REPORTS

COMMUNITY BASED REHABILITATION



JICA DISABILITY STUDY

prepared by jj resources

CONTENTS

-

. 7

Introduction	0000
1.Government Agencies	page
1.1 Department of Social Welfare	1
1.2 Ministry of Health	5
1.3 Ministry of Education	13
2.Voluntary Organisations	
2.1 Children's Spastic Association (Selangor & FT)	24
2.2 Bethany Home	30
2.3 CBR Cheras	38
2.4 CBR Selayang	52
2.5 CBR Rawang	66
2.6 CBR Sarawak	70
2.7 ACS Penang	80
2.8 Malaysian CARE	90
2.9 Malaysian Association of the Blind(MAB)	95
2.10 YSIS – Ipoh	100

e

-

- v

~ · · · ·



INTRODUCTION

This undertaking to document the CBR experience in Malaysia is a significant one. In one single document we can read the experiences of government agencies and the voluntary organisations.

Data was gathered through a questionnaire and the participating agencies and organisations also made submissions during the workshops and expert group meetings. CBR is not only the venture of the State related agencies but more a partnership between government, voluntary agencies and local communities.

These case studies especially from the voluntary organisations provides a variety of models of community mobilising in addressing the issues, concerns and needs of disabled people

I take the opportunity to thank all the participating agencies and organisations for the valuable input. Thanks to the JJ Resources team for documenting the reports and Mr Victor Jospeh for formatting this document.

DR DENISON JAYASOORIA JJ Resources

1.Government Agencies

.

1.1 Department of Social Welfare

The direction of the Department of Social Welfare, which has been in existence for 50 years, is towards improving the quality of life in society in a wholistic manner.

The department provides services for eight groups, that is, children, juveniles, elderly, women, families, community, volunteer welfare groups and disabled persons.

In providing a variety of services for the disabled, the department has faced constraints like lack of funds and manpower. This is because up to December 1998, there were 73,107 disabled persons registered with the department. Till August 1999, the number was 84,120 disabled persons. A total of 1,041 disabled persons are in institutions under the care of the Department of Social Welfare.

	December 1997	Decembe 199
Sight impaired	11,202	10,99
Hearing impaired	12,967	13,27
Physically impaired	24,205	25,38
Intellectually impaired	21,383	23,45
Total	69,757	73,10

Disabled persons registered with Department Social Welfare

Total	Percentage
51,175	70
3,655	5
3,655	5
14,622	20
	51,175 3,655 3,655

Source: Department of Social Welfare

There are five Taman Sinar Harapan or welfare institutions that provide training and rehabilitation to disabled persons. These centres can only take in 800 disabled persons at a time. At the centres, the department faces difficulty in getting the families to visit the trainees or take them back during holidays.

There are also cases of trainees who have completed their courses but whose families do not bring them home and they continue to stay in the centres. This results in limited places being taken up by residents who are abandoned by their families and the training of more disabled persons cannot be carried out.

Community-Based Rehabilitation

A rehabilitation programme that emphasises the active involvement of parents, families and local community was introduced. This was Community-Based Rehabilitation and it was introduced in 1984 in Batu Rakit, Kuala Terengganu and involved 55 disabled persons. As at August 1999, there were 213 CBRs with 4,781 disabled children and 453 CBR workers.

Programme

The CBR programme is one where disabled persons are rehabilitated within the family and community so that they will have equal opportunities and interaction with society. CBR was an early measure involving community participation in implementing prevention, development and rehabilitation programmes with focus on children and their families.

It is targeted at disabled persons who only require rehabilitation and training in terms of movement, special education or daily living skills. There is no age limit for trainees.

There are three CBR models - centre-based; home-based and a combination of home and centre-based. The activities include fine motor skills, language and social development, self-care, reading, writing, counting, drawing and creativity. The students also receive training in vocational skills.

A CBR Committee manages the programme and it comprises parents, local residents and community leaders. More CBRs are being set up due the greater awareness of disabled persons among parents, local residents and community leaders and also among the private sector. The responsibility of rehabilitating and guiding disabled persons is not only that of parents but also the community and voluntary bodies. Two important aspects of the programme are that the children are not separated from their parents or families and that the rehabilitation and training takes places in the community.

In 1994, the department in a report said parents had found that CBR:inculcated an independent attitude among the students.provided suitable education for the students and managed to alleviate the effects of their disability managed to improve the knowledge and skills of parents in helping their children and understanding of the children's problems through active involvement in the programme created awareness among parents that their children could possess special and unique abilities if given systematic guidance and training CBR was implemented after taking into account of traditions, financial capability of the parents and local community.

CBR has been an effective alternative in rehabilitating disabled persons. For example, the operational costs for 240 disabled persons in CBR is RM209,160 per year (seven CBR centres x RM29,880) which means a daily average of only RM2.40 per disabled person. In contrast, the costs under Taman Sinar Harapan is RM1,228,for 240 trainees 905 or RM14 per day for each trainee.

In CBR, the teachers can give full attention to students and also visit the homes to teach the parents about rehabilitation and also observe the progress of students. Parental and community involvement is optimised in CBR and any problems can be shared and solved together.

Future directions

The department plans to improve and widen the centre-based CBR programmes to every district. For the year 2000, 20 new CBRs will be set up to meet the training and rehabilitation needs of the disabled.

To improve the effectiveness of the programmes, the department plans to set up three levels of CBRs. These are Level 1 - Early Intervention (0-7 years); Level 2 - teenagers (8-18 years); Level 3 - small industries involving the disabled and local communities.

Malaysia has had some 16 years of experience in implementing CBR. In implementing CBR in the coming decade, there will be emphasis on training and rehabilitation programmes which will cover areas like medical, eye and ear care, physiotherapy, work therapy, psychological counselling, orthotics, prosthetics and assistive devices.

To spread information about CBR, the department will use information technology like computers, email, Internet and home page. This can attract the public to be involved in CBR. Each CBR centre also needs computers to prepare the disabled for the age of information technology and multimedia. Information Technology will also help the CBRs to communicate, exchange information and ideas.

Name of Institution	Eligibility	Number of Residents
Rehabilitation Centre, Cheras	Physically disabled; 14-25 years; male and female; mentally healthy, able to be trained and needs rehabilitation.	119
Industrial Training & Rehabilitation Centre for Disabled Persons, Bangi, Selangor	Physically disabled; 18-35 years; male and female; SRP academic qualifications; possess basic skills training.	21
Taman Sinar Harapan, Kuala Kubu Baru, Selangor	Severely disabled; below 35 years; male and female.	125
Taman Sinar Harapan, Tengku Ampuan Najihah, Seremban	Mentally disabled; below 14 years; needs protection, shelter and rehabilitation.	90
Taman Sinar Harapan, Tampoi, Johor Baru	Mentally disabled; male; 14-25 years; able to care for self and with potential to be trained (socialisation and normalisation).	133
Taman Sinar Harapan Jubli, Johor Baru	Mentally disabled; female; 14-25 years; able to care for self and with potential to be trained (socialisation and normalisation).	139
Taman Sinar Harapan, Bukit Besar, Terengganu	Mentally disabled; below 14 years; male and female; needs protection, shelter and rehabilitation.	58

Welfare Institutions for Rehabilitation of Disabled Persons

Source: Department of Social Welfare, 1999 (CBR_DSW)

1.2 Ministry Of Health

PART A : INTRODUCTION

Name of Organisation

Ministry of Health (MOH)

Vision:

Malaysia is to be a nation of health individual, families and community, through health system that is equitable, affordable, efficient, technologically appropriate, environmentally adaptable and consumer friendly, with emphasis on quality, innovation, health promotion an respect for human dignity, and which promotes individual responsibility and community participation towards an enhanced quality of life.

Mission:

- Mission of Ministry of health to built partnership for health to facilitate and support the people to:
- Attain fully their potential in health.
- Motivate them to appreciate health as valuable asset.
- Take positive action to improve further and sustain their health status to enjoy a better quality of life.

Areas of involvement

- Prevention of disabilities
- Health education and health promotion on prevention of disabilities (e.g. Healthy Lifestyle Campaign on injury prevention ,health talks in health clinics)
- Providing specific protection in prevention of disabilities (e.g. immunization, supplement of iodized salt to pregnant women and malnourished children in iodine deficient areas)
- Screening of newborns for preventable conditions (e.g. jaundice congenital hypothyroidism)
- Development assessment and early detection of disabilities
- Service are provided at health clinics, hospitals, schools (through the school health teams) and work place.
- Medical rehabilitation ;
- Rehabilitative services by the Ministry of Health focuses on medical rehabilitation i.e. care provided by rehabilitation professionals;
- In hospitals (secondary and tertiary levels of care, Categories and numbers – Appendix 1)

- In health centers (primary care level) under the care of of Family Health Development Division, Department of Public Health. Public Health Nurses trained in basic care for children with special needs provide training in self help skills that will lead to independent living. Number of Public Health Nurses that have been trained is 1,057.
- Services provide by the Ministry of Health
- The expanded scope of services provided by Ministry of Health includes promotive, preventive, curative and rehabilitative care at first point of contact. In line with this, rehabilitative services have been provided for the persons with disabilities, such as;

Of floaten				
Year	Ministry of Health	Hospital	Public Health	Family Health
1997	3,254,62 1,240	2,077,280,116	666,904,390	327,845,772
1998	3,313,87 0,816	1,783,317,133	658,511,015	339,237,941
1999	3,612,25 8,200	1,813,772,920	713,099,760	339,105,110

Annual budget for Ministry of Health

- Payments for services;
- Maternal and child health:Free
- Outpatient Department: RM 1
- Specialist Clinics: RM 5
- Assistive devices :Have to pay cost.

PART B DISABILITY

Definition of Disability

MOH defines disability as defined WHO (1980). Any person unable to ensure by himself wholly or partly, the necessities of a normal individual and or social life, as a results of a deficiency either congenital or not in his physical or mental capabilities.

PART C COMMUNITY BASED REHABILIATATION(CBR)

Definition of CBR

Community based rehabilitation(CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities.CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health ,education ,vocational and social services(ILO, UNESCO and WHO, 1994)

History of CBR in Ministry of Health

Initial project was started in a Health Center in Kuala Langat Disrict. The services were successfully shifted to a community center to be fully managed by the community with the health personnel giving technical input in rehabilitates care Community based rehabilitates centers are generally under the auspices of the ministry of National Unity and Community Development.

The MOH,with the aim of making medial rehabilitation services ,accessible to all, is currently providing rehabilities services for children with special needs at health 54 clinics. The trained Public Health Nurses as an interim measure provide the rehabilitative services .In future with the increase in specialized manpower in the field of rehabilitation, physiotherapist and occupational therapist will be placed at health clinics.

lssues

Some issues that need to be addressed in Malaysia with regards to Community Based Rehabilitation,

Services

The current provision of rehabilitative services is mostly centered in cities and urban areas thereby limiting the accessibility of rural population. The services available lack physical accessibility. As a results of the above problems, there is a high "dropout" rate in the utilization of rehabilitation services by parents and cares

Physical Accessibility

Distribution of facilities providing rehabilitation services is not equitable. Physical access then becomes an issue.

Range of Services Provided

Range of services provided in the Community based rehabilitation centres does not cater to all types of disabilities in terms of physical infrastructure, personnel and equipment. Therefore many fail to continue or deteriorate to baby sitting service.

Social Accessibility

The services provided are at fixed hours making it inaccesssible for some of the clients. Most services do not adequately address the emotional burden of the family and carers

Lack of integration between service provided

Person with disabilities are often managed by a number of different agencies with little or no integration. Services provided by the different providers focus only certain aspects of rehabilitation;

Health Department : medical and physical rehabilitation

Social Welfare

Social and pre school educational (registration at the District office)

Education : Education and vocational training

There is a need is to provide an integrated and coordinated rehabilitative service by combining the efforts and networking of the existing services and centers i.e. working in partnership.

Presently there is no one center where the client can access all the services and information required by the disabled.

Human Resource and Training

Manpower limitation is a major problem either in number or in expertise. Present training is more of a stopgap measure. There are only a small number of nurses with specialised training on rehabilitation in the Ministry of Health. The Ministry of Health is trying to close the gap by providing inservice training for the Public Health Nurses working in the health clinics, i.e. presently the first line of contact providing screening and rehabilitative services for children with special needs.

Community Based Rehabilitation Workers presently are not trained to carry out all aspects of rehabilitation. They have only 2 months of formal training and presently focus in on training of social skills and activities of daily living.

Lack of Support Services

Social Support

Presently, most of the rehabilitation services are focused on the persons with disability. There is lack of support services for family

and carers. Most services do not adequately address the emotional burden of the family.

Assistive Devices Support

Presently support to the persons with disability in acquiring assistive devices is not well integrated. Both the process of getting assessed for suitable assistive device becomes a hassle for the persons with disability and their family.

All persons with disabilities, who need assistive devices, should have access to appropriate as well as financial accessibility to assistive devices. Presently however, these devices are not easily made and service production, distribution and servicing the assistive devices are still inadequate.

Information and Awareness

There is a lack of awareness on disability issues among the public as well as rehabilitation service providers. Parents awareness on development potential for the child with special needs is sadly lacking. This stems from the lack of information on the availability of facilities and resources.

The role of parents/family members and carers in community based rehabilitation need to publicised. Parents need to be educated on the importance of participating in the CBR programme and the need for continuous involvement for the benefit of their child. Information needs to be made accessible to the community

Monitoring and Regulatory Mechanism

presently there is no standart indicator to measure the effectiveness of qualify and impact of the programme in existance. Currently each department carries out their own monotring system.

Non Govermental Organisation

There are not enough of NGOs to carry out rehabilities services and each funcition indipendently .Some of the existing NGOs only carry out rehabilities services for specific types of disabilities. There are also not enough support groups to help the cares and the clients.

Implementing CBR Project in Malaysia

Advantage/ Strenghts of Implementing CBR projects

- Makes the service readily available in the community
- Bring the expertise to the community making it more convenient for client
- Can mobilize participation from the community through aware programme
- Can be developed into a one stop centre for resource and information
- Once a disabled understand the CBR concept, the can be mobilised to provide service at the CBR.
- The structure is already in place with more then 2000 CBRs already functioning in the whole country.

Disadvantages/ Weakness

- If not properly monitored and manned, the project will collapse.
- There needs to be one person in charge of the CBR and it cannot work on volunteer basis.
- The CBR may be missued by parents turned into a free baby Service centre.

PART D INDEPENDENT LIVING

Definition of independence living

- Independent living is when the disabled is able to overcome his/her disability and live independently(taking care if him/herself in the daily needs)
- In a normal social environment with or without medical and social support.

Promotion of independent living

- Services on promotion of independent living is provided at the primary,
- Secondary and tertiary care levels .

Primary care level

- Screening early detection of disability and referrals to rehabilitions
- Specialist at hospitals are provided at the health clinics. Basic
- Physiotherapy services and exercise programme are also provided.

Secondary care level

Assessment, rehabilitions and training by the physiotherapist and Occupational therapist at the hospitals.Assessment for assistive devices for corrective seating posture ,eating, writing and other daily functions are also carried out the occupational therapist.

Tertiary care level

Provision of specialised services such as corrective surgery rehabilitions and assessment for assistive devices. The rehab professional assess and train in the disabled and their carers on self help skills to enable them carry out activities of daily living.focus is on both;

- Functional Activities of daily living which include feeding, eating wearing clothes .
- Instrumental Activities of daily living which includes mobility e.g.going out to the shop, catching a bus

Issues on Independent Living need to be Addressed

- Accessibility to public facilities /transport
- Financial support
- Improvement of access to facilities procurement of assertive devices.
- Increasing public awareness through development and dissemination of generic health education material to all public places, including making information on rehabilitions accessible through both electronic and non –electronic media.
- To establish sheltered workshop in all states to provide training for client in preparation for suitable job placement.
- Formulation of support groups /self help groups and networking for disabled and carers.

PART E STATUS AND SITUATION OF PERSONS WITH DISABILITIES IN MALAYSIA.

The 12 action targets as proposed under the declaration includes the following:

- National coordination
- Legislation
- Information
- Public awareness
- Accessibility and Communication
- Education
- Training and Employment .
- Self-Help Organisation
- Prevention of Disabilities and Causes
- Rehabilitation Services
- Assistive Devices
- Regional Cooperation

Among the 12 action targets , health Sector plays a major role in 3 targets areas; as follow;

- Preventation of Disabilities and its causes
- Antenatal and child Health Services
- · Screening , early detection ,early referrals and treatment
- Promotion of health living and lifestyle

Rehabilitation Services

- Early Intervention programme/children with special needs programme
- Physiotherapy /occupational therapy
- Correction surgery

Assertive Devices

Assessment for Assertive device

Much has already been done for the person with disabilities but there is still much more to do. However one main aspect that needs to be seen to is the dissemination of information ,making right to attain equal opportunity and be independent.

