

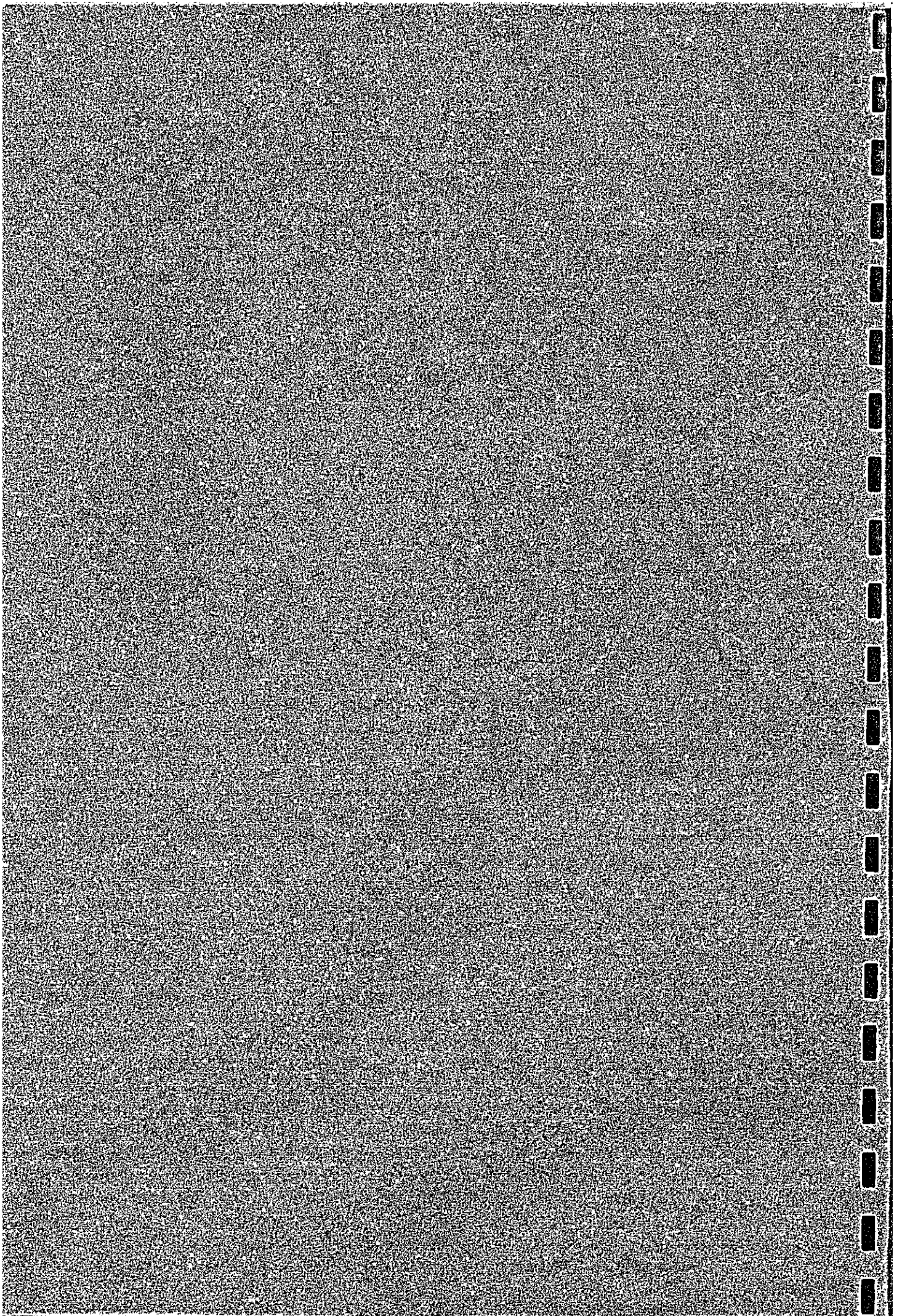
REPORTS

INDEPENDENT LIVING



JICA DISABILITY STUDY

Prepared by JJ Resources



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INTRODUCTION

The Independent Living Movement is a very recent development in Malaysia. Data on this theme from a Malaysian perspective is not easy to come by. With the assistance of a questionnaire an attempt was made to receive feedback especially from self-help groups in Malaysia.

A government agency namely the Department of Social Welfare has developed group homes in an attempt to provide alternate care to the institutional set up. Voluntary organisations have attempted to develop a notion of IL as described in the three reports in section two of this report.

This theme has been further developed and enhanced by self-help organisations. This we read in the third part of this report. There are some differences to how these organisations perceive IL in comparison to the government and voluntary sector.

I take this opportunity to thank all those who have made a contribution in the preparation of this report. The participating agencies and organisations have been very kind in sharing information. A special word of thanks to all the individuals who assisted in the production of this report especially Mr Victor Joseph.

DR DENISON JAYASOORIA

Research Consultant.

1. Government Agencies

1.1 Department of Social Welfare

Disabled Persons & Independent Living - Department of Social Welfare

The Group Homes Programme was started in 1993 by the Department of Social Welfare as an extension of the Taman Sinar Harapan programme.

Residents of the institutions who are trained, want to work and are able to look after themselves are encouraged to stay together in the community and not rely on the institution to manage their daily needs.

The Group Home is a model or example of independent living for the disabled. This approach is similar to a family unit. Those who live in the Group Home will have a father-child relationship with the home supervisor. There are two main categories of Group Homes:

1. As a home for the long-term for those who do not have families or relatives.
2. As a halfway home for the intellectually disabled where they will be supported to boost their confidence and ability to return to live independently with their families or friends.

The Department of Social Welfare has prepared rehabilitation programmes and training to prepare disabled persons for Independent Living. There are two institutions doing this:

1. Cheras Rehabilitation Centre, Kajang, Selangor. This was set up in 1966 and has programmes for those between 14 and 25 years of age.
2. Industrial Training and Rehabilitation Centre for Disabled Persons, Bangi, Selangor. This centre was set up with comprehensive facilities and services for disabled adults to receive medical rehabilitation and vocational training.

Apart from the department, NGOs and the corporate sector should play a role to help prepare facilities to encourage disabled persons towards Independent Living. There are presently seven Group Homes - two in Selangor, three in Johore, one each in Negri Sembilan and Malacca - with 29 residents. They are located:

- 1) Taman Sinar Harapan Tampoi (Lelaki)
26, Jalan Padi Ria 19,
Bandar Baru Uda,
81200 Tampoi, Johor.
- 2) Rumah Kelompok
Taman Sinar Harapan Jubli
33, Jalan Saksama
Taman Larkin
80350 Johor Baru
- 3) Rumah Kelompok (Wanita)
Taman Sinar Harapan Jubli
Jalan Datin Halimah
80359 Larkin, Johor Baru
- 4) Rumah Kelompok Melaka (Lelaki)
Lot 270, Jalan Kesidang,
Taman Sari Bayu,
Lorong Pandan, Melaka
- 5) Rumah Kelompok Seremban (Wanita)
393, Lorong Angsi 5/3
Taman Kelas Tengku
70300 Seremban
- 6) Rumah Kelompok (Wanita)
9, Jalan 4, Taman Seri Teratai
44000 Kuala Kubu Baru,
Selangor
- 7) Rumah Kelompok (Lelaki)
5, Jalan 8,
Taman Seri Teratai
44000 Kuala Kubu Baru,
Selangor

2. Voluntary Organisations

2.1 Bethany Home, Perak

PART A

1. Name of Organisation
Bethany Home

Address:

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

2. 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

Vision

- 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.

