- *sale of souvenirs*
- *contributions from families of persons with disabilities*
- *donations from individuals*

2.2.9 Limitations of CBR programmes in Malaysia (Ranjit Kaur, 1998)

- Existence of a stronger individual model as compared to the much encouraged social
- model.
- Organisations are still desperately seeking the expertise of therapists and other
- medical and special education professionals instead of training CBR workers and
- families to utilise simplified manuals.
- Social issues surrounding persons with disabilities are not addressed.
- Centre-based rehabilitation misinterpreted as Community-Based Rehabilitation.
- Lack of formative and summative evaluation of CBR programmes.
- Emphasis is more on medical rehabilitation rather than community mobilisation.
- Disability is defined more in medical terms rather than activity restrictions and social
- limitations in the community.
- Social and physical barriers are not addressed.
- Limited participation of disabled persons and their family members.
- Ideas flowing in from the city do not get fine-tuned to suit the community.
- Lack of recognition of CBR workers.
- Limited community awareness and education programmes.
- Limited use of appropriate educational and training tools.
- Local resources and expertise within the local community, e.g. artisans are not fully
- utilised.

2.3 Critical Issues & Concerns

2.3.1 Some Issues and Concerns

The popularity of CBR, since its introduction in Malaysia from 1984, has grown steadily in terms of the numbers of centres set up, staff employed, Government funds allocated and disabled people who are reached. Many disabled children and adults who were once deprived of rehabilitation services have since come into contact with such services. Many families and communities have also been affected in some way by these services.

While many have noted the success and progress of these CBR projects, many problems and obstacles have also emerged and been highlighted. This section looks at some of these problems and also highlights some of the issues, concerns and challenges ahead. Unless there is a seriousness to tackle these issues and concerns, CBR in Malaysia may just grow in terms of numbers but may lack in terms of quality, long-term changes and transformation in the lives of the disabled and their communities. Any transformation may remain little than just surface-level and cosmetic if the fundamental and basic issues are not addressed.

There is a danger that while the numerical statistics may be assuring, the multiple objectives of CBR - including equalisation of opportunities; attitudinal changes in society towards the disabled; social and economic development; and deeper and more lasting results in favour of the disabled may be missed. The problems faced by many CBR centres, whether Government-supported or solely managed by NGOs, seem to centre on the same set of issues. Some problems are related to issues at a higher policy or macro level, including coordination and policy implementation, Government funding, CBR concepts and practices, and the training and certification of CBR workers.

On a more practical level, many CBR projects are grappling with issues like lack of funding and staff to run programmes, parental neglect, ignorance and lack of awareness among the public about disability, poor support services, and other day-to-day concerns. Manpower, in terms of lay volunteers and professionals, is also lacking and holds back CBR programmes from developing and improving. Even those groups which are well supported and managed often cite the lack of and shortage of funds, staff, volunteers and professionals. Even a leading and well-funded organisation serving disabled children finds staffing and funding major problems.

Bethany Home, one of the earliest agencies to start group homes and the move towards self-help and independent living cites several obstacles to its CBR programmes. These are the "lack of volunteers; lack of commitment and cooperation among some family members; local communities failing to see the need to make the lives of a disabled person meaningful in the society; and the lack of supervision during programme implementation." These adequately summarise some of the major concerns in CBR in Malaysia work today.

2.3.2 Funding

After all the hard work is done to lay the groundwork and then launch a CBR project, the people behind it have the task of ensuring there is enough funding to keep it viable. But feedback seems to indicate that many projects find it difficult to raise funds just to sustain the programme, let alone develop it into an effective service and programme to achieve its objectives. For example, a major CBR project in Kuala Lumpur says it has "insufficient funds to operate and provide services of professionals like speech therapists, psychologists etc."

Another Government-supported CBR programme in Selangor says there is a lack of funds from the Social Welfare Department to help the CBR run its activities. As a result, centres have to spend considerable time and resources to raise funds from the public and private sector. And not all CBR projects have people who are effective fund-raisers. Not all have rich and well-connected patrons who can help raise funds. And in many cases, the parents of children with disabilities are not financially well-off to support the CBR projects. And most parents are not so high-profiled and prominent so as to attract funding and patronage for the centres.

CBR projects, while considerably less expensive to run and maintain than large institutions and residential programmes, still require funds to pay for teachers, resources, rental of premises and also the fees of professionals like speech therapists and physiotherapists. The expenses in urban centres will be much higher due to the higher costs of living. One project in Kuala Lumpur suggests that the Department of Social Welfare consider full funding or subsidy for items like rental of premises; furniture and basic rehabilitation equipment; professional services; and transport costs for children who are not mobile to come to centres. An association for the disabled called for increase in Government funding and its budget for social welfare services.

2.3.3 Training

Many CBR programmes lament the lack of staff to run the programmes. To manage and provide an effective service, covering a multitude of areas, staff have to be well-trained, motivated and supported. But with the low salaries and low esteem of the social work profession, CBR projects are unlikely to attract well-qualified and motivated professionals to work with the disabled and communities. And even when there are staff to run the programmes, there are the related problems of staff who are not well-trained, poorly-motivated or lacking commitment to do a good job.

There are also the question of the quality of training, curriculum, standards and evaluation. The training is often not coordinated and with little follow-up. This 'manpower limitation' is a major problem, both in terms of numbers and quality. Any existing training programme is an ad-hoc, stop-gap measure. Even in the Ministry of Health, where the hospitals and clinics are the first line of detection of disability in babies and children takes place, most of the nurses are not trained for this role. But more public health nurses are being given in-service training for this.

Some projects say that the CBR workers are not trained to carry out all the various aspects of rehabilitation. The staff may have only two months of formal training and the focus is on training of social skills and activities of daily living. Few are taught about carrying out awareness programmes, liasing with the community and professionals doing home visits, equipping parents with basic rehabilitation skills etc.

A Government-supported CBR says that its staff only gets a basic training of 2-4 weeks by the Department of Social Welfare. This does not render them capable of carrying out their duties effectively. Another CBR programme laments the lack of a standardised curriculum for the centres, with new staff depending on the experience of senior workers to guide them. But senior and experienced staff are few in number and most have little time to train other staff.

CBR researcher Zakiah from Sarawak notes, "Most of the training and reference materials and manuals are in English. But many CBR workers and committees use Malay as their first language or other dialects. There is a need for materials to be translated into local languages to benefit the workers, committees, parents etc."

Thus, if many CBRs have a problem of staff who are not well-trained, how can these centres really help in the rehabilitation of the disabled? And if the role of the staff is also to support and equip parents to continue rehabilitation at home, how can this be done if the staff are themselves ill-equipped?

2.3.4 Community

The community is one of the key links in CBR concept and practice. The community, with its resources of people, expertise and infrastructure, is meant to be the base for which the rehabilitation and other CBR objectives take place. It is also the arena where attitudes are changed to be more positive, fair and just towards disabled persons. Without this community involvement, CBR programmes can merely become day care or kindergarten programmes.

The reality of community involvement is not very encouraging, with very few CBR projects managing to involve the community in a tangible, positive manner. Much has to do with perceptions and realities of community life. Many in the community think the responsibility of caring for disabled persons lie with the authorities, specifically the Department of Social Welfare, hospitals and residential institutions.

The community is not able to see that its resources and attitudes can play a role in uplifting the life quality of disabled persons. Many in the community are also ignorant of disability issues and disabled persons and unaware of how they can contribute to the well-being of such persons. Very few CBRs have community outreach and awareness programmes. Often, neighbours might not be aware of the existence of a CBR programme in the neighbourhood.

A CBR Cheras official feels that `society has not accepted the disabled and considers them outcasts or a waste or time and money'. The CBR Selayang found that a lack of community participation in CBR activities, with the local community not very willing to give children with disabilities a chance to participate in communal activities. There is also less emphasis by the community on children with disabilities compared to other disadvantaged groups like orphans. It is therefore difficult to get the community involved despite attempts made to promote CBR and its activities.

It also found that a lack of response from various professionals needed to run its programmes, for example, therapists. Many such professionals do not have the time or commitment to be involved in social welfare work. An association for the disabled laments the lack of community support and involvement in its CBR activities. CBR committees that run the projects are meant to have a cross-section of different groups involved but many just consist of parents and a few interested outsiders. The responsibilities also often fall onto a few people. People from the community are not tapped into these committees.

Negative attitudes towards disabled children still persist because of ignorance, prejudices, superstitions and lack of knowledge and interaction between the disabled and able-bodied. For example, many parents of able-bodied children are afraid to allow their children to interact with disabled children.

Some CBRs find themselves involved with community leaders but the latter may only be interested in holding positions for the sake of publicity and political mileage. But such persons may be able to help generate publicity and funds for these centres.

Bethany Home has found that community support for the programmes is generally poor and people in the community do not have the time to be involved. And in the case of centres like those in Cheras, the community is involved during fun-raising projects or as in Rawang, the community assists occasionally like taking the children for outings and gotong-royong projects. The Selayang CBR faces a similar situation where community participation is available during special occasions and some volunteers participate when there is some form of benefit or reward. It was also found that most of the ones who got involved were those with children with disabilities.

Bethany Home has targeted community leaders, private firms, religious leaders, local health clinic doctors, hospital doctors and nurses, and Government agencies as part of its efforts. Several other CBRs have enlisted the aid of service clubs like Rotary and Lions, religious bodies and private firms for funds and support. Another CBR is concentrating on family members of the disabled and the immediate community The workers in the CBR feel that they should get the immediate community to understand the role that the CBR plays in community development before they focus on targeting other groups.

Acknowledging that there was still ignorance, negative attitudes and social stigma attached to disabilities, an NGO has targeted groups of parents in its awareness and educational efforts and also conducted courses for parents, CBR workers, volunteers and community leaders. Another CBR has distributed brochures and pamphlets, participated in public exhibitions and taken its clients for outings for exposure and to let the public realise that persons with disability exist.

While some argue that the community development component of CBR is vital, often the reality is that rehabilitation and direct services to disabled persons become the focus of the CBR programme. Many CBRs then leave out the community development component out of the picture and become day care and centre-based rehabilitation programmes.

2.3.4 Volunteers

Volunteerism is not a common practice in Malaysian society. While it might be easier to enlist volunteers to be involved in a major project requiring a short-term commitment, many groups encounter obstacles in recruiting long-term and committed volunteers.

Time and energy are precious commodities in a society where adults spend much of their time working or with family and other commitments. There is, as one official in a CBR project, says, a "lack of spirit of volunteerism." Getting volunteers like qualified teaching personnel and professionals to come in and assist in the rehabilitation of the disabled is major challenge to most CBR groups.

Professionals like speech therapists and physiotherapists, whether employed in the Government service or private sector, may have the interest and desire to help, but are just too busy in their own work.

The professionals who are involved with CBR projects are mainly those who do so as part of their work, for example, those in the Government sector, or are employed directly by groups and agencies working with the disabled. Many of the volunteers found in CBRs today are the parents or guardians, and in some cases, maids employed by the families. Volunteers who continue in the work do not receive any monetary compensation and many do so out of a sense of charity, compassion and love for the people they serve. Many volunteers also drop out of a programme after a while due to burnout, lack of motivation and challenge, and the lack of training and other opportunities.

CBRs need to re-think on how they can recruit and maintain a pool of committed volunteers. Then there are the related questions of training volunteers,. keeping them motivated despite the problems encountered. Otherwise, many CBRs will continue to go on with a depleting number of volunteers.

2.3.5 Family members

A major goal of CBR is to equip families to be able to continue the rehabilitation process away from the formal learning conducted in a centre. Awareness and educational programmes should be targeted at families so that they will have a more positive outlook towards disability and their disabled loved ones.

Many of the problems faced by the disabled are related to families who are over-protective, ignorant or too busy to help in the rehabilitation and normalisation process. Ideally, CBR programmes should involve family members so that the entire family will be challenged and equipped with some basic skills to assist the disabled family member. In practice, the opposite is the norm. In an age of two income families, it is difficult to have at least one parent coming with the disabled child to the centre for the sessions.

In the local set-up, parents are to play an important and active role in the management and operations of the CBRs. But the reality is otherwise. In a Kuala Lumpur CBR, the parents are too busy to contribute to the running and management of the centre and heavy responsibilities fall on the few parents who are involved. Often, the stress, burdens and pressures fall on those few parents who are involved in managing the centres.

A CBR in Selangor found that not only do parents have no time to send their children to the centre but also they expect their children to be fetched for the sessions. Parents also have a lot of misconceptions about the CBRs. For example, some think that because the Government is involved, the service must be provided free and many are reluctant to give financial support.

A major problem facing CBRs is that parents treat the centre as a day care nursery and at the same time have high expectations that the CBR workers can do 'miracles' for the children. They do not realise that the process towards rehabilitation and normalisation is a long-term one. Part of the problem lies in the lack of awareness programmes aimed at families. Thus, many families, as a CBR in Selangor discovered, do not become actively involved because they do not have a good idea of their role. Bethany Home found some families not ready to let go of their disabled members for training and are over-protective.

Parents also face a very practical problem because many have other children to take care of and are unable to be fully committed to accompanying their disabled child to the CBR. Some parents also do not have enough knowledge about their children's' disabilities and do not see the importance of a rehabilitation programme in the CBR. Some children are therefore only enrolled when their disability has become more severe. Other parents also have a low self-esteem and image of their own disabled children and reluctant to let their mix with non-disabled children.

2.3.7 CBR workers

It is acknowledged that CBR workers and staff play a crucial role in the success or failure of the programme. They form an important link between the disabled persons and families with the rest of the community and also between the clients and other professionals like speech therapists and physiotherapists.

In addition, these staff have various other responsibilities and roles. Realistically, they may not be able to perform these roles because of the lack of training, qualification and experience, rewards and compensation. A Rawang CBR official feels that these carers be given professional training and certification and that there should be a standard CBR curriculum. Disability involves complex issues, including the myriad types of disabilities and degree of disability, and yet CBR staff are ill-equipped to handle these. Many are restricted to helping in basic rehabilitation and living skills. In many centres, the CBR workers mostly consist of housewives and retirees and parents of disabled children.

Another problem CBR workers encounter is related to the initial screening and assessment process involving the disabled children. Many of these children were not assessed by professionals, resulting in some conditions being wrongly assessed in an unsatisfactory manner. Then, no proper recommendations were given to the CBR workers to help the child. The CBR workers are then left to help the child although most CBR workers come without experience and training in working with the disabled.

The CBR Selayang found that many CBR workers regarded their work as restricted to the classroom and were not willing to work extra hours going on home visits, which is an integral part of CBR. The workers would only go for home visits reluctantly. The result is that some CBR centres do not have home visit programmes. Some CBR workers also bring their own children into the programme as they treat the centre as kindergarten.

Several centres noted that CBR workers lacked the knowledge needed to work with children with disabilities and that there have not been enough training programmes. CBR workers also have their own expectations from their involvement in the programmes. The allowances paid to them by the Government is at a standard rate and not commensurate with experience, qualifications and responsibilities. And they are not entitled to other allowances like transport claims, bonus and increments.

Part of the problem may stem from the perception that they are working in Government-supported CBRs and paid by the Government. The CBR programme was not intended to be Government-run but was to develop into self-sufficient agencies with some Government support and assistance.

This misconception has led many to treat some CBRs like Government projects and for the staff to be entitled to maternity leave, bonuses and other benefits.

A CBR Cheras official cautions that if the staff do not have adequate financial remuneration, the centres might be left with only clients but no CBR workers. Most CBRs struggle with the lack of teachers, for example, the CBR Rawang feels its ratio of teachers to children at 1:8 is too large. One reason is that there is little prestige, esteem and compensation related to working with the disabled. The stigma faced by the disabled often rubs off onto the staff who work with them.

2.3.8 Professional and assertive support

The shortage of rehabilitation professionals, support services and training opportunities is another challenge in the development of CBR in Malaysia. Many centres are not able to provide better services for the clients because of the shortage of professionals like speech and physiotherapists. This lack of professional advice and support further hampers the work of many centres because the CBR workers are not adequately supported.

More than a few CBRs face the dilemma of having staff who are not adequately trained about disability work, including knowledge on basic rehabilitation and care of disabled children, and yet there are not enough training opportunities for them. Added to this is the shortage of suitable reference and resource materials in simple English or translated to Bahasa Malaysia as not all CBR workers are fluent in English.

