

REPORTS

CBR - IL WORKSHOPS & INTERVIEWS

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JICA DISABILITY STUDY

prepared by JJ Resources

Contents

Introduction

page

1. Workshop Reports

- | | | |
|-----|---|----|
| 1.1 | Workshop in CBR & IL (Nov.3,1999) | 1 |
| 1.2 | Workshop on Independent Living
(Dec.19,1999) | 12 |
| 1.3 | Discussion Group on CBR & IL (Jan.22,2000) | 17 |

2. Interviews

- | | | |
|---|---|----|
| • | Beautiful Gate | 23 |
| • | Reflections on IL in Japan with Christine Lee | 29 |
| • | IL & the Blind : An interview with Godfrey Ooi | 31 |
| • | Department of Social Welfare Group Home
(Malacca) | 34 |
| • | IL for People with Disabilities : by Stephen
Chow | 35 |
| • | IL Workshop-Press release | 38 |
| • | Independent Group Homes : Bethany Home,
Perak | 39 |
| • | Hopehaven Center and IL | 43 |
| • | IL – Some Reflections : By Christine Lee and
Chan Wing Hon | 47 |

3. Correspondence



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1. *Workshop Reports*

1.1 Workshop on CBR and IL

Date : Nov 3, 1999, 9am-4pm.
Venue : National Council for Social Welfare and Development Training Centre Bandar Baru Sentul, Kuala Lumpur.

Participants :

Datuk Ghazali Yusof, Khatijah Sulieman and Haji Mustafa Albakri	National CBR Coordinating Committee
Godfrey Ooi and George Thomas	Malaysian Association of the Blind (MAB)
Ranjit Kaur	Tanjong PLC
Ms Harumi and Kenji Kuno	JICA
Dr Saini Jeffery	CBR Selayang
Dr Yusnizah	CBR Cheras
Aina Khor	ACS, Penang
Christine Foo and Pauline Wong	Malaysian Care
Zakiah	Sarawak
Fauziah Tahar	Spastic Children's Association, Selangor & FT
David Khoo	Special Education, Ministry of Education
Dr Aminah Bee	Public Health, Ministry of Health
Wan Noraida	Department of Social Welfare
Meme Rashid	Department of Social Welfare
Lucy Lim	Pusat Majudiri
Chandra and Jeyasingh	Bethany Home
Bathmavathi Krishnan	MASIA
Anthony Arokia	DAMAI
Mathilda John	Dignity & Services
Chrystyn Lee	Chinese Disabled Society
Dr Denison Jayasooria	Researcher
Rose Jayasooria & Lim Ming Haw	JJ Resources

1. Introduction

Datuk Ghazali and Dr Denison Jayasooria gave a welcome and introduction to the workshop.

2. Sharing experiences

Participants were asked to reflect on their experiences using the questions:

- i. Where is the place of the disabled in all that we are doing?
- ii. How do the programmes lead towards empowerment, independent living and self-help?

What are the values, perceptions and vision of the work with disabled people?

3. Participation of Disabled Persons

There was much discussion centred on the role played by disabled people in disability work.

Godfrey Ooi shared that since 1981 and the IYDP, disabled people have been given more opportunities to participate and be involved in the work. But they still mainly play a subsidiary role because of the charity and patronising mentality present. Although there has been much progress since 1981, there is a lot of tokenism.

In the pre-1981 period, disabled people couldn't speak for themselves. There were comments like "How can the blind make decisions in the MAB?" After the 1980s, there were more exposure, education and opportunities and the disabled could speak up more. But many are still only employed at lower levels and request for higher level jobs in administration are still not recognised. The main committees are still run by non-disabled persons.

"If you want to win, you need to struggle and fight for positions. The blind are not ready for higher positions because many are still poor and with low level of education. We can't fight for our rights," he said.

He added that many NGOs in developed countries received funding from governments and therefore they had the time, will and ability to do things. NGOs here are not well-funded and self-help groups need to raise their own funding. Thus disabled people are still struggling. There is a need to bring in more blind people to get involved.

Membership in organisations for the blind is restricted and it is difficult for blind to become members of decision-making bodies. Blind people are not given the opportunity to get in, are still sidelined and there is tokenism.

George Thomas said most institutions set up the programmes for their clients. In CBR, clients are asked what they want and groups try to cater to the needs of the clients and parents. The goal is rehabilitation till they become independent. "We are still a society for the blind, not of the

blind. In community programmes, if the parents do not help, these will not be successful."

He added that institutional programmes usually catered for blind persons who are academically qualified. CBR thus helps those who may not be academically qualified, for example, blind persons in rural areas.

Christine Foo said there has been a healthy emergence and progressive shift towards self-help. But for the learning disabled, there is no society for them yet, except for parents' support groups. "There is a long way to go."

Datuk Ghazali asked if the Government will encourage this shift or allow it to go on its own steam? Puan Khatijah responded that we cannot just ask the Government to plan. "We who are involved and committed should place disabled persons in planning and management."

Ranjit Kaur felt that much depended on 'attitude'. "The attitude of the public, including the disabled, believe that disabled persons can't cope and are incapable ... negative attitudes lead to a lack of empowerment."

For example, children who are born disabled do not get opportunities like other children. "They become segregated. They are registered under the Welfare Department and labelled recipients of special education facilities. But if disabled children get equal opportunities, they will grow and will be considered as peers by other children."

A. Arokia said it was important for disabled persons to make the decisions because "it is our lives at stake." Parents are over-protective of disabled children. Then problems arise when parents die and can't care for disabled child anymore.

Haji Mustafa Albakri noted that most programmes are carried out by the able-bodied. The disabled have no chance to draw up programmes. In CBR, there is no interaction between able-bodied and disabled children. There is segregation and no socialisation among them.

Datuk Ghazali noted that many groups of disabled people were not strong enough to organise themselves. Ranjiti Kaur said there must be an environment where opportunities are given to disabled persons to organise and empower themselves. But in the 'Caring Society' concept, there is a

strong charity model. "Here the disabled are not seen as our equals, we take care of them. Instead of an inclusive society, we are segregating them. In CBR, disabled children are further segregated."

Leadership and responsibility were not instilled among young disabled persons, Godfrey Ooi said. He said that many things are given free and that many disabled persons feel the world owes them a living. Dr Saini Jeffrey noted that CBRs don't provide the children with basic skills to live their own life, eg daily living skills.

Parents tended to do everything for their disabled children. There is a need to instill the ability to live independently among the disabled. Godfrey agreed that there was a need to provide basics and also instill the value of responsibility.

Chan Win Hon commented that the 'culture of dependence' is perpetuated and that social structures pose a barrier. He asked what the role of government was. There should be funding for facilities for the disabled and subsidy for home renovations for families with disabled children.

4. CBR Models and Programmes

Lucy Lim said that in 1973, the first group for deaf persons was formed. In the work among deaf, there is emphasis on leadership development and mindset change, to raise own funds, self-determination. With the right support and public attitudes, the deaf can do a lot. But some groups for the deaf do not allow the deaf into their decision-making committees. CBR Cheras was started in 1995 by parents who wanted their children to continue receiving education and training.

The centre was started in a church by parents and was maintained by them. It serves like a kindergarten for children. There are 40 children aged between 1-12 years with different disabilities and some with multiple disabilities.

It doesn't have many elements of either CBR or Independent Living. Why? It places much emphasis on the academic, eg, learning colours, shapes, ABCs. It acts like a day care centre. The parents want their children to socialise with other children. The parents do not seem keen for their children to 'grow'.

There is a lack of funding for the centre. The children are provided with the services of Early Intervention Programme and speech therapy and the parents are satisfied. But they are not sure where they are going.

The children are mainly from Cheras but also some from Klang, Subang Jaya, Ampang and Kajang. A mother with a child who is blind, deaf and mentally disabled comes to the centre because it is the only one that caters for her child. The mother says the programme helps her child.

The staff are from outside the community. Generally the neighbours know what is happening at the centre but some do not even know of its existence. The centre provides a service for parents who do not know where else to send their children.

CBR Selayang started in 1992 with 15 clients. There are now 175 clients from Selayang and other areas, mainly referred from hospitals. About 30 are active clients who come daily. Most are learning disabled with a few physically disabled. There is a lack of parental involvement - most leave their children at the centre and go to work.

It resembles a day care centre and it has too many children to handle. Community involvement is sorely lacking and there are problems getting volunteers. The community is not keen to give the disabled a chance to take part in community activities.