Mission

- 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.

Age

From 1 year - 50 years old

Sex

Children and adults of both sex

Race

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 varies 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 : INDEPENDENT LIVING (IL)

1. Your understanding or definition of Independent Living.

Our understanding of IL is a group of young people who live in a house on their own look after themselves, see to their cleanness of the house, able to cook their own meals, interact with their neighbours and be able to travel from home to centre / work place. This group of people makes their own decision.

2. History Of IL in Your Organisation.

Started in April 1999, but preparation for Independent Living has been going on for many years.

3. What are the aspects of IL being implemented in your organisation ?

Group Homes

5-6 young adults live in a house in the community with the supervision of the staff. As the client undergo training with the Home staffs, mainly in area of daily living activity skills and other related skills which will help them live a more independent and meaningful live when they return home to their family.

Advocacy Group

Young adults in their own peer group surrounding share their feelings and at the same time learn about appropriate things of these age group level.

Job Placement

We have students who are employed at places like Caelygirl, Garment Factory, Furniture Factory, Plastic Making Factory, Painting Contract Job, Working with the Fishing boats, Caring out small business on their own and others. They receive salary and find their own transport from the working place.

Sheltered Employment / Workshop

Not all our students get a chance to be employed in open employment, sheltered employment opportunities are created at Bethany Home and its surroundings community to offer training and as a paid job for our graduates.

Sports / Recreational Programme

Throughout the year, sports and recreational activities for the special population is staggered. Students are encouraged to participate and complete in sports events at district, state, national and international levels like Japan International Wheelchair Race. The latest achievement in sports was a young man with Down's Syndrome who climbed Mount Kinabalu in Sabah at Sabah Special Olympics.

4. Past and Present attempts and future plans to promote IL among disabled people you work with

More independent group home with parents support. Hope to find homes nearby Bethany Home, so that we can be their activity centre. To start/create transition programme from school to home, e.g. supervised group homes, independent non-supervised group homes, transition programme such as from sheltered workskills training real situation to job groundwork training. Create opportunities for independent travel use money, manage time, opportunities for social and sport activities, own problem encounter with least supervision.

5. Problem areas in implementing IL in your organisation

Lack of staff to follow up after implementation over protection by parents not allowing them to be exposed to independence.

6. Success and progress in implementing IL in your organisation

We have seen some of our young people graduating from Bethany Home and working in factories - going to and from work independently using public transport and factory bus. Some of the young people staying at Home with their own family and helping in their family business.

7. What are some IL issues you feel need to be addressed and tackle in Malaysia ?

At the macro level

The Government and department of social welfare need to look into the disabled people usually after 21 years of age where will they go to if the family members are not able to manage with them. The Government and Social Welfare need to be able to say that there are job placement or even sheltered employment or workshops that they can go. Is the Government and social welfare looking seriously into the Employment area awareness in mass media and other Public Place for Job placements for young adults to make disabled person full participation.

Training Programme is important - to train person with disabilities as trainers in the leadership and management of self-help organisations. Having had implemented various opportunities the Government and Social Welfare need to encourage and allow participation main trimmings.

At the micro levels

As for the recipients we need to have on going programme. We cannot be looking at the recipient on short term instead we need to look now and future.

Awareness among disabled of IL

We need to have more job placement, more sheltered workshop and encourage them to keep in contact with other peers. More sports and Recreation activity need to be introduced so that among them interaction will take place and they can encourage one another. Counselling is essential to make them know the awareness of IL.

Training and background of staff - Selection of staff is vital- there has to be commitment and some academic level so that must be carried out and implement to other staff so as to see the success of the Independent Living. Lack of training of staff sometimes effort the preparing of disabled people to Independent Living.

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

To implement Independent Living and for us to know how adequate are the measures taken by NGOs and the

Government - first we need to educate the so-called 'Normal People'. The 'Normal People' need to be together and educate the Independent Living awareness with the Normal Peers which make lives much more easier for everyone.

For example some parents are not able to allow their so-called 'Normal Children' to be independent. How much more can parents allow the disabled person to be Independent? Therefore having had seen the Normal Peers together - we can see more Independent Living among the disabled person. Both the 'Normal People' and the Disabled People having had interact together we can than see togetherness with the normal population where Independent Living can be seen.

9. What is the level of participation in IL by persons with disabilities ?

The level of participation in IL by persons with disabilities is still slow. Both micro and macro level - there still needs to be awareness and support from family. They need full support from both macro and micro level so that they can see the togetherness and this will motivate them to lead on Independent Living by persons with disabilities.

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

Independent Living be encourage and Government must provide more job opportunities and create more activity and recreational centres for jobless disabled people. Independent living for the disabled must be focused clearly even as Malaysia moves towards being a developed Nation as these principal to make disabled people independent will be part and puzzle of being a developed Nation. It should be carried out in parallel with normalisation to make every Malaysian as independent as possible.

11. What are some of the advantages, disadvantages, obstacles and strengths in implementing IL projects in Malaysia ?

In the developed countries we see more disabled people in the community because they have started Independent Living long ago and the community is more prepared to accept them. Our media should play more active role in

sharing success stories of disabled people and Independent Living - obstacles will always be there but we need to encourage them and move forward.

Advantages in implementing Independent Living projects in Malaysia would be:-

- In the long run, the country itself would save a lot of money if disabled people are independent and being able to look after themselves.
- Disabled people themselves would have a more meaningful life to carry on living if they become independent.
- Disabled people can become contributing people to their family, community and country.

Disadvantages in implementing Independent Living projects in Malaysia would be:

- A great deal of immediate cash needs to be set aside to carry out this programme. This programme is a continuous affair and cannot be carried out in stages.
- Well-trained staff are needed to plan and implement this training programme from young to adolescent disabled people. This will again involve qualified dedicated staff, time and finance.

Obstacles in implementing Independent Living

- Non-readiness by family members to let go of their disabled loved ones for independent training, family being over-protective of their child.
- Lack of understanding by other agencies, companies and people of independent living for the disabled can be an obstacle towards implementing of this programme.

Strengths

- It is encouraging to see some of the disabled people learning to make their own decision and able to live independent living in their own areas, e.g. centres, individual homes, companies, factories, sheltered workshops, individual self Helpcare, in their own homes and etc.

PART D:

1. 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

2.2 YMCA Deaf Club

PART A

1. Name of organisation:
YMCA Deaf Club of Kuala Lumpur

2. Description and background of organisation:

The YMCA Deaf Club was inaugurated in March 1973 with only 12 members under the guidance of Mr. Tan Yap who was then a member of the Board of Directors. The club was started to cater to the needs of Deaf youths in the Klang Valley and Selangor. Facilities, encouragement and support in the form of providing a staff related were given by the Board. Since then the club has been a part of the YMCA of K.L and being integrated in all its programmes and services. The objectives then was for fellowship, job placement and basic Education (3 R's- reading, Writing and Maths). It has been acknowledge that the YMCA Deaf Club was the first such club to be set up in Malaysia for Deaf Youths. This was followed by the YMCA Deaf Club in Penang in 1981. It is heartening to mentioned that many Deaf Clubs/ societies established in the states of Malaysia currently were started by members of the YMCA Deaf Club of Kuala Lumpur for example KLSD, Sg. Petani Deaf Club, Teluk Intan, Kuantan and Johor. (More details on pages 6 – 9, of the YMCA Deaf Club's 25th Anniversary Dinner Handbook.)

Projects/Programme

The YMCA Deaf Club's areas of involvement include

Advocacy

Leadership Development

Social & Recreationál Activities

Fund Raising

Community Work

Participation in International / Regional Programmes

(Please refer to our Deaf Club brochure.)