The role of specialists who serve as back-up support in the CBR programme is another point to be considered. If CBR is also about social change, challenging mindsets and attitudes, altering the environment to be more disabled-friendly etc, are these professionals and specialists trained in this aspect of social work? Some would argue that professionals might bring in narrow medical model or approach to problems related to disability that can be counter-productive to CBR aims and goals.

Disabled persons who need assistive devices should have access to appropriate as well as affordable devices. But such devices are presently not easily available, with the production, distribution and servicing of these devices still inadequate.

Furthermore support for disabled persons to acquire such assistive devices is not well-coordinated. The process of getting Government assistance for suitable devices and the actual acquisition of the devices can be difficult for some disabled persons and their families. And there are no concerted efforts promoting the manufacture or assembly of alternative and cheaper rehabilitation devices that will be more affordable and yet not inferior to imported equipment.

Another type of service that is inadequate is the social support for families or disabled persons. Most existing rehabilitation services are centred on persons with disabilities. Many families and carers of disabled persons lack social, emotional and other support. The starting of parent and family support groups in many states is a positive development in disability work.

2.3.9 Access and physical location

Land and property are increasingly expensive commodities in an industrialising society like Malaysia. So property and premises that can serve as CBR centres are not easy to come by. Some centres are located in Government buildings that are made available at little or no cost. Some others operate sessions and classes in community halls and other public buildings. Other centres are housed in private buildings where rental or purchase can be high, depending on the locality.

Many centres say that space and physical limitations mean that some activities cannot be conducted properly. Buildings with disability access and facilities like toilets for wheelchair-users are rare and often expensive renovations have to be made to make these places suitable for use by disabled persons.

Accessibility to centres is also an issue because some centres say that clients drop out of programmes because of poor access via public transport to the centres. Not all families have private transport or the finance for taxi fare to enable their disabled children to go to CBR centres. Some centres have enough resources to buy vans and buses but these are few. A Ministry of Health officer notes that the provision of rehabilitative services is mostly centred in urban areas and this limits their accessibility to people in rural areas. Some of these cater to a narrow and limited range of clientele and therefore certain groups of disabled persons are not serviced.

In the case of CBR projects in large states like Sarawak and Sabah and those with scattered rural populations, the question is how CBR can be applied to such situations. There are problems of accessibility to hill and mountainous regions like in Sarawak; dealing with traditional beliefs and practices; lack of support from professionals and other sectors.

The range of services offered in CBR centres also often do not cater for all types of disabilities in terms of infrastructure, personnel and equipment. Therefore many fail to continue or deteriorate to 'baby-sitting services'. When the distribution of rehabilitation services is not equitable, certain sections of disabled people are denied much-needed services.

Another point raised is the inflexibility of some CBR centres that open at certain fixed hours on a limited number of days each week. And if the centres do not have home programmes, then certain clients and their families have no access to these services. But some services can become more flexible in service-delivery with adequate staffing, funding, resources and support.

2.3.10 Government - Support, Evaluation & Role

An official in a CBR in Selangor says the Government needs to do much more in terms of the numbers of CBR centres being set up. He says there is a lack of initiative or encouragement on the Government's part to set up CBR centres. He claims that it is estimated that Malaysia needs about 600 CBR centres but till late 1996, only 196 CBR centres serving some 4,000 clients had been set up. On a macro level, the Government has been urged to look into the setting up more training and vocational centres, recreational areas, disabled-friendly buildings, transport systems and rehabilitation centres for persons with disability.

Another NGO feels that there needs to be proper supervision and understanding of CBR that would lead to better implementation of CBR principles and practices. It says, "Government officers need to be trained and knowledgeable of CBR and one common approach and understanding of CBR is required."

A criticism of current methods of managing the problems of disabled persons is the lack of integration between service providers. The result is that such persons are being managed by a number of different agencies with little or no integration. For example, services provided by the different agencies focus only on certain aspects of rehabilitation. The Health Department is concerned about the medical and physical rehabilitation aspects while the Department of Social Welfare handles the social and pre-school education issues. And the Education Department is left to handle education and vocational training. Therefore there is a need to provide an integrated and coordinated rehabilitative service by combining the efforts and networking of existing services and centres.

A major concern regarding CBR practice in Malaysia is the lack of an effective monitoring and regulatory mechanism. Even the term 'CBR' can be misused by any centre or NGO. It is the contention of many that a number of CBR centres are merely day care or kindergarten-types services for disabled children. There are no guidelines to measure the effectiveness, quality and impact of a CBR programme. No proper evaluation standards have been set up to gauge the performances of CBRs which can help the CBR committees improve the way the centre is run and managed.

There needs to be a coordinating agency that will set the standards for CBR performance and have some form of monitoring. The aim is not to be critical of CBR centres but to help ensure that the centres provide satisfactory service to the clients and community. A recent workshop on CBR raised the issue of the Government's role in CBR. Is it restricted to finance and paying allowances of staff in those CBRs it has helped set up? Will the Government play a more active role in CBR policy and macro-level decisions and initiatives?

2.3.11 Information & Awareness

To fulfil its goal of social change, a certain level of awareness and education has to be created about CBR among the parents and community. There is still a lack of awareness on disability issues among the public and even among rehabilitation service providers.

Parents are also uninformed of the developmental potential for their disabled children, a reflection of inadequate resources channelled into awareness programmes. The role of parents and family members and carers in CBR needs to be publicised more. Parents need to be informed about the importance of their involvement in the CBR programme and the need for continuous learning and for the benefit of the child. Such information needs to be made accessible to and easily understood the people who need such information.

2.3.12 NGO-Government efforts to implement CBR

In the 15 years since the first CBR project was launched, what progress has there been? How popular is CBR as a concept and in practice in this country? Has it enabled more disabled persons to be served and rehabilitated? Has it changed society's attitudes and actions towards those with disabilities?
Do the disabled now have greater access to opportunities, skills and quality of life? Is there a difference in service-delivery between centres run by NGOs and those set up and supported by the public sector? These are some questions to consider when evaluating the impact of CBR programmes as implemented by the Government, associations and NGOs.

An official with a CBR in Kuala Lumpur feels that the measures undertaken so far have been `grossly insufficient and CBR is still far from popular due to a lack of public awareness about it. She notes that some CBR centres are so badly managed that parents do not want to send their disabled children there. Many people also assume that CBR centres come under the Department of Social Welfare and therefore do not need public donations and funding.

It is interesting to note an official of a Government-funded CBR saying that measures taken by the NGOs have largely been more successful than those taken by the Government. "Most CBR centres run by NGOs are successful as they have the financial resources not available to the Government-run CBR centres. They are also not bogged down by the numerous Governmental protocol, which is a common problem with Government CBR centres,' he adds.

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

Both the Government and NGOs have not been able to meet the demand for CBRs. The Social Welfare Department has assisted in setting up 185 CBRs while the Ministry of Health has set up 20 centres and NGOs another 8 centres, bringing the total to 213 for the whole of Malaysia. This figure is far below the required number of 600, according to a 1996 survey. In terms of clients registered with the Department of Social Welfare, few have actually come under the programmes of CBR centres. Out of the number of disabled people who are registered, it is estimated that only 8% are being served in the CBR centres.

An official of a leading NGO in disability work feels that while measures taken by NGOs have been adequate, this needs to be extended to more CBRs.

2.3.13 Participation of Disabled People

A key issue in disability work is the question of participation by disabled persons in planning, decision-making and choices in the projects. Several CBRs responded that such persons did not participate at all in these activities. A leading NGO described their participation as minimal and low. Is the role of the disabled persons in CBRs merely that of a client who receives and is the attention of all the efforts of others? Has there been any effort in the areas of empowerment, advocacy and choice in the work among disabled persons in CBRs?

A doctor on attachment with a Klang Valley CBR notes that a CBR in its fifth year of operation operates like a kindergarten and day care centre for some 40 children with different disabilities. The centre does not, she adds, contain many elements of CBR or Independent Living. Other problems in the centre include an emphasis on normal academic activities, lack of socialisation by the children, insufficient funding, and parents who are unsure of their goals for their children.

Another large CBR in Selangor has more than 150 children registered with it but about one-fifth are actively involved in the centre's programmes. There is a lack of parental involvement, with most parents leaving their children at the centre and going off to work. The CBR resembles a day care centre and has too many children to handle. Community involvement is lacking and the community does not seem keen to give the disabled a chance to take part in its activities.

SOME POINTS FOR FURTHER CONSIDERATION

By Ranjit Kaur* (a leading writer/researcher on disability and CBR issues). *Extracts of paper "CBR in Malaysia – The Past, Present And The Facts" presented at Cheshire Home Far Eastern Regional Convention, 1998, Kuala Lumpur.*

Food for thought

The philosophy and approaches are indeed very difficult to put into practice. Working with a multicultural community can be a mammoth task. The varied traditional practices and cultures can sometimes contradict one another. It may take years to see a CBR programme develop to a mature stage when the members of the community have attained a positive attitude towards disability.

Many external planners, funding agencies are usually eager to see CBR programmes develop and sustain themselves overnight. They also have preconceived ideas and definite plans that they expect should take place. If the plans change, the CBR programme is considered a failure. The following text is food for thought for all of us CBR practitioners and those intending to embark upon this interesting journey. These pointers could serve as good discussion material.

- **Oversupply of Interpretations**

One of the shortcomings of CBR is that it has an abundance of interpretations in the way it can be implemented. Due to the fact that CBR is a "concept" or a "set of ideas" its application can be limitless and broad. There. could be a disadvantage here as practitioners will interpret it in their own respective ways. The word QQ community" means people who strive collectively for a better life. The community in question is the "base". As Mendis (1992) puts it the base is "the responsible unit for the building of strategies". Thus the concept of the term Community-based Rehabilitation. One must bear in mind that Community-based Rehabilitation is not the same as Community-level Rehabilitation. CBR is not a non-institutional service, and neither is it an outreach or extension of conventional services.

- **Segregation vs. integration**

Is CBR really supportive of segregation or integration of persons with disabilities into society? Day care or CBR centres can segregate persons with disabilities from the mainstream activities of the community. They are also misunderstood by families and local community members as formal education centres. Hence it is misconstrued that there is no need to place the child in mainstream schools or special education classes.

- **Expectation of volunteers**

Is the concept of recruiting unpaid volunteers truly applicable in a country like Malaysia? The low monetary allowances, lack of appropriate training, lack of recognition and the lack of career development can demotivate CBR workers. Attractive salaries in the industrial and private sectors have lured many a CBR worker away from this field.

- **CBR and Community Development**

Is CBR implemented as a separate programme or is it part of community development? If it stands alone it becomes a segregated service. The members of the community will leave it to the service providers, persons with disabilities and their families to participate in it. This will lead to lack of community ownership. However, if it is part of community development, will it get any priority as compared to other pressing needs? Although CBR should be incorporated into every community development programme, it would take a long time for the planners and practitioners to get used to the idea and to implement it. It takes a great deal of consciousness raising to implement CBR as part of community development programmes. Local persons with disabilities and their advocates can be given a major role to play in the planning committees and to be accepted as practitioners when implementing community development programmes.

- **Working towards equal access for persons with disabilities**

Has CBR in Malaysia created waves in terms of equal access to physical facilities for persons with disabilities or is CBR only concentrating on a small number of children with disabilities? Such user-friendly environment would include appropriate public transportation, ramps, railings, user-friendly lifts, modified toilets.

- **Persons with disabilities - whose responsibility**

Numerous heated discussions have been held as to whose responsibility should persons with disabilities be. The three main Ministries that make such claims are the Education, Health and Welfare sectors. Such an argument has never taken place for persons without disabilities. Shouldn't the same standards apply for persons with or without disabilities?

- **CBR centres vs. day care centres.**

What is the difference between day care centres and CBR centres?

CHALLENGES & ISSUES IN CBR

By Ghazali Datuk Yusoff (Chairman, National Coordinating Committee on CBR) *Extracts from paper presented at the Workshop on Children with Special Needs - November 5-6, 1999.*

Issues

What are the issues? Longer term vision of CBR in the context of:

- Rehabilitation programmes in general.
- Its positioning in relation to medical, educational and employment perspectives
- CBR development:
- need for guidelines.
- rationalization of training programmes and consistency and acceptability financing related social issues
- inter-sectoral and inter-disciplinary linkages
- recognition of CBR as an essential and important element of social development.

Challenges

In the absence of the above requirements, CBR programmes tend to face the following problems:

- Awareness of its purpose and role.
- Confusion to some extent as to its utility and longer term sustainability.
- Public and private sector support, not consistent throughout the country.
- Need for a database to operate on, eg statistics on disability, facilities offered by various CBR etc.
- Consistency in quality and availability of trained staff.
- Differing quality in communication with relevant Government departments.

The future

Generally CBR programmes are successful and amongst those that are successful a lot has been due to:

- Leadership
- Relationship
- Management
- Sacrifice

There is an urgency to build upon the momentum created through establishing:

- Vision
- Clarity
- Direction
- Recognition

so that sustainability and synergy are created.

3. Independent Living

3.1 Definitions & Concepts Of Independent Living

There are varied definitions and understanding of what the term 'Independent Living' (or IL) means. The concept of IL itself is wide and embraces a whole range of human and civil rights, and consists of various layers and levels.

Independent Living was originally a medical concept where patients underwent physical or occupational therapy in order to be able to do things for themselves. But for people with disabilities, IL goes beyond this medical definition. An alternative approach towards IL is the whole concept of being in control of one's own life. It is about being part of a community or society - like everyone else. The disabled should not be segregated or marginalised because of a disability.

In IL philosophy, the aims include activities others take for granted, like having a job, going out, socialising with others and exercising one's rights. It also means the right to acquire skills and support to enable disabled people full control over their lives. Others have defined IL as a process involving awareness, empowerment and freedom that allows disabled persons to achieve equal opportunities, rights and full participation.

The Independent Living Movement (ILM) is a growing movement and network of disability groups and individuals with disabilities and which mainly originated in developed nations. There are a few basic aims and goals of this movement, including the right and ability of people with disabilities to participate fully in society and community. As the movement continues to grow, other issues have emerged as persons with disabilities and self-help groups and networks begin to articulate their needs, aspirations and desires.

3.1.1 Philosophy

The roots of this philosophy and movement lay in the resistance against institutional care in which many disabled people were confined and restricted to. Coupled with this was the move against discrimination and segregation that faced people with disabilities.

They lacked control over their own lives and felt that they were being dictated to by others just because they were blind, disabled, deaf or had some form of disability or dependence on others. Jenny Morris notes that its origins lay in the resistance to imprisonment within institutions. In the UK, the movement has roots in attempts by disabled people to leave residential care.

The question of rights is a major one in IL philosophy. It is about the right to have personal relationships, to be a parent, equal access to education, training, employment and leisure activities and right to participate in the life of the community. And Morris notes that these human and civil rights cannot be achieved if the disabled are segregated and institutionalised within residential care.

Part of the mission of the Independent Living Movement is to empower the disempowered' - empowering the disabled to take responsibility, taking control of their own life and control of what services they think are appropriate. It's not up to others to decide for people what services are appropriate to them. The disabled need to set their own agenda in terms of what services they feel are appropriate.

Jenny Morris (1993 : 21) identifies four basis assumptions that provide the philosophy of the ILM. Firstly, that all human life is of value. Secondly, that anyone, whatever their impairment, is capable of exerting choices. Thirdly, that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives. Fourthly, that disabled people have the right to participate fully in society.

3.1.2 History

The roots of the Independent Living Movement in the US lay in the aftermath of World War II where many veterans were disabled and the polio epidemic. Ed Roberts and John Hessler are credited as two of the founders of the movement in the US. They were students at the University of California, Berkeley and lived in a medical facility while attending school. They soon began to see that it wasn't the appropriate place for them to live. They felt they ought to be living in the community.

Together with others, they got funding for the first Center for Independent Living. Not long after, other centers started in Boston, Houston, and Denver. These took place in the 1970s and were the beginnings of independent living programs, independent living centers, and the start of the movement. Roberts was disabled by polio and could only breathe with a respirator. However he later became director of the state Division of Vocational Rehabilitation. They had turned him down as a client as being too severely disabled to ever work when he first applied!

Disabled people control the boards of Independent Living Centers, formed mainly in the US, Canada and Britain, that help disabled individuals set up the services they need to live in the community. In developing nations, where the IL movement has yet to make a major impact, disabled people have formed self-help organisations to lobby governments to provide services such as rehabilitation, technical aids, housing and employment.

