encountered and their solutions. The exercise will not only benefit Nyimbwa clinic and its clients but other outreach clinics conducted on a smilar basis.

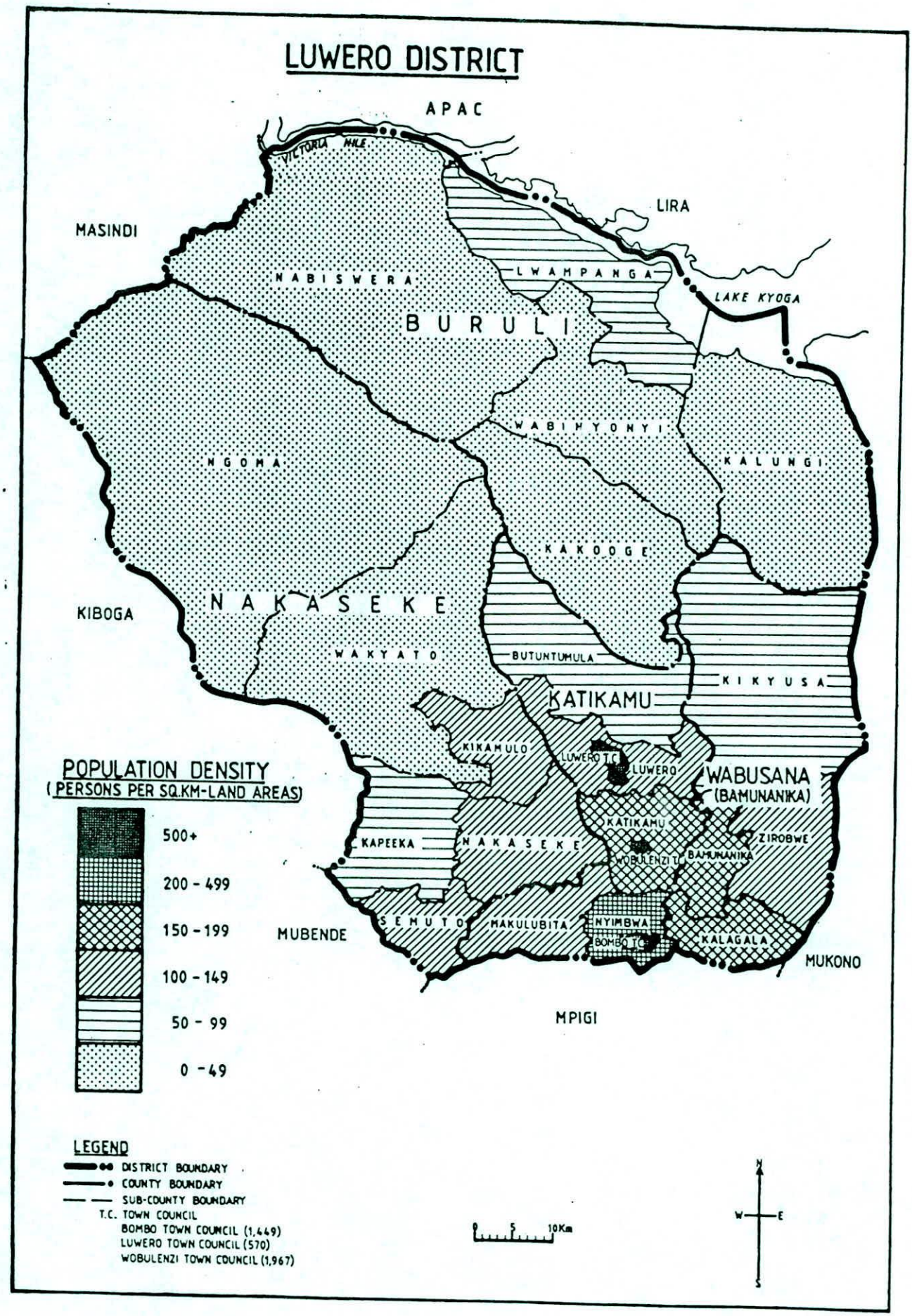
As partners in the evaluation we will be grateful if you could think over the following questions which will be the basis for our discussions on 29.10.93. Pre-written responses will be very welcome. Some of the points for discussion are:-

1. What problems do you face in drug procurement?
2. How readily have clients accepted the revolving fund system?
3. Is phenobarbitone affordable at 5/= per tablet?
4. What suggestions do you have to improve drug supply to clients?

Looking forward to your participation,

I remain yours

Dr. Baingana Nganwa.


LUWERO DISTRICT
APAC
VICTORIA NILE
LIRA
MASINDI
NABISWERA
LWAMPANGA
LAKE KYOGA
BURULI
WABIHYONYI
NGOMA
KALUNGI
KAKOOGE
KIBOGA
NAKASEKE
WAKYATO
BUTUNTUMULA
KIKYUSA
KATIKAMU
KIKAMULO
LUWERO T.C.
LUWERO
WABUSANA
(BAMUNANIKA)
KATIKAMU
KAPEEKA
NAKASEKE
WOBULENZI T.C.
BAMUNANIKA
ZIROBWE
SEMUTO
MAKULUBITA
NYIMBWA
BOMBO T.C.
KALAGALA
MUBENDE
MUKONO
MPIGI
POPULATION DENSITY
(PERSONS PER SQ.KM-LAND AREAS)
500+
200 - 499
150 - 199
100 - 149
50 - 99
0 - 49
LEGEND
DISTRICT BOUNDARY
COUNTY BOUNDARY
SUB-COUNTY BOUNDARY
T.C. TOWN COUNCIL
BOMBO TOWN COUNCIL (1,449)
LUWERO TOWN COUNCIL (570)
WOBULENZI TOWN COUNCIL (1,967)
0 5 10Km
N
W
E
S