There are also problems getting staff to do home visits and also a problem of getting physiotherapists and speech therapists to come. There is also a lack of guidelines on what the staff are to do. Staff training is insufficient and many do not know enough about disabilities and how to cope with disabilities.

The centre also has problems in raising funds and it does not cater for adult clients.

CBR Rawang began in 1992 as a day care centre with 7 children. It now has 26 kids aged 8 years and above who are mostly from the lower income group and who have different types of disabilities.

Some problems include parents who do not have the time to send their children and think that because it is a Government-supported project, its services are free. Parents also treat the centre as a nursery or tadika and also expect CBR carers to do miracles with the children.

George Thomas described the work of the MAB CBR programme in its Temerloh centre. The staff conduct home visits and also training of clients at home. There is also a vocational rehabilitation programme.

The staff do surveys and identify disabled persons and will refer non-blind persons to other agencies and CBRs. They also consult with parents and disabled as to their aspirations. It is noted that most CBRs do not accept blind clients. Where can the blind go to get assistance? The MAB is trying to link up with other CBRs to handle blind clients.

Initially, there was also concern that large institutions for the disabled would be closed down if more CBRs were set up. But now, there is realisation that each complements the other.

As for community participation, CBR the response was not good at the start and only parents were involved. But the community began getting involved later.

It was noted that one weakness of many CBRs was that they operated like day care centres. Another is that many CBRs do not know where to refer blind clients.

The Public Health section of the Ministry of Health adopts a medical rehabilitation approach for its disabled clients. It does not focus on socialisation, education and other aspects of CBR. It mainly practices a clinic-based rehabilitation approach to CBR.

The Malaysian CARE CBR work in Rawang took a few years to establish and the team worked with the village headman and health clinics. It also helped organise registration exercises and liaised with Government clinics and welfare officers to make it easier for parents to register their disabled children. But it had to move out of this CBR work due to its limited resources.

Asia Community Services (ACS) has tried to adopt a new approach to its disability work. For example, as a policy and criteria for admission, parents must come along to the programme with their children. It started more than 2 years ago with 10 children and now has 52 kids. It does not provide food or arrange for transport, as part of its efforts to change the mentality of the public.

It also charges fees for its services because it feels that if the programme is of value, there ought to be a price tag to it. And instead of focussing on rehabilitating a disabled child, as most CBRs tend to do, it is trying to change or rehabilitate society. Its teachers are called facilitators and the aim is for the parents to take up the responsibility of being teachers because they spend the most time with their children.

The children, as clients, are also given choices, eg in games they play or books they want to read. And it is also teaching functional living skills to the clients, eg, counting money. The idea is that these special children will need more than just academic skills to live independent lives later. They need basic living skills.

MASIA finds its clients, the severely disabled, often come with a mentality that the problem is basically a medical one and so they act as patients. Instead, they need to learn to cope with their new condition, associate with other disabled persons, get the right information and find new job opportunities.

But MASIA does not have an established system to help such disabled persons. It hopes to have a halfway house. There is a group home set up by MASIA members presently.

5. Some Issues in CBR

Ranjit Kaur said CBR helped demystify the rehabilitation aspects of the medical model. It is a handing over of responsibility to the community and getting the community involved. CBR is a way to change attitudes towards disabled and disability.

But current CBR practice in Malaysia seems to be leaving out the disabled and the community! She asked, "Is the community involved? Is there participation and community awareness? Are staff and parents from the local community?"

Godfrey Ooi raised several questions about the role of CBR? Is it a temporary halfway house? Does it only provide single-disability services or also cross-disability services?

In states with large rural populations like Sarawak, the problems of geographical location and access are important. The question then is how CBR can be implemented for rural disabled persons?

Several speakers observed that CBR in many instances had become baby-sitting or child care services. There were several reasons for this sad state of affairs, including lack of understanding of the concept, lack of training, insufficient funds and staff; and lack of evaluation etc.

Ranjit Kaur also asked if CBR in Malaysia was promoting integration or has segregation taken place? Are disabled persons now placed in a special place for them? On access, some CBR centres are not even disabled-friendly. Have the community development aspects of CBR been ignored? What is the difference between a CBR centre and a day care centre if the community aspects of CBR are missing?

She said CBR programmes in Malaysia had become day care centres, eg where children go twice a week and stay home the rest of the time. She argued that CBR was meant to involve the community but the original aims of CBR have been changed in the Malaysian experience.

Other areas that require looking into are the lack of funding for both CBR and IL programmes, lack of suitable staff, the presence of a strong charity mentality (among the public and the disabled); why CBR has a narrow focus on those with mental disabilities.

6. Identifying Issues in IL

Chrystyn Lee shared some thoughts at the start of this session.

"From the Independent Living perspective the critical issues/concerns are relatively simple and straightforward. Are disabled people in charge? Have their needs and wants been heard, really heard and

given heed to? Are they self-determining, allowed to be, encouraged to be, enabled to be?

Are they given all the assistance and support facilities that the governing authorities provide for all their other citizenry to enable them to live and enjoy their lives to the fullest?

Are disabled people given a social structural environment that is friendly, convenient and enabling so that they can have a fair chance to experience life in its fullness and abundance. Are they allowed the means to attain their aspirations like every other citizen of a civil society?

As I have said the answer to these questions for all this other categories of disabled people are obvious and relatively easier to arrive at. But for persons with learning difficulties the answers may not be so obvious. The form it takes may be quite different.

With due respect to the experts who have all the answers and others who have given much time and energy working and reflecting on such serious issues in search of answers, may we be more secure and at home with pursuing the right questions than be over-anxious about giving the right answers.

Chan Wing Hon gave a summary of some of the issues involved. They included:

- *attitudes of disabled people and the public is a barrier*
- *cash, finance and funding - who will pay for all the services?*
- *the role of the Government - finance and policies*
- *participation of disabled people in planning and decision-making*
- *policies and structures - a responsible society*
- *training for staff - certification etc*
- *personal assistance programme*
- *legislation*

Godfrey Ooi said it was not a choice of either CBR or Independent Living for the disabled. There is a place for both. CBR is mainly for those where intervention is required while Independent Living is for those who do not need intervention. The question then is whether Independent Living is the ultimate concept for the disabled?

He asks if there is a process where disability work moves from a state of neglect to a charity approach and then to CBR and Independent Living.

It was noted that there were basic differences between CBR and Independent Living Centres. In CBR, there are organised programmes for clients to help in their rehabilitation. It is structured and a means to ensure recipients get help. Independent Living Centres serve mainly as resource centres, controlled and managed primarily by disabled persons.

Jeyasingh felt that Independent Living is for those able to make decisions, He noted that many disabled people are not ready for decision-making. Some defined Independent Living simply in terms of the ability to live independently, with some support from individuals and the community.

The term Independent Living itself raised some questions. It was suggested that the term was not accurate because no one is independent and all of us depend on others to provide some things for us. We are inter-dependent and also dependent on others.

Independent Living also took some time to be established in the US and Japan and it would probably take time to be established here too.

Kenji Kuno asked whether Independent Living, as a concept from the West, is applicable in Asia where the emphasis is on interdependence. Will a civil rights movement, as in the West among disability movements, work in Malaysia? What are other strategies to implement Independent Living?

On funding, it was suggested that it might be cheaper to fund personal assistants for disabled persons than to fund residential centres for disabled persons.

It was noted that Independent Living will probably take off much faster in urban areas because of the breakdown in family units and the more independent lifestyles of urban residents. With the change in family structure, more disabled people will not be able to depend on family members to care for them and will need to live as independent a life as possible. If they cannot be independent, the alternative may be for them to return to large residential institutions.

7. Other issues.

The group also briefly looked at three areas - Financial Resources; Training and Awareness Programmes; and Legislation.

1.2 Workshop on Independent Living

Date : December 19, 1999.
Venue : National Council for Social Welfare and Development Training Centre, Bandar Baru Sentul, Kuala Lumpur.

Participants :

Eugene Lau and Mathilda John	Dignity & Services
Francis Siva and Reena	Independent Living Home, Rawang
Francis Yap	Disabled Persons Welfare, Society, Ipoh
Sia Siew Chin	Beautiful Gate
Bathmavati Krishnan	Malaysian Spinal Injuries Association (MASIA)
Lucy Lim	Pusat Majudiri Y
Mohamad Sazali Shaari	Malaysian Federation of the Deaf
Wan Zuraidah Abu	Interpreter
Leon Chee Heon	POCAM
Kamaruzaman Harun	KL Society of the Deaf
Lee Tur Cheng	YMCA KL Deaf Club
Dr Denison Jayasooria, Rose Jayasooria and Lim Ming Haw	JJ Resources

1. The group began with some discussion about what Independent Living means and also shared about some of the activities the various groups were involved in. Other issues touched upon included the Role of NGOs; Personal assistance and Counselling; Training programmes; and the Role of the Government.
2. Francis Yap describes Independent Living as living positively. For Lee Tur Cheng, it means "full participation and equal opportunities, living with families and receiving the support of non-disabled persons." It is also about making decisions and learning from mistakes. He felt that Independent Living involved helping the disabled in various aspects of their lives, not just setting up group homes.