In the UK, the context in which the movement arose was in the 1950s residential homes where residents started demanding for greater control over their lives and the centres in which they lived. Residents in such homes often felt that society treated them like they were 'socially dead'. Ken Davis and Maggie Hines left residential care to live independently and set up Grove Road scheme where disabled people occupied ground-floor flats and help was provided by tenants who lived in the first-floor flats.

This became an inspiration for others trying to persuade housing associations, housing departments and social services authorities to put together housing with personal assistance. Davis and Hines wanted more independence and later moved on to ordinary housing. Hines describes her experience of institutional living

"...institutions were places people like me died in. The longer I lived there the more I realised I was one of society's social outcasts thrown onto the ultimate human scrap heap." (Disability Challenge, 2, p. 6)

One of the original reasons for starting independent living and part of the independent living history and mission was to get people out of institutions, and have them live in the community. Apart from the desire to leave the institutions, it was also cheaper to live independently than to live in institutions, nursing and similar homes. These kinds of struggles led to the creation in 1974 of the Union of Physically Impaired Against Segregation. The fight against residential care and for the housing and personal assistance services necessary for independence was a key foundation of what became an increasingly strong civil rights movement amongst disabled people. The UPIAS Constitution stated:

"The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, undertake productive work, and to live where and how we choose with full control over our lives. (Disability Challenge, 1, 1981)

In 1974, the Spinal Injuries Association was founded and run by disabled people themselves and it became an important part of campaigns around independent living issues. But other associations for disabled peoples, mostly founded in the 1950s and 1960s, were still run by non-disabled persons. But in the 1970s and 1980s there was a dramatic increase in the number of organisations controlled by disabled people.

The resistance to segregation in residential care provided an important impetus for a growing consciousness amongst disabled people of their rights as human beings and citizens. The formation of Centres for Independent (or Integrated) Living (CIL) provided advice and support to disabled individuals who wanted to live independently. The concept of independent living was starting to take shape. The formation of the British council of organisations of disabled people in 1981 provided a national forum for bringing together ideas on independent living and how to achieve it. Disabled Peoples International (DPI) was founded in 1981 and the European Network on Integrated Living (ENIL) in the late 1980s.

3.1.3 Aims

There are some basic aims of this growing movement and its philosophy. They include:

- Disabled people must be able to control their own lives individually and collectively.
- As equal citizens they have the right to the same access to the basics of life including: food, clothing, shelter, health care, assistive devices, personal support services, education, employment, information, communication, transportation, and the physical and cultural environment. This also includes the right to sexuality and the right to marry and have children.
- Disabled people must obtain all the requirements for equalisation of opportunities and full participation by defining their own needs, choices and degree of user control.
- The Independent Living Movement is opposed to the development and maintenance of systems that promote dependency through institutional responses.
- Disabled people must involve themselves in research and development, planning and decision-making, at all levels, in matters concerning their lives.

3.1.4 Issues

What are some of the key issues being addressed by the Independent Living Movement? The European Network on Independent Living (ENIL) was founded in 1989 by over 80 persons with extensive disabilities. Its aim is to address the under-representation of person with extensive disabilities (i. e. daily dependence on personal assistance) in disability politics, not the least within organisations of persons with disabilities.

Its goal is to participate equally in the community - exercising their self-determination. At an ENIL conference, Adolf Ratzka outlined some of the key IL issues as :

- Anti-discrimination To work against discrimination of people with disabilities and for more personal and political power. People with disabilities are disadvantaged in education, work, income, housing, transportation, family life, and in the social, political and economic lives of the community. The more practical assistance needed, the worse is the discrimination disabled people are exposed to. One of the goals is to introduce legislation in all countries that makes it illegal to discriminate against anybody on the basis of disability.

- De-medicalisation One reason why disabled people are discriminated against is that they deviate from what people think is "normal". Society has a tendency to label people who are different as "sick". Sick people do not have to work, are exempted from the normal duties of life, and are marginalised.

- As long as disabled people are considered sick by the public, there will be little understanding, for example, why they want to use regular public transport and are not satisfied to go by ambulance. One of the main goals is to make clear to the community and to disabled people the difference between being sick and being healthy. Citizens with disabilities have the same rights to the good life as everybody else.

- De-institutionalisation Since disabled people are often considered sick, many are shut away in hospitals and hospital-like institutions. There, it is claimed, they can be better "cared for".

With this argument they are put in special kindergartens, special schools, special workshops, special housing and special transportation. The only places that are still not segregated are the cemeteries! Disabled people have to shut down these special, dehumanising and degrading Apartheid solutions and force their way into the mainstream of society.

- De-professionalisation Many people think of disabled people as sick people who have to be "cured" or at least "rehabilitated". Many believe that they need special, tender loving care by lots of people in white coats. The more disabled they are, the sicker they are and the more professional training the people need who are charged with the task of taking care of disabled people. In this way, society has handed over to the professionals control over the lives of disabled people. Many disabled people have been raised in the belief that a medical doctor or a social worker is best qualified to make decisions regarding their lives. The more power attributed to the person in the white coat, the less disabled people believe in their own strength. It is time that disabled people come to a realistic assessment of what other people can do for them and what they can do for themselves. It is time that disabled people take back the power they have handed over to the professionals.

- Control over their organisations Do we have organisations for disabled people or of disabled people? Are non-disabled professionals in control who look upon disabled people as clients? Or are people in charge who themselves know what it is like to be part of an oppressed minority, people who are fighting for their own rights? This does not only apply to the board but also in staff positions where day-to-day decisions are made. Society looks upon disabled people as helpless people who cannot speak for themselves. If disabled people allow non-disabled people in our their own organisations to speak on their behalf, they are confirming these prejudices. What would the public think about a women's liberation group with mainly men in office?

- Self-management of services Another reason why disabled people need people with disabilities as staff in their organisations is that they are the best experts on their own needs. Services such as transportation or assistance are typically designed, controlled and run by non-disabled professionals. These people, however well-intentioned they may be, simply cannot have the insight in the disabled person's needs, lifestyle and aspirations. As a result there are paratransit systems that run Monday through Friday, as if disabled people had no need to leave home on weekends. If disabled people leave design and control over such services to others, it should not be any surprise if they come up with solutions which fit the needs of their existing bureaucracies instead of the needs of disabled people.

- Peer counselling Independent Living is really basic applied psychology. The most important change disabled people have to make is the change within themselves. They do not need to wait until other people get around to changing their attitudes. When disabled people look at themselves differently, others too will see them in a different light. When disabled people respect themselves as citizens with equal rights, it will be easier for them to convince others that they indeed have equal rights.

- Networking In providing examples for one other and in sharing experiences, disabled people need each other. They all are in the same situation, they all face oppression in society. Once this is realised, it is only a small step to see that they have to support each other, that they must band together to fight the system and together make this a better world. Only together can they gain political power. That is the only power to move things. For this reason they have to organise themselves.

- Personal assistance At the same 1989 conference, Ratzka pointed out that personal assistance was the key to Independent Living. Here he outlines some of the principles related to personal assistance. What is "personal assistance"? Everybody uses assistance and nowadays we all are dependent on each other. Nobody can perform all the tasks necessary to sustain his lifestyle. By utilising somebody else's knowledge and resources we can compensate our lack of ability or lack of time. People like to specialise in doing what they are good at. Most other things they delegate to somebody else. In this way one can be more efficient in the sense that one gets more done. I would like to use an analogy. An entrepreneur or administrator will realise that he or she alone can get done only so much. By employing other persons the entrepreneur can delegate work and in this way increase the total output. Would it be wise for a factory owner to try to do everything all by himself? Most likely such a person would either die of exhaustion or be out of business pretty fast. If entrepreneurs and administrators are not ashamed to utilise manpower to achieve their goals why should we hesitate to do the same?

  "Personal assistance" means that we compensate our disabilities by delegating tasks to other persons. These tasks involve activities which we cannot carry out ourselves or which we are not good at. We delegate in order to have the time and energy to specialise in those activities which we can perform well. "Personal" connotes that the assistance has to be customised to my individual needs. "Personal" also means that the user decides what activities are to be delegated, to whom and when and how the tasks are to be carried out. I think in a world of personal computers and personal telephones the term "personal assistance" is quite descriptive. In what forms has assistance been available so far?

- Family as assistance provider Reliance on the family may work for some time but the limitations are given. Family members get older, they are risking their health in assisting us. Children often have to take too much responsibility too early in their lives. Adults cannot pursue their career and feel locked in. The results are relationships of mutual dependence, sacrifice and guilt. Facing the alternative that often is institutional placement of the disabled family member most families hold out as long as they can - often without any outside assistance - burdened by immense physical, financial and emotional strain.

- Volunteers The virtues of volunteerism are most often praised by conservative politicians whose motives are to cut taxes for the benefit of their voters. Obviously, users of assistance from volunteers cannot demand the same competent, punctual, and courteous work from volunteers as they might from assistants who are paid competitive wages. But most often users do not have that choice.

- Institutions The alternative that most of us in Europe have is to live in some sort of institution. Institutions are administrative entities and as such are governed by the necessities of administering buildings, workers and inmates within the boundaries given by budget, labour unions, and state regulatory agencies.

These constraints are expressed in a multitude of rules that cannot be adapted to the needs of each individual. Otherwise there would be chaos. As a result, a certain order has to be maintained to guarantee the smooth functioning of the whole. The individual's challenge, then, is to adapt himself or herself to the existing order both physically and psychologically without losing one's integrity as a human being. That is very difficult. One of the survival strategies is to develop a pleasing personality with which you can achieve privileges at the expense of other inmates who are not as adaptable.

The general results of institutional living are known as "hospitalism", that is loss of social skills, foregone life opportunities, and stunted human growth. The problem we are facing in helping people who have been staying in institutions is that they often have lost their self-confidence and are frightened by the prospect of leaving their secure confinement.

3.1.5 Empowerment

This is another important theme and element of IL philosophy. Ratzka shares some thoughts about what it means in relation to personal assistance services.

- to have personal assistance schemes that guarantee the same degree of geographical and social mobility that other people enjoy. This includes choice of residence, work opportunities, travel, to have a family, to run for political office, etc.
- to be able to customise individual solutions according to individual needs which may change over time.
- to have access to several different solutions at the same time.
- to take individual control over the funds for paying wages and administrative costs.
- to organise personal assistance users into a pressure group which negotiates with governmental bodies. Together we have political power, individually we have none.
- to help and teach each other through peer counselling the skills it takes to run one's own personal assistance scheme and get the most use out of it.
- to devise ways to allow all of us, regardless of physical or mental disability, to take more responsibility over our lives.

3.2 Independent Living in Malaysia

3.2.1 Definitions and philosophy – A Malaysian perspective

Disabled individuals, NGOs, self-help groups and Government agencies that have been working in this relatively new area called Independent Living have attached different meanings and definitions to it. Some have defined Independent Living in terms of services rendered or as an approach to help and support disabled persons. Others have taken a more philosophical approach to it and introduced certain concepts from the West like civil rights, self-determination, decision-making, self-empowerment, peer counselling and personal assistance.

One such definition from the US states that Independent Living means taking control over one's life based on freedom of choice in making decisions and in daily living. This includes reducing dependence on others. A similar definition is centred around the desire of disabled persons to be like everybody else who are in charge of their own lives, making decisions and choices. It also means the right to make wrong choices and to fail and make mistakes. It is about being human.

Disabled persons in developed nations do differentiate between Independent Living services and other activities that support the rights movement and the movement itself. On the other hand, disability groups in developing nations do not make distinctions between Independent Living philosophy, services, Independent Living Centres and the overall disability rights movement.

In Asian societies, the term 'Independent Living' is not well-understood and some feel that the term 'self-reliant' might be more appropriate. Others have suggested that it is not possible for anyone to live independent of others, and so the term inter-dependence is more useful. In the first-ever Independent Living Workshop held in Malaysia in August 1999, a group of participants described Independent Living as a philosophy and way of life for disabled persons. They called it a 'movement by disabled persons, of disabled persons, for disabled persons' who are working for equal opportunities, self-determination and self-respect of disabled persons.

This definition also encompasses concepts like `full participation'; access to jobs, recreation, education and commerce. The philosophy of the Beautiful Gate NGO is to view disabled persons as having worth and value, taking a distinctly religious or spiritual view that humans are created and valued by God. Their stand is that disabled persons are of equal value and worth to non-disabled persons.

Some groups have defined it in a way to emphasise that disabled persons have to regain control over their own destiny and future. Thus, disabled persons have to take charge of self-help groups, NGOs and organisations involved in disability work. Their position is that non-disabled are not able to fully understand their struggles and aspirations and that disabled persons should be their own leaders. The non-disabled have a role which is supportive and collaborative.

Yet others understand Independent Living in a very practical way like how disabled persons can live `independently', take care of themselves, go to work etc. Some groups have confined it to projects and programmes like sheltered workshops, group homes, job placement, training and living skills. Self-help group leader Francis Yap describes Independent Living simply as `living positively' while another self-help group leader Lee Tur Cheng feels it means "full participation and equal opportunities, living with families and receiving the support of non-disabled persons."

For Stephen Chow, a social worker who is also disabled, Independent Living means not only being able to perform daily activities but also possessing the right and dignity to express "what you want to do, what to wear, what food to eat." He contrasts this with institutions for the disabled, where residents are treated like babies and children, even adults or senior citizens.

Some have taken a more radical stand and say Independent Living includes the right to assert oneself and demand certain rights due to disabled persons because of society's discrimination and barriers. Self-help groups have emphasised issues like advocacy, family support groups and awareness programmes.

A key achievement of Independent Living philosophy is the shift from the medical model of disability to a social model that sees disability as being determined by attitudes of society and the presence of physical and other barriers. The key leaders of the international disability movement have basically accepted the social model as the foundation for Independent Living philosophy. The basic principles of this philosophy are rights, self-determination, self-help, peer support, empowerment, inclusion and integration. And the services related to this concept include peer education, advocacy, training in independent living, transportation services, equipment and repair, and personal assistance.

In Malaysia, there has yet to emerge a dominant understanding of Independent Living which most or all of the groups involved can agree to. In addition, steps to begin an Independence Living Movement in Malaysia seem to replicate measures and steps developed in the US and Europe. Even the use of a term like 'Independent Living' is debatable because of misconceptions and misunderstanding of what it actually means. Others have suggested that a term like Inter-Dependent Living might be more suitable to a developing nation like Malaysia. Many have perceived the term 'independent living' to mean living alone, which is a concept still new to a more family and community approach to living in most Asian societies.

There is also some discomfort about some aspects of the Independent Living Movement like civil rights, self-determination and empowerment. In Germany, for example, some disabled persons have chosen the term 'Self-Determined Living' instead. This is to avoid confusion because Independent Living has been associated with disabled people who are living by themselves. There is a feeling that a shift will merge from Independent Living to 'Interdependent Living' that is a more accurate description about how people actually live.

With more groups and individuals coming together to debate and discuss Independent Living, a consensus or agreement of what it means in theory and practice will likely emerge.

3.2.2 Moves Towards Independent Living

The Independent Living programmes arising from the social model in developed countries have yet to be established in a significant way in Malaysia. In recent times, there have been some attempts at setting up Independent Living homes where disabled persons come together to live and share a home. They make the decisions and are in control This is in contrast to group homes established, managed and controlled by Government Departments, NGOs, voluntary organisations and the able-bodied. The nearest examples we have are Independent Living Centres in Japan that provide a range of services to support disabled persons to live as independently as possible. These are managed and controlled by disabled persons.

Group Homes in Malaysia have been taken to reflect an aspect of Independent Living in Malaysia. Thus, the Government through the Department of Social Welfare began a Group Home Programme in 1993. These are an extension of its Taman Sinar Harapan (Rehabilitation Institutions) programme. Those selected are mobile, able to work and live quite independently. The main criteria seem to be that they either do not have any families or their homes are far away from their place of employment.

There are presently seven such Group Homes - two in Selangor, three in Johore, one each in Negri Sembilan and Malacca - with 29 residents. There are no plans to introduce this programme to more areas. The department hopes that the private sector and NGOs can set up more group homes. The Department also has two main centres where trainees are prepared for hat it terms Independent Living. This mainly involves rehabilitation and vocational training and the centres are located in the Cheras Rehabilitation Centre and Bangi Industrial Training and Rehabilitation Centre.

A leading NGO in disability work is Bethany Home where five supervised Group Homes started in early 1987 for students. These students had been enrolled in its training programmes or were there for respite care. Taking another step towards Independent Living, Bethany selected three mature students as the first residents in its Independent Group Home. This was in April 1999. Another three more students will join this programme. And in early 2000, it hopes to start a similar project for women.