Staff:

The Club does not have their own staff , however the YMCA Self - Reliance Centre has assigned a staff related to assist the club activities.

Membership - Our Club is only for Deaf Youths and membership up to November 1999 is 225 active members and over 100 "friends" (those who come to YMCA on Sundays for fellowship even if their membership has lapsed or if they are not members of the club as

yet). Most of our members are youth from 18 – 45 years. Causes of Deafness among our youth are high Fever, accidents and unknown. Some are married and some are still single. Every member of the club receives a quarterly newsletter and a laminated membership card. Most of our Deaf youths are employed and working in a variety of work situations – factories, restaurants, offices, schools for the Deaf or are Self-employed. Their salary ranges from RM400 – 2,500. However a majority of them (salary) are in the range of RM500 – Rm1, 800. The members pay an annual membership fee of RM12.00.

For workshops admission is free but for outdoor programs the members pay a subsidized fee to cover cost of transport/ food. The club annually sponsors members to attend Leadership Training organised by the club or other societies. Most of our members are Chinese – 70%, Malay –15%, Indians 10% and others 5%. Our membership is open to only Malaysian Deaf Youths and does not discriminate on the basis of race, sex, religion or age. To apply for membership in the Club, they are required to produce the Kad Kenalan orang orang cacat issued by the Jabatan Kebajikan Masyarakat or a letter by an ENT Specialist to certify that the person is Hearing-Impaired.

PART B: DISABILITY

Our organisation defines disability as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within range considered normal for a human being.

In our organisation, the abilities and potentials of the Deaf are being enhanced and highlighted rather than their impairment. All members are treated equally and full participation is encouraged in all our programmes.

PART C: INDEPENDENT LIVING (IL)

Independent Living means being able to participate fully in society and having equal opportunities in Education, Employment, Health, Job opportunities, housing, having own families, and enjoying the social and recreational activities that are being provided. It refers to the improvement of the quality of life and to be able to share about Deaf culture with society so that they may understand us further. We want to learn from the mistakes we make and be able to make the choices rather than having them decided for us. We wish to overcome some of the barriers created by society towards the Deaf potentials and

capabilities and be able to contribute to society in a meaningful manner.

- (History- Look at pages 8 –9, 13 and 15 of the YMCA Deaf Club 25th Anniversary Dinner Handbook)
- In order to develop Independent Living among the members of the club, the club stresses on the importance of Leadership Training for its members. Annually an Outdoor / In house Leadership Training is organised. These skills are essential as the Deaf youths are able to apply that not only in the club activities, but also in their work and in the home environment. Members also get the opportunity to socialize with other Deaf members and thus will seek help among themselves. We have many members from outstation coming to Kuala Lumpur to work and being a member of our club is helpful as they get information. Sharing of rooms/ flats is very common among our members. In addition, the club organizes workshops (2-3 times a month) on Sundays for members. The issues are varied- traffic laws, health matters, financial investments, loans, advocacy issues, legal issues and personal development. We also highlight the Deaf youths about new technologies – fax machines, e-mail, pagers etc. In addition our newsletter highlights job opportunities available in the market .

In 1989, we started the Deaf Employment Network (DEN) to improve the employability of Deaf persons. We carry out an annual employment Support Programme/ Pre-employment Training for those who have completed their secondary education or those have just joined the workforce.

Job counseling and interpreting support at interviews are also provided. These employment support activities have helped the Deaf greatly in their strive towards economic independence.

Silent World Sdn. Bhd., wholly owned and managed by the Deaf was started in 1990. This business venture was initiated by the YMCA Deaf Club members and it has 23 shareholders. The business carries out a laundry/ sale of souvenir items at its premises. The business is managed by 2 Deaf adults and 5 Board members (all deaf).

Attempts to promote IL – The club tries to gear the programmes carried out towards IL . The club has an AGM annually to elect their own committee members and plan their yearly programmes for the benefit of their members. The staff of the Pusat Majudiri Y assist in Tel calls/ correspondence. In the early years, the programmes were

carried out by hearing staff. However since 1985, the club has been able to manage their own affairs. The introduction of Family Life programmes among the youths that are either married or will be getting married has helped them to cope with being independent and taking care of their family members. Various workshops on issues related to parenting, financial management & Family Life were conducted to help our members gain knowledge on their roles as parents. Interpreters were also provided in the Registrar of Marriage, during delivery and divorce cases. Our club has seen a growing number of members who have started business to supplement their income. Others, due to the situation have invented gadgets to make them more independent for example - Vibrating alarm clock, or flashing light in place of door bells. Our project next year will be to encourage entrepreneurial skills/ business among our members and to market their products.

Problems- The main problem of implementing IL is communication. Sign Language is the language of the Deaf. However society does not understand nor recognises and value its importance to the development of the Deaf Persons Educators and Family members who have Deaf children are encouraged to sign to the Deaf child as early as possible to help them move towards IL . Deaf Persons who are unable to write proficiently will depend heavily on the use of Sign Language and an Interpreter who is proficient in Sign Language to translate his ideas and perspectives. This access (to interpreters) is very essential to the Deaf Community to enable them to participate in meetings, conferences and in other areas as well (personal & business)

The need for social interaction is probably the most important reason for the Deaf to interact among themselves as they find that the Hearing community depends heavily on spoken language and writing. If a child is born to Deaf parents the Deaf child is naturally exposed to other Deaf adults/ families at an early age compared to children who are born to Hearing parents. Their development is delayed as their parents need time to adjust to their child's deafness and to seek professional advice rather than look for an organisation serving the Deaf Community for support and help. Therefore many Deaf adults socialize predominantly with others who are Deaf.

Success & Progress – Our members are still committed to the cause of Deaf community. Peer counseling is very much evident especially among members who are married. Annually our Committee members attend training conducted by the YMCA Self-reliant Centre on Volunteerism and Personal Development. Two of

our members have received Vocational Award from the Rotary Club of Petaling Jaya and Brickfields for their contribution to the Deaf Community.

In Malaysia the concept of IL is still in the infancy stage. Members of the public still are not aware of the needs of the Disabled. Times have changed but the attitude of some policy makers and the public remains the same. Teachers who teach the Disabled are not exposed to their culture and are not involved in social work. If only they become involved, it makes teaching easier as they may understand the child better. Those who work with the Disabled take years to understand about the needs of the group they work with. Many disabled people are passive. For the Deaf community the need to survive in a Hearing society has made them move towards IL without them fully comprehending what the meaning of IL is.

Issue on Interpreters

The position of Interpreters can be created within the Social Welfare unit and thus provide the Deaf with a means to integrate and participate in society at all levels. By having these Interpreters, the Deaf could further their studies, participate in conferences and would not lack information through the media e.g. TV.

Awareness- Public Awareness needs to be addressed in order for IL to be fully successful.

Staff Training – It is recommended that a study be carried out to look into the Training of NGO staff on the Rehabilitation of the Disabled. On many occasions, the positions are filled by non-disabled staff, thus leaving the Disabled staff at lesser work as the reasons being that the Disabled are not ready / qualified.

Attitude change and allowing the Disabled to decide their direction should be encouraged to implement Independent Living. The thinking of “we help you” should be changed to “we help ourselves”. Greater roles in the community and at Board levels would provide the hands on training for disabled to lead their group. I believe much has to be done for the government and NGOs to address the issues of IL.