The YMCA KL Deaf Club runs projects like leadership training, social and recreational programmes, marriage advice and counselling.

Kamaruzaman Harun said in his visits to IL Centres in Japan, he came across an integrated centre catering for the

deaf and blind. These centres were controlled by disabled persons, with assistance from the Government.

3. Bathmavati Krishnan said Independent Living aims to encourage independence and self-independence and help the disabled learn to do as far as their ability allows.

She added that MASIA caters mainly for those who have suffered spinal injuries as adults. It provides advice to help such persons in their social and inter-personal relations and also to deal with trauma and depression resulting from their injuries.

Independent Living is linked with economic independence that will help disabled persons have self-esteem and dignity. Transportation is one way to be self-reliant and is an important issue related to Independent Living.

MASIA is aiming to have a halfway house to help provide training for newly-disabled persons towards Independent Living. Disabled persons could live in a group home, share the expenses and employ assistants to help them.

4. MASIA is presently involved in peer counselling and would receive calls from hospitals to go and counsel physically disabled patients. Bathmavati said peer counselling - where a disabled person shares and counsels a newly-disabled person - is more effective than other forms of counselling.

It can also help some disabled persons who are withdrawn to come out of their shells and learn to cope with daily living again.

5. The plight of rural disabled persons was raised and it was felt that they don't get the same opportunities as those in urban areas. It was noted that many rural disabled persons preferred to live in Kuala Lumpur and major towns because of the facilities, jobs etc. There is a need to enable those in rural areas to have access to peer counselling. It was suggested that disability services and information should be de-centralised.

6. Eugene Lau, secretary of a self-help advocacy group, said there was still a lack of awareness about disabled people and their abilities. He said, "Let the community tap into what we can do and not let them look at what we cannot do all the time." As an example of what the disabled could do, he said that they had managed to come up with a book containing their own stories and also a newsletter.

He said Dignity & Services sees the need for Independent Living among the disabled and was organising parents and family support groups. One project it wants to undertake is a group home for disabled young adults.

Mathilda John added that however there is still much misunderstanding of the concept of group homes. Such homes are still equated with old folks' homes and that families were abandoning their loved ones in group homes. There is therefore a need for awareness and education.

7. Mohamad Sazali Shaari said the Malaysian Federation of the Deaf had plans to introduce Independent Living in line with the 12 agendas of UN ESCAP.

It would also emphasise its human development programme to help deaf persons be more independent. The programme is meant to help deaf persons discover themselves and deal with issues of self-awareness and life goals.

There would also be motivation sessions for self-improvement and dealing with social problems that can arise when there is a lack of family communication. He added that as self-help organisations, disabled people know what they want and are able to decide for themselves.

8. Beautiful Gate is a ministry run by disabled persons. To help members be independent, the Chinese Disabled Society runs computer classes and gives loans for business ventures.

It was also given a plot of land and has raised funds to put up a training centre that will be open to both members and non-members. It presently has its own three-storey building with lift access and where its computer classes are held. It also has a contract with a local company to employ its graduates.

9. Agenda for action. Francis Yap felt that NGOs were not working together on common issues and suggested that NGOs come under an effective umbrella body to network and coordinate their work. He added a directory of social welfare organisations would be useful.

Mohamad Sazali Shaari said a way to strengthen leadership role of NGOs was to ensure that the grassroots are strengthened. The Malaysian Federation of the Deaf has nine state affiliates and was trying to set up more in other states. With a stronger voice, it can play a role at national level and influence the Government to act. He added that there were several groups representing the deaf.

10. Deaf persons are dependent on interpretation services and have to pay for such services. Some deaf groups have full-time interpreters. The Department of Social Welfare has given grants for such services. But funding from the Government should go through national bodies so that all groups will have a chance to get the funds and for better planning etc. Otherwise only some groups will receive funding.

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11. Bathmavathi Krishnan said self-help groups were mostly urban and KL-based and suggested that groups outside Kuala Lumpur should recruit new members and strengthen themselves. They could register with the Department of Social Welfare and network at local level. National associations can set up regional offices to serve members located outstation.

12. To assist disabled persons towards Independent Living, the Government should allocate funds to enable disabled persons to renovate their houses to be accessible.

13. On personal assistant services, it was felt that this was essential, especially for the severely disabled like quadriplegics. Such services were common and popular in developed nations.

In Malaysia, there were disabled persons who could afford to hire foreign maids to work as personal assistants. But the majority of disabled persons are not able to do so and there is no Government subsidy for such a scheme. In developed countries, there was also a large pool of people willing to serve and work as personal assistants.

Here it is mainly couples and families who could apply to bring in foreign maids. It was suggested that disabled persons who are single be allowed to hire foreign maids as well. The Government could also waive fees and allow other exemptions to make it less costly to hire a foreign maid.

14. It was also noted that disability-related work could be commercially viable, for example, in the supplying of aids and equipment, counselling services etc.

1.3 Discussion Groups on Community-Based Rehabilitation & Independent Living

Date : January 22, 2000
Venue : National Council for Social Welfare and Development Training Centre Bandar Baru Sentul, Kuala Lumpur.

Session 1: Community-Based Rehabilitation - 9.30am-12pm

Participants

Datuk Ghazali Yusof and Khatijah Suleman	National CBR Coordinating Committee
Dr Denison Jayasooria, Rose Jayasooria and Lim Ming Haw	JJ Resources

Dr Jayasooria listed some critical issues raised by participants in previous workshop and also from responses from some 10 organisations on CBR and disability-related issues. These issues included:

- *community dimension of CBR*
- *participation of disabled persons in CBR*
- *personnel needs and development*
- *resources - funding etc.*
- *future of CBR and the role to be played by NGOs, Government and others.*

1. Datuk Ghazali said that there were some 'pockets of excellence' in CBR programmes and that these centres had involved the community in the work. He noted that the Department of Social Welfare's social workers for CBRs had different grades of commitment to the programme and that some were overloaded with work.

He said the Government must be serious about CBR and should appoint staff who are fully committed to the project. Some leaders in the Department were not fully aware of CBR programmes under their charge. He added there were some CBR centres that had leaders who were very capable and who could mobilise the community for CBR work. But CBR remains a vague concept for many people.

2. Puan Khatijah said that there was a great need for professionalism and that CBR workers needed proper training. Some of the CBR courses run should be re-evaluated because they were too basic. Many CBR workers tended to go for courses run by NGOs and other agencies. She noted there were two levels of courses for CBR workers presently - those Government-organised and NGO-run courses. She noted that CBR training courses had not received certification.
3. Datuk Ghazali pointed out that the focus in CBR in Malaysia tended to be on quantity and not quality. The whole field of CBR needs to be upgraded and there is a need for recognition of CBR and training.

He suggested that in the Department of Social Welfare, one person in charge of CBR should be appointed to focus solely in this field. He said that there was a need to create expertise in CBR if it is to be an instrument of social development in the country.

He commended the Ministry of Health which runs CBR programmes, based mainly on a medical approach, which he said were very focussed and progressive because of the mindset and quality of staff.

One reason for the poor quality of many CBR centres was that social work was often a job of last resort and thus did not attract suitable persons into the profession.

4. An evaluation of CBRs in Selangor is being carried out by a team of researchers and is believed to be the first such major assessment. It was also noted that most CBRs did not have proper impact evaluation and assessment of their programmes. Only a few centres did their own evaluation and assessment.

However many CBR centres do not have basic equipment for physiotherapy and other services, although allocations are available. Instead, some CBRs set up by the DSW have registered with the Registrar of Societies so that they can go on fundraising campaigns for their work.

5. It was noted that the well-run CBRs in Selayang, Gombak and Cheras had CBR committees made up of committed and

capable parents, and effective chairpersons with good rapport with others.

6. One major weakness in many CBRs was committee members and leaders who had personal agendas in their involvement. Another problem was that there were no national guidelines or standards for CBRs to follow. There is also no proper monitoring of CBR programmes, accounts etc undertaken by one single body.