It hopes, with the support of parents, to set up more supervised and independent group homes. It also has 'transition' programmes to help its students move from sheltered workshops to placement and employment and create opportunities for independent travel, use of money, and opportunities for social and recreational activities.

The move towards Independent Living has been a slow one and groups that are now moving into this new phase of disability work have been laying the foundation for many years. What began with residential centres and later developed into day care and community services and later into supervised group homes and perhaps into Independent Living services in future.

Another NGO, the Beautiful Gate, has set up several Group Homes and its first Independent Home for physically-disabled adults in the Klang Valley and Perak. It runs two training centres in Petaling Jaya and Kepong located in five houses. These also provide accommodation for the 30 trainees. The residents undergo skills training for one to two years and then leave to work or return to their families. There is also a lot of emphasis on self-development, counselling, teamwork and relationship-building a part of its wholistic approach. Residents are also taught practical skills like using a special motorcycle to travel and carry their wheelchairs. It also assists trainees to set up small businesses and get loans. Then in July 1999, Beautiful Gate set up an independent group home in Kuala Lumpur for nine of its graduates.

Hopehaven, a special centre in Malacca for disabled children and adults, mainly the intellectually disabled and some physically-disabled persons, is also moving towards setting up an Independent Living programme or group home.

It sees it as a crucial part of its package of services like Early Intervention, Day Care, skills and employment training. The new home will have a variety of residents with different needs. The aim is that disabled adults will be able to live on their own with some support when their families cannot care for them any longer.

Several groups like Kiwanis, Malaysian CARE, Perkobp (association of families with disabled children) and others have moved significantly into the area of sheltered workshops and employment training. These are part of efforts to ensure that disabled persons are gainfully employed and occupied, able to earn some income and live as independently as possible. These complement the Government efforts to spread similar skills among disabled persons.

Another agency, Asia Community Services in Penang, has introduced some aspects of Independent Living into its programme among young children. For example, the concept and principle of choice and freedom is introduced. The children have some choice over the type of daily activities they want to participate in. Its philosophy is that the organisation and its staff are not the teachers but facilitators for the children.

And in 1999, it was significant that several workshops were organised to discuss and explore the theme of Independent Living and moves have been set in motion to establish IL Centres and Independent Homes. This coincided with Campaign '99 conference that took place in Kuala Lumpur. It is only a matter of time before more features of Independent Living are introduced and take root in Malaysia. Individuals and groups, whether Government agencies, voluntary organisations and self-help bodies, are moving towards ensuring that disabled persons can create a brighter future in society.

3.2.3 Participation of Disabled Persons

Much of the work in establishing Group Homes, sheltered workshops, employment and vocational training centres and other projects towards Independent Living have been initiated and managed by non-disabled people. This is reflective of the role played by the non-disabled in leading and controlling disability work and of the dominance of the charity model.

Government agencies, NGOs and voluntary agencies have been the pioneers in these areas but increasingly the disabled community – individuals, groups and self-help organisations – are taking the lead to establish Independent Living as a concept and practice in Malaysia. On the other hand, the types of services provided by self-help groups of disabled persons are quite different. For example, self-help groups like organisations for persons with spinal injuries, physically disabled and wheelchair-users have begun to seriously look into advocacy, peer counselling and empowerment issues.

Some have begun peer counselling services and there are moves to set up training programmes to create more peer counsellors. Other groups have been giving out loans and grants to their members for various activities. These include buying wheelchairs and assistive devices, setting up and upgrading their businesses, doing home renovations to make them more disabled-friendly.

This scenario basically reflects the situation of disabled persons in Malaysian society. Much of the pioneering work in disability has been the preserve of the non-disabled. It is also reflective of the strong charity model and approach that has dominated social work among the disabled for a long time. For too long, disabled persons have been mere recipients of the charity shown by non-disabled and society. Parents who have been over-protective have also played a part in stifling any moves towards self-expression and self-advocacy by disabled persons.

The level of participation by disabled persons is still slow. Family support at the basic level and community and Government support at macro level are still not forthcoming. And years of conditioning to be recipients of services and labelling as being less than capable than the non-disabled are factors that hinder disabled persons from playing an active role in the disability movement.

Even disabled persons and groups realise the need to be more effective in their representations and advocacy work to ensure disabled persons receive what is theirs from society. To them, too many disabled persons are left out of the mainstream of society and are neglected and marginalised. Furthermore, the various umbrella bodies for disabled groups have not been as effective as they could be. And it is generally acknowledged that the pool of capable leaders among the disabled community is small. The results of this leadership shortage can be seen in the lack of effective programmes and initiatives to help disabled persons.

The lack of unity and cooperation among self-help groups is another issue that has been raised and there is a need to move towards complementary work. A non-disabled person, who heads a disability work, feels that the non-disabled majority need to be educated about Independent Living so that the disability movement can progress further. He cites as an example the protective nature of parents of so-called normal children. He says that parents of disabled children are even more over-protective and this is counter-productive.

It is only in the last two decades that self-help groups have emerged in the disability field. But the main bulk of disability work is still being managed and controlled by Government agencies, residential centres and organisations led by the able-bodied. Indeed, a group of disabled persons in an Independent Living workshop, expressed the view that the time has arrived for disabled persons to play a proactive role in society.

But with awareness of overseas trends and exposure to self-help initiatives in developed countries, more disabled persons are beginning to assert themselves and becoming advocates for their peers. And the more radical among the disabled community are more vocal in their demands for self-determination, civil rights and empowerment.

3.2.4 Group homes

Group Homes seem popular among organisations in disability work. These are usually small in number and cater for more mature students and trainees who are able to 'graduate' to these new living units. Many have come from living at home with families into training centres and then to group homes. Group homes are also popular because it allows the disabled persons a choice over staying at home. Many are already adults who desire to live on their own with their peers.

Other considerations also play a part, for example, group homes that are located near places of employment or in urban centres where disabled persons have better sources of support and income.

A typical group home seems to be a rented house where several adults live together, providing support for each other. For those who are independent and from self-help groups, they do not require supervisors and guardians to look after their interests and care for them.

But for younger disabled adults, who may have come from a more sheltered lifestyle or ex-clients of disability organisations, some from of supervision is often necessary. For example, the Bethany Home group and independent homes have some level of supervision to ensure safety and adequate support.

Malaysia has yet to reach a stage where the severely disabled can live in group homes and most are still confined to residential institutions or with their families. In the local setting, Group Homes are an ideal staging and preparation point for eventual move to independent homes.

3.2.5 Training

The results of neglect, charity mentality, over-protection and low self-esteem take time to reverse and many disabled persons will need much support and training to be able to live with a more positive outlook and attitude.

There are different levels and types of training being pursued by self-help and disability groups. There is focus on basic living, personal development and self-awareness skills to develop the person in a balanced manner. Independent Living Skills Training is the next phase which several self-help and other groups are getting into. To prepare clients, trainees and students to move into Independent Living, these groups are introducing such training programmes. For example, a handbook developed by the Human Care Association, Japan has been translated into Bahasa Melayu to enable more local disabled persons and groups to incorporate it into their programmes.

These skills will allow disabled persons, even those with severe disabilities if they have adequate support, to lead more independent lives in society rather than depend on families or live in an institution.

Beautiful Gate ministry runs training centres where a wholistic approach is taken. Its philosophy is that practical skills must also be accompanied by important personal values, personal development, self-esteem, teamwork and cooperation in order to ensure that a disabled person will be truly independent.

The Malaysian Federation of the Deaf has plans to introduce Independent Living and is seeking to emphasise human development programmes to help deaf persons be more independent. The programme deals with issues of self-discovery, self-awareness and life goals.

3.2.6 Placement & Employment

Another increasingly popular area of Independent Living is centred on open and sheltered employment and the pre-employment phases of job training and placement. Disability groups have found that man disabled persons, who previously stayed at home all day or were considered unemployable, are able to hold jobs given sufficient training and support. For example, intellectually-disabled persons and slow learners have been able to find employment in factories, offices, restaurants and other places. They are considered stable and good workers who do not job-hop.

While some disabled persons may not venture into open employment after their training, they have been equipped with valuable skills that they bring to the family businesses. Hopehaven Centre in Malacca trains nearly 40 students in its centres and has had 10 students who have found jobs. Like many other groups, it has staff who liaise with employers and the staff to ensure the students are able to work effectively.

Sheltered Workshop have been in existence for some time in recognition that some disabled persons will not be able to compete in the open market or work full-time. Disability organisations also realise now that certain disabled persons have been identified with traditional jobs that are no longer appropriate. For example, the blind have often been associated with basket-weaving, telephone operations and massage services. Blind groups acknowledged the need to look for new employment sources. Information technology and computing are new areas of possible involvement by the disabled community. There are now more companies that employ disabled persons in these fields.

Self-help groups have also been giving out loans and grants for members and other disabled persons to starts business ventures.

Education is an important factor in the advancement of the poor and marginalised and this includes disabled persons. Through no fault of their own, many disabled young people may not have acquired academic qualifications because of the lack of facilities and resources in many schools and an adverse school environment. But many self-help groups are giving grants or raising funds to enable disabled students who have potential to do well academically to pursue further studies.

3.2.7 Awareness & Advocacy

In the developed countries, more disabled people can be seen active in the community because Independent Living services began much earlier and their societies more prepared to accept them.

In Malaysia, many myths and misconceptions are still attached to disability and the disabled still face many hurdles and barriers as they begin to be more active in the community and society. Acceptance, freedom to choose and empowerment and other aspects of Independent Living are still out of reach for most disabled persons because of a lack of awareness about their rights, struggles and aspirations.

There are more efforts going into increasing awareness among the public about disabilities and disabled persons.

Self-help groups like Dignity & Services have played a role to encourage more disabled persons to speak up for themselves. This is done through its advocacy groups, public events and books written by disabled persons themselves. Eugene Lau, secretary of a self-help advocacy group, noted the lack of awareness of the capabilities or disabled people and that society was constantly looking at what disabled people "couldn't do" than what they could do.

More support groups and parents groups are being formed as there is now greater awareness. There is also a need to improve self-awareness among the disabled. Many, who are in remote and rural locations, and who are neglected and marginalised, are unaware of their own capabilities and rights. They have little concept of better quality lives that they could lead if they received enough support and services.

Advocacy is a central aspect of Independent Living but in Malaysia has long been neglected here because of the circumstances and cultural traditions present. Advocacy is about being able to participate in making decisions and community affairs, like any other citizen. It is about inclusion in society as against the many years of exclusion and marginalisation of disabled persons.

Godfrey Ooi sums its up accurately when he says that disabled persons are "not vocal" and that this is reflective of society as a whole which is places more emphasis on self-interests and not seeking controversy. But disabled individuals and self-help groups are becoming more vocal and are expressing their opinions and views on various issues. Many feel that the disabled person is his best advocate because he understands better than anyone else what he wants and needs.

3.2.7 Self-Help Organisations

In recent years, more small self-help groups have emerged to complement the role played by older groups. Many of these include groups formed by wheelchair-users, physically-disabled, intellectually-disabled, deaf and even parents of disabled persons. The growth of such groups is positive and provides valuable insight into the world of disabled persons and results in greater exchange of ideas and resources.

While older groups like the YMCA KL Deaf Club runs projects like leadership training, social and recreational programmes, marriage advice and counselling. some of the newer groups have included advocacy and empowerment issues into their agenda. Some have even organised peaceful demonstrations to highlight their grievances and plight. Other groups like Beautiful Gate incorporate a mix of approaches like self-help, residential care, advocacy and support services into their work. Several new self-help groups have begun group and independent homes for members as they make the move towards Independent Living in a tangible way.

3.2.8 Peer counselling

Such services are also relatively new to disabled persons and disability groups. But MASIA, the self-help group for those disabled with spinal injuries, has been involved in peer counselling for some time. Although it is still done on an ad-hoc basis and proper training programmes have not been started, it receives requests from hospitals to help newly-disabled patients.

In a December 1999 workshop on Independent Living, many participants acknowledged the importance of peer counselling. Not just for the disabled, but also for families and parents. They realised that the trauma, depression, anger and other emotions that accompany a disability need to be dealt with. Several groups mooted suggestions for more formal training programmes to develop peer counsellors, including the need for a range of skills to be acquired.

3.2.9 Assistant services

While assistant services like that practiced in the US, Europe and Japan - where grants, funding and personnel are available - have yet to be introduced here, disabled persons and groups acknowledge that such services are an important component in Independent Living. For the severely disabled like quadriplegics and their families, such services will go a long way towards improving the quality of life for the disabled persons and families as well.

While public funding and insurance pay towards the cost of assistant services in developed countries, it is not envisaged that similar schemes will be available in Malaysia. It is unlikely the Government will fund such services because of the enormous costs involved and also because the public have yet to be aware of the benefits of such services. The public still tend to see the importance of funding for residential institutions and homes.

There are individuals in Malaysia who have used insurance compensation from accident cases or who have the financial means to employ maids as personal assistants. But the number such persons is a small percentage of the thousands of disabled persons who require such services. Disabled groups and leaders now feel that some grants and funds should be given by the Government, for example, the Department of Social Welfare, to certain categories of disabled persons to enable them to have access to assistant services. This could start with the severely disabled who have greater need of such assistant services.

Others like Godfrey Ooi, a leading disability leader and advocate, have suggested that one personal assistant could serve a small group of disabled persons. For example, one assistant could be hired by the hour to drive a group of blind persons to do their weekly shopping, read to them or do their housework.

For deaf persons, the issue of interpretation services is a crucial one. Some deaf groups have funds to pay for interpreters but most individuals do not. The Department of Social Welfare has given some grants for such services but this is still limited. Mohamad Sazali Shaari, another key disability leader, said grants could be given to the severely disabled or multiply-disabled persons as a start.

3.2.10 Leadership Development

In the 1980s and 1990s, some disabled leaders were exposed to the Independent Living Movement and concepts like assistant services through participation in conferences and visits to developed countries. They noted that international exchange programmes that provide opportunities to learn more about Independent Living activities in other countries was an important factor in leadership development.

And in 1999, the first-ever Independent Living workshop was held in Malaysia which brought together a group of disabled leaders and workers. This was supported by disability movements from other countries and the Asia Disability Institute. More leaders in the disability movement are trying to network with international agencies like ESCAP and groups in Japan and other developed nations to train potential leaders and to keep up with trends and developments.

Groups have also felt the need to train disabled persons in leadership and management skills to build up the capabilities of self-help organisations and the disability movement. The pool of leaders and potential leaders among the disabled is small, due to factors like lack of education and exposure opportunities. And as a matter of self-preservation and growth, self-help groups have no choice but to train better leaders, managers and supervisors to ensure the groups are healthy, adequately funded and staffed, and able to achieve their objectives.

3.3 Hurdles to Effective Implementation of IL in Malaysia

There are various factors and hindrances which prevents the concept and practice of Independent Living from being more firmly established in Malaysia. These include:

3.3.1 Mindset and attitude

There is in society, voluntary organisations and even among some disabled persons a mindset that is still entrenched in the charity and medical models of disability. Basically it means that there is a mental block which prevents people from seeing disabled persons from living independent lives.

Many people who think the disabled can't be independent do not realise that in many develop countries, even severely disabled persons have been able to live on their own and carry out many activities through support of family, community and assistants.

The disabled continue to be seen as requiring help and assistance because they are not able to help themselves. The elements of pity and patronage are still very strong in some sectors of disability work. Unless these issues are addressed, there will continue to be obstacles in implementing Independent Living concepts and services.

3.3.2 Vision & Leadership

Many disabled leaders and groups are so caught up in the daily activities and programmes of their own that there is little effort that goes into long-term planning and having a vision for the future. Staffing and funding problems and the lack of leaders and leadership development programmes result in short-term planning and practices.

Many of the leaders have also a lack of understanding of independent living concepts and services and this means little or nothing is done about Independent Living. There is a need for greater exposure and learning opportunities for leaders and potential leaders so that the disability movement can move forward towards ensuring better services for the disabled.

3.3.3 Expertise & Manpower

It is generally acknowledged that there is a severe shortage of specialists, experts and resource persons who will be able to implement Independent Living programmes and services. Trainers are also needed to teach others, for example in Independent Living skills, while staff to implement programmes are also in short supply.

Even for on-going residential day care and community programmes, there is already a lack of staff. For newer areas like Independent Living, finding staff of calibre and commitment will be harder. It is therefore imperative that more training and academic programmes be available to ensure more personnel are trained in this field.