Lee Tur Chung (YMCA Deaf Club Chairperson 1999)
Ms. Lucy Lim (Assistant Executive (Deaf Work)YMCA KL

2.3 Dignity & Services

Main Topics :

- I. Which aspect of my life creates independence for others & me.
- II. Which aspect of my life restricts independence.

The aspects of my life that creates independence for me and other people with Learning Disabilities are:

- Having family, friends and relatives who have in more than one way supported me through schooling, Day Training Center, Job Training Center, and attended my graduation. I still get ongoing support from my family, friends and relatives. This enables me to live the life I want to lead.
- Being able to take my own transport, I take the Feeder bus to the PUTRA LRT(from Taman Bahagia station) and back again from Taman Jaya LRT station.
- I am now working in the Dignity & Services office as a full-time office assistant. I am paid on a monthly salary basis, covered with both Employees Provident Fund (E.P.F.) and S.O.C.S.O. It makes me able to earn my own money. I save some of the money in a bank. The remainder I use to buy whatever I want, for outings, etc.
- I learnt Computer when I was in Form 2 when I joined the Computer Club. I use these skills to do my office work and use these skills to do my office work and use this skill to write articles for newsletters.
- I am also the secretary of the Self-Advocacy Group that meets once a month on Sundays. We lead our own meetings. We have common things to share and contribute organising camps and seminars. We are part of the organising committees of D&S' activities. We speak to the media, both press and Radio Television Malaysia (RTM) on Disabilities issues. Our plan is to have our own clubhouse and to register ourselves as a group.
- I am also able to express my views and opinions on different issues. I am good in writing, both in English and Malay. I contribute articles to our own newsletter, "OUR VOICE".

- We were able to write a book by people with learning disabilities, the first ever in Malaysia entitled "Difficult but Not Impossible". The launch itself made me proud and happy.

The aspects of my life that restricts me and other people with learning disabilities are:

- When society does not understand people with learning disabilities, they do not know that we are capable of doing things they never expected. They shun us, think that we are worthless, and should be ignored. Well, they are wrong. Repeatedly, we have proven our worth in many ways. For example, I attended the second day of Campaign'99 Conference and spoke at a Sub-Group workshop on Advocacy & Empowerment. I raised the following points: That people with learning disabilities can speak up through self-advocacy groups and that we had written our first book in Malaysia. The response from the chair-person was annoying, that it was a sales promotion. This gentleman completely missed the point and failing to understand how important it was to speak up in front of a crowd. I felt that the chairperson needed to understand what I spoke of, to give due recognition for the courage it takes to speak up in front of a crowd.
- Society needs to look at our potentials. Often, it is the disabilities, not the abilities that they look at. Some of my friends have been out on job placement; some are working steadily or even helping at parents' offices. Some might surprise their superiors with dedication and loyalty. Again, it is time to explore our capabilities and not the incapability. This is one thing that must be accepted by Society.
- Society needs to show honor to others, just as much we people with learning difficulties do by marvelling their technological concepts. We likewise, deserve it, although we may not be much of a top-grade scholar, or anyone successful. But, we are who we are. Please give us that honor.
- Society mustn't discriminate in terms of religion. Everyone, both able-bodied and people with learning disabilities have the freedom of choice over religion. No, I'm not trying to be religious. But, this must not be taken for granted. Everyone should respect each other even though their religion is different. This has happened between me and my ex-colleague, Lynn, who was the office secretary of D&S. We were good friends and shared plenty of things trying to highlight to everyone. We

respected each other. I feel I should be given the chance to follow my own faith. Just as it is with my parents, friends, and relatives who follow their own faith.

- Skill of road crossing is my weakness. Others are streetwise. They can get across safely, but I need community help. I need community members to think of ways to help me overcome this problem.
- Everyday, we read newspapers and find that even able-bodied people become disabled because of accidents caused by irresponsible drivers. Provisions are not made for pedestrians, especially people who are disabled. Most roads don't have walk-ways, pavements are too high, and the ramps are treacherous; not properly built. We need everything upgraded by the community for people with learning disabilities, even the wheelchair-bound.

CAMPAIGN'99 CONFERENCE REPORT

During my pre-conference stint at the Palace of the Golden Horses Hotel, I was involved in a workshop called Advocacy & Empowerment. I interviewed some advocacy group members from Chosen Power, based in Hong Kong. During the interview, I found out that there are at least 120,000 people with learning disabilities advocate for their rights. 1/5 of the population speak up for themselves. Chosen Power's members are: Cheuck Hong Chi, Chung Wing Kin, Eva, Lee Wai Hong, May Wong, Raymond and Simon. Just like the D&S Self-Advocacy Group, they meet monthly, have promotional talks and they have parents, teachers, social worker, youth and friends who support them. They meet in a rented office for 2 hours the most. No parents are involved in these meetings. They have postal box, liaison person, send newsletters. They do plan for hiking, picnic, horse-riding, karoakae, etc. They have plenty of interests to share. Initially, the assistants did plenty of work like: Setting meeting agenda, charing, and attending meetings. They also contact others, send and take messages, set the table and venue. Their probation is 3-6 months. They are very supportive. They have desired for more members, more exchange, better friendship and own future. The session ended at 5.30 p.m.

3. Self-Help Organisations

3.1 PERKOBP

PART A

1. Name of Organisation:
Pertubuhan Keluarga Orang-Orang Bermasalah Pembelajaran (PERKOBP)

2. Description & Background of Organisation:

PERKOBP was founded in 1992 as a Family Support Group by parents who were concerned with the welfare of their mentally disabled children. It was registered at the end of 1993 under the Society's Act (1966).

Objectives:

- To develop care services and activities
- To offer help and training to the families
- To act as an advocacy group to raise awareness on the causes of handicap needs and rights of persons with learning difficulties

Staff

TWO and one full-time volunteer

Annual Budget

Expenditure for 1997	– RM58,328.54
Expenditure for 1998	– RM58,730.58
Est. Expenditure for 1999	– RM60,500.00

Location of service centres:

PERKOBP ETC & THE SHELTERED WORKSHOP
6 ½ Miles, Jalan Puchong
off Jalan Klang Lama
Kuala Lumpur

Member/Clients:

Types of Disabilities

Learning Difficulties

Age: Between

17 to 43 years old

Gender

Males & Females

Race

Chinese, Indians & Malays

Socio-economic status:

Majority of trainees are from middle class families

PART B : DISABILITY

1. How does your organisation define disability?

Our society caters for persons with learning difficulties only, for example the mentally handicapped as is commonly known. Persons with learning difficulties have problems in learning skills such as the following:

- The skills of communication (speaking and following directions)
- The skills of self-care (personal hygiene, bathing and dressing)
- The skills of decision making, for example to know what to do and when
- The skills of academics, for example the 4 Rs
- The skills of work (disciplines of work)
- The skills of personal safety
- Community living skills

(Note: Membership is confined to parents, guardians, and siblings of people with learning difficulties. Care-givers and social workers can be nominated as Associate Members.)

PART C : INDEPENDENT LIVING (IL)

1. Your understanding or definition of IL:

A person is deemed to be living independently if he is able to attend to his personal hygiene, hold down a job, use public transport and other public amenities independently. On the social level, he is able to blend into the social strata and become a useful person in the community.

2. History of IL in your organisation:

March 1995 – started PERKOBP Employment Training Center

August 1997 – Graduates of PERKOBP ETC started a social club

December 1997 – started a sheltered workshop for graduates who could not be gainfully employed in the open market

3. What are the aspects of IL being implemented in your organisation?

Presently, PERKOBP is involved in training persons with learning difficulties simple work skills. The Employment Training Center conducts a two-year programme where trainees follow a curriculum tailored towards open employment.