Datuk Ghazali said there was a great need for transparency in the running of CBRs. Transparency leads to accountability that leads to responsibility and to work, he said.

The National CBR Coordinating Committee (NCCBR) which gave out Best CBR and Best CBR Worker awards has strict criteria in its evaluation, including accounts which are certified, details of training programmes and skills of staff etc.

7. It was noted that there was poor coordination of CBR programmes at present and it was suggested that a major restructuring was required in how CBR is run and managed in Malaysia.
8. It was observed that CBRs in Malaysia tend to focus on mentally disabled children and adults, and also some physically disabled persons.

Session 2: Independent Living - 3.30-6.30pm

Participants :

Francis Yap	Disabled Persons Welfare Society, Ipoh
Sia Siew Chin	Beautiful Gate
Ch'ng Cheng Hin and Peter Phang	Perkobbp
Jeyasingh, Michael and Chandra	Bethany Home
Mohamad Sazali	Malaysian Federation of the Deaf
Wan Zuraidah Abu	Interpreter
Ho Hea King and Teong Siew Queen	Chinese Disabled Society
Dr Denison Jayasooria, Rose Jayasooria and Lim Ming Haw	JJ Resources

Dr Jayasooria listed some issues raised by participants in a previous workshop, including Peer Counselling; Personal Assistance; Independent Living Centres; and Leadership Training for Self-Help Organisations

1. Peer counselling. A lot of the discussion was centred on this issue. The consensus seems to be that there is a need for such services. For example, to cater to parents who discover their newborn baby is disabled and who may need help and support.

The Malaysian Federation of the Deaf has had requests from mental hospitals to counsel a few cases. In three such cases, the deaf persons did not have any mental problems. There was a problem of lack of communication. In one case, a deaf person who was detained by the authorities had no access to an interpreter and so was sent to a hospital because they thought he had a mental problem.

It was felt that it is good for parents to receive peer counselling. And disabled teenagers are also vulnerable and without peer counselling and good communication with others, many such teenagers are left on their own.

2. The group also discussed ways that people in need could have access to information about disabilities, help and services available. There is a need for an information network and mechanism to disseminate information. Some suggested hospitals, clinics, Department of Social Welfare and police could be places where such information is made available.
3. In the area of training for peer counselling, there was a need for two types - general counselling skills and specific skills related to disability (struggles, trauma etc). Several agreed that it would be unwise and even counter-productive to allow disabled persons or parents to become peer counsellors before they were sufficiently trained.
4. Sia Siew Chin said Beautiful Gate ministry would have a part-time counsellor in July and that and two other staff were going for training to be counsellors.
5. Several agreed that there was a need for a curriculum for training in peer counselling and it could include basic skills, values and practical tips.

6. Jeyasingh of Bethany Home related how it employs role models for young adults in its independent group home. These role models are to help the residents become independent and will withdraw from the home after a while.

This is also a transition period where parents learn to let go of their adult children. He stressed that many parents would go to Bethany Home and voiced their fears of what would happen to the disabled children after they are gone. Jeyasingh said that the next step after supervised group homes were independent homes.

Bethany Home will start an independent group home for women in February 2000.

7. Personal Assistance. Several issues arose from this discussion. They included whether personal assistance was something feasible in Malaysia; different types of assistance; financial aspects and implications.

It was suggested that personal assistance schemes could begin with the severely disabled so that such persons would not have to be dependent on their family or institutions to care for them for life. Several said personal assistance was a good idea especially for multiply-disabled persons like the deaf-blind.

Beautiful Gate once had two disabled residents who employed a maid to help care for their needs. But this arrangement did not last long because of some problems.

It was suggested that personal assistants performed the roles played by volunteers who helped bring disabled persons to places and medical check-ups etc.

Others felt that new job opportunities and small business could be created by personal assistance schemes.

8. Independent Living Centres. There was some discussion about what such centres were and did. Several were not aware of these centres which were now common in the US, Europe and Japan. It was explained that many of these centres were basically resource centres run by disabled persons offering

services like peer counselling, referral, personal assistance arrangements, advocacy etc.

The rationale for such centres was to help the disabled live as independent a life as possible.

9. Other issues raised included training disabled persons to take leadership of organisations and motivational camps for both disabled youths and parents.

2. *Interviews*

Beautiful Gate Methodist Disabled People Caring Centre

'Beautiful Gate' is a project of the Chinese Annual Conference of the Methodist Church in Malaysia. It started in 1994 in response to the needs of the poor and disadvantaged. Beautiful Gate or 'Methodist Disabled People Caring Centre' was set up to provide care for the physical and spiritual needs of disabled persons.

It has five main objectives:

- *to share the love and gospel of Christ to the disabled*
- *to help the disabled develop a healthy self-image*
- *to assist the disabled to become self-sufficient and to integrate into society*
- *to provide opportunities to serve and participate in the activities of the church*
- *to instill greater public awareness towards the plight of the disabled.*

The Chinese Annual Conference has eight districts, with three districts having 'Beautiful Gate' centres (in Kuala Lumpur, Petaling Jaya and Kampar). Its aim is to set up centres in five districts and also more group homes.

Training Centres

It runs two training centres in Petaling Jaya (comprising two large residential houses) and Kepong (three residential houses). These also provide accommodation for those undergoing training programmes. There are presently about 30 disabled persons in these two training centres.

The training centres also double up as a residential care facility for the more severely disabled who are unable to live an independent life on their own outside the centre. A few such residents have been living in the centres for more than two years.

The residents basically undergo skills training for two years or less, after which they will return home, find employment, continue with studies or join a group home. The programmes are mainly directed towards the orthopaedically disabled, with most of the trainees being wheelchair- users.

Pastor Sia Siew Chin, who heads this work, said that the skills taught cover basic computer skills, handicraft (wire crafts and greeting cards), and basic English and Bahasa Malaysia languages. No fees are charged and it is up to what the individuals and their families can afford to contribute. The services are

dependent on financial support from churches, donors and private firms.

The trainees come from all over Malaysia and some from overseas, with most having been disabled for some time. Their ages range from 18 to 50 years.

"While the programme teaches skills, there are other important aspects to the programmes we run. Our main aim is to help the trainees to be as independent as possible.

"The first step is to help them gain self-awareness and manage their own life. Other related issues are teamwork, working together, relationship-building etc. When these basic life skills are acquired, then the trainees are ready to venture out to live and work on their own.

"We also help them to know more about themselves and learn to express their feelings, views and emotions. These are done through the daily morning group sessions," she said.

Each week, the residents or members take turns to lead their own group discussions. They plan activities and programmes, invite speakers, organise outings etc. The role of the staff is to serve as a guide or advisor when necessary. The residents learn leadership and organising skills.

The monthly family or household meetings allow the residents to deal and sort out questions like cleaning problems, roster duties etc. They learn to share openly within a small group setting and also solve problems as a household. They learn to live as a household, which is preparation for the future when they go out and share a house with friends and others.

The residents also come from different backgrounds. Some have lived at home with family or have had maids to care for them.

"As a result, some are not able even to use a wheelchair independently because they have relied on others to do things for them. Our aim is to make each disabled person as independent as he or she can be," added Pastor Sia, who suffers from muscular dystrophy.

Work & Small Business

The residents are also taught how to ride a motorised tricycle or motorcycle modified with a sidecar that can carry a wheelchair. This

Beautiful Gate will set up more such group homes. Further ahead it sees a healthier situation when some non-disabled persons are able to share a group home with disabled persons

Counselling Service

There are two full-time church pastors to care for the spiritual needs of disabled persons in the centres. By July 2000, it hopes to employ more qualified counsellors who will help the residents and train other staff in this area.

Beautiful Gate feels this is an important aspect of its programmes as disabled persons, who have undergone much trauma or struggles to come to terms with their disability, may need spiritual and emotional support and counselling.

"We are helping them to understanding their own selves, deal with problems and issues and learn to talk to someone about their struggles. Other issues are related to their self-image, self-esteem, depression, frustration and emotional relationships," said Pastor Sia.

The church-based organisation places a lot of emphasis on meeting the 'total' needs of the disabled. This includes their spiritual and emotional needs.

"Some disabled persons have to cope and struggle with negative thoughts, depression, low self-esteem as a result of their condition or injury. We have to help them face these struggles before they are ready to work and live independent lives," explained Pastor Sia.

Beautiful Gate also has groups of trainees that take part in concerts, company dinners and shows where they perform dances, songs and drama. Drama, role-playing and acting serve as therapy for the disabled and help them gain confidence and raise their self-esteem.