3.3.4 Cultural factors

Over-protection by parents of their disabled children is a common occurrence and hinders the move towards Independent Living. Many parents will not allow their children to even be exposed to independence because of fears about safety and out of a sense of responsibility.

This can only be addressed through awareness and education and also in small practical ways. For example, Bethany Home appreciates the concerns of parents but assures them that safety aspects have been considered in the group and independent home programmes. Further, it also teaches the residents practical steps to take during emergencies and when facing problems.

3.3.5 Infrastructure barriers

There are still considerable difficulties for the disabled to be mobile because society and its infrastructures are not disabled-friendly. For example, public transportation is not an option for many disabled persons like wheelchair-users.

Taxis are expensive and many taxi drivers avoid picking up wheelchair-users because of the extra effort needed. Buildings, factories, schools and public facilities all pose problems and hazards for the disabled and hinder efforts to promote Independent Living.

Cost constraints, neglect and ignorance are factors preventing better infrastructure from being built to support the disabled. Even with legislation about access to public buildings, there are still numerous problems of implementation and regulation.

3.3.6 Lack of funding

To provide a comprehensive range of Independent Living services, there needs to be adequate financing over a period of time. Well-trained staff are needed implement programmes and resources are also needed. To assist disabled persons in engaging assistant services, grants and funding are also needed and it is unlikely the Government will allocate such funds at the present and near future.

To enable disabled persons to be able to live independently and be mobile, houses and work places need to be renovated. While some self-help groups give loans for this purpose, it is still a long way to go to expect public subsidy for such efforts.

3.3.7 Lack of unity

While there are umbrella bodies for disabled organisations and self-help groups, there are criticisms that these have not been as effective as they could be. These bodies have not been able to come together and agree on common issues

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.

3.4 Appropriateness of IL

There has not been much debate over the question of whether Independent Living, which is seen as mainly Western in concept and practice, is applicable and appropriate in developing nations like Malaysia. But as various groups and individuals seek to implement Independent Living practices and services in Malaysia, the debate will become relevant in the context of Malaysia.

Independent Living, with its emphasis on concepts like justice, rights of the disabled, self-determination and choice, and as practiced in the West and to a lesser extent in Japan, is said to be less than appropriate for Malaysia which its Asian values and different ways of handling disability problems and issues.

It is relevant to ask if there really is a clash of values and culture and also whether Independent Living is a purely Western concept and practice. Many would argue that there are certain universal values, whether originating from the West or Asia, that are applicable to any society. These would include dignity of all humans; the right to education and shelter and other basic needs; right to assistance for those who are marginalised and discriminated against etc.

3.4.1 Rights

While the issue of rights of disabled persons in the West has long been debated, this is still a little-explored area in Malaysia. However some groups and individuals in Malaysia have tried to argue for certain rights for disabled persons.

Dr Denison Jayasooria has noted that on the issue of rights, the Malaysian Federal Constitution does not specifically refer to disabled people. The key discussions during the time of the writing of the Constitution centred on ethnicity, language, religion and culture. However, it is significant is that in recent years, especially after the 1980s, disabled people have been making a claim to full citizenship in Malaysia and highlighting their experiences of discrimination in Malaysian society. Some have even argued that the disabled community have been cut off from mainstream society and are second class citizens

While all citizens are equal before the law, Article 153 of the Constitution makes provision for the special position of the Malays and Article 154 protects the interests of the non-Malay community. The special provisions for the Malay community were intended to secure their advancement and progress.

Therefore it is important to recognise that within the Malaysian context, there is a historical precedent for positive discrimination in legislation and affirmative action which seeks to undo the social and economic disadvantages faced by the Malay community. This illustrates the effectiveness of affirmative action in uplifting the Malay community. But disabled people in Malaysia have not called for similar affirmative action through a special position for themselves. A citizenship framework of rights and responsibilities can ensure that disabled people are equal members of a community like others.

In the discussion on citizenship, two approaches are available to disabled people in how they can experience empowerment. These approaches can operate as two separate and distinct approaches or as a balance and integration between both.

The first enhances participation, group solidarity and collective action through the political process. In this, the aspect of 'voice' is central where disabled people have a voice through direct action to claim their right in society. The other approach is choice through which the markets where disabled people exercise their consumer rights. Here opportunities are enhanced through mutual aid.

3.4.2 Fast-Changing World

Malaysia is fast-changing and moving steadily from a developing nation towards developed nation status. In a world that is increasingly inter-connected and where people and institutions are exposed to other influences, there is a constant exchange of information, values and ideas. In Malaysia, many Western ideas and concepts have bee absorbed and integrated and expressed in the local context.

As the world moves towards globalisation, it will be almost impossible to stop the free flow of information and ideas.

As Malaysia opens up her markets and industries and society and moves towards a more open market economy, people will have a wide range of choices. Freedom, choices, a higher standard of living and quality of life will become more important. The growth of a middle class, urbanisation and rising affluence also brings exposure to concepts like accountability, transparency and other ideals and values. Disabled persons, families, self-help groups and others will increasingly make demands for more services to tackle problems related to disability.

3.4.3 Affordability

Many individuals and groups are now arguing that Malaysia is an affluent nation and able to spend billions on poverty eradication, infrastructural projects, new cities and townships, education and other projects. They claim that the nation has the capacity and resources to address the many needs of disabled persons for services, programmes and infrastructure.

The situation in the nation is unlike the 1960s and 1970s where poverty levels among certain sectors were high. The Government has successfully brought down poverty levels and now only pockets of hard core poor in certain urban and rural areas exist. These problems are now given attention by various Government agencies and NGOs. But the sector that is among the most disadvantaged and marginalised now is the disabled community. The disabled are more likely to be unemployed or underemployed, discriminated against and school dropouts etc. They receive very little services in comparison to the number of disabled persons in the country.

While the Minister of National Unity and Social Development has estimated that there are some 220,000 disabled persons in the country, only a few thousand have access to services and assistance. The needs of disabled persons can be adequately met because of resources like finance and personnel I the Government, corporate sector and voluntary groups.

3.4.4 Health and Technology

As the country develops, health care becomes more widespread and more disabled babies survive. Disabled adults are also more likely to have longer life spans because of services, medical aid and other resources. So there number of disabled persons will increase. Technological changes are also helping make life more viable and fulfilling for disabled persons. Information technology, computers, assistive devices, Internet and transportation means more disabled persons will be able to be connected in their work, education and leisure.

The past practice of maintaining residential institutions and expensive training institutions will not be viable for much longer. These are expensive options in the rehabilitation and care of disabled persons. A cheaper and better option is to assist and provide services so that disabled persons can live in the community, with their families or friends, go to work and participate in community and national life like any other citizen.

3.5 Future directions

Godfrey Ooi is among the many disabled persons who want to see more Independent Living programmes and services being established in Malaysia. He argues that the Government should seriously explore Independent Living because it is a good philosophy that needs a concerted effort to put into practice.

Another disabled activist, Stephen Chow, called for disabled persons to make known their desire voice to the Government to begin a new phase in disability work. He argues that in a civilised society, all persons, including the disable can pursue their aspirations, rights and their fullest potential without encountering physical and attitudinal barriers. People with disabilities should have equal access to facilities, services and opportunities that are taken for granted by others.

For the future, he feels that Malaysian should strive towards Independent Living rather than build more institutions for the disabled. And the disabled must realise that they have to play a role to ensure their rights are protected and because they are their own best advocates.

Some of the arguments for implementing Independent Living in Malaysia take an economic perspective and say that if disabled persons were independent, employed and didn't require residential institutions and other services to care for them, it would be very cost-effective. Such disabled people could also play a greater contributory role to their families, communities and nation if they were independent.

As for self-help and voluntary groups, greater efforts are needed to provide opportunities in job placement, sheltered workshop and training programmes to develop the capabilities of disabled persons.

The whole issue of disabled persons in rural and remote locations have not been adequately addressed in Malaysia. Very few services are located in these areas and many disabled persons are left out of services.

Disability services and information should be de-centralised is common theme raised in the past. But most self-help groups continue to be established mainly in urban areas.

Greater cooperation is another issue to be tackled because Government efforts alone are not enough to support he disabled towards Independent Living. While NGOs have taken the lead in many cases to implement Independent Living services and programmes, their capabilities are limited. A partnership between Government, NGOs, self-help groups and disabled individuals is required to ensure the healthy development of Independent Living in Malaysia.

Christine Lee a key disabled activist in Independent Living, said that the example of similar movements in Japan meant that such a movement could be developed here. "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," she says.

4. Suggestions & Recommendations

4.1 Strategic Action Plan

4.1.1 The effective functioning of CBR, IL, the direct involvement and participation of disabled people needs a strategic action plan over the next few years. This needs to be developed to enhance the potential of disabled people in Malaysia society.

4.1.2 Measurable indicators and outcomes must be clearly defined in order to evaluate the effectiveness and efficiency of the plans.

4.1.3 This could be a joint effort of government agencies, voluntary and self-help organisations. A systematic well thought out plan with specific targets, allocation of resources both personal and funding would enrich the effective implementation

4.2 Review and Evaluation of CBR

4.2.1 There is a need to undertake a comprehensive impact assessment of the CBR programmes in the country both run by the government and the voluntary agencies. This is needful to ascertain the effectiveness and efficiency of the programmes carried out. While a number of individual reports have been done by the respective agencies, there is currently no national level evaluation of the programmes.

4.2.2 The review and evaluation will have to take in to account perspectives from service users, local community members, agency/ organisation staff, and self-help group members from the disabled community. The study could be undertaken through the funding provided by the Ministry for National Unity and Social development.

4.3 Comprehensive policy on disability with specific reference on Community Based Rehabilitation & Independent Living

4.3.1 A Task Force comprising representatives from relevant agencies, voluntary organisation, self-help organisations, parents groups should be set up to formulate a National Policy on Disability. While there are number of references in policy and legislation with reference to disabled people, there is no comprehensive policy which can serve as a national framework for action.

4.3.2 The Ministry for National Unity and Social Development could set up a special task force to undertake this exercise.

4.4 National CBR Co-ordination and Operations Centre

4.4.1 The task of co-ordination is currently co-ordinated by the Department of Social Welfare for those set up by the department. In the case of the voluntary there is currently a voluntary grouping of the National Co-ordination Committee on CBR under the Malaysian Council for Rehabilitation. However what is lacking is an operations centre with resources (personal and funding) to provide leadership to the programme.

4.4.2 The Department for Social Welfare should appoint one Federal officer (at the Director level) with experience and qualifications in CBR to facilitate the developments. Two additional staff with professional training in CBR should serve as support staff in providing co-ordination and training. These could be people who are employed by government on special contract rather then from the civil service.

4.4.3 The Operations Centre could be set up as a smart partnership project between relevant government agencies, voluntary and self-help organisations, and with private sector agencies.

4.5 Independent Living Resource Centre

4.5.1 An IL Resource Centre should be set up to provide accurate information and training for the development of IL centres nationwide. Self-help organisations should be entrusted with this task together will support from relevant government agencies and voluntary organisations.

4.5.2 JICA could provide a 5 year grant for the development of this centre and provide resource staff from Japan to spearhead the project, recruit and train local disable people to manage the centre .

4.6 Capacity Building of Self-Help Organisations

4.6.1 A systematic and co-ordinated programme be launched for capacity building of self-help groups through the strengthening and setting up of national, state, district and local self-help organisations.

4.6.2 Leadership training programmes and the provision of adequate resources for the formation and building up of self-help organisations needs systematic planning and targeting. Employment of disabled people as staff and resources needs to encouraged.

4.6.2 This programme could be funded jointly by The Ministry for National Unity and Social Development and JICA. In addition JICA can continue to fund exposure programmes for the leaders of self-help organisations for exposure and training programmes in Japan and the region.

4.7 Neighborhood Disability Intervention Programme

4.7.1 A comprehensive district level disability intervention programmes be organised and co-ordinated in partnership between relevant government agencies, voluntary organisations, self-help organisations and local community leaders.

4.7.2 Integrated, comprehensive district level intervention programmes can be introduced which will combine a range of services such as CBR & IL in the local neighborhood.

4.7.3 A comprehensive local survey to identify disabled people in the district will be organised in cooperation with government agencies, voluntary and community groups together with self-help organisations. A computerised data base could be develop to monitor the progress made.

4.7.4 After an assessment, required services will be organised catering at the multi-disability, multi ethnic and multi disciplinary dimension in partnership with government agencies, voluntary organisations, self- help groups and the local community. Where services are not available at the district level, these will be set up.

4.7.5 The range of services will include survey and registration, awareness (public education), community mobilisation, information sharing, local level advocacy, co-ordination and networking and direct services such as day cares, employment placement and ensuring that disabled people are integrated in the local community and will experience equal opportunities.

4.7.6 This project will ensure that equal opportunities and access to public facilities are ensured for disabled people at the district level.

4.7.7 The Ministry for National Unity and Social Development, The Malaysian Confederation of the Disabled (MCD), Malaysian Council for rehabilitation (MCR) together with the National Council for Social Development could facilitate this development in an organised, systematic and comprehensive attempt in organising services with disabled people.

4.7.8 This programme could be applied at a pilot stage it at least 5 districts (3 in the rural and 2 at the urban centres) funded by the government and private sector.

4.8 Peer Group Counseling

4.8.1 Equipping disabled people as peer counselors and effectively coordinating these is imperative to ensure a changed approach in serving disabled people. This will ensure the active involvement of disabled people.

4.8.2 The self-help organisations of disable people should set up a co-ordination base. This could be a joint effort of all the organisations. The services should be well publicised and an effective networking system should be developed with relevant agencies.

4.8.3 A well developed counseling course should be organised. This could be developed in two parts. The first part is on Basic Counseling Skills and the second part is on specific aspects related to disability.

4.8.4 This training course is organised specifically for disabled people and family members who with their experience of disability can become enablers to support others.

4.8.5 JICA should provide a grant for this training of key trainers and also provide technical input through Japanese disabled people. The proposed Independent Living Resource Centre could coordinate the training of self-help groups directly providing peer counseling.

4.9 Personal Assistance Programme

4.9.1 An organised provision of personal assistance should be set up and the Malaysian government should provide grants to disabled people for the successful implementation to ensure that disabled people can realise their independence in Malaysian society.

4.9.2 In an attempt to enable disabled people to be independent funding should be made available for the employment of an assistant for a cross section of roles. Some clear guidelines could be developed for eligibility of this service.

4.9.3 The service could be well co-ordinated with a pool of PA's providing contracted roles in the community. This service could be set up by self-help groups as a small contracted business venture.

4.9.4 This service could include the employment of foreign workers male or female helpers to assist the disabled person who requires such assistance.

Appendix

Appendix 1

Disabled People, Charity Care And Enabling Care – A Comparison & Analysis

The voluntary sector is a key provider of social services for disabled people. A study of Klang Valley organisations by Dr Denison Jayasooria shows that four approaches as being dominant in practice. Here we review two approaches through a study of two voluntary organisations.

It is difficult to associate specific approaches with any specific organisations because they do not form watertight categories and there is an overlap of approaches in most cases within an organisation. On the principle of confidentiality the names of the organisations are withheld and they are referred to simply as Charity Care Organisation (CCO) and Self-Help Organisation (SHO). Pseudonyms are used for the names of those interviewed.

1. CHARITY CARE ORGANISATION - ORGANISATIONAL DATA

The initiative in setting up the CCO was by well-placed individuals in society with minimal or no participation by or consultation with disabled people. It was established by an expatriate with the support of well-placed Malaysians, professionals and the Department of Social Welfare. By December 1963 a residential home had been established for 12 persons on land leased by the Government.

It was registered with the Registrar of Societies in 1970 as a society for charitable purposes only. Four of the six objectives reveal the nature of the home, namely

- to establish and maintain a home or homes for residents;
- to provide for the maintenance and welfare of residents;
- to provide facilities to enable residents to engage in fruitful activities and to become
- useful or fitted for employment by suitable care and training;
- to promote, organise, arrange and participate in conferences, meetings and lectures
- and subjects relating to the problems of disabled people and the chronic sick.

There is open membership (with five categories - Ordinary, Life, Institutional, Associate and Honorary) in this locally-constituted charitable society whose office-bearers are Malaysians. It is managed by an elected council of 15 members who serve in an honorary capacity. It meets regularly to make all the major decisions. No disabled persons are members of the Society or the Council.

Implementation of decisions is delegated to five sub-committees under the leadership of a council member. There are employed staff (20 full-time and four part-time) headed by a qualified nurse. There is no disabled staff member nor are there any disabled volunteers.