Besides the appropriate vocational skills, the trainees are also trained to use various public amenities like the public transport, postal services and shopping facilities.

A Sheltered workshop was set up to absorb those who could not meet the open employment standards. Here, the clients are being coached in the appropriate job skills according to the contract work secured by the Society.

4. Past and present attempts and future plans to promote IL among the disabled people you work with:

Past/Present:

• *PERKOBP ETC*

The ETC provides training in the necessary work disciplines and work skills which would enable young adults with learning difficulties to find and secure jobs in the community. It's a two-year programme.

• *THE SOCIAL CLUB*

The club is managed by graduates of the ETC. They are encouraged to play an active part in organising social activities and games. The staff provide assistance whenever necessary.

• The sheltered workshop

This workshop provides simple jobs to graduates of the ETC who are unable to be gainfully employed in the open market.

Future

- (a) To form family support groups in other towns in Selangor
- (b) To set up PERKOBP ETC branches
- (c) To set up group homes
- (d) To set up more sheltered workshops

1. Problem areas in implementing IL in your organisation:

The problem areas are:

- Reluctance of parents to 'let go'. Parents still harbour the fear that their inflicted sons or daughters will meet with some danger when left on their own.
-
- Insufficient back-up at home
- Re-enforcement of skills learned not perpetuated by parents at home.
- Lack of staff and volunteers
- It is difficult to get suitably qualified and dedicated employees and volunteers to carry out the planned activities.
- LD's poor retention power
- There is a need to constantly repeat skills learned
- Financial constraints
- Our resources of income are confined to well-wishers' donations and monthly contributions from the trainees' parents.

2. Success and progress in implementing IL in your organisation:

Success rate in the ETC is low. Majority would end up in the sheltered workshop. The reason is due to the need to constantly repeat the skills taught to them because of their poor retention power.

3. What are some IL issues you feel need to be addressed and tackled in Malaysia?

At macro level:

- Provide monthly allowance to persons with learning difficulties as an effort to relieve their care-giver's (parents and siblings) financial burden.
- Further streamlining of the present special education curriculum to cater for the different levels of learning difficulties.
- More special education and job training opportunities to be offered by the authorities.

- Increase the availability of professional services for persons with learning difficulties.
- Free health care for persons with learning difficulties
- Free use of public amenities.
- Establish sheltered workshops for employment of persons with learning difficulties.
- Set up information centers to enable facilitation of information.
- More public awareness should be created through the media.

At micro level:

- Difficulty in getting suitably qualified personnel.
 - Lack of local courses in the learning difficulties field.
 - Lack of public awareness of services in this field.
 - Weak financial resources.
 - Difficulty in getting volunteers.
- 4. How adequate are the measures taken by NGOs and the government to implement IL concepts, practices and issues in Malaysia?**

There is a need for NGOs and the government to look into the following areas:

- Need to network
 - Presently, such networking does not exist either amongst the NGOs themselves or between NGOs and the appropriate ministries. This has resulted in the various services being fragmented.
 - Need for establishment of communication links
 - With the establishment of communication link between the government and the NGOs, disseminating of information regarding the various services available on persons with learning difficulties would be enhanced.
- 5. What is the level of participation in IL by persons with learning difficulties (both at micro and macro levels)?**
Nil for persons with learning difficulties.
- 6. As Malaysia moves towards developed nation status, how appropriate is IL (which is still mainly a concept developed and applied in the developed nations)? How can it be contextualised?**
- 7. What are some of the advantages, disadvantages, obstacles and strengths in implementing IL projects in Malaysia?**

3.2 Malaysian Federation of the Deaf

PART A :

1. Name of Organisation:

Malaysia Federation of the Deaf

2. Description & background of Organisation:

Year of founding: 1997

Area of Involvement:

- *Policy Making Advocacy*
- *Coordinating Project*
- *Malaysian Sign Language Development*
- *Grassroots Development Programme*
- *Early Intervention Programme*
- *Human Development Programme*
- *Leadership training*
- *Sign Language Interpreter*
- *Volunteer and Social Worker*
- *Religion*
- *Motivation*

Staff and Qualification:

Executive Director (MCE)

Education Development Officer (SPM)

Sign Language Interpreter (SPM)

Clerk (SPM)

Volunteers (University Students)

Annual Budget: RM100,000.00

Mission Statement:

To represent Deaf minorities in upgrading the quality of life and to secure the rights as equal citizen of Malaysia.

Affiliates:

- Kuala Lumpur Society of the Deaf
- Society of the Hearing Impaired Selangor
- Society of the Hearing Impaired Kelantan
- Welfare Society for the Deaf Terengganu
- Penang Deaf Association Kedah Deaf Association
- Society of the Deaf Malacca
- Society of the Deaf Johor
- Kuantan Deaf Club

Others

Sabah Society for the Deaf and Sarawak Society of the Deaf

PART B : DISABILITY

How does your organisation define disability?

Deaf is not a disability but a linguistic minority. We need to overcome the linguistic barrier to be able to integrate into the society.

PART C: INDEPENDENT LIVING

- Awareness of IL for Deaf Community in Malaysia started when the first deaf self-help organisation was established in Johor in 1976. But not much effort was made to expand the movement.
- Kuala Lumpur Society of the Deaf (KLSD) was established in 1987 and became a very important milestone in the birth of other self-help organizations in Peninsular Malaysia. KLSD played a very important role in helping, guiding and providing financial help to strengthen and to assist other self-help organisations.
- KLSD provides services for deaf individuals regardless of membership status or even races. Services are being extended in the area of advocacy, sign language interpreter, education, work, counseling, legal and other related matters.
- KLSD has proven the IL concept by organising the 5th Asia Pacific Deaf Games in 1996, the World Federation of the Deaf Asia Pacific Conference in Bilingualism in Deaf Education in 1996, and the 1st Asia Pacific Deaf Youth Camp in 1999. By organising the important international event we get the opportunity to exchange views and experiences with self-help organisations outside Malaysia, disseminating important issues and information which brings the aspiration in meeting the objectives of IL.
- The involvement of KLSD brought about the birth of the Malaysian Federation of the deaf (MFD) as an important national parent body of deaf movement in 1997
- MFD realised the task that in order to have a stable organisation to meet the IL objectives, the vital focus is to concentrate on the Grassroots Development Programme (GDP). The GDP is to develop and strengthen the affiliates of MFD and to establish self-help organisations in 4 states that are yet to have their own and to expand services up to rural areas by setting up district level branches affiliated with the states following the federation concept.

- The main barrier in achieving the IL is the financial burden of the GDP, a huge sum of money was needed as a launching grant to finance the establishment of the self-help organisations, meetings, training personnel, communication equipment – PC with Internet that helps ease communication barrier faced by the Deaf.
- MFD and its affiliates have proven the success in IL, where as accepted by the government sector at federal and state level in implementing the national policy. MFD sat in as a member of the National Coordinating Committee and the National Council of Education for Children with Special Needs that had given positive impact to the deaf development in this country.
- The main issue to be addressed is public awareness. If public awareness is concrete then any other pertaining issue will be subsequently taken up without greater problem.
- In education policy the Ministry of Education take care of education of the deaf from the age of 4 years to 18 years old. There are vocational schools to train the deaf in some areas and those who possess good qualification is accepted for tertiary education.
- Meanwhile the Welfare Department takes care of the welfare needs with no age barrier. Since there are no Early Intervention Programmes for the Deaf, NGOs need to play a vital role to give deaf babies a language foundation as early as 8 months, but most of the programmes are in urban areas where the self-help organisations exist.
- Most of the counseling jobs are burdened by the NGOs.
- The NGOs usually provide services for deaf school leavers to equip them in meeting the demand at the job market.
- The level of participation in IL for deaf individuals varies from state to national level. Self-help organisation representation in state level are quite encouraging and representation of deaf person in various NGOs like the Malaysian Confederation of the Disabled, Malaysian Council of Rehabilitation , Malaysian Welfare Council plus government agencies. The highest involvement is as a member in the National Coordinating Committee which is chaired by the Minister of Unity and Social Development. Hence these could prove that Deaf people are accepted as members of the public better if there exists greater awareness.
- IL is appropriate as our country develops caused the acceptance of the ideas and voice of disabled persons is vital during the socio-economy progresses immensely. Our voice our need should be included and in the area where it is necessary the formation of policy ought to be considered and we should not be left out.