Independent Living

Beautiful Gate has a simple philosophy. It is "How do we view people? Do we see disabled persons as humans or machines or less worthy than other people?" says Pastor Sia. It has a distinctly Christian perspective of people and the value of each individual. The disabled person is of equal value and worth to the able-bodied. The philosophy of the centre is normalisation of disabled persons who come to it for assistance. Its aim is to support and equip disabled persons to interact with and integrate into society.

Its programmes and outdoor activities are to help disabled persons to be ready to be part of society, The goal is for the trainees to be integrated into society, independent and self-supporting through the skills they have acquired and personal growth achieved.

One understanding of Independent Living in Beautiful Gate is for disabled persons not to be totally dependent on others, for example, in moving about, employment and other areas of life.

It recognises that disabled persons may require support in some areas of their lives. "Personal assistants and maids can provide support for those things a disabled person cannot do. But it can also make a disabled person too dependent on the maid or personal assistant," said Pastor Sia.

Some of the trainees in Beautiful Gate, including those who have received substantial compensation as a result of injuries, have used these benefits to employ maids to assist them.

Beautiful Gate sees the foundation or base to help the disabled is to support them to learn new skills or go to college, venture out to work and find employment, start a business and live independently.

"Like any typical family, the children when they become young adults will leave home for studies or work. Their families will provide the support needed for these persons to be able to cope with life outside the family home. Similarly, the disabled want a similar life and should be given opportunities and support till they are independent," explained Pastor Sia.

Pastor Sia's personal experiences with the disabled had led her to work with this group of people. She started by visiting disabled persons in hospitals and at home.

"Many disabled people I met expressed the need to leave home in order to develop to their full potential. They wanted to follow their own desires and dreams in life, just like any other person who has reached adulthood," she said.

Unique Characteristics

Pastor Sia explains that while Beautiful Gate does not have a specific model of disability on which it operates, it does incorporate various models and approaches. She listed to distinct characteristics in its approach.

helps make the disabled more mobile and they do not have to buy a car or depend on taxis or friends to drive them to work or to go out.

Some of the residents go out to work, for example, to sell handicrafts at night markets. For some of the severely disabled who are not mobile enough to go out to work, the centre brings back work for them. The centre also finds sponsors for those trainees who are able to go for further education and take up courses like computer science in college.

It also assists its trainees set up small businesses selling or making crafts and greeting cards. This allows its graduates to act as suppliers of craft items to shops and other businesses. Beautiful Gate helps its trainees by finding funding and sponsors for these ventures. Several of its trainees have set up their own small businesses.

Group Home

In July 1999, Beautiful Gate established a group home in Cheras, Kuala Lumpur for nine 'graduates' of its training centres. They had found employment doing packing and other work in a nearby factory. This group home is independently run by the residents who however receive help and support from Beautiful Gate. When the group home is more established, Beautiful Gate will no longer have to support it.

The group home concept seems to be working here because the residents have successfully gone through the training programme which had taught them teamwork, cooperation, resolving problems, relationship-building and communicating with others.

Previous attempts at starting group homes in Kepong in 1998 had not worked out. This was probably due the insufficient preparation and lack of teamwork among the members.

For its group home concept, Beautiful Gate will help rent a house and contribute to pay for some expenses to help residents who opt for this. The centre will also link them with others in the community who can support them.

The group home residents feel independent, confident to face society and happy. "They have been given a chance to decide the type of life they want to live," said Pastor Sia.

Firstly, the trainees have control over the question of choice of skills training and career. Like any other organisation, it has rules to follow to keep order in a group setting. Trainees can choose from the various skills programme offered.

Second, is the emphasis on leadership training, in contrast with the charity or residential models where trainees and residents have fewer opportunities to learn to lead and make decisions.

Pastor Sia describes Beautiful Gate's approach as a mix of self-help, residential, advocacy and support model. Within the Chinese-speaking community, it often speaks out on issues related to the disabled and disability.

Beautiful Gate can be described as a halfway house and serves as a springboard for the disabled to venture into jobs, studies and independence.

Experience and reflections on Independent Living in Japan

Christine Lee

It was through a meeting with Yukiko and Shoji at Flamingo Hotel in April 1998, where the regional DPI was meeting, that our visit to Japan was chanced upon. On the trip to Malacca, the possibility was raised for a visit to Shoji's Human Care Association in Hachioji. This took place from June 10-18.

Shoji, who might be considered to be in a condition of severe disability received us at the airport with Yukiko. He drove from Hachioji to Tokyo which takes about an hour. If Shoji were in Malaysia, he would have been reduced to a "vegetable" state. Mr. Shoji needs assistance to get into the car, have a bath, climb onto his bed etc. At Hachioji he is the Director of an Independent Living Center that has brought hope and liberation for many severely disabled persons.

When we arrived at the home of Shoji and Yukiko, we saw that the bathroom was fitted in such a way that a severely disabled person could be air lifted from the wheel chair, transferred to a sitting position and assisted for his bath. It was a contraption that did not need too advanced a technology, but merely the heart and will to design user-friendly facilities for all kinds and manners of physical conditions.

The assistant who came by for the bath was a highly educated, university student earning from such labor to subsidize the cost for his studies. We were informed that there were about 400 of such trained and certified personnel in Hachioji, from all walks of life doing such work. It was not charity as they were paid by the hour. They were not doing the disabled a favor for which the disabled had to be grateful.

Another time it was an ex- police officer who came to assist Mr. Shoji. We were told that the labor charges were put on record and then subsidized/reimbursed by the government. Of course it took years and much struggle for the Independent Living Movement to convince the governing authorities that it was their responsibility to allocate much needed funds for the care of these citizens who voted them into power/responsibility.

As it turned out it has been calculated that the cost for such subsidies came to be less than maintaining charity/welfare institutions for the care of disabled persons. These institutions

were none the most properly run and life for its inmates tended to be subhuman.

The Independent living movement believes that the best in an individual is realized when he/she is allowed and assisted to be independent and self-determining. This is a pre-condition for being human and having dignity.

There were so many other "miracles" encountered. Yukiko traveled to Shinjuku by rail on her electric chair for a day meeting that involved about an hour's ride on her chair. The precondition for this is pavements/walkways that are accessible. Also buildings that are disabled-friendly.

Beyond the road and transport system that is user-friendly the people /assistants from the rail company and the general public has to be re-educated to receive disabled persons as "normal" human beings as anyone else. Of course the disabled person too has apart to play in all of this that is to have the confidence and courage to be and to dare. The confidence and living skills training was developed over the years and many disabled persons have been put through it with much success and good results.

In our country, persons with cerebral palsy are written off as spastic. We met a handsome CP young man with a masters degree in economics who was an editor of a publication which specializes in working out the economics involved for disabled persons living in Tokyo. This would be a guide for the governing authorities to work out their annual allocations for disabled persons.

Another CP person we met was a movement leader who was meeting with government personnel to negotiate and influence policies affecting disabled persons in Japan. He shared with us that while he was at school he experienced that apart from the barrier-filled structures that prevented disabled persons from getting an education the educational content itself contributed much to the prejudice and discrimination against disabled persons.

We were privileged to visit Keiko, a one time elected official of the district/province. Her husband uses a wheelchair but they are both very independent and self-determining. Her house was equipped with a tin dredge caterpillar bucket chain system that pulled a chair up the stairs.

There were so many other significant and impactful experiences that convinced us that all these were available to disabled persons in Malaysia too if we could also develop our own Independent Living Movement here too. What was significant is that disabled persons can take on the world to change it for their own good. It is within reach. It is a historical responsibility.

Independent Living 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 counseling 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 disabled persons in Malaysia.

The Independent Living & The Blind Godfrey Ooi*.

Independent Living, if it merely means disabled persons being able to live on their own, is not a very useful concept for the visually-impaired or blind because "most blind people are already independent", says Godfrey Ooi.

But in its wider meaning and usage encompassing issues like advocacy, access, rights, equal opportunities, personal assistant services and peer counselling, has much relevance for the blind community in Malaysia.

He says many blind persons think and behave individually as they cope and struggle to survive in a harsh environment, mainly working in low-paying and menial jobs. Very few are able to break out of the stereotype careers as telephonists, masseurs, roadside musicians, basket-weavers and producers of handicrafts.

Mr Ooi, a prominent writer/speaker on disability issues and also vice-chairman of the National CBR Coordinating Committee, felt that Independent Living was not a concept that the blind in Malaysia have given much thought to and agreed that Independent Living would help blind progress further.

The blind have other priorities and struggles with jobs, training, education, housing and even marriage.

Advocacy

"Most blind people have some individual independence and so advocacy is not an urgency or priority for them. Advocacy is being

able to participate fully in decision-making and community matters like voting etc. It is about inclusion in society," he says.

He said the issue of certain rights of disabled person was not discussed because of the lack of awareness and education about such issues.

"The disabled are not vocal. This is symptomatic of whole society where people are more self-interested and inward-looking," he adds. Other problems many disability groups encounter are the striving for positions and control and the presence of a charity mentality in Malaysia.

He said that even estimates of the number of blind people in Malaysia was unknown because many parents are not aware that they should register their disabled children with the authorities.

The last official survey of the blind was in 1958 and it revealed some 40,000 blind persons. The blind population would have increased tremendously by now, Mr Ooi said. The MAB has served several thousand blind persons since 1951.

Access

On physical access, Mr Ooi says that despite obstacles and barriers, most blind people can be mobile. "They manage and get along or just live with it when there are obstacles." But access on the roads and in transport could be better the blind community.

Access to facilities, education, training and funds are issues the blind grapple with.

"They need Braille books, talking books, computers and information technology which are very expensive. The MAB has courses in computer knowledge but we lack the funds and staff to train others in this. Government funding is insufficient," he says.

Independent Living Centres

He said such centres, which were now common in the West and Japan, would be very useful in Malaysia.

"These would be owned and controlled by the blind and the services they offered like peer counselling, training and resources heard would be very good for blind persons." He described peer counselling as a very good idea and that the blind needed awareness and training in this

Employment

The blind need to explore new employment opportunities and not rely on traditional jobs. While sheltered workshops are expensive to run, some blind people will need such employment.

"There are some blind persons who are not able to cope in the open market and need sheltered employment. In the past, baskets and woodwork were skills being taught but these may not be suitable anymore."

Personal Assistance

Grants should be given to disabled persons to enable them to have access to personal assistant services. Mr Ooi admitted that it would be difficult to implement this because of the large numbers of disabled persons but suggested that some criteria be set to enable eligible persons to receive grants.

He said that instead of one personal assistant for one disabled person, there would be a system where a group of disabled persons 'shared' the services of one assistant.

"For example, the services of one reader could be used to help a group of blind persons. Or one house help for several blind persons living in one home."

Government grants for such services would be very helpful. He noted that some disabled persons or their families employed foreign maids as personal assistants.

One possibility is for the Government to waive the exorbitant agency fees to allow disabled persons and their families to employ foreign maids at lower costs.

Issues

On disability issues that needed to be addressed, he said the Government should seriously explore Independent Living as a concept and practice to be implemented in Malaysia. "IL is a good philosophy but needs a concerted effort to put it into practice. It is about self-management and decision-making." But he added that the disabled need to have partnerships with the able-bodied and a more useful term might be 'inter-dependence'.

On Community-Based Rehabilitation, he said many centres did not provide effective services to their disabled clients due to many problems and factors, including centres being set up without much thought given.

Group Home, Malacca Department of Social Welfare

This group home is located at 139 C, Taman Kesidang, Lorong Pandan, Melaka Tengah. It was set up in 1994 and caters for only four residents. The three-room house is rented by the department for use as a group home for disabled persons.

The original purpose for the group home was to cater for the intellectually or learning disabled. But the response was poor and so the emphasis was directed towards the orthopaedically disabled. The criterion for eligibility is that applicants require accommodation near their place of work. The aim is to provide a place to live for disabled persons whose families live too far away.

Of the four present residents, two are from Malacca and one each from Selangor and Kedah. They are physically disabled wheelchair-users who work in different occupations. They use motorised tricycles or motorcycles with sidecars to travel and carry the wheelchairs.

The four were the department's clients prior to living in the group home. They are described as independent and active sportsmen who have participated in Paralympics events.

The residents also receive assistance and support from the community. The community is warm towards the residents and often includes them in community functions. The residents also receive religious counselling and take part in gotong-royong activities.

The residents take care of their own meals and housework with an officer from the department visiting them occasionally to follow-up on them. The department does not provide any practical assistance to residents in the group home to show that such disabled persons can function normally in society.

The department has no immediate plans to build more groups homes and hopes that the private sector and NGOs can set up more group homes.

Independent Living for People with Disabilities

Stephen Chow

Independent Living

Every one needs Independent Living and this includes people with disabilities - whether mild, moderate or severe. God has given free will and independent living to all.

What is Independent Living? To me, it means not only being able to do daily living activities by yourself but also having the right and dignity to express what you want to do, what to wear, what food to eat etc.

In contrast, when disabled people are institutionalised, they are treated like babies and children, even when adults or senior citizens.

Independent Living covers many aspects to make a person fully independent developing solidarity with grassroots-level persons with disabilities developing stronger advocacy groups to voice their own rights, and issues of justice and dignity raising awareness about the rights and equal opportunities of people with disabilities, including public access at all levels (Government, non-Government, and private and public sectors) working closely with local authorities to promote Independent Living; formulation, implementation and enforcement of policy and legislation concerning non-disabling environments.

A civilised society is one in which, regardless of disability, gender, ethnicity and social status, every citizen can pursue his/her aspirations, rights and achieve the fullest potential without encountering physical and attitudinal barriers.

At the core of this movement is that people with diverse disabilities have equal access to facilities, services and opportunities that are taken for granted by mainstream society. The process of enabling disabled persons to have independent lives will have a significant equalizing impact on any society.

The Independent Living Centres in Japan aim to encourage disabled people, whether with severe or mild or moderate disability, to be independent and to help them live more positively. If the person is severely disabled, one or two assistants can be employed to assist in daily living activities like feeding, bathing, shopping even carrying the person to bed. The assistant comes when their services are needed and are paid by the hour.

The welfare system in Japan is very different to the one here in terms of environment, culture and economics. Disabled persons there get a monthly allowance, depending on the severity of their disability. The allowance given is sufficient for them to employ an assistant and for daily living expenses.

In Malaysia, we should strive towards the Independent Living Movement instead of building institutions. The disabled must see that it is their role to fight for their own rights for no one else can do it more successfully. It is time that the disabled rise up to prove their talents and abilities to others and in this way make themselves seen and heard and to fight for their rights.

We should voice to the Government to begin a new phase in disability work. We should work together with the Japan Independent Living Centres to start a similar centre here.

Work

I have seen disabled persons work in various disciplines, whether in disability work or others, eg in accounts, computers, management etc. Others use their intelligence to run organisations and give ideas.

Being a social worker is not easy and I face a lot of problems but I take these as a challenge and not as a burden. These problems make me more mature in thinking and in facing the world. Some of the problems disabled persons face include:

difficulties and hindrances at work due to their disability, eg lack of strength and stability in physical work, communication problems (due to speech, lack of experience and confidence); slowness in thinking and action etc
superiors and colleagues who lack confidence and trust in us and our abilities to perform well
lack of education and exposure makes work more difficult and also promotion and other opportunities difficult or impossible.
lack of encouragement from colleagues, family and public) and problems of facilities (transportation, toilets, special equipment, ramps etc).
dealing with staff, clients and families and the public.

There are several ways to overcome these problems. Disabled persons need to exercise and strengthen their bodies and be more independent physically. They should learn to observe and communicate. The disabled must not be afraid to try new things and should realise that everyone makes mistakes.

Read a lot helps, especially those related to the job. We must also make use of opportunities to attend training, workshops and seminars to increase knowledge, skills, exposure and experience.

*He is a staff member with Thesda Social Development Ministries (TSDM), Taiping, Perak and works with disabled persons. Stephen has cerebral palsy. He was in Japan for a year on social work training.

Independent Living Workshop Press Release

We, as representatives of Disabled Persons Organisations and as participants of the Independent Living Workshop (August 28-30, 1999) wish to share the joys of our being, the sorrowful experiences of our lives in our own land and our commitment to Independent Living for disabled persons in Malaysia.

We firmly believe that the time has come for disabled persons to shake off the shackles of their disablement, participate proactively in the life of our country and make their contribution to national life. The Independent Living Movement of Malaysia is committed to the creation of a social and material environment that is just, friendly and convenient for all persons.

Independent Living is essentially a philosophy and way of life for disabled persons as it is for all other persons. In practice it is a movement by disabled persons, for disabled persons, for disabled persons working for equal opportunities, self-determination and the self-respect of all disabled persons and all Malaysians.

Independent Living means that we desire the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up and live in dignity with our families. We want to go to the neighbourhood school, use the same bus and all other means of public transport as our others do.

We want to work in jobs that are in line with our education and abilities and start families of our own too. We do not want to work and live in isolation but be part of society when making decisions.

Just as everybody else, we need and want to be in charge of our lives, to think and speak for ourselves. To this end we will work for social, economic and political changes that lead to the legal protection of our human and civil rights. This is based on statistics that show that disabled people have less education than the rest of the population. We have the worst housing and are more often unemployed.

We should be able to enjoy full participation of living, by having access to employment, recreation, education and commerce. There should be no barriers at all and full support for us to lead independent lives.

In Independent Living philosophy, it does not matter for what reasons we have a different condition of being. What matters is the recognition that people regardless of type or extent of their condition can learn to take on more responsibility, to make more decisions concerning their lives and to contribute more to their families and the community.

Our Independent Living Movement is critical of institutions that practice rehabilitation methods that do not integrate the disabled persons into society in a meaningful and lasting way. Disabled people themselves are seldom asked about what they really need.

Independent Living believes that disabled persons are the best persons for the job of improving their own lot in life. They are the experts by virtue of their condition and position in society. There is a need to break the monopoly of non-disabled professionals who speak on behalf of us, define our problems and suggest solutions to our needs.

We will build effective organisations that represent the views of disabled people themselves. On their part, the governing authorities should recognise our organisations as partners in shaping policy for disabled persons. We ourselves are the experts. Disabled people have to run, represent and control their own organisations. We have to be at the forefront of this struggle. Non-disabled people can only support us and not lead us. They cannot understand the full extent of our being and wants.

Peer support is the central idea to the concept of Independent Living. In a number of countries, disabled persons are helping each other in Independent Living Centres by sharing information, advice, legal aid and peer support and by organising the disabled community.

The people who work in Centres for Independent Living are themselves disabled and know what they are talking about from first-hand experience.

The centres work for changes in the community, such as improved access in housing and transportation. In several countries, Centres for Independent Living receive regular government funding, because it is recognised that disabled people are the best experts on matters concerning disablement.

We believe that any society that claims to be a democracy and respects human rights has to extend these rights to all its citizens, including the disabled persons. In order to guarantee our rights there has to be proper legislation including monitoring, periodic revisions and effective sanctions. The organisations of disabled persons have to be decisively involved in all these stages.

We are the last minority to fight for our rights and we will not go away. Even with the most sophisticated prevention, early detection and rehabilitation services there will always be people with a different condition of being/body and we have to build our societies in such a way that everybody can live in them with dignity and self-respect.

And we have to start now. And we will,

Christine Lee
(on behalf of workshop participants)

Independent Group Home * **Bethany Home, Perak**

It was a dream and vision that finally came to pass by the grace of God. Our Independent Group Home for the intellectually disabled could be the first of its kind in the country.

We are in the beginning stage and a lot of work has to be done in preparing these residents. We are targeting a period of 6 months to a year for them to fully be independent. Not only do we need to train these students, we also need to train our staff and volunteers.

In our culture, our mind is quite set that these students cannot stay by themselves. But we want to try our best. To date Bethany Home has five supervised Group Homes that started in early 1987 for students from outside of Hilir Perak District. They had been enrolled in training programmes at Bethany Home and also for respite care. These homes were started after it was decided to evacuate students out of Bethany Home to be integrated into the community. A total of about 25 students live in these facilities ('home away from home').

As time went by and with the idea of a Group Home not being another hostel facility, suitable places and staff posed a difficulty. To start another Group Home, we needed to find another RM4,000 and at least four more dedicated staff. This was when the idea of an Independent Group Home came into being where less supervision, leading to no supervision of the adults, would cut the main bulk of the RM4,000 and also solve the staffing problem. As we were praying about this, a family indicated their desire to donate a house for Bethany Home. A house in a new housing scheme within walking distance from Bethany Home was purchased.

Three mature students who were performing well from the supervised Group Homes were selected as the first residents in the Independent Group Home. We consulted with the families and guardians. A short transition programme was carried out for them and finally in the beginning of April 1999, they started living in the Independent Group Home.

Two Bethany Home volunteers share a room in this Independent Group Home to provide minimal supervision. This supervision will fade off slowly to enable the students to live on their own. But the students are still very dependent and wait for instructions.

Communication picture charts are put up in various places in the home to indicate duties, responsibilities and daily tasks to be carried out by each one resident. When daily tasks are repeated regularly, we pray and trust it will become a way of life.

These three residents - Robert, Chin Chong and Yoke Yin - are putting into practice all the independent living skills learned in their former supervised Group Homes and Bethany Home. They are beginning to realise the home belongs to them, as they go around inviting staff and volunteers to their home for 'chit -chat' or even dinner.

A month passed and the boys were doing well. The home is well kept and clean and they have learnt to live in harmony and care for one another.

Another three students will be selected to join them in about six months to a year. Then these three seniors will "buddy" and supervise the new recruits in Independent Living.

The fear of parents for their children's safety is very much in our heart. That's the reason we have volunteers staying there. Accidents can happen but we will try to teach what they have to do, help one another, contact neighbours and phone the staff.

Bethany Home has taken a bold step forward. Please pray for us and for our adults. "Life is not a bed of roses, it will have some interesting moments".

Bethany Home can be reached at Tel: 05-6411276

- Edited article from Dignity & Services Review, January-July 1999

Hopehaven Centre & Independent Living

Salvation Army Hopehaven Centre for Special Children, Malacca

The centre's aim is:

- "To develop all students to their full potential educationally, physically, socially, emotionally and spiritually, and thus assist them to lead independent and fulfilling lives."

Independent Living

A major objective of this Salvation Army centre, which caters for children and adults with learning and other disabilities, is to assist them to lead independent lives.

After many years of hard work and encouraging results in establishing programmes like Early Intervention, Day Care, Special Classes, Employment and Training courses, it is moving into the area of Independent Living.

This can be seen in its efforts to introduce and run programmes like an Adult Training Centre, Sheltered Employment, Secure Employment and a proposal for an Independent Living Programme. These programmes have been introduced in recent years and the Independent Living Programme is the next stage.

Hopehaven Training and Resource Manager, Mr Ang Teck Hin, says that it is "critical" to have such the Independent Living Programme. He explained that society couldn't leave disabled adults in the lurch when their parents die and no family members want to care for them. Where would such person go in the future?

He said many parents have voiced their fears of what would become of their disabled child when the parents die or are too old to care for the child. The parents realise that siblings and other family members may not be able to want to care for the disabled family member.

The parents want a place where their disabled child will be looked after well and seek qualified people to take care of their child. "The Independent Living Programme is the next logical stage in our services because the students have been trained and equipped with skills in education, social and living skills, emotional and personal growth, and employment," Mr Ang says.

Such a programme has been planned for some time and in 1999 a proposal was prepared. When there is funding for this project and the staff have been trained for it, the programme will be introduced. There is a need to think and plan for the students' long-term future.

Many disabled persons, with sufficient support and training, are able to lead as full as possible an independent life. He added the disabled need to have dignity in life and to be able to lead a life worth living.

The aims of the programme are integration into society, mainstreaming and normalisation. The project will take off slowly and it is important to make it successful as it will be a pioneer project for the centre. The staff will also need to be well-trained, as will the students and parents under a new programme

Choices

While there is a need to give disabled persons freedom and choices in life (in terms of where to stay and work), the reality is that many disabled persons and the public have not been exposed to the idea of freedom and choices and also concepts like Independent Living.

"Many people do not see Independent Living programmes as a priority, compared to residential or day care centres." He found disabled students keen to go out and explore things and sometimes this was a reflection of over-confinement at home or over-protective parents who mean well.

Four Hopehaven students spent some time away from home and managed to scale Mt Kinabalu. Mr Ang noticed that the teenagers were so "full of life and opened up" and he could see their real character. Given the opportunity, they managed to accomplish much on their own.

He felt that many of the students needed to learn decision-making skills and noted that there is often too much control by families at home as parents are over-protective of their disabled children.

Practical Issues

While many disability service-providers managed Group Homes, the Hopehaven Centre will modify the group home concept to suit its learning disabled students. The plan is to rent a house and have supervisors or a couple who serve as wardens.

Independent Living is good as disabled persons live on their own. But Mr Ang feels that for the learning disabled, the programme will offer as 'near-normal independence' as possible and hence the supervisors or wardens.

He said that parents needed an assurance that their disabled children will be safe. Many feel that for some categories of learning disabled persons, it is not possible to have full independence because of concerns of safety.