Clients

The home serves the physically handicapped, who are mostly under 40 years and come from the three major races. The services are open to "men, women and children of all classes and communities regardless of religion who are chronically ill or permanently disabled and who are without any means or resources or are of limited means and resources. (Constitution).

There are 44 residents, the majority of them Chinese (64 per cent) as compared to Indians (23 per cent) and Malays 11 per cent. It is uncertain why there is a higher number of Chinese, as this does not reflect the general population ratio. Wong Poh Wan (1993:78) in her study of three Early Intervention Programmes for children with learning difficulties also noted a higher proportion of Chinese service users in comparison to the national population distribution. She noted 35 per cent Malays, 58 per cent Chinese and 7 per cent Indians.

Jayasooria's (1995a) study of 19 voluntary organisations in Selangor noted 46 per cent of service users were Chinese, whereas Indians made up 32 per cent and Malays 22 per cent. There are two possible explanations. Firstly, the voluntary sector largely caters for non-Malay communities since Malays tend to turn to Government agencies for assistance.

Philip Eldridge (1991) notes, "Malays have learned to look to politicians and state structures for provision of services, making them less willing to form their own grassroots organisations or undertaking self-reliant initiatives." (Eldridge, 1991 : 4). Secondly, culturally the Malay community provides for disabled persons within the family unit and would not be happy to have them isolated in an institutional setting.

Table 1 : CCO Residents - Breakdown by age, gender and race

Age	Malay		Chinese		Indian		Others	
	M	F	M	F	M	F	M	F
21 – 39	1	3	5	8	2	2	1	-
40-59	-	-	6	6	2	3	-	-
60 and above	-	1	1	2	1	-	-	-
Total	**5**		**28**		**10**		**1**	

Malay = 11 per cent
Chinese = 64 per cent
Indian = 23 per cent

Services

The main service is residential. Its Constitution draws a distinction between a home and an institution, and its service is, "to be run as far as possible on the lines of a Home and not an Institution". Forty-three residents have 'live in' facilities, with three main meals provided along with medical and care support. It also organises social gatherings and outings.

The home aims to provide the fullest life possible for its residents within a secure family environment of affection and encouragement. The emphasis is on all-round personal development rather than merely treating medical conditions.

It is to be more than just a welfare home for the disabled.
"It is a place in which the residents can acquire a sense of belonging, and of ownership, by contributing in any way within their capabilities to its functioning and development; a place in which to gain confidence and develop independence and interests; a place of hopeful endeavour, and not of passive disinterest." (CCO brochure)

The residents' physical, psychological, social, occupational and recreational needs are provided for. It emphasises self-reliance and a majority of residents are involved in some economic activity, in full-time employment outside or self-employment. Their work bring in the extra money for personal expenses and also allow residents to contribute towards their stay at the home. Residents contribute 20 per cent of their incomes to the home. Their work enhances their sense of self-worth and dignity.

Finance

About 60 per cent of the funds for the organisation are raised from the public. The Department of Social Welfare provides a grant amounting to 15 per cent of the budget. About 12 per cent comes from contributions by residents and their families. The remaining 13 per cent is raised by sale of handicrafts and other items.

Table 2 : CCO Income and Expenditure Figures

Year	Income	Expenditure	Government Grant
1991	RM 425,229.00	RM 302,108.00	RM 44,129.00
1992	774,390.00	689,471.00	31,317.00
1993	630,747.00	331,693.00	43,934.00

2. CRITICAL ISSUES IN CHARITY CARE

In the course of field visits and involvement among disabled people, staff and Council members, and through interviews, six major observations can be made. While the findings have particular relevance to the organisation, they also have wider application in general to charity and enabling care-oriented voluntary organisations.

Residential Care - A Medical Orientation

It started with residential services in a home environment and not with an institutional atmosphere. In many ways it is a transplant of a model from the United Kingdom. While independently-registered society here, its conceptual framework is the UK model. Therefore, some struggles of residents (Hunt, 1966, 1981) under similar UK programmes have relevance for the Malaysian experience.

The facilities are good compared to other voluntary agencies, and it is not isolated from the local community, at least geographically. But it has a fenced-in compound and a feel of being isolated from the community.

The CCO has a medical orientation to social work practice, and this is reflected in some ways. The most senior staff are two qualified nurses and one can sense their dedication and compassion. They are also the only qualified staff members. At some sub-committee meetings, a key aspect is receiving the medical report from the senior staff and volunteer doctor. The medical report has a prominent place. This likewise forms an important focus at the Council meetings and Annual General Meeting.

Over the past 30 years many of the long-term residents are beginning to age and there are medical complications. For the Home these are major concerns and all cases are reported and discussed. There is a strong emphasis on nursing care.

A Council member, who is a doctor and also a founder member, chairs the Admissions sub-committee and once declared admitting each resident and closely followed their medical conditions. She said, "I regard them as my children". This affection reveals both a matriarchal and patronising attitude.

The Home is now responsible for residents who have left their own homes and are in its care. To avoid any bad publicity through lack of care. utmost care is taken to ensure their good health. The medical profession has a strong influence over the residents and their existence is conditioned by their medical well-being. Non-disabled people tend to focus on the ability of disabled people to cope on their own. Therefore, there is emphasis on living skills and training (bathing, dressing, self-care).

For the residents, it is a situation of powerlessness in the presence of a dominant medical perspective that conditions their outlook and experience. To move away from the individualised and medical focus, Council members and senior staff should be introduced to the development of independent living schemes in other CCO programmes. This orientation will widen their current perspectives and foster more positive images for assisting disabled people.

None of the residents can live outside as they do not have the financial means or to employ personal assistants. Neither do they have family members willing to assist them. One major problem with the voluntary sector is that freewill contributions are made to the organisation and not to disabled people directly. While funds are raised in the name of disabled people, they have no decision-making power on how these funds are best utilised.

Residents' Involvement

Residents are not involved in the main decision-making processes of the Council and sub-committees. None of the residents are members of the CCO. The majority of Council members are well-placed, affluent members of society. This reflects one aspect of charitable work in Malaysia where the rich and affluent give some of their time for charitable work, which in turn gives them a lot of media publicity.

In interaction with Council members, one notes their lack of exposure to contemporary changes in social work practice in general among disabled people, both at international and national levels. They also seem uninformed of changes that have taken place in similar programmes elsewhere, not least in the UK agency with which the CCO is associated. They lacked knowledge of international developments with regard to the Charter on user-involvement and independent living centres around the world. There is only one formal gathering where residents can give feedback. It is the Residents' Disciplinary sub-committee chaired by a Council member.

Residents are provided with an opportunity to bring up any problems they have in the Home. Common problems include household matters and even personal matters like false teeth or spectacles. But this forum is ineffective. As one resident said, "It is a time for them to talk and we to listen". An overseas student volunteer expressed the problem as follows:

"The Council member stands in front of all the residents and asks 'are there any problems?'. In such a situation no one will speak, other than say the routine, it's OK. Residents are afraid to say what they really feel, because of stepping out of line. As well as afraid they will be asked to leave. They have their views but keep it within them."

In line with the Charter a plan of action needs to be developed. This could be done by inviting members of self-help groups of disabled people to run an orientation workshop for the CCO and Council members. A radical change at this level is essential whereby non-disabled people will have to learn to give up power and play a supportive role.

It will be necessary to open the membership to all residents and for them to be elected to sub-committees and Council itself. It is doubtful the CCO establishment will make such a drastic change. An intermediate phase is for residents to be represented in the sub-committees. Such measures will be meaningless without a clear commitment to user involvement.

Employment

The second major focus is assisting disabled people in employment-related matters. This is to ensure that disabled people have some work skills. Opportunities are provided in sheltered workshops, open employment or in self-employment. But there is little coordination and much more needs to be done.

No staff member looks into employment issues related to disabled people. The major focus of staff is on nursing care and meeting basic needs. The Home environment and the security it provides can de-motivate residents from facing the harsh realities of the world outside. Work progress is not monitored in the way the health care of the residents is. Employing a staff to coordinate and support the residents will enhance the residents' capacities and create new opportunities. This person could serve as a placement officer.

There is a sub-committee on Occupational Therapy but its reports tend to focus on the sale of handicraft items. The quality of the handiwork is high and sale turnover is good. The residents are involved in income-generating activities and are encouraged to be either self-employed, employed in a sheltered workshop, or in open employment. There is need for greater coordination of this.

No analysis or evaluation has been made of the sheltered workshops to assess if residents are making progress in their work and their level of income. Most urgent of all is to question whether this is what disabled people want to do. Two residents who worked at the sheltered workshop left to work in a factory. They commented that the wage at the workshop was low, and the work was monotonous.

In charity care, priority is to custodial care. The CCO does what it feels is in the best interest of disabled persons in its care. Enabling care seeks to prepare disabled people for self-reliance in living and work skills. Hopefully they will be able to support themselves and regain their sense of dignity and independence. The CCO is making a move towards enabling care with the new focus on employment-related matters.

Special Meals

Between September and December 1994 there were 43 special meals for the residents. These included outsiders hosting residents for tea, lunch or dinner, and VIP visits to give cheques or presents. While these are fun and enjoyable, they have a lasting impact upon the residents.

These gatherings benefit the givers more that those who receive. The residents are adults yet these occasions make them feel like helpless children needing the public charity. Food, fruits and cakes are used to cheer up the residents. For the givers it is a time of playing their part in caring for disabled people. It is short-term support. In most cases it's just a meal and some presents. The visitors' overriding perception is that disabled people are helpless, rejected by their families and community.

The constant flow of visitors disrupts the normal course of life for the residents. However, for a majority this has become a way of life. Waiting for gifts and food from well-wishers can be seen as their profession. Some are under-motivated and sit around in wheelchairs, looking and feeling miserable. The atmosphere of 44 disabled people in a small compound provides an artificial environment surrounded by an unfriendly community which erects barriers between itself and disabled people.

The visitors mix and chat with them but the residents are passive. It is difficult to build meaningful relationships. The residents would like to have friends who are prepared to foster lasting relationships and friendships. There is a strongly-felt need among residents to go out. In September 1994 they asked for outings and picnics. They were promised that these would be organised when the new bus arrived. If visitors truly wanted to respond to the needs of the residents, they would enquire what the residents want to do. The visitors often bring so much food that residents cannot finish and the food is wasted or distributed to other centres.

Mindset Issues

Conceptual development and exposure to disability issues is lacking, as the residents do not interact with other disabled people in self-help groups, although a number belong to such groups. One possible factor may be a feeling of inferiority because of the lack of education, as well as a result of being confined to a welfare home. A majority of disabled people in self-help groups have stable jobs and live in their own homes. A majority of the residents in the home have no formal education and are in sheltered workshops. The other factor could lack of transportation, with only two of the 44 residents having motorcycles with side-car.

Most of the residents have been subjected to institutionalisation and isolation from mainstream society. Of 13 interviewed, nine had been in the home for more than 10 years and five for more than 20 years. Institutionalisation once entrenched is difficult to change. A number of examples can be cited from interaction with residents. Muthu has been in the home for 28 years since 14 years old. In the beginning he wanted to have his own home.

"Really dreaming but now my heart don't like anything. Tried to get home, went to *Dato*... and Mr ... [both politicians, the first a Cabinet Minister and the second a leader in the opposition and trade union] but nothing. Heart wants but it's late. Can't manage by myself. This home everything I got".

Foo has a similar story. He came to the home at the age 10 and has stayed 27 years. In 1985 his behaviour caused great concern. The clinical psychologist who assessed him wrote:

"He seems to have idealized the world outside the home of which he seems to know very little, and to see the community of the home as a hostile and unfair environment." (Assessment report).

Ten years later when interviewed, he described life outside the Home as "... very difficult and hectic. want to stay here, outside life is boring and I don't like it". What has happened to both Muthu and Foo was the experience of becoming institutionalised. Isolation is real for most of the residents. Most have spent a major portion of their time in the Home. Their experience of isolation must be great. Their contact with the world, other than the electronic media, is through visitors who come with food and gifts. These experiences reinforce feelings of dependency and helplessness, creating negative conceptions of their personal capabilities as well as a negative sense of pride and a poor self-image.

Staff-related Matters

A majority of the 20 full-time and four part-time staff do not have training related to disability work. Nine staff serve as care assistants. They work closely with the two senior nurses and attend to the care needs of residents such as feeding, bathing, going to bed and getting ready for work. The majority serve as cooks, gardeners, drivers, cleaners on shift. Two work in administration.

From interaction with staff and residents and other sources, one can draw some observations. While having good intentions, the staff lack appropriate training and orientation. There is no annual assessment of residents or comprehensive case history written. None of the domestic staff are educated nor have they received any appropriate training. Some residents indicated major difficulties with domestic staff, many of whom have been long in service. While the policy prohibits staff from verbally or physically abusing residents, verbal abuse is common and has adverse effects on the self-esteem of residents.

The dominant aspect of charity care is the caring dimension of service provision which has a strong medical and individualised orientation, as well as creating dependency. Enabling care allows disabled people through rehabilitation to develop daily living and employment skills.

While humanitarian concern to care for another is commendable, it must be done within the framework of caring 'about' rather than 'for', as in taking custodial control. It is essential to give serious consideration to the views expressed by disabled people when they define their needs and the ways they would like services delivered.

This does not mean residential care is one option or choice for the better. Rather it is the reality that is currently available. What is needed in the Malaysian context are independent living units or group homes with the support network of personal assistance available under the control of disabled people. Therefore, direct involvement of disabled people in identification of needs, making appropriate assessments and decision-making in allocation of resources, is essential. In so doing 'organisations for' can make radical progress in setting a new agenda for social work practice alongside disabled people in Malaysia.

3. DISABLED PEOPLE, ADVOCACY & SELF-HELP ORGANISATIONS

The advocacy and self-help approaches are examined here through the study of an 'organisation of'. This 'organisation of' disabled people is referred to as a Self-Help Organisation (SHO) and names of those interviewed are pseudonyms. While the SHO is a national organisation, its services in the Klang Valley form the focus of our attention.

4. SELF-HELP ORGANISATION - ORGANISATIONAL DATA

Historical and Structural Information

The inaugural meeting of the SHO was in August 1975 and registration was in September 1976. While other disabled people were catered for by groups, the orthopaedically-disabled. who were greater in number, had been neglected. The Society's constitution has 11 aims and objects, of which four are particularly significant, namely:

- To find ways and means of improving the physical, social and economic conditions of the orthopaedically handicapped
- To help in the education, training, employment and resettlement in society of the orthopaedically handicapped
- To organise sporting, social and other events for the benefit of the orthopaedically handicapped
- To make recommendations to the government, and to advocate and promote laws, amendments to laws and other government regulations in the interest of the orthopaedically handicapped

It has four membership categories - ordinary, associate, life and honorary. Ordinary membership is 'confined to persons who are orthopaedically handicapped' while associate membership is 'open to non-handicapped persons who desire to assist the orthopaedically handicapped'.

The SHO is unique in that while set up and run by disabled people, it has provision for non-disabled people to be associates. Members with voting rights can nominate and elect non-disabled people onto the committee. Non-disabled persons who are associate members do not have voting or nominating rights.

From its inception, a partnership model has developed with disabled people having controlling interest and power and non-disabled people being invited to participate. There is a shift in the power base which is radically different from 'organisations for' disabled people.

An elected committee runs the SHO. Elections are held every two years. There are sub-committees on Employment, Welfare, Sports, and Aids/Medical and three regional committees in Kelantan, Johore and Penang. It has two full-time staff, an executive secretary and clerk, both of whom are disabled and ordinary members. It has about 70 to 100 regular volunteers who assist in the programmes. The SHO has a member of royalty as Patron and three leading Malaysians as advisors. All of them are non-disabled and play a supportive and advisory role. This is one which disabled people have involved non-disabled people to serve as 'allies' for the enhancement of their movement.

The SHO networks closely with other agencies and is a member of the Malaysian Council for Rehabilitation (MCR), a coordinating committee of organisations working 'for' and 'of' disabled people. It is a founder member of the Malaysian Confederation of the Disabled (MCD).

Target Group

The SHO's membership at December 1994 was 920 ordinary members and 66 associate members at national level. It has members in every state. A majority are self-employed and its current unemployment rate is only about five per cent. However a large number could be underemployed. In the Klang Valley there were 369 ordinary and 33 associate members (at December 1994).