- The advantages of implementation of IL through GDP is making MFD's role as the only channel of deaf community and thus avoiding much confusion if there exist many channels out of IL. It also brings the vital unity to the deaf community in general and together facing the challenges of IL. GDP will birth the line of leadership with skill from district, state, national or international level. It will give a healthy competition for the deaf community and bringing the deaf to become loyal citizens and as taxpayers.
- The disadvantages are much on financial and personnel assistance.

PART D

- No national policies for the deaf currently that needs to be abided.
- Slow awareness of government and private sectors in meeting the needs of the deaf.
- Communication barrier, not enough sign language interpreters.

3.3 Society of the Blind Malaysia

PART A

1. Name of organisation:
Society of the Blind in Malaysia (SBM)

2. Description and background of organisation:
The Society of the Blind in Malaysia is a non-religious, non-political, national voluntary organisation of blind individuals of all races and from all walks of life resident in Malaysia. It is dedicated to the task of securing equal rights and opportunities for blind people in this country by working collectively and fraternally for the socio-economic advancement of blind people, with the view of enabling them to become responsible, useful and productive citizens.

Registration No.: 1852 (Selangor) (registered on 25st March 1964)

Place of business:
40A Jalan Padang Belia
50470 Kuala Lumpur.
Tel.: 03-22746162
Fax: 03-22743818
E-mail: admin@sbm.org.my

Membership:
Ordinary membership open to blind persons above age of eighteen years; associate membership open to sighted persons above age of eighteen years.

Objectives:

- To encourage blind people in Malaysia to work for their mutual socio-economic advancement and their common good.
- To uphold the rights of blind people to live as participating and contributing citizens of this country and promote their legitimate interests.
- To promote communication and understanding among members.
- To promote sports and recreation for blind people.
- To monitor and/or assess services provided for blind people by Government and non-Government bodies, and to present the considered views and recommendations of the Society on matters concerning blind people to the relevant bodies.
- To co-operate with other organisations to achieve the objectives of the Society.

- To work towards overcoming social barriers and to promote integration between blind and sighted people.
- To promote the general well-being of blind people.

Activities:

- Education & leadership training - training for members, assistance to members' children and blind students, mini-library services.
- Employment - computer literacy classes, exploration into assistive devices, courses/seminars for specific categories, provides equipment and small business loans.
- Library services - Braille magazines, audio news clippings and magazines, promotion of creative writing and artistic activities - drama, novels, poetry, etc.
- Sports, recreational and social activities, indoor and outdoor.
- Sale of Braille items - white folding canes, Braille writing frames, talking clocks, watches and calculators, Braille paper, Perkins Braille, loop needle threaders; items are sold at reduced rates to members, and at cost to organisations and firms.
- Computer Resource Centre - to promote access to computer information and technology for the blind; to educate the blind on various devices they could use to work with computer technology at work, in education and at home.

Coverage

The Society has 9 branches all over Malaysia, with the head office in Kuala Lumpur. Membership strength stands at more than 1,600 ordinary members and more than 500 associate members.

Staffing

1 full-time administrator at Head Office, 2 technicians specialising in production of audio information and use of computers, 6 full-time clerical support staff and at least 2 part-time support or maintenance staff in each of the 9 branches.

Budget

1997 - RM 957,440
 1998 - RM 1,162,842
 1999 - RM 1,145,229

PART B: DISABILITY

1. How does your organisation define disability?

For the purpose of determining eligibility for ordinary membership, the applicant's disability is ascertained through documentation from the Welfare Department of Malaysia in the case of an applicant not known to the members of the Executive Committee responsible for processing membership applications.

PART C: INDEPENDENT LIVING (IL)

1. Your understanding or definition of IL:

The ability to assert what you want rather than passively accepting what others decide for you.

2. History of IL in your organisation:

From day 1 it was decided that this would be an organisation of the blind speaking for themselves. We have survived for almost 36 years, in the face of numerous challenges, some from people all out to destroy this organisation in its early days. Today, we continue to train our members to be in charge of their own organisation through training seminars and workshops, but mainly through practical day-do-day undertakings. Even the most professional of our associate members do not tell us what to do but wait for us to instruct them as to what is to be done for this organisation.

3. What are the aspects of IL being implemented in your organisation?

- For economic advancement - interest-free small business loans; career-related training/seminars.
- For educational advancement - Assistance to blind students; incentives for blind students with excellent examination results.
- For organisational advancement - leadership training courses and programmes (internal and external).
- For social advancement - brainstorming sessions at branches; viewpoint gatherings at branches; trips to learn and to enjoy; recreational expeditions and programmes at resorts.

4. Past and present attempts and future plans to promote IL among disabled people you work with:

(Refer to previous pages)

5. Problem areas in implementing IL in your organisation:

- Low number of voluntary participants.
- Diversity of members requiring programmes to be conducted for many small groups
- Shortage of resource persons
- Infrastructural difficulties, particularly with regard to public transportation outside the Klang Valley.

6. Success and progress in implementing IL in your organisation:

- Programmes have been conducted all over the country, bringing the organisation closer to members at grassroots-level.
- The involvement of local authorities opens the opportunity for advocacy for the members of this organisation.
- Most of the programmes involving cooperation with other organisations have yielded positive results when the members of this organisation were able to steer the direction of such programmes.

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

With the advent of computerised information pervading our lives, access to information for blind people in this country is becoming more challenging. Hardware and software have to be imported at high cost and they become obsolete before too long even in our own country. NGOs have been stretching their resources to cope with this demand which is often linked to productivity in employment, but the Government sector has been doing precious little to help this group of citizens in this area.

Disabled citizens as a whole need an effective body to influence the Malaysian Government establishment in regulating various aspects of our society. The National Council for the disabled in its present form is insufficient for it is still a domain of the Government. The Malaysian

Confederation of the Disabled has shown proof that disabled people are more effective when united but this parent body is facing a leadership crisis (Not conflict, but shortage).

The number of disabled persons with great potential for mobilising the cause of disabled persons in this country is ever growing but these people are, more often than not, competing with, rather than complementing each other. We need to unite, and unity asks for a great deal of effort, sacrifice and compromise.

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

Over the past 10 years the Government has been making efforts to get concerns of the disabled heard and they have met with a little success, say, in making public facilities more accessible.

The Minister of National Unity and Social Development has held dialogue sessions with NGOs albeit in a somewhat messy way. Haphazard though these sessions may seem, issues and concerns have been repeated often enough on both sides, hopefully efforts by both sectors could be coordinated more effectively in time to come.

While NGOs complain that the Government has been leaving too much work for the disabled in the hands of NGOs, these same NGOs will be most reluctant to relinquish their undertakings to the Government. And the disabled are grateful to the NGOs for up till this point it is mostly through NGOs that disabled persons in this country have the opportunity to enhance their independent living skills further.