1.3 Ministry Of Education, Malaysia

Introduction

Historical Overview

In the early years, special education was provided by voluntary organisations. However it was to provide that the government with more access to financial resources was in a better position to provide the deaf and the blind that had hitherto been run by voluntary organisations were taken over by the Ministry of education of Malaysia (Chua & Koh, pp 53). It was not sufficient for special education to be provided only to the blind and the deaf for there were still children from many other categories of disabilities who were left out of the opportunity of an appropriate education. To ensure that all children with disabilities ha the right to an education. Education services for children with disabilities were further to include children with learning difficulties. This was only carried out in 1988. This step was in line with the decision of the interministerial meeting of 1981 demarcating the responsibilities of the various agencies providing services to people with disabilities. This decision had a marked impact on the subsequent course of development of special education in country (Special Education Unit. Pp. 130-131)

The present set-up of the system of providing services to people with disabilities has been shaped by this decision. Essentially the Ministry of Education was given charge of the education of the blind, the deaf and children with special needs who could be appropriately placed in the school setting. The Ministry of National unity and Social Development was given the responsibility of providing services to children with a severe degree of disability and people with physical disabilities. The Ministry of Health was assigned the task of carrying out screening and diagnostic activities. Non-Governmental organisations to were encouraged to continue with their work with people with disabilities to complement as well as supplement the services provided by the government agencies. The 1996 Education Act delineates the terms of reference for the services provided by the Ministry of Education. (See Appendix A)

Special Education Programmes.

Today the services provided by the Ministry of Education Includes :

Programmes for the Blind : Special schools for the blind (secondary and primary) Integrated programmes for the blind (secondary and primary)

Programmes for the Deaf

Special School for the deaf (secondary and primary) Integrated programmes for the deaf (secondary and primary) Inclusive programmes fir the deaf (secondary and primary) A secondary vocational school for the deaf Placement of deaf students in regular vocational schools

Programmes for Children With Learning Difficulties

Under this type of programme, children from various categories of disabilities are grouped together to receive the same type of education. The categories of disabilities include mental retardation, autism, epilepsy, emotional disorders, hyperactivity and slow learners. These children study in special classes that are located in regular schools. Students who have attained an encouraging standard of performance in their academic studies are sometimes selected to study together with regular students. A few of the students selected for placement in regular vocational school are students from this programme for students with learning difficulties.

Programme for Remedial Students

Remedial education for students who are academically weak and have difficulty mastering the 3 R's has been carried out for a long time. It was one of the essential components of the primary school integrated Curriculum that was introduced in 1984 (Chua & Koh, pp.187). In 1998, rmedial education was brought under the control of the Special Education Department for more effective monitoring and implementation. Two types of delivery systems are generally practised, namely, students are grouped together to be taught in a special class or are pulled out for separate instruction in the area of difficulty.

Preschool

Early intervention has always been regarded as an essential component of special education. For a long time, the Ministry of Education did not have any preschool programmes for children with special needs as legislation dictated that the ministry only caters to the educational needs of children of school-going age. However, on an informal basis, some special schools did take the initiative to carry out simple preschool activities for children with special needs. Recently, a new legislation was introduced that would enable the Ministry of Education to provide preschool services, including that for children with special needs (Laws of Malaysian, pp.24-25). Only seven preschool have been opened at the moment for children with visual impairment, but there are plans to establish a preschool within every special school in the country.

Provisions for Special Education

Resources for Special Education

It is the policy of the Ministry of Education to ensure that educational that are implemented in school have the basic infranstructural, administrative and professional support and resources for successful implementation. Some of the necessary support provided include :

Training for Special Education Teachers

For special education to be carried out effectively, it is important that the teachers who are directly involved in teaching children with special needs have the knowledge and skills related to the area of disability. It is for this matter that teacher training in the field of special education is provided to would-be teachers, or teachers currently teaching children with special needs. The Teaches Training Division of the Ministry of Education provides the training required for competency in the field of special education through the teacher training colleges. To further upgrade the knowledge and skills of the teachers, special education teachers are also sent for further studies in universities overseas. Recently, local universities have also begun offer also begun to offer course in special education and this has opened the door of oppurtunity for special aducatio teachers wishing to further enhance their skills and qualifications in the field of special education. The Ministry of Education also conducts a number of in-service training courses for the professional development of special education teachers. (See Appendix E)

Extra Allocation for Special Education

The Ministry of Education provides a monetary grant to every school based on the number of students and the types of subjects offered in the school. This is known as per capita grant. Since special education requires the use of assistive technology and a lot of extra teaching aids, children with special needs are provided with per capita grant that is higher than that provided to regular students. This is to ensure that the teaching-learning process for student with disabilities is not hampered by a lack of funds.

Administrative Control

The implement of speech education programmes in school has to be monitored and supervised to ensure that official policies are practised and directives followed. There are two types of administrative control. The Special Education Department of the Ministry of Education, set up in October 1995, (Special Education Bulletin, pp. 9) is responsible for drawing up policies related to the education of students with disabilities and charting the course of development of special education. Besides this, it also directly control the administration of the 31 special school for the deaf and the blind in the country. In each of the 14 states is a State Education Development that through the special education unit within the organization, sees to the implementation of all special educational programmes within the state. This will be further elaborated on later in the report.

The Special Education Department

The Philosophy and Mission of Special Education

The special Education Department was set up with the intention of better serving students with disabilities who have their education in the public school system. The philosophy of special education is similar to that of education for regular students. The philosophy emphasizes the importance of education as an ongoing endeavour to produce well-rounded students who besides having positive moral, social and religious values are also equipped with the knowledge and skills to be independent and able to contribute to the development of society and the nation. Towards this end, special education should be appropriate to the needs of students with disabilities and provide them with the opportunities to live.

The Organization

Before the establishment of the Special Education Department, special education as implemented in the public school system was handled by the Special Education Unit which constituted one small branch of the schools division of the Ministry of Education. Over the years as the number of small education programmes increased and there was growing awareness of the need for equally in all areas for people with disabilities, it was deemed necessary for special education to be handled by a single department for better administration and more effective delivery of services. Thus on 1st October 1995 the Special Education Unit of the School Division was upgraded to the status of Special Education Department, Ministry of Education of Malaysia.

As a complete organization itself, the Special Education Department has several divisions to handle all the various aspects of special education that need to be attended to. Heading the organization is the Deputy Director-General of Education who has to plan and formulate policies related to special education. There are three major divisions in the organizations to attend to all the important aspects of planning and implementation of policies and programmes. These three divisions are the Planning and Development Division, the Special Education Service Division and the Training Support Services Division. A Director who is assisted by a few officers working under him heads each divisions. There is also a service unit in the department to attend to the routine and daily affairs of the department. (See Appendix C) There are a number of supporting staff to assist in the smooth running of daily office affairs. Altogether there are thirty-three personnel serving in the Special Education Department.

The following represents the breakdown of the number of personnel in the Special Education Department.

37

PositionNumber

(a) Deputy Director-General of Education	1
(b) Divisional Directors	3
(c) Assistant Directors	20
(d) Supporting Staff	13

Total Number Of personnel

Administration Aspects of Special Education Special Schools

There are altogether 31 special schools in the country, 25 schools for students with hearing impairment and 6 for children with visual impairment. All these schols come under the direct administration of the special Education Department. This means that all matters pertaining to special schools such as funding for the schools, teacher placement and transfer, teacher salaries, appointment and promotion of school heads and monitoring of school management and accounts are all the responsibility of the Special education Department.

Special Education Policies and Programmes

In addition to overseeing the overall administration of the 31 schools in the country, the Special Education Department is also responsible for drawing up appropriate special education policies and the planning of special education programmes. To ensure that

the policies and planning are comprehensive and address issues of current concern, the special Education Department hold regular discussions with all the school heads and the heads of all the special education units from the state education departments. These officers are directly involved in the implementation of programmes and are therefore more in touch with the various problem faced at the ground level. They would thus be in a position to provide accurate feedback on the kinds of the problems faced in the implementation of special educational programmes.

The heads of the special education units play an especially important role as they are responsible for the successful implementation of special implementation of special education programmes in their respective states. However, although they handle all matters to special education in their respective states, they are not directly under the administration of the Special Education Department. Notwithstanding this, they have to follow official directives from the Special Education Department. Placement and transfer of teachers and students in the integrated programmes are the direct responsibility of the heads of the special education units. Other responsibilities include monitoring the implementation of special education programmes and the establishment of new programmes in the state.

The heads of the special schools are under direct supervision of the Special education Department. They have to know the various needs of the schools and the overall costs of running the school. This will be conveyed to the special Education Department which will bid for the money to cover the annual financial costs of operation and to purchase whatever thing that are required by the school. The heads will also report to the Special education Department problems and issues which they are unable to resolve.

Some Issues in Special Education

For effective implementation of programmes for students with disabilities, special education teachers need to have the required basic qualifications. This means that they should have undergone the necessary teacher training in the field of special education to acquire and knowledge to handle effectively children with special needs. At the moment, a number of teachers teaching in special education programmes are trained but not in the field of special education. This implies that children with special needs may not be getting the best from education. This situation will charge in time to come where there is a sufficient numbered of trained special education teachers in future. This is foreseeable of teacher training courses and schemes in the field of special education has increased and teachers have the option to choose special education as their area of specialisation.

Integrated special education programmes are special classes that are established in regular schools. There are a lot of such programmes for children with special needs. The programmes are directly under the administrative control of the school administrators and as such are subject to the same policies and practices of the school. A problem that has constantly arisen because of this situation is that because of this situation is that because emphasis is placed on students achieving excellent academic results, children with special needs do not get the attention they deserve. Special education programmes occupy a low priority in many school as the education system is very much academically inclined. A number of programme receive little support from the school administrators and are not carried out as how they should. The special Education department has taken steps to address this problem by conducting seminars to introduce school to the unique nature of special education. A better understanding of the needs of special education will enhance their sensitivity to the importance of the education of children with special needs.

There are still a shortage of specialist to provide the necessary complementary related services to special education. At the moment there are only two trained speech and language pathologist serving the population of students with hearing impairment. Teachers teaching in the programmes involving in the children with learning difficulties are not specialist in any of the areas of disabilities but rather are general special education teachers. Each category of disability has its own unique needs which requires the attention of specialists in that particular area of disability, but this aspect has still not been fully addressed because of the lack of professionals specialising in one particular area of disability. The ministry of education is looking into this need for specialised services to help students based on the category of disability of the students.

Training Students to Be Independent

. .

The major aim of special education as provided by the ministry of education of Malaysia is to produce students who have the skills to function independently in society after they have their education in the public school system. A holistic approach is necessary to achieve this aim of equipping students with skills in the social, emotional, spiritual and vocational spheres of life. In their pursuit of knowledge that is imparted through the public school system, students needs are constrained in their ability to learn to their maximum potential by their disabilities. As such, consideration is given to their disabilities in the delivery of education by providing the necessary accommodations and modifications in the teachinglearning environment to facilitate the acquisition of knowledge. The provision of different types of educational placement for children with special needs is a direct response to the need to facilitate the teaching learning process of students with special needs.

Incorporated into the normal practices of special education is the training provided to help students with special needs to function as normally as the extend of the handicapping condition of their disability will allow. In the case of students with visual impairment, skill training in the area of orientation and mobility is provided to help them move around independently despite not being able to see the surroundings. A large number of programmes for the visually-impaired, although labelled as integrated programmes, are in fact inclusively in practice for the students with regular students and only receive special instruction from the special instruction from the special education teachers for which they face difficulty.

For students with hearing impairment, training in communicative skills is given to enhance the communicative ability of the students. Total communication with the philosophy that any means of communication that could help the population with hearing impairment to communicate should be used for communication purposes is the medium of instruction. Emphasis is placed on using signed language and speech as the main modes of communication. Students are taught the Malay language Hand codes and providing with speech to help them with communication. Most of the students with hearing impairment do not pass the qualifying public examinations that will enable to be promoted to continue their upper secondary education. This situation is not so much the result of poor cognitive abilities as poor language mastery. If no step were to address this situation, most of the students with hearing impairment would reach the end of their formal education early age without any concrete, employable skills and this could possibly give rise to a social problem. To address this issue, a vocational school was established in 1987 to provide vocational training to students so that when they come out to society, they will have skills that are sought by the employment sector. Presently the school takes in students who have completed their Lower Certificate of Examination. The school has a capacity of about 350 students and is open to students from all over the country. In 1998, a group of selected students with special needs who applied for vocational training after their lower secondary education were placed in

regular vocational school for vocational training in an inclusive setting.

The Ministry of Education also runs special programmes for students with learning difficulties. This group of students is from all categories of disabilities, other than students with hearing and visual impairment. The degree of severity of their disabilities however does not inhabit their mobility, nor their ability to look after their daily needs. All the programmes are integrated within regular schools. The children are not required to sit for public examinations to sit for public examinations and they are allowed to study in school till the age of 18 years. The major aim of education for these children is to help the students be independent when they have completed their education. To achieve this aim, a lot of programmes for these children emphasise the acquisition of socialisation, prevocational and self-help skills. The curriculum for this group of children has been modified to enable the students acquires this skill. Students who are assessed by their teachers to be able to follow the regular curriculum are sometimes include in the regular classroom and the special education teachers will advise the regular teachers on matters pertaining to the academic instruction and behaviour management of the children.

Inclusive Education in Regular Vocational Schools: A Brief Report

Introduction

Since the Secondary Vocational Special School, Shah Alam was first opened in 1988, it had been the only school that provided fulltime vocational training to children with special needs in the public school system. The school was for students with hearing impairment, the majority of whom had failed the qualifying public examination into upper secondary school. The school had a student capacity of about 350 students and took in students from throughout the country. At the initial stage, there was no problem finding placement for all the deaf students who applied to study in the school as the number was still small. However, over the years as the number of students applying for vocational training in the school increased, some applicants had to be rejected as the school had already reached full capacity. There was only one other special school that accepted students for full-time academic studies at the upper secondary level, and these schools only had a capacity of about 40 students. The Ministry of Education had to find a way to address this issue. One way of doing this was to find an alternative placement for the students.

Thus, at the end of 1998 a proposal was put forth by the Special Education Department to place some of the students with special needs in regular vocational schools. This proposal was especially appropriate for it met some of the ideals of special education. The setting would be inclusive and thus students would be studying in the least restrictive environment. In addition, students would undergo training to acquire skills that would help them find employment in future. The employment sector had been especially encouraging in providing students with special needs the opportunity to make a living from the skills they had acquired.

Implementation Scheme.

The proposal was accepted and became reality at the start of the school season in 1999. The Special Education Department and the Technical Education Department met several times to discuss the details for implementation. It was agreed that a vocational school in every estate would take in 2 to 4 students with special needs to study with the regular students. The students could be from any category of disability. A panel would select the candidates. Representatives from the Special Education Department and the Technical Education Department, heads of the special education units and principals of the vocational schools would form the members of the panel. The criteria for selection include satisfactory academic results, ability to be independent, interest of students, behaviour that would not cause problems to others and recommendation from the principals of the school.

The course offered to the students are limited to those that the students could do. Vocational training includes courses in airconditioning., welding, woodwork, electricity and food catering. As the regular teachers might find difficulty in handling and communicating with the students, the Special Education Department would make the necessary arrangements to send a resource teacher to help in the teaching-learning process. Dependency on the resource teacher as an intermediary would be gradually reduced, as the students become more accustomed to the inclusive school environment.

This type of inclusive education started with a first batch of 33 students in 11 vocational schools. To ensure that the programme would be run smoothly, officials of the Special Education Department made trips to each of the school to get feedback on the implementation of the programme.

Feedback of Programme Implementation

Officials from the Special Education Department visited the vocational schools involved to monitor the implementation of the programme. Feedback from the principals, teachers and the inclusive students themselves revealed that there were both positive and negative aspects to the programme.

On the positive side, the acceptance of the students by the administrators and the teachers was very encouraging. The concept of students with disabilities studying together with regular students was something new but what proved surprising was that some of the students with disabilities could perform better that their regular counterparts. However, communication with the students with hearing impairment was a problem. As such, the teachers could not fully understand the needs of these students, and provide more effective assistance. With the resource teacher acting as intermediary, however, this problem was resolved.

On the negative side, generally the students with special needs feit isolated from the rest of the regular students. This was especially so with the students with hearing impairment who because of the communication problem, were not able to make many friends. This sense of isolation resulted in a few of the students dropping out of the programme The special students, especially the students with hearing impairment generally socialise among themselves.

One unexpected problem that arose was the opposition from some parents who did not think that including their children in a vocational school was a good idea. These parents still held on to the belief that the best choice of placement for their children would be the vocational school in Shah Alam.

The Ministry of Education will continue with this programme of sending students with special needs to regular vocational schools. There may be a slight modification to the programme to address the problems faced by the students With this kind of programme students with special needs will nor only acquire vocational skills that will help them find employment in future, but also have the opportunity of interacting closely with regular students on a daily basis 2. Voluntary Organisations

2.1 Children's Spastic Association

PART A

<u>Name of Organisation</u> Spastic Children's Association of Selangor & F.T or Persatuan Kanak-Kanak Spastik Selangor & W.P

Year of Founding

The Centre was founded in February 1960 with 7 children. It started in a garage of the Red Cross Soc. In mid 1966. The centre moved to the current premise, 14 Lorong Utara 'A', P.J.1960-1981 The name of the Centre was Spastic Children's Association of Selangor.1982 onwards the centre is know as Spastic Children's Association of Selangor & F.T

Area of Involvement

The Centre provides rehabilitation, education, training (Independent Living Skilss), sheltered workshop and also seek open employment for them.

The rehabilitation services are Physio Therapy, Speech Therapy and Occupational Therapy.

The Physio Department

Is also coordinationg the hydro Therapy pool programmes, Hippo therapy (horse riding). The Physio therapist works closely with a neurologist who does selective Rhizotomy operation for those who needs it.

Speech Therapy

Language Communication & Feeding/Swallowing

Occupational Therapy

Provide Skills training for functional independence

Annual Budget

1997-RM 1,513.944 (old building) 1998-RM 2,620.009.05(2 buildings) 1999-not available yet

<u>Location</u> 14, Lorong Utara A, Petaling Jaya P.O Box 48, 46700 Petaling Jaya Clients Number of clients 134 plus 40 getting rehabilitation services.

Type of disabilities

CP (mainly) in addition a few cases special of Muscular Pystrophy, Spina Bifida.

Age 18 months - 41 yrs old

Gender 80 Male 54 Female

Race 51 Malay 65 Chinese <u>15 Indian</u>

Socio-economic Status

Ranges from the rich to the average.

Services are free. A nominal sum of RM 50 is paid per year for stationary if they can afford.

.

PART B DISABILITY

Defination of disability is the inability to do what is within the norm.

PART C

COMMUNITY - BASED REHABILITATION (CBR)

Your understanding or definition of CBR

Providing rehabilitation Services for a community (centre & outreach programmes).

History of CBR in your organisation. Home visits, occasional assistance & training to CBR centres.

What are the aspects of CBR being implemented in your organisation?

Past and present attempts and future plans to promote CBR among disabled people you work with : (please list programmes, activities and projects)

Staff recommending to the management that another team is set up to perform the following: Home visit of those registered with the centre but cannot attend.

Assisting CBR centres upon request.

Problem areas in implementing CBR in your organisation: Funding & Staffing

Success and progress in implementing CBR in your organisation:

Implementation is still at the planning stage.

What are some SBR issues you feel to be addressed and tackled in Malaysia?

(at macro and micro level)

<u>At macro level</u>

How much importance given to it by Department of Social Welfare, Government policies, implementation process, budgets, training etc.)

Increase funding/budget for social welfare improving services e.g. accessibility.

At micro level

Recipients, training, background of CBR staff, social impact of programmes, CBR Committees)

Staffing of CBR centres should be team (medical, teachers, social workers etc) oriented.

How adequate are the measures taken by NGOs and the Government to implement CBR Concepts and practices in Malaysia?

In cases measures taken by NGOs and the Government to implement CBR. In cases measures taken by NGOs are adequate but it needs to be extended to all CBR Centres.

What is the level of participation in CBR programmes by persons with disabilities?

(at macro and micro level)

Level of participation at both macro & micro level is minimal & is more significant at the macro level.

To what extent is the community mobilised to participate in your CBR programme?

Which group in the community have been targeted and mobilised for involvement in the CBR programmes? (Local community, leaders, schools, private sector companies government agencies?)

Have there been attempts at community mobilisation through awareness and education programmes?

What are some of the advantages disadvantages obstacles and strengths in implementing CBR projects in Malaysia?

Advantages:

Increases area more community involvement, which hopefully increases awareness, descries stigma associated with people with disabilities.

<u>Obstacles:</u>

- Lack of professional/ trained staff.
- Lack of community support
- Lack of infrastructure
- Lack of government funding
- Lack of support from private insting

Strengths:

- Strong community spirit
- Supportive NGOs1

PART D INDEPENDENT LIVING (IL)

Your understanding or definition of IL

- Independence terms of: -
- ADL
- Basic Care
- Financial

History of IL in your organisation. Since inception (39 yrs ago) What are the aspects of IL being implemented in your organisation?(e.g., group homes; advocacy; self-help group; independent living support programmes like assistant service, financial/credit schemes, job placement; and sheltered workshops)

- Pvt-
- Time management
- Butgetting
- Recreational
- Use of facilities within community or training classes

Past and present attempts and future plans to promote IL among disabled people you work with: (please list programmes, activities and projects)

Past: - MAS headphones & car plugs

<u>Present</u>: - Security seals, hydroponik, 2nd handshop, selling (entreprevecurship)

Problem areas in implementing IL in your organisation: Lack of support, staff, creativity, private industry, parents, and community accessibility.

Success and progress in implement IL in your organisation: Not up to expectations

What are some IL issues you feel need to be addressed and tackled in Malaysia? (at macro and micro level)

<u>At macro level</u>

How much importance given to it by the Government and Department of Social Welfare, awareness, budgets, training programmes, implementation

Improving community awareness, improving infrastructure.

<u>At micro level</u>

Recipients, awareness among disabled of IL, training and background of staff

Advocacy by the disabled & their parents qualified staff.

How adequate are the measures taken by NGOs and the Government to implement IL concepts, practices and issues in Malaysia?

Much room for improvement

What is the level of participation in IL by persons with disabilities? (both micro and macro levels) Much room for improvement

As Malaysia moves towards developed nation status, how appropriate is IL?

(Which is still mainly a concept developed and applied in developed nations)

How can it be contextualised?

•

.

2.2 Bethany Home

PART A

Name of Organisation Bethany Home

Address:

Simpang Empat, 36400 Hutan Melintang, Teluk Intan, Perak.

Description and background of Organisation

Bethany Home was established in 1966 by the Evangelical Lutheran Church of Malaysia. This is a voluntary organisation providing services for children and adults with varying disabilities. It offers a wide range of training programmes for children and adults with varying disabilities. It is situated in Simpang Empat and caters mainly for the local community.

Areas of involvement:

- Day school programmes that offers:-
- Early Intervention Class
- Academic Class
- workskills Class
- Integration in the Local Kindergarten Class
- Physio / Occupational / Speech Therapist Class
- Handicraft Class
- Toy / Wood Workshop
- Sheltered Workshop
- Sheltered Work Employment
- Group Homes
- Independent Home
- Parent Training Programme
- Second Hand Shop
- Respite Care
- Toy Library
- Home Visit Programme
- Community Recreational. Playground
- Job Placement Programme
- Community based Rehabilitation Programme.

Number of staff 48 Teachers 19 Support staff 10 Maintenance / Domestic staff 13 Administrative staff 6

Qualification / Academic background

Staff qualification is from SPM holders to SRP and below. Some teachers have attended the New Zealand Christchurch Advanced Certificate Course for Disability, Wisma Harapan Course and Special Need Community Based Rehabilitation Course.

Volunteers

Local and Overseas.

Annual Budget

Please see Appendix.

Vision / Mission Statement

<u>Vision</u>

Bethany Home Vision is to continue providing a comprehensive service for children and adults who are disabled mainly in Hilir Perak District and also throughout Malaysia.

- More Group Homes in other states.
- More Independent Homes for boys and girls.
- Bethany Home to be a Training Centre for people with disability.

<u>Mission</u>

- To continue giving good quality of training for people with disability in Hilir Perak District and throughout Malaysia.
- To encourage and support people with disability to live within their own families and community.

It aims to equip them with skills needed to become as independent as possible and contributing members of that community. Continue to support and encourage families to work and live within their own families and community with proper accessibility in their own house and within their community.

By providing the services, Bethany Home hopes to become one possible model of how each community in Malaysia can provide services for its disabled population no matter how young or old or how severe their disability.

Location Of Services

Bethany Home, Simpang Empat, 36400 Hutan Melintang, Perak.

- 1 Group Home Teluk Intan
- 3 Group Homes Simpang Empat
- 1 Independent Group Home- Simpang Empat
- 3 Second hand shop Teluk Intan
- Simpang Empat
- Bagan Datoh
- 3 Early Intervention Programme- Simpang Empat
- Teluk Intan
- Bagan Datoh

All the above services are located in Hilir, Perak.

Clients - Total number of students - 178 children and adults

Types of disabilities

Catered for at Bethany Home are children and adults with Intellectual Disabilities, Cerebral Palsy, Autism, Epilepsy. Down's Syndrome and small group children with slow learners.

<u>Age</u> -

From 1 year - 50 years old

<u>Sex</u>-

Children and adults of both sex

<u>Race</u>-

All races and religion with various socio-economic background.

Do clients pay for services?

The clients have to pay fees of RM 50.00 per month for Day School and RM 300.00 for staying at the Group Home. Here again not all the families can afford to pay the above contribution and therefore this various according to the family socio-economic background.

PART B DISABILITY

How does your organisation define disability? Any restriction or lack of ability to perform an activity within range considered normal for a human being.

PART C

COMMUNITY BASED REHABILITATION (CBR)

Your understanding or definition of CBR.

CBR is to enable the community to have a good understanding of disability issues and create a suitable environment to improve the life of the disabled.

History of CBR in your organisation

- 1966 from Institutional approach to Centre Based Rehabilitation in 1987.
- 1990 EIP started in Teluk Intan
- 1996 CBR Early Intervention Programme started in Bagan Datoh Clinic.
- 1997 started CBR Programme among 4 disabled people in one family.

What are the aspects of CBR being implemented in your organisation ?

We are trying to identify more people with disability and their families.

EIP Satellite Unit - whereby the families bring their children to the nearest class where the programme is conducted at 3 different places.

Centre Based Programme - whereby the clients come to Bethany Home for various training programmes.

Home Based Programme - At the village whereby the staff go their homes to provide the necessary help reaches for them.

We are trying to identify more people with disability and their families. Also identifying areas that might benefit from CBR work.

At present we are focusing EIP work in the community and poor families with one or more disability children / adult.

Finding jobs for Intellectual handicapped people to live independently.

Past and present attempts and future plans to promote CBR among disabled people you work with ?

- From Institution to Centre Based Programme which will be the Day School Programme.
- CBR Satellite Unit where parents do not have to come to the centre instead start the programme near their own home.

Problem area in implementing CBR in your organisation

- Due to lack of voluntarism
- Lack of commitment and co-operation among some family members.
- Some local communities fail to see the need to make the lives of a disabled person meaningful in the society.
- Lack of supervision when the programme is implemented.

Success and Progress in implementing CBR in your organisation

The CBR Early Intervention Programme in Bagan Datoh is successful and progressing well, as the local health clinic nurse together with the families are continuing with the programme. In the past the programme was conducted at the local clinic and now the community together with the families and the local health clinic.

What are some CBR issues you feel need to be addressed and tackled in Malaysia ?

<u>Macro Level:</u>

Proper supervision and proper understanding of CBR. Proper implementation with CBR concept and general training to be given to Government officials so that they have some knowledge of CBR. There must be only one approach of the concept of CBR and than directing to different Handicap e.g. Hearing impairment, Intellectual disability, Visual impairment and physical handicap as each one need their own needs and training need to be individualised.

Micro level:

Recipients need to be disabled persons. Training background of CBR staff important as staff need to look in the client individual EIP so as to run the programme.

CBR Committees

We need to know who is sitting in the committee of the individual CBR programme, so that the committee will make sure the CBR programme is carried out well.

How adequate are the measures taken by NGOs and the Government to implement CBR Concepts and practices in Malaysia ?

It is important that the measures taken by NGOs and the Government to implement CBR concepts and practices in need to come out with one idea so that everybody will know what CBR Programme is all about.

What is the level of participants in CBR programmes by persons with disabilities ?

The level of participation by persons with disabilities is still very early stage. Therefore we need to have one policy in the macro level. Training must be emphasised and making sure the Community Leaders and Department Leaders should have Training Programme, so that they will understand the person with disabilities.

To what extent is the community mobilised to participate in your CBR programme ?

The community support for participating in our CBR programme is generally poor. However efforts are being extended to the local leaders and members of the families to participate. Most of the time the community is not able to give their time.

Which groups in the community have been targeted and mobilised for involvement in the CBR programmes ?

Local Community, Leaders, private sector companies, religious Leaders, local health clinic doctors, hospital doctors and nurses and Government agencies have been targeted for involvement in the CBR Programme.

Have there been attempts at community mobilisation through awareness and education programmes ?

Ignorance, wrong beliefs, negative attitude and even social stigma are still widely associated with disability. Parents groups, awareness and educational efforts have been conducted. Basic courses for parents, CBR workers, volunteers and other local community leaders, have been conducted at Bethany Home in an attempt to help community mobilisation.

What are some of the advantages, disadvantages, obstacles and strength in implementing CBR projects in Malaysia ?

Advantages

The advantage is that CBR approach can bring some positive outcomes, including the attitude of family members and the immediate community.

We can see positive approach towards the disabled people themselves. This programme is cheaper than the Centre Based Programme. We are able to get the community involved in the programme.

Disadvantages

Some people do not understand the importance of CBR and the involvement for the disabled person. Staff training is lacking and funding is limited. Lack of Training equipment/ material and Resources. Not much of publicity and awareness of CBR.

Obstacles

Family members not giving much of their time.

<u>Strength</u>

If there is a need a special chair it is convenient to get a carpenter from the village or local community to help out. Neighbours can take turns to help Respite Care - when parents go to work neighbours can make sure the food is given or even prepare the meal for the child. Neighbours can do the marketing and transporting whenever the need rises.

PART D:

What is the status and situation of persons with disabilities in Malaysia at present ?

Now as we see more and more Disabled people are accepted as a human being in Malaysia.

Special Rate for Transportation and other public places have been introduced.

People are coming to know more about Caring and awareness for the disabled person needs.

The Concepts of 'Caring Society' is being more instilled to the public.

Public accessibility is improving eg public toilets in certain buildings and ramps in some public places for wheelchair access.

More centre services providing the needs for the Disabled Person and their families. More families are sending their children to Centre for training rather than keeping them at home.

Family members are now aware and realising the need to help their child with Special Need.

Family programme is being introduces and this makes a lot easier for some volunteers families, Care givers and other to accept.

The Disabled Person and try to tackle their problem according to their need.

Respondent's Details

NAME : MR. JAYASINGH RAJIAH POSITION HELD : DIRECTOR DATE : DECEMBER 27, 1999

2.3 CBR Cheras

PART A HISTORY & OVERVIEW

Persatuan Kanak-Kanak Istimewa Hulu Langat Akal Pusat Pemulihan Dalam Kominiti Cheras.

Started in September 1995 by a group of 10 parents. Pioneer parents couldn't find a suitable place for the children so decided to form a centre that will provide further education and therapy for their children.

Most of the pioneer children EIP from Wisma Harapan but unable to continue there due to immobility or not toilet trained.

With assistance from the Jabatan Kebajikan Malaysia (JKM), they formed a committee to run the persatuan.

Currently, located in Tama Coop Cuepacs that is accesible by road. There is a bus service but one has to walk about 500 metres to reach the centre. This is under the hulu langat municipal council whose office is in Bangi, Selangor

It is a day-training centre, which provides education, training workshop and resources for parents. In future, sheltered workshops will be part of their service.

Funding :

JKM provided a launching grants of RM5,000. The 10 parents chipped in to help raise funds from friends and relatives to purchase teaching aids, furniture and fittings. The standard items were cabinets, tables and chairs, most of which were donated (some were used furniture). Rented a hall from a church premise at RM 700 p/month. JKM provuded RM500 permonth for the rental.

Teaching staff started with I paid staff and volunteer foundr parents. Allowance for paid was provided by JKM at RM350 permonth. JKM provided RM500 permonth for the rental. Teaching staff started with one paid staff and volunteer founder parents. Allowance for paid staff was provided by JKM at RM 350 permonth then. JKM now provides allowance for teaching staff at RM 500 permonth. Staff number has grown to 6 teaching staff, 2 admin staff, 1 physiotherapist, 1 part-time speech therapist, 1 van driver and 1 housekeeper.

Background on Staff

- Administrator -Ex-government servant
- Admin Assistant-Ex-secretary
- Teaching staff-2 with Diploma in Montessori
- Teaching with more than 15 years of experinece with 10 years teaching experience in early intervention programs former remedial teacher in a government school with 25 years of experience former kindergarten teachers with 1-2 years experince
- Physio-therapist-Diploma in Physio-therapy
- A Japanese national marries to a Malaysia
- Speech therapist-Degree in Speech Pathology
- Others-1Housekeeper who is a registered parent
- · Van driver whose grandson is registered with the centre
- Volunteers-1Volunteer Founder Parent with Montessori Diploma in Special Education (Full Time)
- Housewife (Part Time)
- Ex-government officer (part-time)

Annual Budget :

- 1996-RM108, 043
- 1997-RM122,264
- 1998-RM167,613
- 1999-RM211,374

Client Description :

Supposedly to cater for residents from the Hulu Langet region, namley Cheras and Ampang. However, there are also children who comes from other parts of Kuala Lumpur, Petaling Jaya, and as far as Port Kelang.

A total of 57 clients since inception, out of which, 7 have entered government schools, some to other special schools and some left the program due to various reasons.

Total number of clients this year is 40. Comprises of children aged 1-12 years old. Mixed in gender and race but predominantly chinese. Caters to a wide range of disabilities e.g :

- Cerebral Palsy
- Down's Syndrome
- Microcephalus
- Hydrocephalus
- Intellectually Disabled
- Deaf
- Blind
- Sppech Delayed
- Autistic
- Learning Disabilities eg Attention Deficit Disorder
- Other Syndromes
- Majority of children are from middle income families with a handful from the lower and higher income group
- Parents have to pay the Persatuan an (one-time) entrance fee of RM20 and yearly subscription fee of RM15
- As monthly payment, parent have to pay RM100 permonth which includes I.E.P., Physio-therapy and sppech therapy.
- The Management tries to look for sponsors for children who are form the lower income group
- Parents /caregiver must accompany the child duing the classes

PART B : DISABILITY

A condition that renders any person incapable of performing normal functions due to either physical or mental or both abnormalities which inhibits or obstructs the person's life whether it be at home or external environments.

The disabilities could be in terms of :

Physical :

- Restricted Body movements due to hypertonia or hypotonia, polio, incomplete lims, etc.
 - Deaf, Blind
 - Others

Mental : Mental Retardation

- Dyslexia
- Autistic

.

- Attention Deficit Disorder
- Behaviour Problems
- Emotionally Disturberd
- (but not in category of Psychiatric Disorders)

PART C : COMMUNITY BASED REHABILITATION

CBR is an holistic or comprehensive approach including social aspects. People suffered with impairment, disability, handicap, poverty, etc, in our society, through promotion, awareness and prevention, they are able to live a better life.

- Professionals and people in the community analyse their society, decide appropriate actions and avaluate it together.
- Professionals and the community are co-decision makers. Therefore, service are flexible and general and can be maintained by the community itself with professional support.

With regards to the professionals, a physio-therapist as give on loan from the chsire home for about a year in 1988 but services were stopped when the physio-therapist had to return to her home country in Japan.

In between the absence of therapist services provided in the centre, the children goes to hospitals for their checks or therapies. Some do not even go to the hospitals at all due to various reasons.

Since inception

Not much apart from parental involvement. Some service clubs like Lions Clubs, Soroptimist Clubs, Kiwanis Clubs, a few small time business organisations, individuals, a church and some chinese temples have contributed in cash or kind to provide aids or equipment and towards the operating expenses.

Most of our programmes/activities conducted were mainly to enable parents to understand and manage their children better. The following workshops were conducted by volunteers :

Year 1996	Workshop Physio Therapy Occupational Therapy Deafness Speech Therapy Makaton	Conducted By En. Nasri Nazaruddin En Rosli Awang Ms Lucy Lim Ms Sumathi Sinnapan Prof. S.Sebastian
1997	Counselling – How to see a handicaped child	
	Speech Therapy Makatan	Ms Sumathi Sinnapan Prof Sebatian
	Setting Up a Trust Fund for special children	Ban Hin Lee Trust Fund
1999	Makaton Workshop Music Workshop	Prof Sebastian Ms Jenny Ong

5a)Getting Voluntary workers i.e teaching staff,

professionals, skilled labour for making rehabilitation equipment Insufficient funds to operate and to provide services of professionals e. Occupational Therapist, Psychologists, etc Raising funds to purchase equipment and aids. Parents invived are

not high profiled and therefore do not have the influence of obtaining funds easily.

Parents involved in the management have minimum time to spare and therefore unable to contribute much in the day to day running

of the centre. Responsibilities therefore lies heavily on just a few parents who tries to manage the centre to the best of their abilities.

Mainly on the part of the parents

Changing of attitudes form hopelessness to hope and from rejection to acceptance Increased desire to help own child Obtained support of Local council, Lions Club of KL South, Land Office to secure a piece of land measuring 939sqm to build a training school.

<u>Macro</u>

JKM should consider providing full funding for some standard itme i.e :

Rental of building (fully subsidized as rentals in the city are very high as compared to those in the rural areas)

Furniture and basic rehabilitations equipment eg corner chairs, standing frames, walkers (if cannot be fully funded, should at least subsidized)

Professional services eg PT, OT, ST, Psychologist, etc (it is impossible to get these professionals to work on a voluntary basisi and furthermore their services are very costly)

As these services are crucial for the rehabilitation of the childre, JKM should consider the following options :-

Provide fully these services, or

Subsidize or pay an allowance to the CBR to employ private therapists if JKM is unable to provide fully. If JKM does not have the allocation of funds for this, Ministry of Health (MOH) could alsoo be approached for the funds, or

Approach MOH to start a program to second their therapists to CBR centres for certain days of the week.

However, since there is a great lack these therapist even in Moh, this option may seem improblae. Therefore, former option may still be better temporary measure until such time both ministries are able to provide fully such services. Provide or subsidize transport charges for those especially immobile children to hva access to the CBR Centres

CBR workers are not given the same considerayions or perkas of a governmet servant. It should therefore consider the following :-

Allowances for CBR workers should be not calculated across the board

CBR workers living in the city faces higher costs of living as compared with those working in the rural areas and should therefore not be given the same amount of allowance as those living in the rural areas.

Some transport allowance should be given to cover for the high cost of transport in the city.

Allowance given should also commensurate with qualifications and experience in order to give due recognition.

There should also be a scheme to increase their allowance for evey year served and a bonus be given at the end of the year in appreciation of their service.

Note :CBR workers are crucial to the smooth running of the centre. Their interests should be valued and appreciated dua to the fact it is very difficult to get committed staff to work with disabled.

If their basic means of supporting themselves financially is not taken care, the CBR centres will one day find themselves left with clients but no workers.

This would lead to qualified and experienced workers looking for greener pastures.

When the centres are being run by inexperienced workers who do not what they are doing, would you consider sending your disabled child to a CBR centre?

There is no proper curriculum or guide to teach for CBR workers.

Teaching workshops organised by JKM in the past have nerely touched on general issues related to the mentally retarded. Not much emphasis have been given on the rehabilitation of physically disabled and how to help them to achieve independent living. Issues on Autism, Speech Delay and Learning Disablilities e.g Attention Deficit Disorder and Dyslexia have also not been touched on. Considering the fact that more and more cases of this nature are surfacing. JKM should urgently, seriously look into the training of CBR workers to handle these issues. Perhaps the assistance of Ministry of Education (MOE) and therapists should be sought on these matters.

Micro:

Recepients :

Most of the children who come in do not have proper assessments done by profesiional beforehand. Some were wrognly diagnosed, many were diagnosed vaguely as having 'global development delay' which does not tell much of the child's condition at all. There is no specific recommendations of what needs to be done with the child at all.

Based on what is provided to us and with our own centre based assessment, we draw up our own individuals eductaion program (IEP) for the child.

Even though, the children attending the centre have shown marked improvement in different areas of their development, we feel that much more have been done with proper assessments and recommendations from the professionals themselves. This would help the CBR workers tremendously instead of doing guessing work and thus achieving better progress in the children.

CBR Workers :

Workers are picked by the management committee.

Most CBR workers come in without experience and training in wotking with the disabled. Most of them are at a loss as to what they are supposed to do with their clients.

Workers may consists of ordinary housewives, retirees, etc. Some are parents of disabled children themselves who have to juggle between looking after their own disabled child and teaching the other disabled children as well. From experience and comments from such parents, they tend to have even less time for their own disabled child and the rest of the families as well. As such, progress intended for the disabled child may not be as good or at worse, no progress at all.

CBR Committees :

In our organisation, it consists of parents only.

Problem Area : being parents of disabled children themselves, some of whom have other children too, find it had to contribute much in terms of seeing to the day to day running of the organisation, fund raising and activities of the organisation.

Much of the responsibilities fall onto a handfull of people only who are trying at their best to maintain smmoth running of the centre.

Social Impact

Not much. Except for some political figures much political leverage by attending certain functions held by the centres, the general public are still very much unaware of the existence of the centre.

However, hospital rehabilitation doctors, especially in UKM are now quite aware of the organisation's existence and are referring quite a number of their parents to the centre now.

Grossly insufficient. CBR in Malaysia is not 'popular' yet. Some CBR centres are so badly managed, parents do not even want to send their children there.

General public still do not know what CBR is. Public Awareness is not there.

When it is mentioned that the centre is under JKM, public assumes that JKM is providing all the funding to carry out its activities, thus giving the impression that CBR centres do not need funds from the public.

Not sure about other organisations, but there is none in ours.

Only in fund raising projects

So far, only the Lions Club of KL South has been actively involved. Some Chinese agencies/companies have come in to give donations. A church and some chinese temples have supported in cash or in kind.

No.

Advantages Brings the services nearer to the disabled's home Disadvantages: Puts additional burden, pressure and stress on parents who are involved in the management

Obstacles:

Society has still not learnt to accept the disabled and considers them as outcasts or waste of time and money

Inadequate workers willing to work with the disabled because of the stigma

Unavailable or readily available resources, rehabilitation equipment and aids

Inadequate rehabilitation professionals advice/support

Inadequate funds to operate and run programmes.

Public facilities not disabled friendly thus hindering independent living training programs

Strengths

:Might probably succeed better in rural areas than in cities where communities closeness is more evident.

Part D : Independent Living (IL)

Ability to perform daily living activities independently within the home and external environment which includes making use of public facilities eg transport, toilets, lifts, mobility on the roads.

Children at our centre are quite young. Apart from basic self-help skills, have not been teaching other ascpects. Will have to look into this area soon as some of the children are now going into their teens.

<u>Macro :</u>

Government agencies are not giving sufficient backup, in terms of funds, premises, facilities for e.g providing transport, rehabilitation professionals like therapists and psychologists, etc.

Laws provided are not sufficient and implementation is not effective.

Public awareness are either not available or insufficient to provide for IL.

JKM

Insufficient/non-existent funding given to needy cases for purchase of equipment/aids to improve their conditions and to organisations running programmes for the disabled.

Poor attitude and lack of compassion of some officers towards the disabled. There should be a complaints bureau set up to handle grievances and ineffective officers.

Officers do not take initiatives to do surveys on how many disabled people there are within their own district level.

They expect the disabled to come for registration when there are so many obstacles for the disabled to cross in order for them to get the JKM offices for e.g.

Unavailable private/public transport. Even if there is, public transport are not disabled friendly.

JKM offices too far from the disabled's homes. Some don't even know where the JKM offices are.

Some JKM offices are not even on the bus routes.

Buildings that house the JKM offices are not disabled friendly.

Language barriers.

Registration process takes too long and tedious for the disabled.

Scenario :

Disabled has to collect a form from JKM office. (Note the obstacles mentioned initem 3)

Disabled has to take to hospital for certifications by medical doctor. Goes through the various medical departments for checks.

Disabled has to submit form back to JKM office.

Disabled has to wait for application to be processed. Duration : Sometimes as long as 1-2 years. Fastest was 6 months.

When card is ready, disabled is requested to go to JKM office to thumbprint.

Disabled finally gets his registration card after the numerous trips he had to make.

Benefits given for those with registration cards.

Half fare on domestics flights. Not every disabled person can afford to fly even with the discounted fare.

Half fare on KTM trains Very few disabled utilizez this mode of transport as it is also disabled friendly.

Free medical treatment only in government hospitals Privatised hospitals like UKM and UH do not necessarily give free treatment so patients being followed up at these hospitals will still have to pay for their medical treatment.

Income Tax Deduction

The Income Tax Department, recognises medical reports certified by medical professionals that are not from government hospitals als. Therefore, the JKM registration card is not a necessity.

Based on all the above, put yourself in the position of the disabled

In order to encourage the disabled to register with JKM, the Department, shoul take the following into consideration :-

Seek the disabled and not the other way around.

Make registration form readily accessible by providing registration forms at hospitals including private hospitals and private hospitals and private clinics instead of keeping them in the office only.

At hospital level, make forms readily available at all departments so that the disabled would not have to hunt for the person in charge (hospitals can ne a big maze for anyone who is not familiar with it and even the hospitals itself are not disabled friendly.

Provide a counter for submission of forms at :-

Hospitals and have an officer to process the application immendiately or

If item a) is not possible, submit forms to JKM office and officer to process applications immediately.

Registration card should be given back to the applicant within the same day to reduce the amount of travelling he/she has to do. This could be made possible with the advancement of IT in the country.

Ministry of Education

Special schools are only available at some states i.e students from other states will have to uproot themselves from their families to attend these special schools.

Regular schools with classes for special needs are not disabled . friendly for e.g

- Squatting toilets (not suitable for physically disabled)
- No rails in toilets
- Toilets doors do not permit wheel chair movements
- Sinks and taps not adequately fitted
- No ramps or lifts to higher floors
- No security for hyperactive children
- Tables and chairs unsuitable for physically disabled

Teachers teaching in classes for specail need are not well trained and without resources to hep them in their teaching. Results of children in these special classes have not been encouraging.

Teacher/Pupil ratio is too high. Ideally, should be 1 :2-3. IL cannot be effectively taught with a high ratio level.

Ministry of Housing

Poor implementation of laws on buildings to cater for the disabled.

Public buildings like shopping malls, hotels, comercial buildings, etc. residential houses, recreational complexes and facilities like sports complexes, playgrounds, theatres, etc.

Some consideration are as follows :-

Toilets fitted with appropriate basins, urinals, toilets bowls, taps, rails at appropriate heights. Ramps to be made available at every floor. Lifts to have a voice indicator for the blind to know which floor they are at and buttons at appropriate heights for the wheel chair bound.

Sensorial markers to be placed at strategic spots to help the blind to find their way around.

•

.

-

Ministry of Works

- Poor maintenance of roads:
- Potholes
- Kerbs without ramps
- Uneven turfing
- Streetlightning and signboards in the way making it impassable for the wheelchaired bound
- Roads too narrow and dangerous for wheel chairs to pass.

Part E No Comments

Respondent's Details

Name Position Hold Date : Aimee Chan :Honorary Secretary 2 November 1999

2.4CBR Selayang

Part A:

Name of organisation

Pemulihan Dalam Komuniti (PDK) Selayang d/a Rumah Amal Cheshire Batu 7 1/2, Jalan Ipoh 68100 Batu Caves Selangor Darul Ehsan.

Year of founding: 15th February 1992

Areas of involvement

Training. Training of people with disabilities in terms of activities of daily living as well as teaching them especially children to read, write and do simple arithmetic. The clients are also given physiotherapy and speech therapy. The parents of children with disabilities are also taught the skills so that play can an active role in the care of their children.

Day Care. It is also a day care centre where the younger disabled children are taken care of when their parents are not around. This is not encouraged but parents' perceptions of CBR programmes are such that this becomes unavoidable.

Referral centre. HUKM and private hospitals at times would request the CBR in Selayang for placement of their patients especially those who live in that community or in the vicinity of that community, for aspects of rehabilitation like physiotherapy.

Resource centre. The CBR is also a resource centre for undergraduate students involved in various courses from Universiti Malaya and Institute Pengajian Sumber Manusia, UPM.

Staff:

The PDK has 5 staff members of which 2 are teachers with Sijil Tinggi Pelajaran Malaysia (STPM) qualification as well as 2 teachers with Sijil Pelajaran Malaysia (SPM) qualification and one teacher with a Sijil Rendah Pelajaran (SRP) qualification. One of the teachers with STPM qualification has had 2 years' experience as a teacher in a normal school.

There are also physiotherapists who come to the CBR once a week on rotation from GHKL and also a speech therapist who also comes once a week. The therapists are paid for their services but are not considered CBR staff.

Annual Budget:

The budget of the CBR was initially combined with the Selangor Cheshire Home's budget at inception. Funds were given to the CBR from the Cheshire Home's budget as yearly allocations. It was only in 1996 that the CBR had its own separate budget and had financial reports tabled at its annual meetings.

Income comes mainly from the Department of Welfare for example rental allowance, and donations from the public as well as money obtained from the various activities held by the CBR centre like jumble sales and joggerthons.

Most of the expenses incurred were for rental of the premise from the Cheshire Home, utility bills, payment made for the services of the physiotherapist and other helpers and the various activities that the CBR centre holds from time to time.

1996 Budget

Income: RM 2,927.51 Expenditure: RM 1,789.32

1997 Budget Income: RM 1,5038.39Expenses: RM 1,2469.71

1998 Budget: Income: RM 3,4444.21 Expenses: RM 2,5774.88

Vision/Mission Statement:

The CBR programme has a simple mission statement that is 'of the community for the community to the community' and emphasises the importance of total community participation and global community involvement.

The CBR has as its objectives:

1. To make available a rehabilitation and academic service for children with disabilities and to inculcate a feeling of responsibility in parents towards the needs of their children by utilising resources available in their own community.

To cater for the lack of places in government and NGO institutions.

To unite a multiracial community through charitable activities and to help children with disabilities and their families undergo appropriate rehabilitation as stipulated by the Government's call for national integration and a caring society. To share ideas/experiences/knowledge as well as to save the time and finances of families involved in the rehabilitation and education of children with disabilities.

To reduce the pressure on parents and families of children with disabilities on their failure to get their children into an institution.

Location of services:

The CBR is located in a rented building in the premise of the Selangor Cheshire Home. However, clients to the CBR come from various places in the Gombak district and also as far as Hulu Kelang.

Clients:

The CBR has caters for various types of disabilities and has about 175 registered clients since 1992. However the total number of clients given in the tables below is less than that as some have passed away or have been transferred to other schools or CBR centres or have a combination of disabilities (number given being for single disability/disease) or other disabilities not classified by the CBR.

Age group	No. of clients with specific disabilities/disease						
	MR	C P	Au tis m	SL	D S	Blin d	Deaf
Below 6	2	30	3	7	15	1	1
7 – 12	8	14	5	4	9	2	
<u> 13 – 17</u>	9	5	1	3	4	10	0
<u> 18 – 24</u>	2	2	0	1	0	0	0
Above 25	3	0	0	0	0	0	
Total	24	51	9	15	28	3	1

MR: Mental Retardation, CP: Cerebral Palsy, SL: Slow Learner; DS: Down Syndrome

Table of number of clients with impairments/diseases according to age groups.

Race	No. of clients with specific disabilities/disease						
	MR	CP	Autism	SL	DS	Blind	Deaf
<u>Malays</u>	17	42	6	12	19	1	1
Chinese	5	5	2	1	7	2	0
Indians	2	4	1	2	2	0	10

MR: Mental Retardation, CP: Cerebral Palsy, SL: Slow Learner; DS: Down Syndrome

Table of number of clients with various impairments/disease according to the various races

There is no information available for gender differences between the various disabilities as well as the socioeconomic status of most of the clients. However most of the people in the community that the CBR serves is involved in business and white-collar occupations.

Payment of services:

Clients pay a nominal sum that is actually considered a donation. There is no pressure on the parents of children with disabilities to pay or contribute.

Part B

Disability

Organisation's definition of disability:

- All types of disability be it mental or physical that comes about during birth or after birth as a result of accidents, illness or inheritance.
- There are basically 5 types of disability:
- Physical disability
- Mental disability
- Visual disability
- Hearing disability
- A combination of the above.

Part C: Community-Based Rehabilitation

Organisation's understanding or definition of CBR:

CBR is basically rehabilitation for people with disabilities that is conducted in the community involving parents, family and the persons themselves with the help of government bodies like the Jabatan Kebajikan Masyarakat and Jabatan Kesihatan, non-governmental organisations and volunteers. It is a rehabilitation and educational centre for people with disabilities who are unable to enter certain institutions due to financial reasons, logistic reasons, unavailability of vacancies or failure on the part of the persons with disability to meet certain criteria of the institutions.

The resources for the CBR such as teachers, caretakers, buildings and finance must be available in the community and the community must have full responsibility for the CBR. One of the CBR workers has the opinion that the focus of a CBR should be only on a particular disability to enable on to

judge the progress of the clientele. If the centre concentrates on all disabilities then it will merely function as a Care centre instead of being a rehabilitation and educational centre.

History of CBR in the organisation:

In 1991, Encik Othman Jamaludin went to the Social Welfare Department for help. He needed help as he has been told that his son who is a person with disability cannot continue in a normal school due to his disabilities.

The social welfare officer asked him to get help from Malaysia Care to help identify the number of children who require such assistance before agreeing on assisting in setting up a CBR. The survey showed that 90% of parents want a program to help parents with children who cannot enter normal school.

The Selangor Cheshire Home agreed to provide a premise for setting up a CBR while Malaysia Care was willing to provide manpower. Thus PDK Selayang was set up on 15th February 1992 with a clientele of 15 children. Classes were held every Saturday and the other days of the week were devoted to home visits.

The Minster of Integration and Community Development on 29th August 1992 officially opened the CBR. The CBR encourages parental and family participation in running its activities as the programmes are for them and their children. Thus far the running of the CBR has been smooth especially with the help of the Social Welfare Department. Currently the CBR has 5 teachers of which 2 of them are trained in education for children with disabilities. Furthermore the CBR also has help from other professionals so that it can run its programmes efficiently. The CBR now has 175 registered clients. Classes are run 3 days a week and physiotherapy is available on Sundays. The CBR has also managed to have a speech therapy class every Friday.

Aspects of CBR practised in the organisation:

The CBR programme in Selayang practises the following CBR aspects:

Involvement of the parents and family members. They are involved in the training of their children as well as the running of the CBR programme as some parents are committee members. Teachers are from the same community.

Home visits are made when the clients are unable to come to the centre or when the client is attending special class in a normal school.

Physical therapy sessions are conducted at the centre.

Academic sessions are held at the CBR's premises.

Certain aspects of ADL are taught to the clients.

The CBR also advises parents on the care of the children.

There is participation from government bodies and NGOs in the community like the Lions club, Rotary club etc. in their activities.

Past, present and future plans to promote CBR among the disabled:

Past and present undertakings include: Direct promotion: Persons with disability in the community were identified either through sources such as the neighbours of such persons, other persons with disability etc. The CBR would attempt to promote its activities by meeting these identified persons and giving them more information about its programmes through handouts and brochures.

Registration campaign for persons with disability: This is held 6 monthly at times with the help of the social welfare department.

Participation in various exhibitions: The CBR has also taken part in various exhibitions. Below is a list of such exhibitions which the CBR has taken part in exhibition held in conjunction with 'Hari Membaca' at the National Library on 1st August 1996.

Program pameran jumble sale, derma darah dan pemeriksaan kesihatan' done with the Gombak Rotary Club on 29th June 1997.

Pameran fungsi PDK' at the Central Market KL on 1st – 6th March 1998.

Pameran perasmian Pusat Khidmat Sosial' at Taman Permata, Hulu Kelang on 15th March 1998.

Pameran fungsi PDK' at PD Gombak on 15th - 16th July 1998.

Exhibition at ITM, Shah Alam on 21st August 1998.

Pameran fungsi PDK' at Selayang Mall on 29th – 31st August.

Pameran fungsi PDK' at the Mall KL on $3^{rd} - 11^{th}$ October 1998

Future plans include further participation in exhibitions and working with various NGOs like the Rotaract and Rotary club to promote its activities.

Problem areas in implementing CBR:

There have been many problems faced in setting up CBR and during the implementation of its activities. Among the problems faced are:

Financial: Among the financial problems faced is a lack of funds from the Social Welfare Department to help the CBR run their activities. As such the CBR have to try to raise their own funds from the public and private sectors. Parents of children with disabilities also do not have enough money to assist in the proper rehabilitation of their children.

Parental involvement: There have been problems in getting parents to become more actively involved in the various programmes. The parents of the clients do not seem to have a good idea of their, role in the running of the various programmes. Parents are reluctant to come to the CBR when their children are there as they have other children to take care of or have work commitments.

Some parents also do not have enough knowledge about their children's' disabilities and thus do not see the importance of a rehabilitation programme offered by the CBR. This results in some children being enrolled only when their disability has become more severe.

Community: There has also been a lack of community participation in the implementation of the CBR's activities. The local community has also not been very willing to give

children with disabilities a chance to participate in the usual communal activities. There has been less emphasis placed by the community on children with disabilities as compared to other disadvantaged groups like orphans. Thus it has been difficult to get the community involved despite attempts made to promote the CBR and its activities. There has also been a lack of response from various professionals needed by the CBR to run its programmes for instance trained therapists. Many trained professionals seem to be more interested in financial gains than in welfare work and as such the CBR has been having problems in getting these people to help them out in implementing its programmes.

CBR workers: Many CBR workers regard work at the CBR as restricted to the classroom and as such are not very willing to work extra hours like going for home visits which is an integral part of a CBR programme. The workers would only go for home visits when they are forced to do so by the CBR supervisors. This has resulted in some CBR centres not doing home visits especially those CBR centres without supervisors. The CBR workers also lack the knowledge needed to work with children with disabilities and there have not been enough training programmes to help them. CBR workers also tend to bring their own children into the programme as they themselves tend to treat the centre as a kindergarten.

Environmental limitations: The CBR has limited space and thus is not able to carry out some activities. The CBR also does not have enough vehicles to reach the children with disabilities who need their services.

Lack of knowledge: There is a lack of knowledge about disabilities among CBR workers and this includes knowledge on basic rehabilitation and care of children with disabilities. There is also a lack of knowledge on construction of low cost aids of daily living.

Success and progress in implementing CBR:

The CBR has had many successes since its inception in 1992. Below are some of the progress made and successes achieved in the past 7 years:

The increasing number of registered clients. It started with 15 clients and has 175 clients now.

It has successfully increased the number of operating days from one to three.

It has managed to send some clients to special classes in normal schools.

It has also managed to send some clients to institutions and special schools e.g. Rumah Kendiri.

It was chosen as the best CBR in 1998.

It has become an informal training centre for CBR workers from other CBR centres.

It is a centre where certain children with disabilities followed up in HUKM and GHKL are referred to for further rehabilitation.

The CBR has also become a resource centre for those interested in CBR and CBR organisation.

Some CBR issues that need to be addressed and tackled in Malaysia:

Macro issues:

Government policies: The lack of initiative or encouragement on the part of the Government to set up CBR centres in Malaysia. Studies have shown that Malaysia needs about 600 CBR centres but as of October 1996, there were only 196 CBR centres with about 4000 clients. There has also been a lack of concern in setting up training and vocational centres, recreational areas, disabled friendly buildings and transport system as well as rehabilitation centres for persons with disability.

Budgets: There should be more allocation in the national budget for people with disability as finance is a big problem in CBR centres.

Status of CBR workers: CBR workers in Malaysia have not been fully recognised by the JPA and are currently considered part-time workers. They also do not get the same salary as some states pay CBR workers less than other states. There has also been a lack of guidelines on the minimal qualifications for these workers. In certain states for example Penang, certain CBR workers are not given annual leave or maternity leave.

Curriculum: There are also no guidelines as to the curriculum of the CBR centres. The current crop of CBR workers depend on the experience of the senior workers but these workers are few in number and most of them are involved with NGOs.

Training: There is a lack of facilities available for the further training of CBR clients as well as a lack of employment opportunities when they have progressed to a stage where beyond what the CBR can offer.

<u>Micro issues:</u>

Training of CBR workers: There is a lack of training for CBR workers in terms of courses, workshops and seminars. Most of the workers have only got a basic training of 2-4 weeks given by the Social Welfare Department. As such many are not really capable of carrying out their duties effectively.

Social impact of programmes: The programmes have not yet had much impact on society, as many parents are still sceptical about their children mixing with normal children.

The parents of normal children also have negative feelings about this. Some CBR function without any assistance from then JKKK, religious groups or other charitable organisations.

CBR committees: The 'pengerusi' post should be held by parents or family members of the persons with disability with leadership qualities. Those who are actively involved with CBR activities should also hold the secretary and the treasurer posts. However this is not true in most CBR centres. There is also a tendency to involve politicians. Though this is not discouraged, political issues should be avoided.

How adequate are the measures taken by the NGOs and the government in implementing CBR concepts and practices in Malaysia?

The measures taken by the NGOs have largely been more successful than those taken by the government. Most NGO CBR centres are successful, as they have the financial resources not available to the government CBR. They are also not bogged down by the numerous governmental protocols, which is a common occurrence with government CBR.

The CBR run by the NGOs tend to have better service from rehabilitation professionals as they can afford their services. However this translates into higher fees which only more well to-do clients can afford.

In terms of the number of CBR, both the government as well as NGOs have not been able to meet the demand for CBR. The Social Welfare Department have assisted in setting up 185 CBR while Kementerian Kesihatan Malaysia have set up 20 and NGOs have set up 8, bringing the total number of CBR centres to 213 for the whole of Malaysia which is far below the required number of 600, according to as survey done in1996. In terms of registered clients, too few have actually registered with the existing CBR centres. Out of the registered people with disabilities in Malaysia, only 8% are actually registered with CBR centres. Thus measures taken by both the government and the NGOs are still not adequate, as there are not enough CBR and too few clients, from the potential number of clients, who are actually registered with CBR centres.

Level of participation in CBR programmes by persons with disabilities:

<u>Macro:</u>

Only about 8% of registered persons with disabilities are actually registered with CBR centres in Malaysia.

<u>Micro:</u>

In CBR Selayang, there are 175 registered children with disabilities. Out of this number, only 55 are actively involved with the CBR activities. This represents about 30% of the registered population. Out of the 175 registered clients, about 45% of them come from Selayang while the other 55% come from areas outside Selayang.

All of the registered persons are children or young adults (as the oldest client is 22 years old) as the CBR is unable to run activities for adults with disabilities due to a lack of resources. Thus participation by older persons with disabilities is sorely lacking.

Community participation in CBR programmes:

Voluntary community participation is lacking as there is little interest shown by the community at large. Community help is required in certain activities organised by the CBR such as 'gotong-royong', bringing persons with disabilities to parks/supermarkets/malls etc. However it has been difficult to get volunteers from the community unless they perceive some form of benefit or reward from their participation.

Most of the ones involved are those who have children with disabilities whereby they tend to have a greater feeling of responsibility towards other children with similar problems.

Most of the other volunteers are from the youth wings of political parties, RELA, religious organisations and the Rotaract club.

There have also been activities to rise money for the CBR organised by certain organisations to enable the CBR to purchase much needed equipment and aids.

However the spirit of volunteerism is sorely amiss in the present community.

Groups targeted and mobilised for involvement in CBR programmes:

Groups targeted include parents, family members, political and social leaders, private companies, local NGOS such as RACS, Lion's Club, Rotary Club etc.

However for the moment the CBR is concentrating on family members and the immediate community in Selayang. The workers in the CBR feel that they should get the immediate community to understand the role that the CBR plays in community development before they focus on targeting other groups.

Attempts at community mobilisation through awareness and education programmes:

Such attempts have been made through the distribution of brochures and pamphlets as well as participation in various exhibitions held in public places like malls. Outings have also been carried out whereby the clients are taken to malls etc, to expose them to the public and to let the public realise that persons with disability exist and that help is needed from the community.

Other attempts include exposure on TV and radio as well as reports in articles in magazines and the newspapers.

Advantages, disadvantages, obstacles and strength in implementing CBR projects in Malaysia:

Advantages:

Gives a chance for children with disabilities to receive an education.

It reduces the burden of parents.

It is a place where such children can receive some form of rehabilitation therapy.

Allows children with disability to interact with other children or peers.

Gets the community involved in welfare work and strengthens the community bond.

Disadvantages:

Tends to be treated as a day care centre or kindergarten by parents.

The better to-do parents do not send their children for CBR because they have little faith in a centre that operates on such a low budget and uses community resources.

Tends to be run like a kindergarten or school.

Obstacles:

Lack of sufficient funds.

Lack of spirit of volunteerism.

Lack of community involvement.

Too many protocols involved when conducting activities or implementing programmes.

Lack of guidelines from the government.

Lack of trained personnel.

Lack of buildings, vehicles and equipment.

Lack of knowledge among workers and the community.

Lack of suitable reference or resource material in Bahasa Malaysia (a language, which the CBR workers are comfortable with).

Many people in the community think that the responsibility of care for people with disabilities rest solely with the social welfare department

Strengths:

Resources are readily available in the community for instance community halls, clinics and manpower.

There is assistance from the government to set up the CBR.

The unique administrative system in a district makes it easier to set up a CBR centre.

The strong spirit of neighbourliness in certain communities such as FELDA communities makes it easier to implement CBR centres.

Respondents:

Puan Norini Othman (Penyelia PDK Selayang) Encik Mohd. Yusuf Tawil (Setiausaha PDK Selayang)

2.5 CBR Rawang

PART A :

Name of organisation:

Pusat Pemulihan Dalam Komuniti No.12 Jalan Pos Kampung Kenaga 48000 Rawang Selangor Darul Ehsan

Description and background of organisation:

Year of founding: December 1999

Areas of involvement: Day Care Center

Staff:

1993-1996 Two (Ladies) 1997-1998 Four (Ladies) 1998-1999 Four (Ladies)

Annual Budget:

1997- RM29,000.00 1998- RM29,500.00 1999- RM30,000.00

Disabled Children

26 persons Day Care persons Home Visit

All the expenditure above are funded by the Government Staff are Sijil Pelajaran Malaysia Holders. Volunteers offers services as when necessary.

Vision of Mission Statement:

To provide guidance to children and to give support services to parents with disabled children, and to have full participation in drawing up plan and programme of the public.

Clients:

26 children – ages from 5 years to 18 years children especially from the lower income group.

Clients pay a minimum of RM5.00 per month but contribution is not compulsory. All raises.

Types of Disabilities:

- Down Syndrome
- Cerebral Palsy
- Slow Learner
- Late in Speech
- Mental Retardation
- Late Developer

PART B DISABILITY

Disability means someone who needs physical and moral support to help him/her to be independent in the most maximum way.

PART C COMMUNITY- BASED REHABILITATION (CBR)

CBR is a project to assist physically handicapped children in that area to get informal education, to socialise, to get professional help like speech therapy, physio therapy etc.

CBR centers are run by the Community with assistance from professionals in organising system programmes

CBR center in Rawang was initiated by the District Social Welfare Office, Gombak in 1992. The center was situated on the ground floor of one of the volunteer's houses. It started with one untrained carer and 7 children ages ranging from the ages of 5 to 7 years.

The center is held 3 days a week:

Programmes are:

- Speech therapy once a week
- Physio therapy once a week
- Art/Painting Classes
- Independent living skills
- Table manners
- Singing/Group Therapy

Home Visit: The carers. Visit 4 carers at their homes regularly. There are 26 children attending the 3 day classes.

In the past the Social Welfare department through its network helps to refer cases to the CBR Centre. The parents of CBR spread the activities of the centre in the area where they live, helps the centre to receive organised visits by Village Committees, schools and service club.

Activities

Children are taken for educational visits – to Zoo, LRT Rides, Cinemas and Sports event Project: The center managed to renovate its premise, as week as built a bigger room for the children to do their activities. The expansion is a form of the donation by are of the volunteers of the Home.

Problem Areas in Implementing CBR

- Parents do not have the time to send their children to the centre
- Parents expect children to be fetched from their homes
- Parents think that it is a government project, as such must be free
- Parents treat CBR centre as a Day Care Nursery
- Parents expect the CBR Carers to do miracles for the children
- Parents are reluctant to give financial support
- Teachers are not fully trained
- The ratio of carers 1 to 8 children is too wide

The success of running programme is the support of the 4 carers and a few mothers who support the day to day programmes.

(a) Training

Carers should be given professional training, a certificate/Diploma to be awarded.

(b) Allowances

Since CBR Carers must posess the Sijil Pelajaran Malaysia Carers allowances should be received from the present given them

(c) Seminar/Forum/Workers CBR Curriculum

The above programmes on CBR – for parents JKKK members should be organised by the government

(d) CBR Curriculum

There should be a common CBR Curriculum for the Carers. In this respect the National CBR Coordinating Committee is formulating one.

(e) The Social Welfare Department on NGOs responsible for CBR activities should also provide training the micro level, hold workshops and forums.

(f) There should be a uniform scheme of service for CBR Cares like:Paid maternity leave Holidays to coincide with School Holidays Free Medical Services at Government Hospitals

The NGOs through National CBR Coordinating Committee Malaysia and the relevant Government Agencies Department of Social Welfare, Health Ministry, Education Ministry (Special Education) and professional from Institution of Higher Learning, also working closely to upgrade the programme in CBR

The participation of persons with disabilities in CBR programmes is NIL- in my CBR center.

Community in this area assist in the CBR programmes as and when necessary – like- helping to take children in on things, gotong royong etc.

CBR Centre works very closely with JKKK of the area, and some service clubs – like Lions and Rotary.

No

Advantages:

The Disabled children will not be left at home without being given all the emotional, physical and psychological help to grow into a healthy human being, it also will enable the parents to explore the strengths and weakness of their children. Society will be more caring if the disabled persons are given the same opportunity as their normal brothers.

2.6 CBR SARAWAK

PART A : BACKGROUND OF OUR ORGANISATION

Social welfare council of sarawak was born on 14 september 1949. Before that time, there was no central welfare organisation to refer to for advice or assistance. With the formation of the council, they coordinate all existing voluntary social welfare activities in sarawak, sponsors welfare project committee was formed through its standing committee. Fund raiusing committee was formed to responsible for the raising funds and to allocate as directed by the council. Untill today, the emphasisi on the voluntary efforts and on the felt need of a local area have remained the patterns of social welfare work. In 1963, when sarawak joint malaysia, a welafe division of ministry was established to look after welfare matters in the state. The first task of the division was to take over the funds from the council. Upon the copulation of taking over the function by the government, the council's constitution was revived.

As an independent voluntary organisation with the membership comprising of various welfare organisation the council welfare organisation the council became a consultative and advisory body. It also initiated a service hitherto not undertaken by any existing welfare organization. In 1982, a school for mentally retarded children (ID) was initiated at the same time recognise the importance of caring for the disabled. Then the council registered disabled people for the purpose of employment through the cooperation of its member organisation.

Upon the establishment PERKATA SARAWAK (Welfare association for mentally retarded children) to take over the school, the council held a critical appraisal on its work and searched for new in social services. The attention was focused on social welfare conferences. It was from such conferences that a new approach to social welfare called community based rehabilitation was mooted, adopted and presented to the government for consideration.

Being conscious of the development of social services, at the social welfare conference, jointly by the council and ministry of social development in December 1987, resolutions pertaining to community based rehabilitation were passed and forwarded to the assistant minister of welfare. A visit to CBR and RSRB (rehabilitation services for rural blind) at Batu Mukim, Terengganu was organised. The report was then forwarded to the ministry and the proposal for setting up a community based rehabilitation project was agreed.

The main objective of the community based rehabilitation were to integrate the disabled into active family and community life. Care was duly exercised so that the community based rehabilitation project could not encroach on the areas of services which belonged to the welfare organisation for which it was set up to serve. Hence, only the type of welfare services which no one had set foot on would come under the CBR scope of work. This clarification was necessary as community based rehabilitation was created to serve all types of disabled people in the community.

It was recognised that community based rehabilitation could be implemented both in the rural and urban areas. For a start and as a pilot project, the council would work along the ministry of social development in urban community based rehabilitation projects. The target groups would be the ex-pupils of SMRC, school for the blind and school for the deaf : ex resident of sarawak Cheshire home, blind training centre and Pibakat. (Association for parents of children with disables)

When CBR project was approved in 1988 and with a provision of \$28,400, priority was given to 70 ex pupils of school for mentally retarded children (ID) aged 18 and above. Two CBR workers were appointed in 1991 and later another 2 were recruited. All the CBR workers were trained locally. It was realized that the CBR project should be backed by professional services such as Speech Therapy and Counseling services. In 1990, the federal department of social services Malaysian approved 5 community posts for social welfare council with the provision of RM 54,000.

Since 1993, the CBR project of Social Welfare Council is fully operated at No. 6, Lorong Bisayah of Jalan Ong Tiang Swee, Kuching serving 92 adults with intellectual disabilities by 4 CBR workers, 1 JOCV (OT) 1 visiting volunteers (PT) and counselor. The present CBR program, the professional services such as counseling, occupational therapy, physiotherapy will be further strengthened in scope, both in the target groups and areas to be covered. To do so, the council need to raise a quarter million a year to supplement their income.

PART B DEFINITION OF DISABILITY

Our definition of disability is a weakness or failure of some part of the body or head.

PART C Community based rehabilitation (CBR)

Community based rehabilitation is a process of involving disabled people, parents family members, relatives and other community. It can be implemented to what people with disabilities and their families are saying. Identifying their needs and 'match ' it with community around them and involve them (the community) into the rehabilitation program therefore, the rehabilitation would not only focusing on people with disability and their disability and their families but also the community as a whole.

Through services for adults with intellectual disability, we tried to meet their needs at CBR centre, at home and through Social Club activities. Based on the data we have collected before the intervention, we create activities that will allow us to identified their skills and what they need to develop for each participants and sometimes we use existing resources which available in the community for example : at swimming pool we will include dressing, undressing, personal grooming, gross motor etc, shopping or eating out will include money skills, choosing food or drink, toileting (recognizing which is male/female) etc.

At CBR centre : we asses their capability through activities of daily living such as cooking, cleaning etc. Once the skills identified, we then decide what training to be provided. During the assessment session, we also assess the family needs. Involving them to participate in each activities is the main task of the CBR workers either through discussing or observing the participants at home with their partners as a trainer.(For this particular activity, we also provide follow up at home). The session at CBR centre is carried in 2 levels, for the parents and for the participants (different time). To motivate some of the parents (who thinks that her son/daughter could not perform any task, videos on the participants were shown to them at the same time we guide the parents). Parent were encouraged to give feedback on the participants performance at the same time on the activities given to him/her. After 3 years running such activities, it was learn that some of the participants are ready for work placements. At that time there were no agencies or services provided services for adults with intellectual disability, preparing them to work or place them to work, as a result, we create another activities which also based at the centre called training for work skills. Therefore, the aims of the centre to highlight the unmet needs of adults with intellectual disability were met.

For training for work skills, we approach various organizations, department, clubs, private company, factory aiming at re integrate

into the community at the same time trying to improve the family financial situation. Some of them offering place for us to carry out such activities for example : the Sarawak Club housekeeping department, every week the participants will got to the club to do cleaning work. In CBR, services at Sarawak Club were utilized through the activities. Beside assessing the participants capability, training were also carried out. In between, the CBR workers will identify and contact the potential employer and placement will be arranged when agreed. When their present skills were identified matching with the condition of work place, fully employment will arranged. The CBR workers will continue supporting the participants between 3 to 6 months by visiting them at work at the same time discussing with other member of staff, getting the benefit allowances from Social welfare Department for those income below RM 250.00. Parents were also required to play their role such as organizing transportation for the participant. After 6 months or more, the participants will be fully supervised by the employer and their parents.

At home : At home, the participants received individual attention our CBR workers. Similar activities were carried. The home intervention aiming at developing the participants, parents, home environment and community around the area where they lived. The involvement of the community depending on the family needs for example : some part of the home need some adaptation to meet the needs of the disabled, carpenter etc will be approach. Families were asked to identify the resources, together with our CBR workers, they will approach the person.

Social Club Activities : Social Club activities were held every month. Various activities were carried out such as outing, educational visits, camping etc. It's opened to all participants. They were divided into groups according to their condition. The activity creating awareness and to encourage participation from the community.

These activities allow the community to participates at different levels such as receive the benefit of services and contribute nothing ; in the form of personnel's, material and finance ; decision making such as areas of training interested by the participants, choice of activities etc. The activities also serve to analyze the functional abilities of the participants as well as the employment potential with relevant support factors.

<u>Future Plan To Promote CBR Among Disabled People :</u> : Services For People With Disability

Project A : To form a committee of social club of adults with intellectual disability.

Activities Include :

Organize of social activities for members with Intellectual disability (children to Adults)

Participate in fundraising activities and community oriented program such as telematch organized by Jabatan Perpaduan, Rakan Muda Program organized by Jabatan Belia.

Project B : Out Reach Program (An expansion of Home Based Activities)

Activities Include Initiate and facilitate services within the areas where people with disability and families lived.

Facilitate activities within the community through existing resources for examples social activities at children's clinic etc.

Community Education Program

<u>Project A</u>

Expand the roles of our resources library

Activities Include produce teaching and training materials/ leaflets/ Videos/ devices etc.

Distribute materials on disability, rehabilitation etc, to hospitals, community clinics, mosques, churches etc.

Translate present training materials into local Language such as WHO materials,Robert Dellar, Portage etc.

Upgrade the training materials (to different levels)

PROJECT BTRAINING PROGRAM

Activities Include

- Conduct Training for CBR, PHC Workers, existing and potential CBR committees etc
- Organise community eductaion programme (a joint venture with KEMAS, PHC etc)
- Upgrade CBR workers' skill

ISSUES need to be addressed and tackled in Malaysia

The community based rehabilitation emphasisi that rehabilitation of the disabled in his own home and community setting with active parental involvement and support – where meaningful techniques, adaptations and relationships can ne formed, sustained and made normal as true to life possible.

CBR was introduced in Malaysia when existing services both government agencies and voluntary have limited capacities, long waiting to enter the institution and majority require specific training – rehabilitation in mobility or skills in daily living activities.

Since the inception in 1983 and form the action planning workshop in 1989, Social Welfare department expanded CBR programme. The government shows their commitment by upgrading the CBR programme in 1992, the treasury approved RM129,600 allocation for the volunteers'a llowance. It's consider as a boost in the development of CBR because before 1992, there was no specific budget allocation for the programme, resulting in a high turnover rate in volunteers and other workers.

In mid 1992, the programme enjoyed a windfall of RM1.25 million in a special one-off allocation to increase the number of programmes, purchase training rehabilitation materials as pay rentals of CBR prorgammes premises. With such funds, the Social Welfare Department expends CBR to every district in Malaysia. Currently every district at least have one CBR programme. Total support was asked from the state government agencies and NGO's for the creation and process of the programme.

Implementation Process

Understanding the concept of CBR

The developments of CBR programme in each distrcit in Malaysi require skills that re quite different from each other. Hence, the implementation of CBR depends greatly on evolution of systems of management and techniqus in rehabilitation.

From my observation, similar approach were used by the Social Welfare Department in implementing the CBR – CBR Centre. Committees were formed representing different agencies of government or private sectors. The centre was used to carry out activities for people with disabilities and their families, producing aids or teaching materials etc.

In 1994, WHO, ILO, UNESCO hag agreed on a common definition of CBR. According to the definition, CBR is a strategy within the community development for the rehabilitation, equalisations of opportunities and social integration of all peole with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and appropriate helath, education, vocational d social services.

The defination has clearly stated that 'within community development and implemented through the combined efforts disabled people etc. A centre is part of the community however there are other forms of community that existing such as groups, Carpenter, KEMAS tabika, PERPADUAN tadika, private nurseries, community clinic etc. What is the role of the centre? Where do they go from here? Do all people with disability need to to go to the centre? Budget for the implementation has been increased at the same time numbers of CBR centre also increased. How do the Social Welfare Department identify the needs of disabled people and their family ? What is the roles of the organisation of/for people with disabilities? How they can be involved in the planning and the implementation of CBR programme?

A Local NGOs who is taking part in the implementation of CBR received limited budget from the government and to cover such costs of their activities, they hold a fund raising activity. Most donors for rehabilitation prefer a charitable approach that is more visible and easy to eavluate. They are satisfied with pictures and numbers of people with disability have received rehabilitation services. The centre based activities may meet the needs of the disabled outside the centre especially in Sarawak being the biggest state in Malaysia with a small population, without more definate means and source of income, how can such organisation survived?

Geographical Factors etc

In Sarawak, the diversity of races, languages, cutoms, thick jungles, mountains and other difficulties of communications, a unique approach to social problems need to be created. Other than that, the traditional way of living, beliefs also contribute challenged in implementing CBR. Although the transportation and other communication have been improved, to reach out to those in the deep interior for example the Orang Ulu community, the journey may take more than one hour on foot. People with disability experience segregation by his or her own environment and also could meet the needs of the disabled and develop the concern community? With such factors, a comprehensive evaluation is needed with regards to the implementation of CBR programme between Peninsular Malaysia and East Malaysia.

Staffing Strategies

From ny experience as a CBR worker, there are four levels of responsibilities. At the beginning of the services, the CBR workers will collect data, assessed the particpants, plan the training programme, implement the plan, secondly from the implementation they will approach other resources which can contribute towards the training as planned, thirdly raise the needs if cannot meet within the plan, they begun to facilitate if the resources elsewhere ; forth, establish a networking with other agencies, promoting as well as informing the needs of disabled people and their families. In some CBR programmes, activities were carried out differently. The CBR workers background in terms of their educatin and their existing knowledge of the community setting etc cntribute to such development.

In our CBR programmes, the CBR workers responsibilities includes creating awareness (radio/fund raising etc), taking part in community orientated programme, assessing needs, reffering to other services, making simplified technical devices, facilitate services, assist the families to obtain benefits from Social Welfare Department, Syarikat Telekom etc. In trying to meet the scope of CBR for example ; raising certain issues about people with disability lives at all time, the CBR workers face day to day stress which will affect the ability to function. Instead of trying to meet the disabled people in integrated situation, it becomes isolation or segregation.

Need to strengthen the roles of specialists

It was realised that specialists such as therapists are the back up of CBR programme. Before designing any treatment plan, the family and the disabled peole will be assessed. Such approach is commonly used and applied by our CBR workers. Skills and knowledge of basic medical is required as to how CBR workers can assess the disabled and such skills can be obtained from those with medical background. Between specialists and the CBR workers who is not educated in any medical background can share tehir knowledge with each other for example : if the CBR workers came from the community where the CBR programme is implemented or where disabled people and their families lived, her or his knowledge being part of the community should be

considered. How many specialists see the needs to develop such knowledge? If CBR is about social change, were they trained in social work? Beside the medical needs of the disabled, do the specialist aware of the social needs? Were the specialists informed about CBR? Were they any guidelines given as how they can support the CBR workers?

Strengthened the Roles of people with disability and their families In most activities, people with disability and their families seen as a recipient to such services and yet in CBR, it's offered empowerment. Views of parents and the disabled were not included in some of the activities. The needs of the families were not stated to guide the treatment plan. Thepsychological affects were not seen as one of the main factors that contribute towards the effectiveness of such treatment plan, similar to those who develop disability later in their life. To empower peole with disability and their families opportunities and choices should be given and created.

The need to translate the training materials into local language Currently, there are 248 CBR centres in Malaysia and a total of 453 CBR workers under the supervision of Social Welfare Department. The available training materials need to meet the needs of the background of CBR workers. WHO training manuals, actions aid disability news, CBR newsletter, Robert Dellar, Portage and many more, they offered ideas, information on training and learning experiences from every part of the world in CBR etc. Almost all materials available in English and yet many CBR workers or local committees use Malay etc as their first language. Videos also used as a training material for parents (especially illiterate parents). It's from my own experience that parents, disabled people, CBR workers preferred to use their on dialect or language, therefore to train and to develop CBR workers, parents, disabled people and the community, there is a need to look into translating such materials into local language.

Advantage of CBR Programme

It's highlight the unmet needs of the people with disability and their families

Create working relationship between agencies

Reaching out wider community (different types of disability etc)

Develop local people expertise for example ; local carpenter into making special aids

Disadvantages of CBR programmes

- Scope to wide, scattered community require more CBR workers
- Create discrimination amongst disabled people and their families eg people with intellectual disability have limited voice compared to physically disabled (acute cases)
- Create discrimination amongst the professionals and non professional CBR workers on their field of expertise

BIBLIOGRAPHY

Participatory Rural Appraisal (PRA) – an experiment in Central Java (1996)
Towards the 21 st Century : Challenge for CBR in Asia & the Pacific Region – By Action Aid Disability News (Vol.9 No.1 : 1998 pg 9-12)
The Value of Physio Therapy and Occupational Therapy in CBR. By Friday Meeting Transactions (Vol 1, No.1 : 1999 :pg 6-7)
Suara Kebajikan, SWCS, 1994
An introduction to CBR, what CBR, how CBR Japanese Physio Therapy Association (1997)
Empowerment of Mothers of hearing impaired children in CBR programme By Asia Pacific Disability Rehabilitation Journal (Vol 10, No 1, 1999)
Full participant and equal opportunities for pwd in the development of Bangladesh – the importance of cooperation By Action aid disability news (Vol 7, No.2, pg 49-51)
Where should research into CBR be directed in the next ten years ? By Action aid disability news (Vol 9 No.1 : 1998, pg 2-4)

2.7 ACS Penang

PART A

Asia Community Service Bhd has been set up as a company limited by guarantee with no share capital, governed by a board of directors. It was incorporated on the 26th September 1996, with the aim to provide direct services as well as support services to people with special needs, particularly to children and adults with mental handicaps and those involved.

The need to incorporate ACS arose as a result of an extensive 3 year survey that was conducted by Visiting Professor Ken Nakazawa (Japan ollege of Social Work) and Dr Angeline Cheah of USM.

See attached survey reports submitted to EPU. Also see attached ACS' flyer for vision / mission statement.

Current Projects

The Provision of Direct Services

First Step Centre

An early intervention centre currently catering for 52 young preschool children (birth to six years) with mental handicaps, through the provision of assessment, educational, therapeutic services and home visitations.

Adult Training Programme

Currently supporting 6 young adults with mental handicaps in the area of vocational training and independent living skills. This area will be expanded with the set-up of the Support Centre for Community Living next year for about 30 young adults above 16 years in the rural area of Balik Pulau.

Resource Library

The specialised library with over 350 books and videos caters for the education of parents, volunteers, staff and the general public.

The Provision of Support Services

Organising of training courses, workshops and seminars to provide parents, care-givers and volunteers with training opportunities in the area of serving people with special needs.

Counseling and consultation services for parents in educational prospects for their child with special needs.

Offer support and advice to other NGOs and GO's working for people with special needs.

Organising Registration Drives for people to be registered with the Welfare and Education Department.

Conducting on-going research on community needs.

Coordinating exchange programmes (training and exposure) for child care workers between Japan and Malaysia.

Future Projects

<u>Support Centre for Community Living</u> – to be based in the rural district of Penang, catering for 30 young adults with mental handicaps.

<u>Mobile Toy Library</u> – an outreach to promote the importance of play and toys ; recreation and leisure to the rural community.

Staffing and Volunteers

Total number of fulltime paid staff : 6

(3 teachers*; 1 assistant teacher; 1 clerical staff; 1 director) 2 teachers are holders of Advanced Certificate (Christchurch Course) and 1 currently undergoing the Certificate Course.

Total number of fulltime volunteers : 4

(1 occupational therapist ; 1 speech therapist ; 1 social worker ; 1 director)

Clientele

Racial / Gender Breakdown

	CHINESE	MALAY	INDIAN	OTHERS	TOTAL
Male	28	3	3	1	35
Femal e	16	3	3	1	23
TOTA L	44	6	6	2	58

Types / Conditions

Down Syndrome	29
Autistic Tendencies / ADHD	10
Slow Learner	8
Global Developmental Delay	8
Hydrocephalic	3
TOTAL	58

Age					
Below 3 years	22				
3+ to 6 years	30				
Above 16	6				

Annual Income / Expenditure

ACS was awarded a grant to set up the First Step Intervention Centre but have to resort to public donations for its running expenses.

	1997	(6	1998	1999
	months)			
Income	RM 67,899		RM 213,065	RM 151,845
Expenditure	RM 37,038		RM 114,747	RM 136,725

No fees are charged for services rendered at the moment, even though families are encouraged to contribute towards the running expenses of the centre at an amount comfortable to them. Unfortunately, parental contribution amounts to only about 1/5 of the monthly expenditure. ACS is at present looking at revamping this matter and may propose a minimum charge for its services.

PART B – DISABILITY DEFINITION

We tune our definition of disability based on the UN's 1989 classification of :

- Impairment
- Disability
- Handicap

PART C – C.B.R

We have to bear in mind that the concept of Community Based Rehabilitation was popularised by WHO in 1996 as a means of accomplishing "Health for All by 2000", aimed at making rehabilitation widely available to people with disabilities particularly in remote rural environments of developing countries.

ACS' main objective is to ensure that people with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities and achieve full social integration within their communities and their societies.

There is no common position on the methods of implementation of CBR. It is, in fact a lot of different activities all focussed on helping solve disability issues. ACS promotes the community involvement and development aspect in its activities through the following :

Ensuring the involvement of parents / family members in order to give them the necessary skills (main criteria of admission into the early intervention programme)

Support for the family through home visitations

Participation of the community (utilising of lay volunteers in our programme)

Promote public awareness (talks to service clubs, schools, hospitals, corporate sectors etc..)

Encourage and support integration in kindergarten and schools (staff to visit and support students in the regular schools)

Encouraging the placement of school children, college, university students in our programme as part of their community services / training.

Utilising public facilities as far as possible (exposing our clients to the usage of swimming pool, public transport, telephones, restaurants, hair dressers etc..)

Welfare Department-Run CBRs / PDK

It is an interesting fact that the CBR projects in Malaysia are focussed on one single disability group i.e. children with mental handicaps.

One has to acknowledge that the JKM-run PDK projects have been a tremendous outreach to those in the rural setting, more than any one single NGO group can provide. It is therefore sometimes questionable whether the PDKs are redundant in the urban areas e.g. 2 PDKs in Georgetown, right in a 4 kilometre radius where 5 other facilities exist, one of which is the General Hospital.

It is also most unfortunate that with the quantitative delivery of these CBR projects, the concept and essential elements have often been overlooked. Most of the centre-based CBRs have turned out to be mini-schools or centres where their workers are known as 'cikgu' instead of CBR facilitators.

This leads to another interesting question – what difference then is there between the welfare-run PDK centres with the autonomous NGOs e.g. Kiwanis Down Syndrome Centres, Spastic Centre, Pusat Harians, where they are also providing day care centrebased and home based programmes? The Government in its effort to promote the PDK projects should also give equal recognition and support to the autonomous NGO groups. This will cut down on any unintentional discriminatory connotation. It has been noted that where there are 2 types of services in one district, more often than not, one can see a racial distinction i.e. the Malays attending the PDKs whereas the Chinese and Indians will attend the NGO run centre.

We should be reminded that CBR is a strategy within community development for the rehabilitation, equalisation and social integration of all people with disabilities. By right, CBR should be grafted into the existing system or programmes as far as possible.

Future Focus

Therefore then, all, both NGOs and Government alike, will have to take a shift in focus, with a stress on the following :

To concentrate on training and facilitating people in the community rather than providing direct service.

To concentrate on problem based learning approach rather than skill training.

To concentrate on family centred approach rather than medical rehabilitation services

To concentrate on educating the clients on their rights and entitlement rather than just providing educational services

To concentrate on changing the community rather than changing disabled people.

Overall, even in ACS' short history, we have been able to witness attitude changes in the community of Penang. The government too in her own way is seemingly moving towards a positive trend especially evident in the past couple of years.

Example No 1

SERI is the Penang State Government's "think-tank" for long-term strategic planning and policy formulation. It also provides consultancy for social, economic environmental and sustainable development issues pertaining to Penang.

The Penang State Government established the Socio-Economic & Environmental Research Institute (SERI) in 1997 to support its

mission of building a fully-developed Penang, believing that "the fundamental purpose of development is the betterment of the quality of life for all through adherence to the principles of sustainable development which seek an optimal balance between economic growth, social progress, cultural enhancement and environmental conservation."

As an outshoot of that, several sub-groups have been formed, with 2 groups focussing on disability issues such as BOLD (Bureau of Learning Difficulties) and SILA (Sustainable Independent Living and Access), which is a network of people with disabilities committed to promoting non-handicapping environments in Penang, formed in 1998.

Example No 2

I was encouraged to learn that the Penang Wheelchair Tennis Association which was officially formed recently, was registered not under the Registrar of Societies but under the sports council. It is exciting to see the recognition accorded to them as a professional sports body and not as a charity organisation. This is a good move towards being in the community and a fine example of fitting into the existing system.

Emergence of Parent Groups

It is encouraging to note the interests of parental involvement (for the mental handicap population) in recent years. In the past, parents' involvement have been limited to the Parents' Teachers' Association (PTA) commonly found in many centres and schools. While there are quite a few informal parent groups in different parts of the country, PIBAKAT (Pertubuhan Bagi Ibubapa Kanak-Kanak Cacat) in Sarawak became the first officially registered group in 1990 followed by PERKOBP in the Kelang Valley in 1993.

The recent formation of the Penang Down Syndrome Association (<u>http://dsapenang.freeservers.com</u>) on September 11th 1999 is a commendable effort by a group of parents and family members of children with Down Syndrome in Penang. PEKAKA, the acronym for Persatuan Bantuan Pendidikan Kanak-Kanak Khas Sungai Petani (<u>http://www.geocities.com/Heartland/Oaks/1181/</u>), is also another attempt by a group of parents of children with learning difficulties in Sungai Petani.

Other efforts by parents have also resulted in the formation of Centres for Autistic Children (e.g. Shalom House run by Streams of Joy in Penang) as well as organisations such as CLAPAM (Cleft Lip and Palate Association of Malaysia). These are evidences of parents' awareness of their needs to support one another in a common effort to ensure that a voice for their children is heard.

See attached list of registered Parents' Support Groups in Malaysia.

A note of caution to the formation of parent groups – while it is important for parents to voice out the needs of their young children, the parents should not deem it their right to control their children who have grown up to be young adults. The needs of the parents should not overshadow the aspirations and rights of their children.

Part D Independent Living

Definition

"Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves.

To this end we need to support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights"

Adolf Ratzka, Director of Swedish Institute of Independent Living. User of personal assistance, ventilator and power chair since 1961.

Supported Living / Community Living for People with Mental Handicap

It may be difficult, but not impossible for a physically handicapped person to live independently once the physical barriers and hurdles are removed. However, in our society, it may be unrealistic to expect a person with learning difficulty / mental handicap to live a totally independent life. Nevertheless, with support, they can be enabled to live as independently as they desire. For example, an adult living in a small group home may require help finding a job through an employment programme. Hence, Supported Living or Community Living would be a more realistic term to refer to than Independent Living in this case.

Our goals should then be to assist and support the individual with learning difficulty / mental retardation to reach his or her optimal level of independence, and to achieve an independent lifestyle in community through individualised choices and alternatives by providing quality, community care and services which meet the individual's strengths, needs, and preferences.

On the other hand, according to Fujiura & Braddock, (1992) only about 15% of people with mental handicap live in licensed residential environment in the U.S. The others live with or under the supervision of their families. As such, in order for this population to live independent lives, we may also have to shift our focus on providing support to the family. For example, a family caring for a child with mental handicap may need occasional respite services so that they can take a break from caregiving or attend to other needs.

In order for a person with physical impairment to be independent, the physical environment needs to be remedied e.g. ramps, lifts, transportation, buzzers etc... This will cost money. However, in order for a person with mental handicap to be independent, manpower is necessary to enable them to take the bus, go shopping and do the things they so choose to do. This does not require any money, but requires the consciousness of the community to have a helpful spirit. And only then will this type of human development lead to a true caring society.

Living independently for a person with mental handicap is not just a physical arrangement. One can reside in his own apartment but if he is totally dependent on others to make decisions for him, then how much is he really living independently? However, if the person is given the opportunity and feels free to make his own decisions while living with his family, then this is a noteworthy aspect of independent living.

Major Concerns

ACS is looking at this aspect of Community Living in depth particularly in our next project for those young adults above 16 years of age to be launched in towards the end of 2000. As this project will be in a rural community, we do envisage 3 major problems such as :the inner desire of the individual himself to be independent the readiness of the individual towards employment or training the willingness of the family in "letting him go".

In the meantime, we are trying our best to incorporate some of the key elements in our present activities in an effort to empower the children and adults with mental handicaps.

Case Study from ACS' E. I. P. Centre # 1Giving of Choices

- Even though the children that we serve are below 6 years old, we try to emphasize more on child-initiated activities. While the programme is generally set with a routine, the activity within each programme is laid out in such a way that the children will be given choices, e.g. pretend play section will have 2 themes such as "kitchen" or "supermarket". They will be allowed a to choose which story book they want to be read to during the reading session ; which computer programme, etc

This way, rather than the adult selecting the activity, the child's interests are identified. Then the adult joins the child in the activity of interest. From the educator's point of view, the activity and actions initiated by children are more likely to engage and maintain their attention and involvement rather than those initiated by adults, hence learning will be hastened.

And needless to say, the experience of making choices and decisions at a young age is a vital aspect towards independence in adulthood; instilling in them self-confidence and self-esteem.

2Self Evaluation

For the children age between 5-6 years old in our programme, they will be asked to evaluate their own performance at the end of every session, whether they think they have been obedient, or have followed instructions etc... This contract is drawn up with them before implementation.

This exercise teaches them to take responsibility for their own behaviour, the outcome of which can either be positive or negative.

Case Study from ACS' Adult Training Programme

1Problem Solving Approach

The sky was dark the afternoon the young adults were due to go shopping. They were asked to anticipate rain but none suggested carrying umbrellas. It did rain on their return journey. It took them some time before one of the young adults suggested that they take the taxi back instead of walking. Another realised that they could not afford the taxi and took out a 10 sen to make a call to the centre for transportation!! What the staff had to be careful not to do is to give them the solution immediately, but to allow them the opportunity to solve the problem and to take responsibility for their own action and decision whatever the outcome may be.

2Functional Skills – Bank Savings

As part of the their training programme, arrangements were made to have the family give a certain sum of pocket money / weekly allowance to the young adults. This is banked into their account beginning of the week when they come to the centre. They will have to draw out money each time for their own lunch. At the end of each month, with the savings that they have, they will have to decide amongst themselves where and how they want to spent their own money e.g. movies, bowling, haircut etc.. They also learn to spend according to their means.

3Community Volunteer Work

In order to contribute to the society, the young adults make a monthly visit to the nearby Home for the Aged to help out in various tasks as volunteers. This instills much pride in them the fact that they are able to be of assistance to the senior citizens.

In Conclusion

We could argue over the definitions of CBR and IL (till Kingdom come and not get any work done) over and over again but still have no one perfect answer. Interpretation will be different and will vary depending on the culture and the community, whether it be in the US or Sweden, or Mexico or Philippines, or even in Penang or Trengganu.

What remains important is that the dignity of people with disabilities needs to be upheld, and opportunities given to them to be rightful citizens of their local community and to enjoy life to its fullest.

Khor Ai-Na, Director Asia Community Service October 26th 1999

2.8 Malaysian CARE

PARTA:

<u>Name of Organisation</u> Malaysian Christian Association for Relief (CARE)

Description and background of Organisation:

Year of founding: 1979

Area of Involvment :

- Children & Families Services
- Rumah Care
- Family Care
- Urban Community Services
- Rural Development Services

Mental Health Services

Rumah Harapan (a day care center providing individual and group psychoterapy,

psychodrama, occupational and diversional therapy, recreational therapy)

Sheltered workshop

Awareness and training programmes in mental health care The Family Support Group and The Precious People Group

Drug Rehabilitation & Prison Services

Rumah Petros (a residential half-way house for male ex-prisoners) Drop In Centre Aids Unit Prison & Government Drug RehabilitationCentres Coordination

Services for People with Disabilities

Early Intervention Programmes (an educational programme designed for young children with developmental delays from birth to 6 years)

Day Training Centre (which offers and independent living skills programme for young adults with learning difficulties) Social Clubs (for persons with learning difficulties) Toy Library and Resource Centre (open to the public) Referrals and other support services

Employment Development Unit

Summit – CARE Goodwill Shoppe (a unique retail outlet designed to provide employment training and opportunities) -Job Referrals & Assessment -Specific Skill training Career counseling service -Supportive employment Partnership and networking

FRAMEWORK FOR ACTION

The first phase of CARE's work had been to provide relief and rehabilitation to people who are socially deprived through residential services. Our residential programmes are designed to offer support, understanding, love and acceptance in a family home environment which is kept small in nature than an instituitional character.

In the second phase in CARE's provision of services, there was a clear new emphasis and direction to development, self-reliance and empowerment. We are committed to empower our service-users in order to develop their potentials and abilities in decision-making on matters affecting their lives. There is an emphasis on training for young adults with learning difficulties towards income generation and development projects, our services are now mostly community based. We are committed to maintain a high quality of care to be holistic and integrated in service.

We are committed to work in partnership with local churches. We will continue to conduct social awareness programmes, provide consultancy, training, encourage and support the setting up of social/caring services by local churches.

The firm that we play a complimentary role with the government in providing services. We will network with other NGOs for the betterment of our service users.

OUR VISION

Malaysian CARE is called to be the visible expression of the holistic mission of Christ to a broken world; displaying his love, compassion and justice to the poor and socially deprived.

CARE believes the community of God's chosen people is a visible evidence of his presence in the world. Therefore, we seek to assist the Christians to fulfill the biblical mandate.

LOCATION OF SERVICES

Our head office is situated at Jalan Hulu Kelang, Ampang. Most of our own services/projects are in the Klang Valley.

Our networks or Partners in Caring manage their respective centres/projects independently and these are nationwide. For Services for People with Disabilities (SPD), we have helped to establish 10 Early Intervention Centres on the West Coast of the Peninsular (up north in Penang to down south in Batu Pahat) and 1 centre in Sibu (East Malaysia).

We have helped to establish 4 Day Training Centres and 6 Social Clubs in the Klang Valley.

We have helped to establish 2 PDK in the Klang Valley (PDK Selayang and PDK Kg. Kenaga Rawang).

Staff.

CARE has an average total of 60 staff

The academic backgrounds vary: we have a few Masters holders and about 10 degree holders.

For Services for People with Disabilities, there are 8 out of the 12 staff who hold a degree or above. 6 are in relevent disciplines such as Special Education, Disability Studies, Social Work and Speech Sciences.

CARE affirm that appropriate and proffessional training is essential for effective serve. We are committed to develop the human resource potential among staff and volunteers.

The number of volunteers varies from services to services, and degree of commitment and regularity. The Board of CARE consists of volunteers. It is sufficed to mention that volunteers play an essential part in enabling and supporting CARE to provide effective services.

Annual Budget

CARE's Annual Budget is RM 1.3 million

SPD's 1998 Budget = RM280,800 SPD's 1999 Budget = RM304,500

Clients/Service Users

For our direct structured educational programmes (early intervention or independent living skills), the service users are young children with development delays or young adults with learning difficulties.

The service users/trainees are assessed and admitted in the training programmes irrespective of gender, race and socioeconomic status. The selection depends on the vacancies for intake, compatibility to the group's learning potentials, parental/family support. In our programmes, there are individual and group sessions.

An Early Intervention Centre may run programmes for various agegroups (0-6 years) of 3 to 4 children, averaging 30 to 40 in each centre.

For the Day Training Centre, each class will normally consist of 6 to 8 trainees with one key trainer and volunteers.

For Malaysian CARE's SPD training programmes, there is no fixed fees charged. All contributions are voluntary. CARE has a tax exemption status for all donations.

For the Toys Library & Resource Centre, parents of disabled children, carers ot teachers working for disabled people can subscribe by membership if they want to borrow toys or books etc for home use. Yearly membership for an individual is RM30.00 and corporate membership is RM50.00

PART B: DISABILITY

How does you organisation define disability?

We do not have an official definition of disability per se. We are in the process of revising SPD's philosophy statement.

In brief, we see "every human being is of great and equal value in the sight of God".

In my opinion, I will espouse the social model of disability (Oliver 1983) and affirm the following definitions by Disabled People's International (DPI)

"Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. **Disability** is the loss or limitation of opportunities to take part in the normal life of the community or an equal level with others dus to physical and social barriers." (Quoted in Barnes, 1994:2)

A group of disabled people from all over Europe resolved to redefine and reaffirm their own definition of disability at a recent meeting.

"A disabled person is an individual in their own right, placed in a disabling situation, brought about by environmental, economic and social barriers that the person, because of their impairment(s), cannot overcome in the same way as other cirizens. These barriers are all too reinforced by the marginalising attitudes of the society. It is up to society to eliminate, reduce or compensate for these barriers in order to enable each individual to enjoy full citizenship, respecting the rights and duties of each individual.

By supporting this resolution this meeting on human rights expresses its non-support for the current classification for the current classification of impairment, disability and handicap operated by the World Health Organisation. We call upon the WHO to enter in a dialogue with disabled people's organisations to adopt a new definition in line with the above resolution".

(DPI 1994) as quoted in Barnes and Mercer (eds) (1996, p. 47)

I fully support the above and if needed to, I prefer to use the term "disabled people" or "non-disabled" when warrented.

2.9 Malaysian Association of the Blind (MAB)

Part A

Organistaion: MALAYSIAN ASSOCIATION FOR THE BLIND (MAB)

Background of the Organisation:

MAB was founded in 1951 as an NGO by the Welfare Department/Ministry mainly to look into the rehabilitation, educational, vocational and placement needs of the blind or visually impaired people (VIP) in the country.

In 1953 Gurney Training Centre (GTC) for the Blind was established at Brickfields to provide services in vocational and employment of the VIP's in the country.

Princess Elizabeth school established in 50's catered for the primary school needs of VIP students who after completion of secondary come to GTC for vocational skills. Others continued their studies in college to gain degrees and so.

In 1958 Taman Harapan, Agri Training Centre was established at Temerloh to cater to the needs of the rural VIP's in skills of agri. and handicrafts and the clients were mainly non academic adult VIP's, who missed the opportunity to enter school even though the government established an education policy for all blind and deaf in early 1960's.

Both the above programmes or training were residential and cater to clients from all over Malaysia including Sabah & Sarawak. In 1985, MAB started the CBR programme with its main aim to reach out to more VIPs faster in a shorter time and to rehabilitate the VIP's according to environment specific activities. It was also to reduce displacement of VIP's.

MAB's objective is not mainly to advocate but directly or indirectly help in policies . MAB promotes the abilities and capabilities of the VIP's trying to 'empower' them.

To the VIP's, its not the fact of `not seeing' is the biggest problem, but the reality of not beeing seen by others is the the biggest problem, this also has a direct effect on empowerment opportunity. MAB runs residential trainning programmes but no group homes. MAB has an extensive employment programme, day care services for VIP's and sheltered and homeworkers schemes. MAB has over 80 staff with around 25% VIP's. 8 Senior management who are tertiary or diploma level, 10 mid management staff who have HSc or STPM with special certs.,

35 direct service providers with STPM/SPM with special certs and 28 support staff.

MAB has also over 150 volunters (mainly for library services). MAB's annual budget since 1997 to 1999 is close to 2 million Ringgit a year.

MAB's main aim/objective is to help rehabilitate the incurable VIP and help prevent and reduce the incidence of blindness.

MAB HQ situated at KL (Brickfields) serves all Malaya, with its residential centres it caters for persons from all over the country and its day care centre caters in Klang Valley, Library services caters for Klang valley Negeri, Melaka, Johor and East Coast states, Assistance for Blind Children caters for Klang valley Melaka, Johor and East Coast states through Taman Harapan, Placement/Employment services caters for Klang valley, South Peninsular and east coast states through Taman Harapan, CBR prog.[non JKM] covers the states of Pahang, Negeri Sembilan, Melaka, [Kedah, Perak & Penang by St Nicks].

The residential centres at KL, GTC has served over 1200 clients and Taman Harapan has served over 695 clients to date and to persons of age above 16 years and below 50 years.

The CBR programme has identified and was of assistance to 785 VIP's and rehabilitating economically 386 VIP's in Pahang, identified 302 VIP's and economically rehabilitated 76 VIP's in Negeri Sembilan & Melaka.The clients served through CBR programmes are from all age group and mainly of rural areas and VIP's with additional handicapped are also served (to date 18 clients)

The libraries and placement and assistance to blind children have been able to cater to over hundreds of VIP's.

The clients served by MAB do not pay for any of the services.

PART B

MAB serves any Visually Handicapped Person, And a VIP is one who is testified by any medical practitioner clinically blind.

PART C (CBR)

CBR in developing countries should be cost effective, individual based and result orientated, resulting into the complete integration of the individual into the community.

In other words the CBR should enable the individual to stay within the fold of the family or community and contribute economically and to function as he used to function prior to disability or function utilising the other senses to compensate for the loss of vision.

MAB started CBR in 1985 in the state of Pahang. Mainly to reach to the unreached VIP's faster and to formulate more effective result orientated programmes. ie instituitional programmes caters to facilitites available at the centre and the client on return could not continue or relate to his village or community environment. The centre also catered for limited numbers and only to certain age group.

Aspects or Compenets in MAB's CBR programme, covers all age groups of VIP, also includes intervention, prevention & cure for curable blindness registration of incurable blind, social integration Intervention for education, economic rehab., Support services referalls etc.

Past MAB trained field worker/staff (FW) from a district paid fully by MAB, The FW surveys his area/district, identifies, reports, refers, plans a program and trains rehabilitates economically.

Surveys done house to house system and key informant system.

Now we train staff through trainners from overseas (CBM & Sight Savers).

Future intendto use the core staff to be trainers to train all PDK workers with skills in OM & DLS specific to VIP's. and also Kemas teachers to help handle VIP's. This method will help MAB reach to more states faster and core staff to do follow up and vocational rehab & referals.

Problems in implementing is lack of finantional resource of MAB. Slow, to date only reached three states. (Pahang, NS & Melaka) Initial convicing of project area community for support with resources and lack of confidence in VIP's to perform as a normal person.

Role models used with well trained clients motivates others. The number as mentioned earlier reveals the success of trainning number of persons who are now able to have a more meaningfull life.

<u>Macro</u>

Dept of Socail Welfare has given too much importance leading to, Opening of too many CBR centres without trained workers to record or mark `figures',

Mainly only MR cases are taken, and no training for staff to improve on developmental process of MR clients more emphasis on caring.

Budget = too dependent on Welfare funds.

<u>Micro</u>

Impact or awarness OK.

We have got 'some of' the community to invlove in all process of rehab., eg local weaver to teach VIP skills with help from FW, parents/family to followup on Mobility trainning, trained by FW, items made by VIP to be sold by local retailer/whole saler etc. Identification process with help of community.

The community groups targetted are, Imams religious leaders, Ketua Kampong, teachers (for identification and consent) Private companies (for financial/ employment opportunites) Craftsmen, traders, suppliers (raw material, marketing, trainning) Govt. agencies (for subsidies, financial help, to put up workshops etc).

Community mobilisation awarness not done locally but on state level - very costly.

<u>CBR projects</u>

Advantages: reach more people, more trained and aware how to take care of

Disadvantages: leads to est. centres, and not cost effective

We refer other cases to relevent organisations.

PART D (IL)

As for the VIP all are trained to be ultimately to live on their own.Unlike other handicapped a VIP is as perfectly as a normal person in the dark.

Through CBR prog. in NS we were able establish a very strong SBM (self help org.) branch, also in Pahang both these branches were initiated by MAB staff with clients.

PART E

All areas no significant achievement.

In self help groups importance not at all given. National coordinating body voice less.

Equal opportunities a long way they are still taking orders and advise they are still not given the opportunity to lead.(at least the capable ones) As you may see a lot of blind and deaf are capable since they have got ahead start since education opened up for the from 60's and both the groups have got lot of support and help in staff development and finance and a lot of technical input from overseas earlier papers:

Name : GEORGE THOMAS Post : PROJECT COORDINATOR .

2.10 Yayasan Sultan Idris Shah (YSIS)

Yayasan Sultan Idris Shah(YSIS) is a charitable foundation established in 1982 to alleviate the plight of people with physical disabilities. It had a humble beginning being located in a dilapidated building with only 4 people with disabilities to care for. The foundation has grown over the past years due to the constantly increasing number of people with disabilities who seek our assistance. At present the foundation has more than 3,000 people with disabilities on its register. Being a charitable foundation it was realized from the start that finance is required to expand and maintain the required free services to people will disabilities. Money was raised through organizing charity fund raising projects.

As the foundation believes that only the most severely disabled people require institutional care the CBR concept is that services are given to people with disabilities where they live, in the environment they are encouraged to take part in the rehabilitation programmes .The CBR approach is cost -effective and broad based .It involves the mobilizing of local resources within the community and at the same time developing a caring society .

The foundation started developing its first CBR centre at sitiawan. The good response by people with disabilities to the rehabilitation programme spurred the foundation to develop more CBR approach , as we have successfully established , with the co-operation of local community members ,10 centres throughout the state of Perak.

To cater for the constantly growing needs of people with disabilities who seek care and relief for their disabilities from the foundation, a new rehabilitation centre planned along international standards of health care has been built in Bercham, in the outskirt of Ipoh, at a cost close to 2 million, on an 8 arce piece of land donated by the state government. This building occupied from 1992 and recently named The Sultan Azlan Shah Rehabilitation centre houses the Administration section, the Physiotherapy Unit and the speech

Therapy unit ; and is presently the main hub of our activities. The major activities carried out include centre based programmes which cater for specialized training in the following fields :occupational therapy, physiotherapy, and activities of daily living; community development work carried out at the various established centres which involves regular visits by teams of professionally qualified staff from the foundation to administer necessary treatment to people with disabilities; consultative services in which

our staff assist other organization in areas such as planning programmes for individual clients, designing appropriate equipment and sharing information; resource and information service where we have books for loan, a small collection of conference papers and journals for references, as well as pamphlet, video tapes about disability; and home based rehabilitation programmes carried out in the homes of people with disabilities whenever people with disabilities is unable to attend the nearest centre for necessary treatment.

Under the wings of the foundations we have additional support network for people with disabilities such as the Spinal Wheelers Club, which has 221 wheelchair bound members at present. The main aim of this club for members confirmed to wheelchair to over come their frustrations of limited mobility. Another social / recreational club started by the foundations in the Special Bikers Club which has a membership of 145 people with disabilities who use specially modified motorcycles for transportation as an alternatives for those u are denied access to public transport due to their disabilities. The objective is to promote self-reliance for people with mobility disability. We also conduct horse riding therapy for children with disabilities at the equestrian centre at perak turf club. At the present, the vast majority of therapy assistants attached to some 350 voluntary organizations in Malaysia who works with people with disabilities are sadly lacking in knowledge and skills to effectively care for and treat the people with disabilities. Hence, for the continuing improvement of rehabilitation servicers for people of disabilities, the foundation has set up the skills development centre to train and update more than 450 therapy assistants throughout Malaysian in CBR rehabilitation skills os as to better -equip them when dealing with people with disabilities - particularly children.

The rehabilitations services to people with disabilities rendered by Yayasan has earned international recognition on the news media and recorded television documentaries were in japan and other countries.

Over the past few years his Royal Highness Sultan Azlan Shah has been kind enough to recognize and bestow appropriate awards on the occasion of his birthday to people with disabilities who have been successfully rehabilitated and are an inspiration to other people with disabilities, as well as those who work in voluntary organisation and render humanitarian services to persons suffering from physical and mental disabilities. This noble gesture of recognition by his Royal Highness is highly commendable and is also undoubtedly a motivating factor to recipients. We have proud record in that since, 1982 we have rendered free rehabilitions services to more then 3,000 people with disabilities, mainly children, regardless of race or religion. Some who could not walk are now walking; others who could not use their hands are now able to sit up and even be mobile. A few who were on the verge of suicide found renewed strength to live. Many have secured gainful employment arranged by the foundations either in their factory or at their homes. In a nutshell the centre has trained children and adults to be independent and not to be burden to their parents and families.

During the period of development and growth the foundations has eased the pain and suffering of thousands of people with disabilities. Under the guidence of Yayasan Sultan Idris Shah the standard of life of people of disabilities will be improved so that they could look forward to leading a meaningful life.