Table 3 : SHO Klang Valley members by age, gender and race, as at 31 December, 1994

AGE (years)	MALAY		CHINESE		INDIAN		OTHERS	
	Male	Female	Male	Female	Male	Female	Male	Fem ale
21 – 39	76	37	48	30	8	6	-	-
40 - 59	50	12	39	18	8	3	-	-
60 and above	3	-	1	-	-	-	1	-
TOTAL	178		136		55		1	

Malay = 48 per cent *Chinese = 37 per cent* *Indian = 15 per cent*

Its membership shows a closer reflection of the national ethnic ratios than the CCO's. It is multi-ethnic with members from all major communities. But there is an imbalance in the gender ratio, with female membership not reflecting the national population average. The SHO has a policy of restricting membership expansion in order to adequately serve existing members and membership is around 1,000. SHO officials said practical and realistic considerations in serving members adequately was more important than having a very large membership.

Services

Five principles guide the implementation of services. First is helping members become independent and self-supporting. Secondly, the SHO does not tie up its limited resources in projects like sheltered workshops that benefit a small number. Thirdly, the key strategy is through individual casework, which is given top priority in financial allocations and time.

Fourthly, in order to increase capacity and efficiency in serving members, regional committees are being set up in every State to process local casework. Fifthly, it acts as a third party between members and the Department of Social Welfare and other agencies. Where needed, the SHO highlights the needs of members through referrals and recommendations. Self-help groups like the SHO play a dual role - at the micro level, providing services to members, and at the macro level performing an advocacy role. There is a commitment towards service and advocacy.

Casework Services

The SHO's primary role is to provide support to members. It seeks "to help disabled members to become independent and self-supporting, and to work for a better future for the orthopaedically handicapped in general" (Newsletter, 1995 : 1). It provides direct assistance to members through individual casework and assists members who do not want to be institutionalised in a residential home, old folks home or hospital.

As for orthopaedic and mobility aids and medical treatment, some 2,970 cases have been handled, the largest number handled by any similar organisation. Aid includes artificial limbs, callipers, wheelchairs, bicycles operations and medical treatment. Other help includes house repairs and modifications, water and electric supplies and funds to build special toilets. The SHO also helps members obtain Department of Social Welfare allowances. Some 845 members have received welfare-related assistance from the SHO. It seeks to support members in their own neighbourhoods. It has been able to serve a large number of members with a relatively small staff.

Advocacy and Public Awareness-related Services

The SHO devotes time to raise matters relevant to orthopaedically-handicapped people to the Government and public. General issues, concerns and problems related to other categories of disability are done through the MCD. It has achieved several victories in lobbying for policy change and also experienced some frustrations. Its most notable achievement has been enabling members to be involved in the preparation of a public access code for disabled people into public buildings, now an amendment to the Uniform Building By-Laws.

After seven years of appeals against the payment of highway tolls by disabled people using specially adapted motorcycles, the SHO received an official letter granting exemption in 1994. Appeals since 1990 for a reduced road tax for adapted motorcycles resulted in a token RM1 annual in 1994. The most frustrating experience has been the failure to obtain a lifting of the ban on disabled wheelchair users on the STAR Light Rail Transit System in Kuala Lumpur. This is despite the MCD's protest and wide media coverage.

Sport-related Services

The SHO is a member of the Malaysian Sports Council and International Stoke Mandeville Wheelchair Sports Federation. Members are assisted in training and sent to represent Malaysia in international wheelchair games and some have won medals. A sub-committee on sports coordinates this. SHO members won three bronze medals in Singapore in June 1994 and another three medals at the FESPIC Games in Beijing in September 1994.

Finance

The SHO allocates about 67 per cent of its funds to casework or direct aid to members, 11 per cent to sports and 22 per cent to overheads. In 1994 it provided RM 208,000 in direct aid to members. The SHO does not receive funds from the Department of Social Welfare as it does not want to be obligated to it, especially since it also has an advocacy role. It relies on public donations. The SHO provides financial assistance up to the normal limit of RM 2,500 "for any purpose which will help the member to become independent or ease their living problems such as buying a wheelchair, starting a small business or building a proper latrine" (Newsletter, 1994 : 2). The SHO gives grants only and does not give loans to members. It also does not give monthly allowances, except for some special purpose like training.

Table 4 SHO Income and Expenditure Figures

Year	Income (RM)	Expenditure (RM)
1991	312,278	177,171
1992	140,655	171,387
1993	307,888	242,300

5. CRITICAL ISSUES IN ADVOCACY AND SELF-HELP

Over the period August 1994 to April 1995 through field study, four significant aspects were observed at committee meetings, interviews, field visits, and reading documents. Discussions with officials, staff and members were very helpful in understanding the nature and character of this organisation.

Self-help Initiatives

Its strategy to improve the physical, social and economic conditions of members by individual casework is significant. The aim is to enable disabled persons to become independent and self-supporting. Kassim was assisted in undertaking a computer course with the SHO paying his fees and taxi fare. He described with sadness how he had been under pressure by his family to stay at home since the motor accident that resulted in his impairment:

"My father says, 'stay home, you are sick, you don't need to work, I can take care of you'. If I am not independent who will look after me when they (referring to his parents) are no longer here".

Kassim asserted that "disabled people should express themselves and be in society. I read about water-skiing, parachuting, rock-climbing - doing all sorts of unbelievable things but in Malaysia we are not as adventurous as them. Why can't we do?" Osman received an educational grant of RM 300 to undertake a part-time banking course while working as a telephonist. His intention is to upgrade himself and get a better job. Musa, who has a spinal injury, received assistance to repair his squatter house so that he could continue to live there. The SHO's direct, individual assistance has often been the only help available to disabled people. While the assistance by the SHO is very limited and not comprehensive, it is an attempt by disabled people to provide support to fellow members.

The Casework Process

The goal of the casework process is self-empowerment, reflected in words like 'independence' and 'self-support'. The process includes a number of basic stages, namely:

The SHO also has a very good working relationship with the Department of Social Welfare and other voluntary agencies and cases are referred to them where appropriate. Herein lies its strength. Of the 14 persons interviewed, only one received a negative response to a request. One major shortcoming of the casework approach is that members have to take the initiative to make their requests and the SHO responds. A recommendation has been put forward that an annual review be made of all employment casework. The SHO is planning an annual report system, whereby an overall assessment of members' situations is made.

The Need For Group Work

What has not yet developed in the SHO is a group and community-oriented approach. Oliver and Hasler (1987) recognised the potential of community work or community social work methods. In their experience, problems faced by disabled people were essentially practical ones. The SHO now only does individual casework and has not ventured into group or community approaches. This is due to its limited resources. While help to individuals is useful and targeted, the SHO fails to tap the group solidarity and joint effort that are integral dimensions of self-help movements.

The SHO is modelled on a charity model rather than on a genuine self-help tradition. This is because what it has done as a registered society is to raise funds from donations and re-channelled them on a need basis to members. The SHO is different from other charities in that it is run by disabled people and does not subscribe to a residential or institutional approach to rehabilitation of disabled people. What the SHO has not explored sufficiently is how its members in smaller groups throughout the country can support each other.

A general observation is that even within the community of disabled people there is a dimension of charity and paternalism, where the better-educated or more financially stable disabled seek to do 'a good turn' to the other less fortunate disabled. An element of paternalism can prevail, especially when a majority of those holding office in the Executive Committee or the sub-committees do not themselves receive any funds from the SHO. It is imperative for the SHO to tap the self-help potential rather than make a majority of its members passive recipients of services provided.

Yusof, a member since 1975 and recipient of an employment grant, is critical of the SHO approach. He indicated that members expected to receive what they asked for:

> *"Members ask and they think they will get; if they don't get they don't want to continue. It is more for personal gain and not to contribute to others".*

He further described the notion of "the child of welfare", as creating a receiving mentality. Many SHO members received their initial training at the Government rehabilitation unit in Cheras. He feels it oriented them towards welfare dependency. Although living skills were taught and they were prepared for independent living, their mindset had not been changed from welfare to competing in the open world. This is why many who had received funds from the SHO kept coming back for more. He felt that the SHO should explore other avenues instead of the current approach of direct contributions. He added, "If SHO changes its approach then members will be more self-reliant. SHO should start loan schemes or even a cooperative".

This idea of a cooperative surfaced on two other occasions during the field study. At the April 1994 workshop two participants expressed the need for this. There is some willingness in the SHO to explore approaches adopted by other self-help groups in Malaysia which are group- and community-based. The SHO policy since the 1980s has been to restrict the growth of the membership. However, a small number of new members have been accepted "to replace losses, limited either to a particular region or to a particular group such as spinal damage paraplegics" (Newsletter, 1995).

However, some members feel there should be a change in the admission policy. An open membership policy could have fostered and facilitated the spread of grassroots disabled peoples' organisations all over the county. But the SHO is concerned about the accountability of such groups. The SHO hopes to develop branches in every state but will not open up its membership on a large scale. It has failed to provide an avenue for a majority of orthopaedically-disabled people in Malaysia to be part of a self-help group. It also does not have a national programme of educating disabled people to be independent or self-supporting.

Efficient Organisational Set-up

The SHO is a well-organised society and its scheduled meetings are very impressive and indicative of the dedication of the elected officials. Its computer database on member records and casework strategy puts it ahead of most voluntary organisations. With some 1,000 members and over 4,000 casework records, the only efficient way to handle the data was to computerise the whole system. The administrative and coordinating capability is clear proof that disabled people can efficiently and effectively run their own organisations, raise funds and ensure public accountability.

Level of Participation Among Members

Collaboration between disabled and non-disabled people

The SHO puts to good use the collaborative efforts of joint action by disabled and non-disabled people in a supportive role. It is the disabled person who has the right to nominate and elect non-disabled people. In so doing it has reversed the power equation that the non-disabled in other groups has power and control. There is a need for non-disabled people to play a support role as allies or friends. The SHO's strength lies in asserting the independence of disabled people and acknowledging that disabled and non-disabled persons are inter-dependent. Its Executive Committee has nine ordinary (disabled people) and six associate members (non-disabled people).

Wider member participation

The SHO has about 70 active members serving at national level, with a core of 10 people who are the, 'life blood or live wire' of the organisation. The core group comprises respected members who are also leading disabled personalities in Malaysia. They have exerted a tremendous influence in changing some Government policies as well as in setting up the MCD. There are clear attempts to promote leadership among younger members. This younger group now holds key positions. Three or four younger leaders work closely with the senior leaders in an apprenticeship model of leadership training.

The SHO has yet to activate a large part of its membership. Apart from the newsletter (four issues a year) and the Annual General Meetings, rarely are any group gatherings organised. There are no regular awareness meetings on key issues regarding the struggle of disabled people. As some members have commented, the does not seek to mobilise the strength it has.

What is emphasised is the individual, with a narrow focus on individual problems affecting self-support and the ways to overcome it with the support of the SHO. Many members are active at this level. The SHO could strengthen itself in group-based approaches with more members in smaller self-help groups supporting one another. It has yet to tap the potential of the independent living units of the United States or integrated living units of the United Kingdom.

While the SHO does focus on advocacy issues, it is on micro matters like road tax or highway tolls that seem to be the concern of many members. The wider macro issues of a disabling environment are not shown as urgent. The Executive Committee is regularly briefed on and does discuss national and global disability issues. However, these issues have not trickled down to the grassroots through awareness and mobilisation programmes to address the root causes that disempower disabled people.

The participation of disabled women on the sub-committees and Executive Committee is clearly lacking. There are none on the Executive Committee and only one woman in the sub-committees. One reason is that there is only one woman in every five members. Furthermore, disabled women in Malaysia are also likely to be more disadvantaged than men. In the 14 cases processed by the employment and welfare committees in the Klang Valley, during the field study period, only two were by disabled women.

Although not acknowledged by the Executive Committee, some policies favour disabled men as opposed to women. One example is the grant for deposit on houses where male applicants receive RM 1,500 but a single female applicant will only receive RM 500.

Tapping the Potential of the Market

The market provides an alternative route to liberation for disadvantaged communities. The SHO has tapped this potential and enabled its members to operate viable small businesses. Its contribution is impressive - it has supported 595 small businesses compared to placing 165 people in wage-earning jobs.

Of the 14 interviewed in the field study, five were in small businesses and their experience is really enriching the prospects of tapping this route for disadvantaged communities. None of those interviewed had had any formal education, so that their prospects in wage-earning employment were difficult. Small business was an attractive alternative. The national economy requires small businesses to supplement and complement the larger ones.

For most SHO members the main difficulty is in the initial working capital needed. The SHO provides an initial business grant of RM 2,000 and even larger RM 4,000 grants. Members run successful businesses such as food outlets, tailoring, furniture-making, radio and motorcycle repair shops. The SHO assistance requires them to plan and keep proper accounts and ensures success. The SHO plans to establish links with other agencies set up by the Government for business development. The Employment sub-committee recommended that action be taken to assist members in different aspects of business.

The self-help movement among disabled people emerged in the late 1960s and 1970s in both industrialised and developing countries. The main reason for this was dissatisfaction of disabled people with services provided by the public and voluntary sectors.

What emerged from our critical review is the essential need for disabled people themselves to be involved in the planning and delivery of services. The more difficult dimension to analyse is the issue of the role of self-help groups and new social movements. Oliver (1990) develops arguments to consider the disability movement as a social movement. One clear indicator for this is the role of the new movements:

> *In placing new issues on to the political agenda, in presenting old issues in new forms and indeed, in opening up new areas and arenas of political discourse. (Oliver, 1990 : 130).*

The difficulty in the Malaysian experience is that while disabled people have organised themselves and are challenging inappropriate social responses by the wider community, this challenge to unjust structures is made only by a handful of better-educated disabled persons, rather than by a wider grassroots movement of disabled people.

A majority of disabled people at grassroots level is more concerned about practical day-to-day problems that directly affect them, such as economic and social security. For the SHO where immediate concerns are paramount, the micro continues to dominate the agenda. The disability movement in Malaysia has yet to be as a truly mass movement of disabled people. Unlike their Western counterparts, organisations like the SHO have restricted membership and in so doing, delayed the process of empowerment of more disabled people in Malaysia.

6. VOLUNTARY ORGANISATIONS : A COMPARATIVE ANALYSIS

While the CCO and SHO had major differences, there were three similarities. Both were registered societies. They provided services to physically disabled people. And they had bases in the Klang Valley. We now look at the services provided and structures that facilitate this.

Services Provided

There are three essential areas which highlight differences not only in the type of service provided but also in the priorities set based on differing understanding of disability.

Residential and Community Services

The CCO's main objective is in the running of the residential home and provision for the maintenance and welfare of the residents. It claims its residential service does not create an institutional atmosphere but a home environment. But it does not explain the difference between these.

It is helpful to draw from Erving Goffman's (1961) analysis and description of 'total institutions'. He defines a total institution "as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (Goffman, 1961 : 11).

In the CCO, a majority of residents are long-term residents and have therefore developed a pattern of lifestyle and routine. Most activities centre on meal times. This schedule sets the timetable for the residents. The residents live in one compound in separate rooms but share common toilets. A majority spend most of their time in the centre and those who go out regularly travel in the Home's van. Only two residents own vehicles. The residents also have to rely on taxis, which is expensive or on friends, family or volunteers. Although the CCO says it runs its Home so as to create a homely environment, in reality it has institutionalised a majority of the residents.

In contrast, the SHO does not provide residential services. It supports its members in the community in which they live to prevent them from being institutionalised. It provides assistance by way of grants to adapt existing homes to be disabled-friendly. Grants are given to help pay downpayments for purchase of houses. It also helps members to buy or rent low-cost flats or houses from local authorities by supporting the applications and making representation. It also assists members to purchase motorcycles or three-wheel cycles.

Here then lies the main difference between the two groups. The CCO segregates disabled people while the SHO enhances their living in the community. The recent move by the CCO towards a community-based approach to serve more disabled people in the community surrounding the Home is encouraging. It wants to reach new people in non-institutional ways but the residents were not invited to discuss any proposals regarding group homes and independent living units. Instead of supporting two employed and mobile persons, the CCO provided them with accommodation in the Home. They could have been supported to live in the community.

One possibility for change, as hinted by a CCO Council member, is to develop independent units outside the compound where residents be independent, prepare meals and be free to organise their daily schedule. One practical problem is that because most have lived for a long period within the home they might find it difficult to do so in a unit within the compound.

Employment Services

Both organisations have identified employment services as a major area of service. There is a major difference in emphasis. The SHO has largely assisted its members to be self-employed by providing grants and training opportunities for small business development. A majority of disabled people do not have enough formal education to secure open employment. Assisting members to run small businesses is an effective way of ensuring that they are self-supporting. Providing the initial working capital, encouragement and advice is useful.

In the CCO, most of its residents are in sheltered workshops. Residents see themselves as trapped within this work situation. Many said there was no future in their jobs and they are unhappy with the salary.

From the perspective of most charities, what is essential is the fact that the work routine keeps the resident occupied and regarded as part of therapy rather than as a way of self-support. The Home serves to guarantee all basic needs. What is not realised is that financial independence is a key to empowerment. In this context the SHO has got its strategy right, by enabling its members to operate in the market place with some support and assistance.

In the CCO, no staff is allocated to assist residents, nor is there a reporting mechanism on employment matters. No evaluation has been made of the sheltered workshops. As noted, employment is seen merely as an activity of a resident rather than as a means of achieving economic independence and self-support.

Advocacy

A major difference lies in their commitment to advocacy. The CCO avoids making comment on this in its Constitution and brochures. But the SHO makes a clear declaration in its Constitution and reports on advocacy activities. The SHO states in its constitution that one of its objectives is "to make recommendations to the government, and to advocate and promote laws, amendments to laws and other government regulations in the interest of the orthopaedically handicapped."

It does this in a number of ways. On matters directly affecting orthopaedically-handicapped people, it makes direct representations to Government or other agencies. On major issues that also affect other disability groups it handles the matter through the MCD. The CCO works closely with the Department and networks with other voluntary organisations in the State Social Welfare Council. It has yet to address advocacy-related matters affecting disabled people in Malaysia. It is in an influential position to work within the framework of policy-makers. But the CCO is not oriented to this end and it is an unexplored avenue. In the Community-Based Rehabilitation programme, the CCO serves as the secretariat and the Department of Social Welfare provides most of the funds for this outreach programme into the community.

While active on advocacy issues, the SHO has not developed an enlightened, politically-conscious grassroots membership, that is well versed on issues and rights of disabled people. At the grassroots level the concern is for immediate needs or on issues with which they can identify and campaign. The SHO therefore has a long way to go in developing in-house awareness programmes and leadership programmes to develop potential among members. A national consciousness programme could be organised for its members. In the long run, members in different parts of the country can be mobilised for national campaigns and public awareness programmes.

Comparison of Organisational Structural Matters

Structures are created in order to facilitate the delivery of services. Certain structures facilitate user involvement and empowerment of disabled people while others disempower them. While the CCO and SHO have the same type of registration with the Registrar of Societies, their orientation and approaches differ.

Membership

The main organisational provisions in both constitutions are similar. In the case of the CCO the provision for membership neither encourages nor inhibits disabled people from becoming members. As an 'organisation for' set up by non-disabled people, disabled people have not been accepted as members over the past 30 years. With an attitudinal change, disabled people could be recruited as members. The CCO has not admitted disabled people as members. While an open society in principle, it does not conduct a recruitment drive for new members. Membership is by invitation.

In the SHO, ordinary membership is open only to orthopaedically-handicapped people whereas associate membership is open to others. It is an ' organisation of'. The point here is that disabled people can play a leading role in organising matters which affect them and take responsibility for their own affairs. While it has about 1,000 members, it has a restrictive policy. There are a large number of physically-handicapped people who are not members of any self-help organisation.

Leadership and Decision-Making

In the SHO only disabled people have voting rights as ordinary members. In the CCO, Council members are people who are well-placed in society. Neither disabled people nor residents serve in any capacity on the Council or sub-committees. Decisions are made for them. The only formal provision for consultation in the CCO is the Residents Disciplinary sub-committee which does not seem effective. While residents have some responsibility over recreation, personal hygiene and cleanliness, the CCO does not go far enough to enhance user involvement in major decisions that affect their lives.

In the SHO, there is a lack of effective mobilisation of grassroots membership. Only about 70 of its 1,000 members are said to be active. This large element of passivity is not compatible with the citizenship model that aims to promote activism.

Staff and Volunteers

The CCO has 20 full-time staff, none of whom are disabled. They are task-oriented rather than people-focused. Most of its domestic staff do not have a conception of disabled people as human beings and citizens equal to themselves. The individual and tragedy model of disability dominates their framework. The staff hold much power and control over the residents. Volunteers likewise come to assist residents within the residential setting. Visitors may see disabled people as unfortunate and helpless individuals and do something for them. Some residents take advantage of this and play the role of receivers, something they are now conditioned to play. This further reinforces their dependency and traps them within this cycle.

If residents had a greater say and opportunities to do things, they would be able to re-direct the volunteers to support them in areas that mattered most. A number have good ideas about outings or specific support they need. In a home for 44 persons, each individual's voice and choice is lost. The staff are not oriented to empowerment issues and do not play a supportive role.

The SHO operates its programmes with only two full-time staff and their roles are different to that of the CCO staff. As disabled persons, the SHO staff play supportive roles to fellow members. They do not take control, or dominate the situation, but implement decisions in cooperation with disabled people. The SHO has effectively recruited several professional non-disabled people who are influential in society. The CCO has not utilised services of disabled professionals in its programmes.

Fund-Raising

Both organisations benefit from tax relief and the general public and private companies make regular contributions. The CCO receives an annual grant from the Department of Social Welfare but the SHO does not. There are major differences in fund-raising styles. The CCO tends to draw on public sympathy, with the disabled residents serving as captive symbols of people needing care and assistance. This approach further stereotypes their dependency and portrays them in a negative light.

The SHO makes no public show of members receiving assistance and assistance is delivered directly to members. It does not have any images that will evoke public sympathy. The SHO appears in the media through highlights on its members. It has an annual fund-raising appeal to private firms and writes about its work in supporting its members. The wording reveals their orientation:

Our members do not want to depend on charity. They want to be self-supporting, to have families, to live as normally as they can. But most of them are poor, and their poverty holds them down. They need only a little help to break themselves free and become independent- but they need it badly and they need it now. (Leaflet)

Change possibilities

The key question is what will enable a change from the current understanding and approach in the treatment of disabled people to one that is closer to the social model. For the CCO, the process is more difficult as people in high places do not have the time to expose themselves to changing conditions in the field. For the past 30 that approach has not been challenged. There are, however, some seeds of change which, nurtured over time, might result in significant changes. Three trends can be identified. Firstly, the CCO's role in developing a community-based approach to reach every disabled person in the community is timely. This could spark a change for those in the Home.

Secondly, the possibility of setting up a residents' self-reliance committee is another step forward to enable residents to take control. Thirdly, the CCO's International Charter emphasises the opportunity of disabled people to take an effective part at every level in running services. It is essential to popularise the Charter among Council members and residents.

The SHO already operates within the social model and is ahead of the CCO in enhancing the rights and equal opportunities of members. But it needs to develop grassroots structures to educate and mobilise its membership to become an active force in society. A number of its leaders are already active in the national disability movement and also linked with the Disabled People's International (DPI). One clear way forward for the SHO is the development of state branches to recruit members, raise funds and organise the direct casework programmes. This would allow the national committee to be involved in policy and leadership development, advocacy and networking.

7. ANALYSIS OF THE APPROACHES

Approaches & Dynamics of Operations

What emerges clearly is that 'organisations for' disabled people tend to fall between the charity and enabling care approach, while 'organisations of' are self-help and advocacy-oriented. However, there are times when 'organisations for' have played an active part in advocacy or facilitated setting up of a self-help group. What can be noted is the transitory nature of some organisations. In the case studies there are indicators of a shift from charity towards enabling care and advocacy.

In the case of self-help groups, they are developing a stronger role in public awareness and policy advocacy. In setting the agenda within the voluntary sector, some 'organisations for' are adopting conceptual and strategic plans and developing closer collaboration with disabled people.

Unfortunately, in the Klang Valley there are no indications that 'organisations for' are opening up membership to disabled people and ensuring that at least half the elected officials comprise disabled people. Some disabled people, especially among the visually impaired, are frustrated with their self-help groups and are working to set up a new organisation that will have advocacy as the major priority. For the physically-disabled, a self-help organisation has been set up by those with spinal injuries. This organisation provides alternative models and opportunities for disabled people in the Klang Valley.

The field study shows the drastic differences between the charity and self-help approaches, especially on individual and social models of disability, and charity and self-help traditions. In charity, there is the positive aspect of human kindness and compassion of the giver. But the receiver is often seen as helpless and hopeless. The givers feel good about what they have done and receive public recognition as well. But the receivers, although some needs are met, do not have their personal sense of worth enhanced. They are merely passive recipients of charity.

In contrast, the mutual aid and self-help traditions are based on the potential of the affected individuals and community to organise themselves and address the issues, challenges and needs. The disabled persons have a higher sense of personal worth and society sees them positively as they address issues and problems. Direct participation, involvement and control are elements of empowerment reflected in this citizenship model of social work practice.

It is necessary to make a critical examination of social work practice, voluntary organisations and the citizenship theme to see how they fare in the Charity Care (CC) and Self-Help (SH) divide. Table 5 provides a helpful summary of the critical points.

Table 5 : Critical Points between Charity Care and Self-Help

	CHARITY CARE	SELF-HELP
CITIZENSHIP OF DISABLED PEOPLE	Excluded Passive	Included Active
SOCIAL WORK	Individual model Disempowerment	Social model Empowerment
VOLUNTARY ORGANISATIONS	Organisation `for' Isolation	Organisation 'of' Integration

Citizenship

Citizenship exposes the inclusion and exclusion principles. The charity approach further alienates the disadvantaged from mainstream society by isolating them from other citizens and denying them equal access to available resources. Self-Help addresses this by working out an alternative by fostering collective support. Unlike the CCO, the SHO involves users in decision-making and the main decision-makers are disabled people. In the SHO, those on its Committee, although disabled people, are not recipients of aid. They represent the well-to-do members from the disabled community. Class, gender and racial differences can be barriers within the disability movement.

Central to the concerns of disabled people is the active/passive role. Non-disabled people are called to play a part as active citizens. One implication for non-disabled people being active citizens is to play a part in fostering a caring society. While charity care is an expression of active citizenship within one section of the community, it creates a passive role for disabled people. Self-Help generally promotes the active role of its members.

Social Work in Theory and Practice

The dominant understanding of disability mostly falls within the individual or the social model of disability. In Charity Care, there is clearly an individual focus in contrast with that of Self-Help which falls within the social model. Without doubt, disabled people view their difficulties from a wider perspective, taking into account their problems in education, employment, housing, and transportation-related matters.

Many 'organisations for' also address these issues but often by creating public awareness and facilitating policy input within the policy-formulation process. But a majority of 'organisations for' seek to provide specialised services. The enabling and empowering process they engage in are more individualistic rather than based on developing a mutual aid or collective/activist strategy.

Central to social work theory and practice is empowerment, and there is a constant reminder and challenge from disabled people to non-disabled people to address the issue of `Who is in control?' This may refer to micro concerns like personal assistance, or macro concerns in education or employment policies. Empowerment means letting disabled people have a direct role in analysing the issues as well as being involved in decision-making. Matters related to dependency and independence as well as caring for and caring about have to be confronted. CCOs are oriented towards disempowerment rather than empowerment.

Voluntary Organisations

The dominant focus of CCOs as `organisations for' is doing good to others and this altruistic spirit is not wrong. With public awareness and promoting policies from a social model of disability, many more well-meaning people in voluntary organisations can be channelled to serve the wider community. The dominant approach of CCOs tends to isolate disabled people from the common avenues that other citizens use. Noor Hayati (1991) says, "The handicapped of Malaysia feel excluded from the mainstream of society and they say they do not enjoy the same rights as every other able-bodied citizen. And this rejection persists despite their large numbers." (Hayati, 1991 : 30)

It is important to note that the supporters of enabling care are also strong advocates of integration, as they seek to open up the community for disabled people. This clearly does not mean only physical accessibility but accessibility to all areas.

Reformulating Approaches -Trends and Developments

What can be developed is a three-fold model of Charity Care (CC), Enabling Care (EC) and Self-Help (SH) rather than a four-fold classification with Advocacy. This is because the three approaches involve an advocacy role as well. Advocacy ranges from individual to collective action, and from personal concerns to group and national issues.

Charity Care and Self-Help are dominant approaches, whereas Enabling Care is a transitional phase due to the overlapping nature of its approaches. EC shares some features with CC and shares others with SH.

We have seen the emergence of self-help organisations in Malaysia, with blind people taking the lead. One major reason that sparked this movement among blind people was their exclusion from the decision-making process. When they failed to gain membership in existing organisations they formed their own organisation. There was a similar trend among the deaf whose movement grew out of Enabling Care to become Self-Help. In both cases, the 'organisations for' provided educational and training services but did not create the mechanisms for their involvement in the decision-making process.

Users of other services, such as Community-Based Rehabilitation (CBR), are likely to have a higher probability of reorganising themselves into a Self-Help group, if the non-disabled people fail to incorporate them into the decision-making process.

While CBR has been able to tap the potential of families and of the local community for active involvement, it has not usually increased the involvement of disabled people. None of the 'organisations of' are involved in this new development, while some disabled people employed as staff in the Malaysian Association for the Blind have been playing a leading role in developing community-based services for blind people. It is therefore important that SHOs attempt to influence ECOs to move in this direction. The more affluent members within SHOs can play an active role in both the

CCOs and ECOs with the objective of channelling them towards Self-Help.

ECOs have played a key role in developing self-help among parents and family members. Charity Care, on the other hand, feels threatened by active parents and relatives as well as by active disabled persons. ECOs tend to work closer with families. While ECOs seek to enable disabled people, they do not seem to be sufficiently aggressive in the formation of SHOs. It is disabled people themselves who have taken the active lead in this.

The YMCA, while giving disabled people greater involvement in managing its centre, has not sought to convert it into an independent organisation, outside the framework of the YMCA. However, members of the YMCA Self-Reliance Centre went on to set up the Kuala Lumpur Society of the Deaf. These and other examples reveal the motives of many voluntary organisations, that is, to protect their respective 'turf' or territory. The presence of alternative organisations can be potential competitors in raising funds.

The self-help movement in Malaysia can develop into an activist grassroots movement within the democratic framework of the country. This implies SHOs becoming more localised, operating within the local community as well as breaking away from traditional medical categories. They also need to move beyond the welfare circle. Currently any discussion on disability is associated with social welfare. However, due to the role played by some disabled persons, the seeds have been sown for addressing disability in a wider social context. One clear example is found in the document "Malaysian Charter on Human Rights by Malaysian NGOs" (Suaram, 1994) which includes a section on 'people with disabilities'.

In the past, human rights groups in Malaysia have focused on political detention, gender concerns, conditions of factory workers, environmental issues and urban poverty. Therefore, an inclusion of disability as a human rights issue is a step forward in the conceptualisation of disability in Malaysian society.

Another positive indicator of changing attitudes is the column in a leading newspaper entitled 'Wheel Power'; written by a disabled person, which is popularising disability-related issues through the print media. But there is also the danger that self-help groups might shift closer to Enabling Care through the provision of individualised services. Politically, this is more acceptable than an activist approach. Furthermore, with the campaign of the Government to popularise the `caring society' theme, disabled persons might compromise on their role.

A New Agenda

In Malaysian society the Self-Help model and approach have not been given enough attention. Disabled people in self-help groups have not challenged existing inappropriate approaches but have provided direct assistance to members. Discussions at the conceptual level and comparative studies have not been developed in the Malaysian context. Even the Malaysian Confederation of the Disabled has not challenged voluntary organisations to adopt a social model This is probably due to two factors.

Firstly, Malaysians tend to be non-confrontational and do not really express how they feel. The general approach is coping with a given framework or seeking to change things slowly over time. While SHOs have played an advocacy role to obtain Government concessions, they have not campaigned adequately against the inappropriate services of voluntary organisations or the public sector. Those leading `organisations for' are often 'highly placed' people for whom an activist role might not be acceptable.

Secondly, there are so few services organised for disabled people that any assistance provided is welcomed. This is a main reason why inappropriate and disempowering approaches are not challenged

Change will take time and the disability movement in Malaysia needs to draw upon the resources of both disabled and non-disabled people to create a new agenda Three areas essential for this process are:

- More awareness programmes at national level challenging the attitudinal and structural barriers that enslave and oppress disabled people. The media must be enlisted to assist.
- There must be creation of a larger pool of disabled leadership with appropriate training and experience to develop the movement. Potential disabled leaders must be identified at grassroots level to take the movement ahead
- A strategy and action plan needs to be developed in charting out areas and courses of action to promote equal opportunities for disabled people in education, employment and developing a barrier-free society.

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