However, the Government sector will have to open up their doors a lot wider to give disabled persons a truly meaningful role in the decision-making processes in areas affecting the lives of disabled persons - from A to Z.

9. What is the level of participation in IL by persons with disabilities? (Both micro and macro levels)

For blind people, the training received through active participation in the running and programmes of this organisation have made ordinary members of this

organisation more willing to be involved in decision-making processes on matters related to the livelihood of disabled people wherever opportunities are given.

It is not unusual that the number of persons on the receiving end far exceeds the number willing to contribute. We will continue to facilitate growth in those who seek improvement in personal abilities and capacity to extend a hand to others through teamwork and educational programmes at grassroots-level. We believe the more our members know the better able they will be to fend for themselves and get their voices heard.

10. As Malaysia moves towards developed nation status, how appropriate is IL? How can it be contextualised?

Even in the most developed of countries there are disabled people who are deprived of valuable experiences taken for granted by the so-called non-disabled. IL programmes will always be needed by some but the form and content of such programmes may be different from present day concepts. As family structures loosen, more individualised approaches need to be developed even in Malaysia but the goal will remain - to be able to take care of oneself with dignity.

11. What are some of the advantages, disadvantages, obstacles and strengths in implementing IL projects in Malaysia?

IL projects are generally beneficial for any category of human beings anywhere but they are only advantageous if tailored to meet the needs of a group in their own community, whatever the model may be. The products of institutionalised nurturing tend to be estranged from their communities of origin, thus the advantage of community-based rehabilitation services that may be less comprehensive.

The shortage of specialists willing to train disabled persons poses a serious problem to effective rehabilitation programmes in institutionalised settings and the problem is many times more acute in community-based rehabilitation.

However, we are much more fortunate today as the better-educated parents of today are more willing to nurture their disabled children themselves, inculcating in them the values

of being productive persons capable of living independent lives when they grow into adults. Such strength can only be maintained as long as family values remain strong in our society.

PART D:

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

GOLONGAN CACAT, GOLONGAN ISTIMEWA, GOLONGAN ORANG KURANG UPAYA, 'the less fortunate', the disadvantaged, marginalised, etc - LABELS, LABELS, AND MORE LABELS.

When you receive so much labelling from the so-called able-bodied, you do not feel like a human being anymore - you are just a 'thing' and labels are here to stay for a long time.

The thinking of students on disability and disabled people needs to be challenged so that when they become parents, they will educate their children that a person's disability does not change his psychology. It is the disabled persons' reaction to the abnormal stimulus from so-called non-disabled people around them that makes them appear not normal.

Respondent's Details

Name: CHOK SIEW LEE

Position held: EXECUTIVE SECRETARY

Date: January 12, 2000

3.4 MASIA

PART A

1. Name of Organisation:

Malaysian Spinal Injuries Association

2. Description and background of organisation.

The Malaysian Spinal Injuries Association (MASIA) was officially registered on 11 November 1994. This Association is a non-profit, non-religious, national organisation of spinal injured individuals of all races and from all walks of life, resident in Malaysia. MASIA is a support group for people with spinal injuries and their families. It is controlled and run by the spinal injured people and their friends.

MASIA's aims and objectives in relation to improving the lives of spinal injured persons are as follows :

- to act as a central storehouse of advice, expertise and practical help to spinal cord injured people to get them back to a normal life as quickly as possible
- to provide a vehicle for mutual support and solidarity
- to have a common purpose, that of promoting the rights of spinal injured persons to live as citizens in society ...
- to actively campaign on vital issues affecting the everyday lives of spinal injured persons and campaign for the best possible medical care and rehabilitation services. MASIA welcomes the active support and encouragement of medical and counseling expertise towards better living for the spinal injured
- to act as a bridge between spinal injured people and bodies such as hospitals, government departments, employers and local authorities, encouraging statutory and voluntary improvement in access, mobility, education, housing, employment and social and recreational activities
- to create public awareness about the needs, aspirations and abilities of people with spinal injuries and to promote this awareness through lobbying the government, monitoring agencies providing services and publishing information leaflets and newsletters

PART B : DISABILITY

1. How does your organisation define disability?

Within the context of the spinal cord injured (SCI) disability results from an impairment to the spinal cord. This places the SCI at a disadvantaged position in terms of carrying out his/her daily activities as well as participating fully in community life. The difficulty arises mainly due structural barriers either at home or in the community which restricts the freedom of movement of the SCI who are invariably dependent on wheelchairs for their mobility.

PART C : INDEPENDENT LIVING (IL)

1 Your understanding or definiton of IL:

2 History of IL in your organisation:

As apart of its activities MASIA advocates independent living for its members. This is done mainly through peer counseling whereby its 'older' and more experienced members share their experiences and knowledge with the 'newly' spinal injured. Currently the means of doing this is not formalised - it is carried out on ad hoc basis in response to requests from our hospital contacts (doctors , occupational therapists or physiotherapists) and from families of the newly SCI.

3 What are the aspects of IL being implemented in your organisation?

Peer counselling is being carried out. We also provide medical aids such as urine bags and catheters to our members. Once a year a small sum of money is given to all ordinary members as mobility allowance. Talks and seminars on topics relevant to SCI are also organised for members. The Association also encourages its members to participate in forums and seminars on disability issues.

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

Our plans to promote IL among the SCI are :

a) To set up a Half-way house to provide IL training for new SCI who are discharged from hospital - The programmes will include aids to daily living skills such as techniques of transferring oneself from the wheelchair to the bed or to any other seat, dressing, bathing, toileting, cooking. The programme will also include information on personal hygiene, prevention of bedsores, sexuality, sports activities and driving.

b) To organise seminars and workshops to help promote the concept of IL in other parts of the country.

5 Problem areas in implementing your IL in your organisation:

a) Since MASIA is a relatively new organisation, funding is a major problem. Firstly, the proposed Half-way house project can only be implemented when enough funds have been accumulated . As MASIA does not receive any form of financial aid from the government, we rely solely on donations from the general public and private companies.

b) Government funded services such as t he Personal Assistant Scheme or the Carers' Scheme as found in some countries are noat available in Malaysia . Therefore, to provide any form of personal assistant facilities in the IL centre we will have to either depend on volunteers or meet the expenses ourselves.

6 Success and progress in implementing IL in your organisation

Not applicable. (We are yet to start our IL Half-way house)

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

The need to promote the setting up of IL Centres

At the macro level:

Firstly, the concept of IL is new to Malaysia. Our government needs to be sensitised to the concept and its benefits to people with disabilities. The government should be encouraged to look into the possibility of introducing a Personal Assistant Scheme to complement and facilitate the successful management of IL centres set up by NGOs. They should be either provided free by the government or made easily available to people with disabilities who need them and are willing to employ them. Foreign labour, in the form of domestic maids, can be considered for this purpose. The red tape and exorbitant fees involved should be reduced greatly. The training of the personal assistants can be undertaken by the government.

At the micro level

IL should be promoted among disabled people (especially for the SCIs) so that they can live independently, be able to make choices and decisions that affect their lifestyles and future. Awareness about the importance and advantages of ILs can be disseminated through brochures, seminars or workshops. Disability groups can lobby and seek the cooperation of the government in setting up and managing such IL centres.

Personal assistants can be recruited among volunteers or alternatively the government can play a part in providing trained personal assistants.

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

The IL concept is still new in Malaysia. For a start, disability groups must play their part to advocate the setting up of IL centres in the country.