The programme Hopehaven wants to have will probably see a mixture of residents with different degrees of disability. It will have multi-purpose use - a place for some to stay during weekends to introduce the idea of living away from home; and respite care and day care services. Such services will give the families a much-needed break.

The centre will offer a transition period to see how the students cope with being away from family and home. Most of the students at the centre have not been exposed to the concept of Independent Living.

For Hopehaven, it is important that the Independent Living Programme will help maintain family contacts and links and not break these vital supports in a disabled person's life.

As for its viability, Mr Ang feels that several factors make it advantages to set up such a programme in Malacca. He said expenses are relatively low (eg rental of premises and furnishings etc); availability of jobs suitable for disabled persons; proximity of work places to residential areas; community is fairly open and compassionate towards disabled persons.

Services

Hopehaven has 20 teachers plus workers and administrators and caters to some 90 students. Its services are:

Early Intervention Programme

Daily
children aged 1-5 years
20 students

Day Care Centre

Daily
6-14 years
30 students

Special Classes

Weekly

children with multiple disabilities

9 students

Adult Training Centre

Daily

14-20 years

16 trainees

Sheltered Employment Centre

17-34 years

20 trainees

Secured Employment

10 persons

The Early Intervention Programme

Sessions with a family member are run daily for two and a-half hours. The Day Care, Adult Training and Sheltered Employment programmes are from 8.30am till 3pm.

Independent Living - Some Reflection

Independent living is a philosophy of being and living, a way of life, that can liberate disabled persons from the shackles of their disablement. Beyond this it is also able to free the governing authorities, the institutional 'care givers' and the normalised majority from the burden of having to 'care for these persons with disabilities'.

Independent Living is therefore good for disabled persons. It is good for their immediate families. It is good for the governing authorities and finally IL is good for society as a whole.

It is good for disabled persons in that it restores to them the supreme value and infinite worth that is theirs and rightly due to them as human beings. That which makes human beings human is the power to be, that is the power to be self-determining, to be engaged in the exercise of responsible social-personal decisions. This is the basis for human dignity and a sense of healthy pride.

What is Independent Living as a whole, in its totality?

It is first and foremost disabled persons taking control, taking back control and being trained by other experienced or better-informed disabled persons (peer counselors or trainers) to take control and responsibility for their own lives and for that of society as a whole.

The disabled person, having been adequately prepared and equipped to be socially and personally responsible can through a supportive network of disabled friends, as well as personal attendants, be trusted to make responsible decisions for his/her own life. In fact many disabled persons have gone far beyond being independent to being socially responsible and productive just like (if not even doing better than) persons from the normalised majority who have themselves also been enabled and allowed to do likewise.

There is thus a need to set up and develop this supportive structure for the training and empowerment of disabled persons who desire to venture out towards independent living. Initial peer counseling helps disabled persons to come to terms with themselves and their unique condition through self-confidence building and basic living skills training within as yet a dominantly barrier filled environment

Beyond these, the ongoing growth and development of disabled persons can be ensured through the setting up of appropriate enabling and supportive social structures and processes so that life in its fullness and abundance can be experienced and enjoyed by them. This is not unlike what persons from the normalised majority have done for themselves, albeit-until now, to the exclusion and at the expense of disabled persons.

Along with this preparation and training of disabled persons for IL is the concurrent preparation and training of personal attendants from the normalised majority whose job is to assist disabled persons to

live independently. These will of course be paid accordingly through public/governmental funding. In IL, disabled persons are trained to be in positions of power and control and personal attendants are likewise trained to follow the instructions of disabled persons who are their employers.

This shift in the balance of power frees the disabled person from being someone with no dignity and little or no power to exercise choice (which is radically disabling and dehumanising for disabled persons.) to being an independent person with dignity and power to determine and exercise choice. This affirms his/her self-worth, dignity of being and is humanising in effect.

It is obvious that huge amounts of social resources, human, material and financial, will have to be redirected, re- allocated and re-channelled to this liberating, humanising and enabling process for disabled persons primarily and for all of society ultimately. It goes without saying too, that it is the responsibility of erdightedened disabled persons, the governing authorities and the general public to see that this responsibility towards its disabled citizens is carried out with utmost urgency and the minimum of fuss.

Beyond this is the long and challenging work of change in the direction of a social structural environment that is friendly, convenient and enabling for all persons including especially disabled persons, This will release untapped human potential and creativity that will surely be for the overall good of humanity.

This process actually points to the ultimate re-education of whole societies and cultures, nothing less than the making of a new humanity, the creation of a New World order where disabled persons and the rest of humankind will be restored to their full potential of their being. Life in its fullness and abundance may yet be realised, experienced and enjoyed by disabled persons and the rest of humankind as well.

Disabled persons may well be the chief architects in the making of this new creation, the historical task of the new millennium.

Christine lee and Chan Wing Hon

3. *Correspondence*

JICA DISABILITY STUDY TEAM

P.O. BOX S-14, SENTUL, 51700 KL TEL/FAX 03-4429634

Nov. 25, 1999

Dear

WORKSHOP ON INDEPENDENT LIVING

I have great pleasure in inviting you to a workshop on Independent Living and Disabled People in Malaysia on December 19th, 1999 from 3 to 6pm at the National Council for Social Welfare and Development training centre at Bandar Baru Sentul, Kuala Lumpur.

Please confirm participation by December 10, 1999

Yours sincerely,

DR. DENISON JAYASOORIA

Research Consultant

One Day Workshop

on

INDEPENDENT LIVING (IL)

Date : December 19, 1999
Time : 3am to 6pm
Venue : National Council for Welfare & Social
Development, Bandar Baru Sentul, KL
Tel : 03-44476041

Background

Rehabilitation programmes for disabled people are facing critical changes at both conceptual and practice levels. An emerging approach is Independent Living which has been successfully implemented in more developed societies.

In Malaysia, there are various aspects of Independent Living that have been introduced by individuals and organisations, including group homes run and managed by disabled people. Will Independent Living become as popular and acceptable as other approaches? Can it serve as a framework for holistic integration and the way forward in disability practice in Malaysia?

Focus of Workshop:

- To hear and share the experiences of disabled people and self-help groups working among disabled people, with reference to Independent Living.
- To review the current understanding of disability in Malaysia with specific focus on the move towards Independent Living.
- To analyse the critical issues and concerns of disabled people in how society which inhibits their independence.

• The attempt is:

- To understand the development of Independent Living, noting the factors which enabled its development
- To assess the effectiveness of this approach on the yardstick of empowerment and the social model of disability.
- To chart an agenda for action based on the failures and success of the past.
- To ensure that disabled people have a rightful place in Malaysian society.

JICA DISABILITY STUDY TEAM

P.O. BOX S-14, SENTUL, 51700 KL TEL/FAX 03-4429634

December 21st, 1999

Dear

DISCUSSION GROUP ON CBR

I have great pleasure in inviting you to a discussion group on CBR on January 22nd, 2000 from 9.30am to 12.00 noon at the National Council for Social Welfare and Development training center at Bandar Baru Sentul, Kuala Lumpur.

Please come prepared with thoughts on the following themes which we will discuss in detail.

Agenda for discussion

1. Discussion on some critical issues regarding CBR

- Community dimension of CBR a missing aspect
- Active participation of disabled people in CBR programs
- Personal needs : professional and voluntary staff
- Resource requirement : funding and equipment

2. Proposals for future CBR

- Role of voluntary organisations, government and JICA

Please confirm participation by January 31st, 2000.

Yours sincerely,

DR. DENISON JAYASOORIA

Research Consultant

c.c JICA

Department of Social Welfare

JICA DISABILITY STUDY TEAM

**P.O. BOX S-14, SENTUL, 51700 KL TEL/FAX
03-4429634**

December 21st, 1999

Dear,

DISCUSSION GROUP ON INDEPENDENT LIVING

I have great pleasure in inviting you to a discussion group on Independent Living on January 22nd, 2000 from 3.30pm to 6.00pm at the National Council for Social Welfare and Development Training Center at Bandar Baru Sentul, Kuala Lumpur.

Please come prepared with thoughts on the following themes which we will discuss in detail on independent living.

Agenda for Discussion

1. **Peer Counseling** – define areas, training content of volunteers and management of the team.
2. **Personal Assistance** – for what duties, type of person, funding and management of the service.
3. **Independent Living Centres** – should these be organised at the local level and how they are to be set up.
4. **Leadership Training for self-help organisations.**
5. **Proposals for future IL** – Role of self-help organisations, government and JICA

Yours sincerely,

DR. DENISON JAYASOORIA

Research Consultant

cc. *JICA*

Department of Social Welfare