9. What is the level of participation in IL by persons with disabilities? (both macro and micro levels)?

Currently there are already a few IL centers that have been set up on an informal basis by self-help groups. We foresee that SCI would welcome the idea of IL as it would enable

them to be independent and with appropriate support facilities help them lead a better quality of life

- 10. 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?**

We feel the IL concept can be appropriately introduced in Malaysia. It may perhaps be slow to catch on due to socio-cultural factors. Most of the SCI are still being cared for (financially and otherwise) by their own families who may have reservations about the SCI individual living 'out there' on his/her own. If the IL concept becomes widespread and receives positive support from the government, it can then be adopted and implemented rather easily.

- 11. What are some of the advantages, disadvantages, obstacles and strengths in implementing IL projects in Malaysia?**

IL projects will certainly be a boon for people with disabilities in Malaysia. It will be particularly suited for those with spinal cord injuries who are either paraplegics or quadriplegics. Presently most SCI are cared for and protected by their own family members or relatives. Since most of them are unemployed, they become financially dependant on their families. Being dependants it affects their freedom to choose what they want and how they wish to lead their lives. Hence an alternative such as the IL center can provide the opportunity for the SCI to exercise freedom of choice, learn to be in-charge of themselves, take on responsibilities etc. - which overall helps to restore a sense of dignity and improved self-esteem in the SCI.

However, if the IL centers are not properly managed and monitored, there is a danger that they too may develop into 'homes' and 'institutions'. Hence it is important to have specific objectives and programmes so that the center is run in accordance to the true IL philosophy. Programmes should be effective and comprehensive to be covered within a reasonable length of time.

One important pre-requisite for setting up IL centres is of course funding. Usually it is self-help groups that initiate, or feel the need to set up IL centers. As most self-help groups

rely on donations from the public to meet their expenses, funding is a major problem.

PART D:

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

2. **Please include any materials you have written on the above issues e.g. papers, proposals, research articles etc.**
(Nil)

Respondent's Details :

NAME : BATHMAVATHI KRISHNAN (MS)
POSITION HELD : SECRETARY
DATE : 9 JANUARY 2000

3.5 Disabled Persons Welfare Society, Ipoh

PART A

1. Name of Organisation:
**Persatuan Kebajikan Orang-Orang Kurang Upaya,
Ipoh, Perak D.R.**
(Disabled Persons Welfare Society, Ipoh)

PART B : DISABILITY

1. **How does your organisation define disability?**
We define disability as a gift and it is the society that is disabling us.

PART C : INDEPENDENT LIVING

1. **Your understanding or definition of IL:**
Our definition of IL is to take positively, to change the whole idea of the lives of the disabled. To give control to the disabled person to make his or her own decision in everyday life.
2. **History of IL in your organisation:**
None
3. **What are the aspects of IL being implemented in your organisation?**
- Group Homes and 51 percent of the management committee should be disabled persons
 - People with disabilities should live in their communities.
 - People with disabilities are neither the patients to be cared, the children to be protected, not God to be worshipped.
 - People with disabilities themselves can identify their necessary assistance and manage it.
 - People with disabilities are the victims of social prejudice rather than the victims of disabilities.
4. **Past and present attempts and future plans to promote IL among disabled people you work with:**

5. **Problem areas in implementing IL in your organisation:**
Manpower, financial and the co-operative among disabled persons.
6. **Success and progress in implementing IL in your organisation:**
7. **What are some IL issues you feel need to be addressed and tackled in Malaysia?**

At macro level

- Government and Department of Social Welfare should provide us with financial and training abroad.
- Set up more centers for the IL

At micro level

- Disabled people of IL still do not understand enough for their own benefit

8. **How adequate are the measures taken by NGOs and the Government to implement IL concepts, practices and issues in Malaysia?**
None at present.

9. **What is the level in IL by persons with disabilities?(both at micro and macro levels)?**
We would say there is none.

10. **As Malaysia moves towards developed nation status, how appropriate is IL?**
Well as Malaysia moves towards developed nation status, IL is a dynamic and liberating option for disabled persons in Malaysia. We need to start the process in Malaysia. We need to train personnel, begin peer counselling and living skills training. We need to train assistants and work for legislative changes for our governing authorities to take responsibility for the restoration of rights and social facilities for the disabled persons in Malaysia.

11. **What are some of the advantages, disadvantages, obstacles and strengths in implementing IL projects in Malaysia?**
 - 51% of the board members must be people with disabilities
 - At least one of the top executives who would make important decisions should be a person with a disability.

- At least one of the staff should be a person with a disability.
- Il center must give following essential services:
- Information and referral (personal assistance, housing, etc.)
- Peer counselling (by disabled peers)
- Il programmes (including il skills)
- Individual advocacy
- Besides these basic services, other services should be encouraged like giving services to people with any type of disabilities rather than dealing with one particular disability.

PART D :

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

Very sad to say it is a pity for them because there is no independence for them.

Respondent's Details:

NAME	:	FRANCIS YAP
POSITION HELD	:	PRESIDENT
DATE	:	10 TH JANUARY 2000

Appendix
:Questionnaire

ORGANISATIONAL QUESTIONNAIRE

Independent Living & Disabled People Perspectives of Self-Help Organisations in Malaysia

OBJECTIVES

- The list of questions below serve as a guide to help you provide information and details about the status of disabled people in Malaysia, with specific reference to Independent Living concepts and practices.
organisation and people; lessons learnt and problems encountered; future plans and proposals, will help us draft a final report. This report will be submitted to JICA for its consideration.
- The aim is to come up with a comprehensive study of the above and to make recommendations of programmes to be implemented to benefit disabled people
- Your input from a conceptual and theoretical perspective; practical outworking of the ideas and concepts; experiences of your
- Guidelines for report-writing and submission : Your report and response should be between 10 and 15 pages long (or more). It would be appreciated if the data and any other information can be stored and handed over in a diskette, preferably in Word format. Articles, papers etc can be attached with your report for our study and report.

PART A : ORGANISATIONAL DETAILS

1. Name of Organisation:

2. Description and background of organisation: (Please include details like : Year of founding. Areas of involvement (advocacy, programmes and projects). Staff (number, qualifications/ academic background) and volunteers. Annual Budget (1997, 1998 and 1999). Vision/Mission Statement. Location of services (number of centres, town / state. Members/ Clients (number, types of disabilities, age, gender, race, socio-economic status) Do members/clients pay for services? (nominal sum; according to income level etc)

PART B: DISABILITY

1. How does your organisation define disability?

PART C : INDEPENDENT LIVING (IL)

1. Your understanding or definition of IL.

2. History of IL in your organisation.

3. What are the aspects of IL being implemented in your organisation?

(eg, group homes; advocacy; self-help groups; independent living support programmes like assistant service, financial/credit schemes, job placement; sheltered workshops and leadership development programmes)

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

5. Problem areas in implementing IL in your organisation :

6. Success and progress in implementing IL in your organisation :

7. What are some IL issues you feel need to be addressed and tackled in Malaysia? (at macro and micro level) (macro - how much importance given to it by the Government and Department of Social Welfare, awareness, training programmes, implementation) (micro - recipients, awareness among disabled of IL, training and background of staff)

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

9. What is the level of participation in IL by persons with disabilities? (both micro and macro levels)

10. 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?

11. What are some of the advantages, disadvantages, obstacles and strengths in implementing IL projects in Malaysia?

PART D

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

2. Please include any materials you have written on the above issues, eg, papers, proposals, research articles etc.

Respondent's Details :

1. Name :

2. Position held :

3. Date:

