

STUDY

**STUDY ON  
SOCIAL DEVELOPMENT  
OF DISABLED PEOPLE  
IN MALAYSIA**

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**JICA DISABILITY STUDY**  
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## **CONTENTS**

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	<b>Executive Summary</b>	
<b>1.</b>	<b>Conceptual Framework &amp; Developments in Understanding the Disability Movement</b>	
1.1	Conceptual Framework	1
1.2	Developments in the Disability Movement	3
<b>2.</b>	<b>Community-Based Rehabilitation</b>	
2.1	Definitions & Concepts of CBR	34
2.2	CBR in Malaysia	39
2.3	CBR Critical Issues & Concerns	50
<b>3.</b>	<b>Independent Living</b>	
3.1	Definitions of IL	70
3.2	IL in Malaysia	80
3.3	Hurdles to Effective Implementation of IL in Malaysia	94
3.4	Appropriateness of IL	97
3.5	Future Directions	100
<b>4.</b>	<b>Suggestions &amp; Recommendations</b>	102

### ***Appendix***

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

### ***References***



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***Executive Summary***

## **1. THE STUDY**

This study on Social Development of Disabled People in Malaysia was commissioned by the Japan International Cooperation Agency (JICA) Malaysia Office and undertaken by JJ Resources a consulting firm.

The study looked specifically into issues and challenges with reference to Community Based Rehabilitation (CBR) and Independent Living.

## **2. METHODOLOGY**

### **2.1 Literature Review & Questionnaires**

With the completion of the literature review original data was gathered through two questionnaires. The first questionnaire on CBR was circulated to government agencies and voluntary organisations directly involved in CBR and the second was distributed to self-help organisations. A briefing meeting was held on the aims and outcomes of the study. A number of interviews and field visits were made.

### **2.2 Focus Groups & Expert Group Meetings**

A number of focused group discussions and expert group meetings were held for participants to present their findings and discuss the trends, critical issues and strategies to overcome them.

### **2.3 Participatory & Interactive Method**

A participatory and interactive method was adopted to ensure that a cross section of people directly involved in the work among disabled people are represented namely from relevant government agencies, voluntary organisations and self-help groups run by disabled people and family members of disabled people.

### **3. FINDINGS**

#### **3.1 Dominant Understanding of Disability & its Impact.**

- 3.1.1 While work among disabled people began during the colonial period and there has been tremendous increase in work among disabled people by government agencies, voluntary sector and self-help groups, the charity and medical model is still the dominant framework in Malaysia. Its outcome is segregation in approach.
- 3.1.2 This perspective has an impact upon empowering disabled people to take ownership of their lives and have a voice on matters that affect their lives and the freedom for them to make their choices in life. The active involvement of disabled people as decision makers and active citizens is therefore restricted.
- 3.1.3 Disabled people and their movements are making a challenge of the dominant charity & medical orientation based on a framework of citizens rights and as members of the nation. However the self-help movement of disabled people have not adequately developed alternative models of practice.

#### **3.2 Community Based Rehabilitation**

- 3.2.1 The Department of Social Welfare took the lead in setting a new trend in moving away from institutional care towards a community based approach. The government has made much headway in outreach, namely in the setting up of many CBR centres especially in rural areas. The government has also provided grants to voluntary organisations in developing CBR programmes.
- 3.2.2 The impact of this change in approach is minimal. This is because the Department and voluntary organisations are still operating institutions based on a colonial legacy and did very little by way of deinstitutionalising care. Furthermore the CBR projects have failed to mobilise community involvement and active involvement of disabled people. These CBR programmes are in effect day care programmes in the local neighborhood. The programmes are mono-ethnic, mono-disability basically people with learning difficulties (mentally retarded) and mono-age (basically children). Self-help

organisations and disabled people are not involved in implementation of CBR programmes.

- 3.2.3 CBR programmes faces difficulties with regards to staff training, professional support, adequate funding, and effective co-ordination. Impact assessment and evaluation to ensure efficient and effective delivery of services is absent.

### **3.3 Independent Living**

- 3.3.1 Independent Living approach is a fairly new and underdeveloped approach in Malaysia. The leadership for this approach is by disabled people with the first Independent Living Workshop held in August 1999 in Malaysia. Disabled people call this a 'movement by disabled people, of disabled people and for disabled people who are working for equal opportunities, self-determination and self-respect'.
- 3.3.2 A key achievement of the Independent Living philosophy is the shift from the medical and charity model of disability to a social model that see disability as being determined by attitudinal, physical and communication barriers created by non-disabled people in society which disables, disabled people.
- 3.3.3 While disabled people have taken the lead in rethinking disability however in the provision of services such as 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 where it is imperative for self-help organisations to develop alternative models in order to also challenge and influence social work among disabled people.
- 3.3.4 Self-help organisations of disabled people in Malaysia have begun to develop such services as peer counseling, advocacy, input into policy and financial grants for income generation projects. These need further development in the new millennium.



## **4. RECOMMENDATIONS**

### **4.1 Strategic Action Plan**

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

### **4.2 Review and Evaluation of CBR**

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 needful to ascertain the effectiveness and efficiency of the programmes carried out. The study could be undertake through the funding provided by the Ministry for National Unity and Social development and commissioned to a research group to undertake it.

### **4.3 Comprehensive Policy on Disability with specific reference on Community Based Rehabilitation & Independent Living**

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. 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**

A co-ordination and operations centre be set up to ensure effective implementation of CBR programmes run by government agencies and organisations. This centre should be well staffed with adequate resources. Private sector companies could be enlisted to fund this project.

### **4.5 Independent Living Resource Centre**

A 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.

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 disabled people to manage the centre .

#### **4.6 Capacity Building of Self Help Organisations**

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 through leadership training programmes and the provision of adequate resources.

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**

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.

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.

#### **4.8 Peer Group Counseling**

Equipping disabled people as peer counselors and effectively coordinating these is imperative to ensure a changed approach in serving disabled people.

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 counselling.

#### **4.9 Personal Assistance Programme**

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

**1. Conceptual Framework  
& Developments in  
Understanding  
the Disability Movement**

## **1.1 Conceptual Framework**

### **1.1.1 Disability - Definitions and Models**

There are several distinctive theories and models regarding disability, reflecting the various approaches to the phenomenon that affects a large segment of humanity. In recent times, some theorists have come up with models that comprise elements of different models.

Some researchers have come up with two main models of disability. The focus of the social model is on the experiences of disabled persons in terms of bias and discrimination they suffer. It argues that the response of the environment, society and structures results in barriers and bias against disabled people.

The social model has been adopted by many groups and organisations of disabled people. For example, Disabled Peoples' International has adopted the definition of disability contained in this social model.

The more traditional medical model has its focus on specific impairments and basically states that people are disabled by their medical impairments. This model was developed by the World Health Organisation in 1980 when it devised its International Classification of Impairment, Disability, and Handicap. This model sees disability as a personal problem caused by a health condition like disease or trauma. In its view, a medical approach is the only response to disability. However some changes have been made to this model.

The medical model has been popular with medical and rehabilitation professionals but it has been severely criticised and rejected by many disabled and non-disabled persons. They reject the dominance of medical professionals and labelling of the disabled as 'sick' and the solution of medical cures and interventions in the lives of these 'patients' and 'victims'.

Among others, it is the proponents of the Independent Living Movement who have made the greatest challenge to this 'medicalisation' of care. They advocate its de-medicalisation and have challenged the dominance of medical professionals. Denison Jayasooria has described the works

of three theorists. Bickenbach (1993) has developed a three-fold model of disablement, namely the biomedical, economic, and social-political models. A disabled person, in his biomedical model, is referred to as a sick or injured person needing medical assistance. Under the economic category, the cost benefit rationale is operational, namely, in that the economic cost is taken into account. And the social-political model refers to a 'collective rights' approach.

Finkelstein (1993) has developed the 'social death' and 'social barriers' models, and advocates an administrative approach. He describes how the administrative approach dominates the way services are organised for disabled people. Oliver (1983, 1996) has a two-fold model, namely the individual and social models. Oliver provides a critique of the individual approach which he describes as the 'personal tragedy' theory of disability and which he says includes psychological and medical aspects of disability. He regards this as an inadequate and inappropriate model.

Oliver advocates a social model that is a paradigm shift from the physical limitations of individuals and personal inadequacy towards a focus on the physical and social environments. It is environmental barriers that impose limitations on disabled people, says Oliver. The individual model in practice implies that the major emphasis is upon physical and psychological adjustment of disabled persons. The social model challenges the individual model and its basic presuppositions. Finkelstein and Oliver acknowledge the importance of the 'Fundamental Principles of Disability' document produced by the Union of the Physically Impaired Against Segregation (UPIAS) and its influence on their understanding of the meaning of disability. Paul Hunt and UPIAS say the root cause of problems as disabled people lie not in their physical attributes but in social oppression.

The social model of disability challenges the basic premises of the individualised medical and personal tragedy approaches. It states that the problem is located within society, with its failure to provide appropriate services as well as adequately ensuring that the needs of disabled people are fully met.

## **1.2 Developments in Disability Movement**

### **1.2.1 Overview of Developments in Disability Work**

Organised social work among disabled people in Malaysia is a recent development and can be divided into three distinct periods. During the first period between 1940-1960, the dominant approach was the setting up of institutional services. Between 1960 and 1980 saw the emergence of disabled persons' self-help organisations.

In the present era from the early 1980s, services have been developed with a clear change in approach from institutional care to more community-based rehabilitation programmes. Developments during the three periods were and are however not mutually exclusive. There are overlaps and till today, features from all three eras exist. What changed and evolved were the emphases and directions adopted by those involved, either in planning or organising.

The provision of services to disabled people has been dominated by three main sectors - the Government and its agencies, the private voluntary groups, and lastly, by newer self-help groups.

#### **Services by the State**

Denison Jayasooria (1993) indicates that in the Malaysian experience, the state entered the arena of social services as a 'reluctant provider'. Sushama (1985, 1992), Baginda (1992), Zaharah Awang (1992) and Jayasooria (1993) noted that state intervention was necessitated by the aftermath of the Japanese occupation. As revealed in the 1946 Annual Report on Social Welfare, the colonial administration only recognised its role after the Second World War and provided 'institutional relief' for persons disabled through chronic illness, blindness and loss of limbs. The Department of Social Welfare was established in 1946. Prior to this there had been no organised welfare by the colonial administration. Welfare was organised and supported for a majority of the people at the informal level, mainly by the family. Voluntary organisations established by Christian missionaries also ran institutions for orphans, disabled people and the aged. These were in existence before the war and carried on their operations during and after the war.

The neglect of the colonial government was addressed at the South East Asian Social Welfare Conference organised by the British Colonial Office in 1947. At this conference 'it was recognised by all the delegations that social welfare is a function of government' (Minutes, 1947). One of the principal duties of the newly formed Department of Social Welfare in 1946 was "the care of the crippled, blind and feeble-minded" (Annual Report, 1946 :11) and one of their earliest projects was the establishment of Jubilee Home, a residential centre, in 1953.

Jayasooria and Ooi (1994) indicate that this early period can be characterised as the institutional and custodial care period. Services were provided for disabled persons in institutional settings where residential care, educational and vocational training were provided. Due to the institutional nature it segregated disabled persons from the mainstream of society. The charitable attempts during this period did not empower disabled people for participation in decision-making, policy formulation, resource allocation and service provision. Disabled people were viewed as mere recipients and therefore the service providers did not prepare disabled persons for active involvement and leadership roles.

It is essential to observe, as Sushama (1985), Zaharah Awang (1992), Jayasooria (1993) have done, how the UN Conference of Ministers responsible for Social Welfare, held in 1968 at New York, made a significant impact in the orientation, direction and structure of social welfare programmes in Malaysia. Sushama (1985 : 216) observed that while the traditional responsibilities remained, new attempts in prevention and social development were introduced. This conference affirmed the responsibility of governments towards welfare and that both urban and rural populations had the right to social welfare services, on the basis of equality and non-discrimination' (UN, 1968 : 7). Therefore a broader concept of social welfare emerged in 1968, moving beyond the remedial to prevention and development orientations.

Since the early years significant development has taken place. While different Government agencies (for example the Ministry of Health, Ministry of Human Resources and Ministry of Education), have a part to play in providing services to disabled people, the major role is played by the Ministry of National Unity and Social Development in general



and in particular, the Department of Social Welfare. Certain services are directly administered at the Federal level in areas of policy development, training and running of institutions (Ariff, 1993) and others are run by the State offices in areas such as direct grant provisions and coordination of community services (Rahman, 1995).

- **Voluntary Groups**

The early pioneers of services for people with disabilities were Christian missionaries. As early as 1911, they had established a home for the handicapped and in 1926 set up St Nicholas Home for the Blind.

The Central Welfare Council was established in 1946 to foster voluntary efforts and the Department of Social Welfare was set up the same year. Thus a balanced approach to welfare pluralism was established in service provision for disabled people. In 1959, the then Minister for Labour and Social Welfare at the Annual General Meeting of the Central Welfare Council said:

*I believe that social welfare services flourish best under an arrangement of partnership between government and voluntary bodies ... Voluntary services is important not only in augmenting the government's social services but also as an expression of active and intelligent community life in which each of us understands the opportunities and responsibilities of true citizenship ... Social services can best be performed by voluntary associations working in harmony with the government social services there will always be a place for voluntary effort. (Ong, 1959).*

Like the developments with the Department of Social Welfare, voluntary organisations started with residential forms of care and are now establishing community programmes like Community-Based Rehabilitation (CBR) projects. (Jayasooria and Ooi, 1994). Some of the better-known CBR projects were those run by Bethany Home (in Teluk Intan), Malaysian Association for the Blind (Kuala Trengganu), Malaysian CARE (Rawang) and Program Desa (Sabak Bernam).

In addition community services, three new developments will have greater impact in the coming years. First was the establishment in 1992 of the Society for Families of Persons

with Learning Difficulties, with parents beginning to play a key role in determining the type of services needed. This was the first parents group which is independent of a charitable organisation in Peninsular Malaysia. Since then two other groups have been established. All other parents groups have been set within charitable organisations. These parent support groups have the potential for influencing public policies if they are prepared to play an advocacy role.

Secondly, there are attempts to develop not only citizen advocates to work alongside people with learning difficulties but also self-advocacy groups. This alternative approach is being attempted by certain voluntary organisation like Bethany Home, which is situated outside the Klang Valley, where social clubs have been developed.

*These social gatherings provide opportunities for service users to make choices and develop their potential to speak up. This will eventually develop into self-advocacy groups (Jayasooria, 1993 : 3).*

The third development is the growth of group homes, especially for those in institutional care. The best example of this radical shift is Bethany Home (John, 1989, 1990) which reorganised its institution in 1982 into a community-based service. Long-term service users were placed in group homes in the local community for daily living and came to the institution for training or work on a day basis. Following this successful model by a voluntary organisation the Government has been attempting to reorganise its large institutions along similar lines.

Coordination of voluntary organisations is currently in a state of confusion. The Central Council for Social Welfare which was established in 1946 to facilitate coordination of voluntary effort has over the years relegated itself to its own direct service projects at a national level, and thereby neglecting its networking and coordination role. Khoo (1978: 10) notes that the council "exists in name only and is to all intents and purposes defunct".

A new coordinating agency, the National Council of Social Welfare (NCSW) was established in 1966 to fulfil this task of coordination and networking. Over the years a number of criticisms have been made on the effectiveness of the NCSW. Participants at the 1991 Caring Society Symposium

noted that "The NCSW ... is selective in its membership and is inaccessible ..." (YMCA and CARE, 1993 : 34). This is because the NCSW adopted a restrictive membership policy and has over the years accepted only 16 organisations as members and therefore is not reflective of the total number of voluntary organisations in Malaysia.

There are now attempts now to reorganise the NSWC to enable all national-based voluntary organisations to be accepted as members as well as adopting a social development agenda (Baginda, 1995). Organisations working among disabled people could be members of two coordinating agencies, namely, the Malaysian Council for Rehabilitation (MCR) and/or the Malaysian Confederation of the Disabled (MCD).

- **Self-Help Groups**

The 1960s and the 1970s saw the emergence of the disabled people's movement which challenged the traditional approaches to welfare provision, especially those which isolated them from participation in the mainstream of society. The first to organise themselves as a group were the blind, who in the 1960s clamoured for the right to have a say in the running of St Nicholas Home. When their attempts failed, they set up the Society of the Blind in Malaysia (SBM) in 1966.

Following this, the 70s and 80s saw the establishment of other specific disability groups by disabled people themselves, namely the Society of the Orthopaedically Handicapped (in 1976), the Society of Chinese Disabled Persons, Malaysia (1977), the KL Society of the Deaf (1987), and more recently, the Malaysian Spinal Injury Association (1995). Armstrong (1993), observing the Malaysian context, indicated that self-help organisations remain a minority among voluntary, non-government organisations working in the disability field but they include some of the more active organisations and their combined contribution is considerable and growing. (Armstrong, 1993 : 192)

A significant development towards the enhancement of the self-help movement was the establishment of the Malaysian Confederation of the Disabled (MCD) in 1985 by SBM, POCAM and SCDPM. Both the KL Society of the Deaf and MASIA are members of MCD. The MCD is a member of

Disabled People's International (DPI) and is now the main vehicle for disabled people to express their views and take joint action. They have been called upon by the Malaysian Government to represent disabled people in policy matters affecting disabled people in Malaysian society.

The International Year of Disabled Persons, 1981 and the UN Decade of Disabled Persons (1983-1992) have helped to legitimise the concerns of disabled persons in Malaysia. As a result there are now clear attempts to strike a balance in fostering partnership between disabled people and non-disabled people's organisations in the provision of services. Organisations run by non-disabled people dominate service provisions, but there is greater partnership at the level of policy discussion and formulation. This is because disabled people and their organisations are now included and in several dialogues organised by Government agencies have held prominent positions.

Furthermore, disabled people have become aware of their rights, and they have acquired confidence and credibility as a result of establishing and running their own organisations. They know from experience that they can play a dynamic role in planning and implementing services for the benefit of their fellow disabled. Advocacy and policy input have been the major contributions of disabled people since the formation of their organisations. Both at the level of articulating an alternative framework as well as in concrete cases of action, disabled people have made their presence felt in Malaysian society. Godfrey Ooi, rightly acknowledges this when he says that

*the disabled have proved that with concerted action they can help to bring about some changes for the improvement of living conditions and for a better quality of life for all disabled people. They have also shown that there is a need for them to work in cooperation with Government authorities and with other non-governmental organisations if they want to bring about positive results. (Ooi, 1994 : 8).*

### **1.2.2. Types of Services**

The types of services available to the disabled can be divided into a few main categories, namely, institutions,

finance and equipment support, education, employment and advocacy.

- ***Institutions***

This has been seen in the past as the key service provided by the Department of Social Welfare to disabled people who were abandoned by their families. In 1994, five institutions were run by the Department providing long-term care to 706 people with learning difficulties. The care provided in these homes became the subject of some public debate when the media revealed abuse of the residents. Pictures of naked children tied to their beds were published in the Chinese-language newspapers and later circulated by Reuters news agency. In a Press statement, the Minister concerned said

*I assure the public that the Ministry is doing its best to help these people; it is unfortunate that the inmates have to be tied up but it is for their own safety. (The Star, 1991).*

The Ministry was defensive and had not accepted the fact that the real reason for these people with learning difficulties being tied up was the lack of staff, especially those who are properly trained to provide creative living skills programmes oriented towards independent living. These events have motivated the Department of Social Welfare to establish group homes as an alternative programme towards de-institutionalising disabled people. Five group homes have been set up by the Department, catering for about 26 persons.

Since 1966 the Department has also been running the Cheras Rehabilitation Centre in the Klang Valley which provides training and accommodation for 120 physically disabled people. The vocational training includes tailoring, radio and television repair. The aim is to train and develop the potential of disabled people. According to Zainul Ariff (1993), 1,600 physically disabled people have completed their training since 1966.

Another sheltered workshop for the physically handicapped in the Klang Valley is the Bengkel Daya Klang which also provides employment opportunities. Under the 6<sup>th</sup> Malaysia Plan an Industrial Training and Rehabilitation Centre will be established at Bangi at the cost of RM 37 million. This centre will provide retraining for those disabled through accidents

as well as catering for those disabled from birth. The training facilities will cater for 350 disabled persons in fostering industrial skill related to contemporary times.

These sheltered workshops have been established in response to the realization that there are many disabled people who face difficulties in competing for job opportunities in the open market. Such sheltered workshops provide viable alternatives as they are built on the positive premise that the disabled have an important role in generating wealth and contributing to the country's economic growth despite their disabilities (Sayed Rahman, 1995a : 13)

Tugwell (1992) advocates the mainstreaming of vocational training as opposed to specialised centres set up exclusively for disabled people. This is the position recommended by the International Labour Office, which has stated that wherever possible, disabled persons should receive training with and under the same conditions as non-disabled persons. Special services should be set up or developed for training disabled persons who, particularly by reason of the nature or the severity of their disability, cannot be trained in company with non-disabled persons". (ILO, 1970 : 99)

In this context Tugwell highlights the role of the social welfare department and voluntary agencies should play, namely to ensure the accessibility of mainstream training to disabled people, to offer social support services to the disabled undergoing training and, where necessary, advisory services to the training centres in helping to develop easy use of these facilities. (Tugwell, 1991 : 9).

- ***Finance and Equipment Support***

Disabled people and their families may apply for help from a general assistance scheme. This is a basic residual provision and is given on a means test basis rather than by right of citizenship. Under the general welfare assistance programme, families that qualify for the financial aid are those earning less than RM 300 a month. The assistance includes a family assistance scheme of RM 150, a youth undergoing training assistance of RM 80, and schooling assistance of RM 50. Aid to old folks is set at RM 70 per person per month.

A number of direct grants and support are also available to disabled people. Three notable ones are: firstly, a business grant of RM 2,000 for a disabled person beginning a business; secondly, a work incentive allowance of RM 50 for a working disabled person earning between RM 20 and RM 300 in order to encourage the person as well as topping up his income; thirdly, funds are provided to purchase equipment like wheelchairs or hearing aids.

In 1992, according to Zainul Ariff (1993), 327 persons received equipment grants totalling RM 239,810 and 109 disabled people benefited from the business grant scheme. While these are encouraging examples, there are a number of problems. Firstly, they are granted on the basis of need rather than of right. Secondly, the amount provided is insufficient. The amount provided when compared with the Poverty Line Income (PLI) will reveal the true picture. The PLI is set at RM 405 per month for a household of five (Malaysia, 1995) and the hardcore poor comprise 50 per cent of this figure.

It is estimated that about 143,100 households or four per cent (Malaysia, 1991) of total households live in hardcore poverty. However, there are no figures or research done to indicate the level of poverty of disabled people in Malaysia. Nonetheless, one can conclude that a majority is in a disadvantaged position. The funds available through the Department of Social Welfare are insufficient to enable them to lead a life out of poverty if they do not have a well-paid job, the assistance of family or voluntary agency. Thirdly, the number of those benefiting from the current services provided is insignificant, even in relation to the total number of disabled people registered.

Voluntary organisations depend on the public to make contributions to fund their activities. The Government provides some grants based on number of clients served, especially to day care and residential programmes. In 1993 the Ministry for National Unity and Social Development provided grants totalling RM2.2 million to 63 voluntary organisations working among disabled people throughout Malaysia. (Rahman, 1995). The Department is also currently providing support to 13 sheltered workshops run by voluntary organisations throughout the country which provide job opportunities for 421 disabled people.

- **Education**

Kamariah Jalil (1993) provides a comprehensive description of the educational programmes available for disabled people. She highlights an Inter-Ministerial Committee on Education that met between 1981 and 1983, and formulated a policy of understanding among the different roles different Ministries and Departments would play in the education of disabled people. The Ministry of Education is responsible for the formal education of disabled people under four categories; firstly, those who are visually impaired; secondly, those with hearing impairment; thirdly, the orthopaedically handicapped; and finally, the educable mentally retarded or persons with mild learning difficulties.

The educational programmes are provided through special schools and special classes. There were a total of 141 programmes with 5,100 students and 748 teachers in 1993 under the direct purview of the Ministry of Education. The Department of Social Welfare is responsible for providing non-formal education to those who cannot fit into normal schools, special schools or special classes in normal schools. Therefore the Department of Social Welfare took charge of the severely mentally handicapped and the multiple handicapped in rehabilitation programmes in day centres or in the community through Community-Based Rehabilitation.

A positive step forward was the formation of A National Advisory Council on Children with Special Needs in 1991. It is a platform for joint action among the relevant Government agencies as well as the voluntary sector in providing education. However, as it is only an advisory council, it falls short of ensuring the effective implementation of educational programmes that are so urgently needed by children with learning difficulties.

Educational provision for disabled people falls far short of needs and demands. While education is free in Malaysia at primary and secondary levels for children, it is not compulsory. Therefore, there is no legal requirement for comprehensive provision. Apart from the reference in the Education Act 1961, Section 25, on the provision of special schools at the discretion of the Minister, there are no safeguards to ensure that education is provided as a matter of right to disabled people in Malaysia.



- ***Employment***

As indicated earlier there has been much emphasis on encouraging the private sector in providing employment opportunities for disabled persons. There have been attempts both by the Department of Social Welfare and the Human Resources Ministry to foster employment opportunities. It is estimated that only 10-20 per cent of the 89,000 disabled people who can be considered economically active are earning a living or are self-employed (Ganapathy, 1992).

In an attempt to address this need, the Ministry of Human Resources set up a National Committee for the Promotion of Employment Opportunities for disabled people in the private sector. By the end of 1991 about 744 disabled people were employed in the public sector. In appeals made by the Ministry of Human Resources between 1990 and 1991 a total of 2,152 jobs were offered by the private sector. However, only 1,249 were taken by disabled people between 1990 and 1993. (Ganapathy, 1992)

In October 1999, The Star newspaper (October 21, 1999) reported National Unity and Social Development Minister Datin Paduka Zaleha Ismail had urged government agencies and the private sector to provide more opportunities to the disabled to earn a living and to be self-reliant. She revealed that government agencies had only employed 538 disabled people while 2,964 disabled people had found jobs in the private sector. "This is a far cry from the 70,000 disabled people who have registered with the ministry," she said. The Minister added that disabled people could become telephone operators, stenographers, welders or woodwork craftsmen, adding that they could be also be retrained for other tasks.

Ganapathy (1992 : 1) identifies five reasons for insufficient takers of such job offers. Firstly, there is an absence of a register of job seekers among disabled persons. On the part of both Government and voluntary agencies this is not well coordinated. Secondly, prejudice exists against disabled people. Thirdly, there is poor access to public facilities. Fourthly, comes restricted location of employment, as 70 per cent of the jobs offered were located in the Klang Valley and fifthly, the reluctance of employers to modify or adopt machinery and facilities for disabled people.

In order to enhance the untapped potential of disabled persons in the workplace there is an urgent need for skilled placement services on a nationwide scale. This service must not project a welfare or charitable image and as Tugwell says should have more in common with the world of personnel management than that of social work. (Tugwell, 1992 : 11)

The placement officer must fill the role of honest broker, acting objectively in the best interests of both the employer and the job-seeker. The placement officer is the 'market maker' bringing together the demand and supply. (ibid.)

Ganapathy (1992) like Tugwell, gives high priority to the setting up of the placement services. Jayasooria et al (1996), likewise affirm that both the Ministry of National Unity and Social Development and the Human Resources Ministry should set up professional placement services nationwide and network with both the private and voluntary sectors. Jayasooria et al (1996) further note that employment and vocational training for disabled persons cannot be considered in isolation from other factors such as educational opportunities and issues related to accessibility.

- ***Advocacy***

A recent phenomenon has been a move by some individuals and groups towards advocacy of disability issues and the challenges facing disabled people. The people behind this have been both the disabled and also the non-disabled or able-bodied. One such group is Dignity & Services, a Klang Valley-based NGO that has been trying to build up advocates who would try to articulate the views and perspectives of those who are unable to do so effectively. There are also parent and family support groups that have sought to be more vocal and articulate in issues related to disability and disabled people. In both cases, they aim to speak on behalf of persons like the severely disabled who may be unable to voice their own opinions and views.

One reason put forth for such advocacy work is the notion of justice or fair representation for the disabled who are unable or lack opportunity to voice their views and problems. While other segments of society have access to decision-makers and the public, the severely disabled or those with learning

difficulties often do not have such access. The work of some advocacy groups also includes facilitating networks of disabled people, family and supporters, and others to better further their cause, ideas and aspirations. It is likely that as more disabled persons gain educational and other opportunities, they will be better advocates for their own struggles and demands. And as Malaysian society moves towards being more 'caring' and 'civil society' status, more non-disabled persons will be committed to 'speak up' on behalf and alongside the disabled persons.

### ***1.2.3. Registration and Terminology***

The Malaysian Government takes a conservative approach and estimates that only one per cent of the population has some form of impairment. This figure was derived from a sample survey of five per cent of the population conducted by the Social Welfare Department between 1958 and 1959, some 40 years ago. The survey was to ascertain the extent of disability among the population. Since then the Government has adopted this figure and no other Government-sponsored national survey has been conducted to further ascertain the prevalence of disability.

Four other localised field studies were conducted in Malaysia between 1983 and 1989 but these were not conclusive to determine a national figure. Therefore Malaysia continues to adopt the one per cent estimate, as opposed to the World Health Organisation's estimate of 10 per cent (WHO, 1981). With a population of 21 million, this will mean 210,000 disabled people based on one per cent or 2.1 million based on the WHO standard.

Disabled people are not a homogenous group and in Malaysia the Government recognises four main categories. The terms used are the blind, deaf, physically handicapped and mentally retarded. Medical categories and terminologies are in dominant use. As in other developing countries a majority of disabled people in Malaysia have impairments which are birth-related, congenital, or acquired in early childhood. In recent times however disabilities acquired through industrial and automobile accidents are on the increase.

The Department of Social Welfare is responsible for keeping a register of disabled people. A weakness of such a registration method is that it is voluntary and will not reflect the actual number of disabled persons in the country. Although the Department has conducted campaigns to encourage registration, the majority of disabled persons are not coming forward to register. Cultural and social stigma could be the basic inhibitors. It has been suggested that the authorities need to take a more pro-active approach to this registration exercise. Several organisations and groups do make periodic mass registration exercises where they gather groups of disabled persons to go and register at the same time.

Figures released on the registered number of disabled people, reveal the tremendous shortfall in comparison with the estimated numbers based on either 1 per cent or 10 per cent of the Malaysian population.

**Disabled persons registered with Department of Social Welfare**

CATEGORIES	KLANG VALLEY December 1995 figures	NATIONAL June 1995 figures
Sight impaired	1, 511	10,416
Hearing impaired	1,889	19,358
Physically impaired	3,340	10,197
Intellectually impaired	3,910	15,702
<b>Total</b>	<b>10,650</b>	<b>55,673</b>

	<u>DEC97</u>	<u>DEC 98</u>
Sight impaired	11,202	10,998
Hearing impaired	12,967	13,272
Physically impaired	24,205	25,384
Intellectually impaired	21,383	23,453
<b>Total</b>	<b>69,757</b>	<b>73,107</b>

It is in this context that alternative suggestions have been made to remove the social stigma upon families by two possible ways. Firstly, a register of disabled people should be maintained and updated at a central registry administered by the National Registration Department rather than the Department of Social Welfare. Secondly, all general hospitals and private maternity homes should report births of

disabled children. Likewise, disabilities caused after birth should also be reported by the relevant bodies.

Up till August 1999, there were a total of 84,120 disabled persons registered with the Department of Social Welfare. But in October 1999, the National Unity and Social Development Minister Datin Paduka Zaleha Ismail said Malaysia had an estimated 220,000 disabled people. This figure seems to be based on the estimate of 1 percent of the population being disabled. Even with this, the figure of 84,120 disabled persons registered with the department is still far short of the actual numbers of disabled persons.

#### **1.2.4. Disabled People's Movement**

Disabled people have been coming into the open to express their concerns and views. The social change in the disability movement was spearheaded by visually impaired people. They not only were the ones who first formed an organisation of disabled people, namely, the Society of the Blind of Malaysia, but also have been clearly analysing the issues and concerns of disabled people in Malaysia.

A number of disabled people in Malaysia have presented papers at various seminars through which they have challenged the dominant charity-oriented and segregated approaches in providing services to disabled people in Malaysia. John Kim, one of the founder members of the Society of the Blind, ascribes ignorance and negative attitudes by society in relegating disabled people as 'second-class citizens' and 'lesser people'.

I am saying this because the disabled have been excluded from the general development of the country. From the construction of public roads, buildings and schools, to access to supermarkets, public transport and recreational parks, the special needs of the disabled have not been catered for. This is due to lack of consultation with the disabled to ascertain their views and needs. (Kim, 1991 : 9).

John Kim goes on further to affirm

*that a lot of the problems of the disabled can be solved if they are not treated just as helpless clients but as intelligent consumers and meaningfully consulted in the provision of services and facilities just as the general public are. (Kim, 1991 : 10).*

Godfrey Ooi has been in the forefront of most of the policy discussions for over a decade. He has been one of the key spokespersons of disabled people and has participated in all the major dialogues with Government officials. He affirms that disabled people are deprived of their rights due to public apathy, discrimination and prejudice. He calls for changes in two areas. Firstly, that there needs to be a change in the approach to providing social services from one based on charity that implies goodwill and low standards to one based on social responsibility and human rights. According to him the help disabled people want is one that will enable them to claim their rights as human beings. They do not want the kind of charity that constantly puts them on the receiving end all the time. This means that in planning for the disabled, it is not enough just to give of the heart; 'right mind' and 'right effort' are also required. (Ooi, 1990 : 26)

Secondly, there must be a shift from no consultation to providing the mechanism for disabled people to be directly involved in the decision-making process.

*"The exclusion of the disabled can no longer be justified. (Ooi, 1994 : 4).*

Anthony Thanasayan (1995a, 1995b), who lost the use of his legs when he was 10 and since then has been a wheelchair-user, is an outspoken disability activist. He led a movement of peaceful protest over the reluctance of the management of the Light Rail Transport System to provide the necessary facilities for wheelchair-users. His arguments are based on the social model of disability when he says:

I feel so trapped. It is not fair to exclude the disabled from the infrastructure. It's not our disability that we cannot overcome but the establishment that has not provided the facilities necessary for us to grow and function normally. (The Star, 1995).

- ***Reorganising for effective participation and representation***

To be effective as one voice disabled people have organised themselves. As in the setting up of organisations by disabled people, the visually impaired took the lead when in 1984 the SBM initiated the formation of the National Council of the Blind (NCBM), which is now the coordinating agency for both organisations 'of' and 'for' serving blind people in Malaysia. Another positive move was the formation of MCD in 1985. These developments have had a positive effect on disabled people and on policy-makers because they can now be identified as a coordinated group that has facilitated their role in policy input.

Four key examples can be cited of disabled people and voluntary organisations playing a direct role in advocacy and policy input. Firstly, there is the role played by MCD in making representation on behalf of disabled people. For example, the MCD submitted to the Government a memorandum on access to public facilities in July 1988. This resulted in the proposed amendments to the Uniform Building By-Laws (1984).

More recently the MCD was involved in closed-door dialogues on access for disabled people on the new project of the STAR Light Rail Transit System in the capital city. Secondly, there has been the participation of voluntary organisations at the national pre-Budget dialogue since 1991 where a disabled person has represented the concerns of disabled people and their organisations (Ooi, 1992).

Thirdly, a series of workshops and conferences were organised by voluntary organisations where key policy recommendations were formulated and submitted to relevant Government bodies. Fourthly, disabled people and their organisations were represented in the special committee set up by the Ministry of National Unity and Social Development to prepare a Cabinet report on disabled people which was presented to the Cabinet in December 1992. Of the 12 representatives from voluntary organisations, five were disabled people representing MCR and related organisations.

These opportunities affirm the possibility of grassroots movements discussing major issues affecting disabled

people in Malaysian society and channelling recommendations to relevant Government agencies. These are encouraging indicators, as participation in policy formulation and implementation are an integral part of citizen rights and responsibilities.

Since IYDP disabled people are coming to the forefront to exercise this right within the political process. However, the major drawback is that self-help groups and voluntary organisations are not devoting funds and resources to prepare well-researched documents to make their case clearer during policy discussions. This is the next stage of development that is needed to strengthen advocacy attempts.

- ***Difficult realities for exercising political participation in Malaysian society***

In the Malaysian context disabled people are faced with three harsh realities which they will have to overcome. Firstly, comes the issue of linking micro and macro concerns. Voluntary organisations including self-help groups are often focused on micro concerns. Policy matters require work in social and political analysis, accurate research and documentation that are often beyond the scope of most organisations. They lack the resources and the personnel to effectively carry this out.

The attempts cited earlier are ad hoc attempts where individuals from the various organisations have, for a limited period, devoted attention to a national policy issue. However, this is often not their major task within the organisation. Therefore, effective monitoring is lacking as well. It is necessary for organisations like MCD to be well staffed to do the necessary background research in order to be effective in the policy arena.

Secondly, Malaysians due to the political climate have in the majority withdrawn from public protest, action and public litigation. This analysis is clearly described by Esther Lim who writes that the litigation consciousness among the Malaysian disabled is practically absent and they are mostly in the dark about their rights. (Lim, 1993 : 23).

The popular approaches in the West towards creating public awareness are public protest and court action. This inner



spirit of fighting for one's rights has been curtailed by cultural, social and political factors in Malaysia. According to Esther Lim (1993) the way out is increasing the confidence and assertiveness of disabled people. One will have to do more than this, but it is the first step forward. If not, fatalism will prevail.

While Esther Lim (1993) is right to draw the cultural differences between the West and Malaysia, it is also essential to understand the democratic space within which Malaysians operate. Due to experiences in the past there exists a climate of not wanting to make public demands and criticisms, especially of Government agencies. Lee (1987) notes the threats against human rights, especially with regard to citizens' participation, from within the Federal Constitution which allows Parliament to enact legislation in the name of security and public order. Fundamental liberties like freedom of speech, assembly and association are not absolute and have been limited.

Thirdly the major hurdle is the approach one undertakes within the Malaysian political climate. Any approach that is deemed too critical and confrontational is generally frowned on in Malaysian society. Therefore, the approach taken both by disabled people and some voluntary agencies is to work within the mainstream and make recommendations or changes. The prevalent approach is one of persuasion and friendly 'chit chat' over tea or a meal rather than one asserted on the basis of rights and entitlements.

But what is one to do when dialogues do not materialise into positive action? This was the case with the closed-door dialogues with the relevant Ministries on the issue of access for disabled people on the newly constructed Light Rail Transit System. Although the issues were well published in the media, the authorities have not taken the appropriate action to make provisions such as lifts in order for wheelchair-users to use this major new public transport system being developed in the capital. The MCD called for Government intervention in order to bring positive results. Some disabled people organised a press conference in support of the Prime Minister who said the country was fully committed to helping the disabled and that Malaysia could be a regional model of excellence for the less fortunate.

About 50 disabled people came together for this press conference organised by the Light Rail Transit Action Group set up by disabled people. They took this opportunity not only to support the Prime Minister and in so doing use the occasion to highlight the concerns of disabled people. The media provided good coverage of this gathering. The pro-tem Chairperson of the action group, Christine Lee, said public transport and facilities in buildings should be more disabled-friendly. She said services were inadequate compared with other countries and that buses don't cater for the disabled and LRT will not have facilities for disabled persons.

Anthony Thanasayan, another speaker at the press conference, reflected on the gathering:

*As the flashes from the photographers gleamed across the crowded living room, I was suddenly overwhelmed and all choked up to see my friends who had struggled diligently for our cause coming out boldly and unashamedly to speak about our plight. Indeed, while there has been very little change in attitudes and accessibility for us in our society, over the years, we can be thankful for one positive fact - in our difficulties, there has been much personal growth for us all. (Thanasayan, 1996 : 14)*

What is clearly emerging in Malaysian society is the political consciousness of disabled people and they are exploring different possibilities. However, the wider political climate for pressure group politics reveals the realities. In this context Lim Teck Ghee (1995) rightly observes:

*When issues such as welfare policies or youth and child development are taken up, the government is usually appreciative of input from the NGOs and an exchange of information takes place to facilitate the relevant projects. Tensions arise, however, when some NGOs actively seek to make the political system more accountable to public interests or to make the development process more transparent and people oriented. (Lim, 1995 : 167)*

A clear example of state reaction to the political advocacy role of disabled people is the case of the SBM during the proposed amendments to the Societies Act in 1981. Gurmit Singh (1984) records this illustration. In Malaysia the freedom of association is regulated by the Societies Act

1966. In 1981 there was a move by the Government to create a new category called political societies.

A political society is defined as a society that seeks to influence in any manner the policies or activities or the functioning, management, or operation, of the Government of Malaysia, or of any department or agency of any such Government or Authority. (Singh, 1984 : 83).

The SBM was one of the first organisations along with 18 others who objected to this proposed change. The SBM was part of the Societies Act Coordinating Committee that was set up by 64 societies that launched a national campaign on Freedom and Society in August 1981. The Registrar of Societies acted first against SBM, stating in a letter that due to the nature of its objectives and activities it would be designated a political society. This was sufficient to enable the withdrawal of SBM from the protest activities. In due time the Government made changes to its proposed amendments and the clause defining societies as political was eventually dropped. However, the impact both on SBM and other welfare-based voluntary organisations was to persuade them to toe the official line. SBM today is a service-based agency and any advocacy it does, it works through MCD. It is without doubt that disabled people have now relegated themselves to discussing only issues directly affecting them rather than working alongside others on issues of national concern.

Goh Ban Lee (1991) is right in his general assessment of Malaysian society that independence has only conferred a certain degree of power on the citizens. On the whole the power has been largely limited to casting votes to decide whom they want to be their leaders or which party they want to form the next government. The public has generally been denied opportunity to influence governmental decisions. Even the choice of local councillors has been taken away by the abolition of the local government elections. (Goh, 1991 : 115).

However, it is within this political climate that certain creative attempts to influence public policy working from 'within' and to be seen by the Government as 'insiders' will hopefully bring the needed change to equalise opportunities for disabled persons in Malaysian society. It may be said that while attempts are being made by the Government to

address the needs and issues of disabled people, what is being done is insufficient. The attempts made can be categorised as predominately residual in nature with a heavy reliance upon the voluntary and informal sectors. Current services are not comprehensive and a majority of disabled people, unlike other citizens, are not yet benefiting from the economic progress.

MacPherson's (1992) analysis of the newly-industrialising countries in Asia is significant. He notes that while the Asian Pacific Ministers endorsed the social development agenda, nonetheless the dominant approach was one of 'band aid', 'reactive', 'sporadic' and 'piecemeal'. While Malaysia has made much progress and has demonstrated with great success general poverty eradication programmes, especially among rural Malays, MacPherson's description accurately reflects the reactive, piecemeal attempts to address disability-related issues in Malaysia.

All around the developing world disabled people and their organisations are playing an active role through self-advocacy. This is clearly indicative of the role played by key Malaysian activists and the MCD. The delicate political and cultural context determines strategies appropriate for social change. Disabled people are beginning to tap into the opportunities available.

While disabled people affirm citizenship rights and call for inclusion into Malaysian society their experience in a newly-industrialising country is not the same as that described by Barnes (1991) in the British experience. Barnes points out that in the British experience while cultural considerations had relevance, it was industrialisation which alienated them from mainstream society. He said it was largely due to the economic and social upheavals which accompanied industrial development ... [which] precipitated discrimination becoming institutionalised throughout society' (Barnes, 1991 : 26-27).

However, this is not the case for Malaysia, a newly industrialising country in Asia. Malaysia is currently undergoing rapid industrialisation and disability issues have surfaced due to the social and economic progress taking place. Society is taking account of the concerns raised by disabled people through appropriate action, however inadequate. Furthermore, due to the global awareness on

disability issues and its impact, positive changes are taking place. It is too early to determine the policy outcome in Malaysia but there are positive indicators to ensure that disabled people will not be sidelined in the year 2020. In many ways, economic growth provides a window of opportunity for disabled people. The Malaysian disabled are seeking a share of the economic cake and their role in recent years is beginning to set the agenda for their inclusion and share in Malaysian society.

#### **1.2.5. National Policies and Legislation**

There are a number of policies and social legislation that have relevance for disabled people in Malaysia. The policies basically consist of general directives, to which all concerned are encouraged to respond appropriately. In contrast, social legislation provides for greater protection as there are legal requirements to be fulfilled, as well as sanctions to deter non-compliance.

In Malaysia, there is a greater tendency to rely on political pronouncements and incentives rather than on social legislation and statutory punishment as in the case of employment of disabled people. In other words, the emphasis is put on appealing to the public conscience and goodwill, especially to that of the business community, rather than on relying on the force of law. This provides a clear indication of the situation that prevails in Malaysia where the social welfare of disabled people is not seen as a question of rights but as one which relies solely on the goodwill of the rest of the community to secure social justice for all its citizens.

Another dimension is the impact on the process of formulating Malaysian policy and social programmes of the international instruments, policies and programmes formulated by the United Nations, as in the International Year of the Disabled Persons (IYDP), by the Regional Office of the Economic and Social Commission for Asia and the Pacific (ESCAP) and in the Asia and Pacific Decade of Disabled People. This external input both at the international and regional level has, according to disabled people in Malaysia, contributed towards their well-being. The policies formulated by the UN and ESCAP provide a form of checklist with which national programmes in developing and newly-

industrialising countries can be examined, compared and emulated.

The UN and ESCAP operate on a consultative basis and therefore the policies, especially those promoted by ESCAP, are making a positive contribution to future developments. Malaysia has participated in all recent ESCAP Expert Group Meetings with a representative from the Department of Social Welfare and a disabled person from a voluntary or self-help organisation in attendance.

- **National policies**

There are two national policies that have relevance to disabled people. The first is the National Welfare Policy that describes the nature of caring in general. The second is the Policy on Employment for disabled people in the private and public sectors. The National Welfare Policy (1990) provides the foundation for the Prime Minister's 1991 challenge to establish a caring society and caring culture as part of the overall vision of Malaysia becoming a fully developed nation by the year 2020. The policy is a brief, comprehensive statement that identifies the goal, aim, strategy, both general and specific, and implementation guidelines.

It gives a brief description of 13 target groups needing assistance, one of which is disabled people. The overall goal is to produce a secure and stable society. Its three-fold strategy is significant for policy and practice, namely to create self-reliance, to equalise opportunities for the less fortunate and to foster the spirit of mutual help and support towards enhancing the caring culture.

The theme of self-reliance and equal opportunity is basically a strategy of developing resilience in individuals and communities. While the policy identifies six urgent tasks, that is, the need for cooperation to utilise community resources; the development of social welfare; integration; training of workers; research; and effective leadership, it fails to indicate who will be responsible for them.

The policy is the clearest statement made by the Government on the nature of the caring society. It has been popularised in the media as a result of the political endorsement and therefore serves as the base principle on the theme of fostering a caring culture and society.

Furthermore, academic review and support was established when a leading social and economic 'think tank', the Institute of Strategic and International Studies (ISIS), organised the First National Conference on the Caring Society in 1990.

However, there is a major weakness to the Policy Statement, as a result of which in the long-run equal opportunities for disabled people might not be facilitated. The orientation of the policy is towards seeing needs and problems at an individual level with the emphasis on self-reliance or on developing individual human potential. In taking this approach, the inference is that disabled people are not part of the mainstream of society because they have not taken advantage of economic development, and the problem is approached by focussing on individuals. While the policy indicates equal opportunities, it does not adequately address the issues of attitudinal, environmental and institutional barriers.

In 1989 the Government announced that one per cent of the jobs in the public sector would be reserved for disabled persons. In the following year this ruling was extended to the private sector. While this is not mandated by legislation, tax incentives were provided to the private sector to encourage them to provide job opportunities. The Ministry for Human Resources has been playing a leading role in popularising this policy. A National Committee for the Promotion of Employment of Disabled Persons in the Private Sector was formed by this Ministry. One of its first programmes was the launching of a campaign to promote the employment of disabled people.

Three incentives are provided to encourage the private sector to employ disabled people. Firstly, there are deductions in respect of expenditure on the provision of any equipment to assist a disabled employee. Secondly, double tax deductions are made in respect of the remuneration paid to each employee who is physically or mentally disabled. Thirdly, there is also double deduction on expenses incurred in the training of any handicapped person.

While these policies have been largely political statements rather than a clearly articulated and formulated programme, they do provide the opportunity for future development. There is an urgent need for a clearly thought-out policy with guidelines for its effective implementation and monitoring.

Nevertheless, the direct involvement of the Ministry of Human Resources is a major breakthrough for disabled people. This involvement is breaking down the old stereotype that implied that matters pertaining to disabled people should only be handled by the Department of Social Welfare. The concerns of disabled people are now, at least in a small way, being addressed by the Human Resources Ministry that is responsible for employment-related matters for other Malaysians citizens.

- **Legislation with reference to disabled people**

Wong Teck Meng (1981) draws attention to 17 statutes that have some direct or indirect reference to disabled people in Malaysia. However, he notes that two have relevance to those who have been in the labour market and become disabled during their course of work. They are the Workmen's Compensation Ordinance (1952), and the Employees Social Security Act (1969) which, he says,

*come near to the realm of the rights of the disabled by providing monetary benefits to those who are disabled during the course of employment. (Wong, 1981 : 71).*

Jayasooria et al (1992), Ooi (1994a) and Lim (1993), provide a brief reflection on the implications of the Federal Constitution for disabled people. The basic conclusion is that disabled people cannot claim any rights on the basis of the current provisions in the Federal Constitution. Constitutionally, a disabled person might perhaps claim his/her rights based on Article Eight of the Federal Constitution but not without modification. Clause One of this Article affirms that 'all persons are equal before the law and entitled to the equal protection of the law'. Clause Two however qualifies this by stating 'there shall be no discrimination against citizens on the ground only of religion, race, descent or place of birth'. Tun Suffian (1976) a retired Lord President of the Supreme Court of Malaysia, clarifies that:

*the discrimination which is based solely on the ground that the person discriminated against professes a particular religion, belongs to a particular race or is of particular descent or was born in a particular place, and on no other ground. (Suffian, 1976 : 216).*



He goes on to state that :

*if there is any other ground or consideration for the differential treatment apart from those prohibited by the article, the discrimination will not be unconstitutional". (Suffian, 1976 : 216).*

It is clear that disabled people cannot assert their rights on the basis of the Federal Constitution. There is, therefore, the need to incorporate into Article Eight constitutional protection for disabled people.

The Uniform Building By-Laws 1984 under the Street, Drainage and Building Act 1974 were amended in 1990 to provide facilities for disabled people. According to Esther Lim, a disability activist and lawyer, this is the major breakthrough for the disabled and the first step towards overcoming the environmental and structural barriers. (Lim, 1993).

Under the amendments all new public buildings will have to provide facilities for disabled people and owners of existing buildings have three years to make adaptations. A working committee was set up by the Ministry of Housing and Local Government, on the initiative of the Ministry of National Unity and Social Development, to draw up a code of practice for access to public buildings.

The Malaysian Standard 1184:1991 'Code of Practice for Access for Disabled Persons to Public Buildings' was released by the Standards and Industrial Research Institute of Malaysia (SIRIM). This standard specifies the basic requirements for elements of buildings and related facilities so as to permit access by disabled people. These requirements are applicable to all buildings that disabled people may use as members of the public either as visitors or for the purposes of employment.

The second 'Code of Practice for Disabled People Outside Buildings' is still in the process of completion. Under the Act it is the Local Authorities who are required to ensure its smooth implementation. However, the Uniform By Laws and the Standard Code have to be firstly gazetted by all the State authorities; only then will it be obligatory for the developers to take into consideration the needs of disabled people when planning the construction of public facilities.

Even prior to the enactment of these, Goh Ban Lee (1992) had called upon Local Authorities under The Town and Country Act and the Street, Drainage and Building Act to "play a more positive role in bringing about a caring society" (Goh, 1992). Thus far only six of the 13 States and one of the two Federal Territories have gazetted these two new provisions for disabled people. In addition there are difficulties with monitoring the legislation as well as a lack of understanding by town planning officials of the specific needs of disabled people. The major problem is with regard to implementation and monitoring the By-Laws in order to ensure effective implementation.

Both Esther Lim (1993, 1995) and Godfrey Ooi (1994a) call for more legislative protection for disabled people. In Esther's analysis a two-fold strategy is appropriate; in the first stage to provide laws "for the minimum basic rights of disabled persons" with a parallel public awareness programme. Only in a second stage when the country is ready to accept greater responsibility can more elaborate legislation be provided for" (Lim, 1993 : 23).

Esther Lim recognises the importance of legislative measures when she draws a difference between charity and rights in the context of measures to protect disabled people. She notes:

*To be charitable is seen as a positive trait in most cultures. However, it is often - even through not always - unreliable in the long run and on a scale not large enough to achieve what is needed. It is the legislative measures that can effectively protect the rights of persons with disabilities. It is through establishing the necessary legal basis so that other measures to assist the disabled could rely. (Lim, 1995 : 3)*

She is optimistic that a concrete foundation has been laid for the erection of an effective legal framework to safeguard the disabled. Ooi calls for the introduction of national disability legislation in order to protect and ensure the rights of the disabled as equal citizens.

### **1.2.6 International policies**

Since the 1981 International Year of Disabled Persons (IYDP) the United Nations through its World Action

Programme (1983-1992) has been playing a part to assist policy-makers, planners, legislators, etc., to adopt disability policies and to provide a time frame for the initial implementation of the World Programme of Action. (Barry, 1992 : 1)

In the assessment that Mamadou Barry (1992) made, he highlighted some apparent achievements over the decade, three of which are significant. Firstly, redefining disability issues in a human rights context; secondly, increased public awareness of disability issues; and thirdly, disabled people through their organisations have been able to increase their influence. The major drawback he notes in most developing countries is that there has been a lack of comprehensive planning as well as insufficient funding that reflects the low priority given to disability issues. Rafeeuddin Ahmed (1993) in describing the positive outcome of the decade acknowledges the emergence of a global movement recognizing the importance of the integration of people with disabilities into society as a means of building 'societies for all'. This outcome was a significant departure from a long-held perception of people with disabilities as medical cases and objects of charity, towards one focusing on people with disabilities as citizens, community participants and family members. (Ahmed, 1993 : i).

Godfrey Ooi (1994b) in his assessment of the impact of the IYDP in Malaysia notes three significant aspects. Firstly, Malaysian society has come to the realisation that they have the responsibility that "disabled people are no longer relegated to the dumps of silence and despair". (Ooi, 1994b). Secondly, that the plight and struggles of disabled people have been highlighted; and thirdly that disabled people in Malaysia have realised that they have an important role to play in society. According to Ooi:

*1981 has become an important landmark in the history of disability work for our disabled people [as well as] the watershed between the past and the future with regards to disability work in Malaysia. (Ooi, 1994b : 2).*

Furthermore he acknowledges that the Malaysian Government has taken cognisance of the UN pronouncements and documents pertaining to disabled people. Over the past 10 years or more, explained Godfrey Ooi,

*we have seen greater interest on the part of the Government in providing for the needs of the disabled in such things as the national budget, public awareness and even representation of the disabled on various committees. (Ooi, 1994c : 5).*

Chandra Muzaffar (1989 : 17) in his analysis is more critical and raises the question of how many people in general in Malaysia, and in particular in the Malaysian Parliament, know about the UN Declaration on the Rights of Disabled People. In noting this he implied that there is still a lack of understanding on the fundamental issues. He calls for the popularisation of the Declaration on Rights of Disabled People. It is important to note that Malaysia has not ratified this Declaration.

While we note the positive impact, we also acknowledge that more needs to be done. At the surface level there is a political endorsement of the UN Decade but, as one looks deeper within, much more needs to be done in order to ensure the equalisation of opportunities for disabled people. However, the United Nations in general and its regional office, Economic and Social Commission for Asia and the Pacific (ESCAP), have been systematically and consistently monitoring as well as further developing in specific ways the agenda of the World Programme of Action.

In 1992 at Beijing, China ESCAP proclaimed 1993-2002 as the Asian and Pacific Decade of Disabled People. An Agenda for Action for the Asian and Pacific Decade of Disabled Persons was also adopted. This was adopted because there was concern that the region, which has the world's largest number of disabled people, had not adequately responded to the challenges of the UN Decade. Therefore the promotion of full participation and equality of disabled people in the Asia-Pacific region which is the theme of this regional decade is an appropriate one. Malaysia was represented at this gathering and agreed to ratify the proclamation. On 16 May, 1994 the then Deputy Prime Minister, Datuk Seri Anwar Ibrahim signed the proclamation on behalf of the Malaysian Government. This was indeed a positive step forward for Malaysia and on the foundations of the UN Decade, the policies of the region will be consolidated.

It is further important to note that the Asian and Pacific Decade has been formulated in accordance with the 'Social Development Strategy for the ESCAP Region Towards The Year 2000 And Beyond' (ESCAP, 1991), which was adopted by the Fourth Asian and Pacific Ministerial Conference on Social Welfare and Social Development, held at Manila in October 1991.

Malaysia was represented at this gathering which adopted a three-fold strategy for the region, namely the eradication of absolute poverty; realisation of distributive justice; and enhancement of popular participation. These policy statements and strategic plans address disability issues from a social perspective. They were formulated on the basis of rights of all disabled people through the enactment of appropriate legislation. They addressed essential aspects such as public awareness, accessibility and communication, education, training and employment. A major strategy for implementation was the establishment and strengthening of self-help organisations of disabled people including associations of advocates and families of disabled people.

Since the proclamation of the Asian and Pacific Decade a number of expert group meetings have been organised in the region. Three are notable as they focussed on the heart of the current challenges - appropriate legislation (Malaysia, 1993); matters pertaining to non-handicapping environments (Philippines, 1994); and issues relating to self-help groups and organisations of disabled people (Thailand, 1994). These have been attended by Malaysian delegates from the Government and disabled people's movement. The documents that have emerged from these gatherings will have an eventual impact on national governments in the region for appropriate action. Furthermore the role ESCAP is playing in the region continues to remind the governments of their role in enhancing the equal opportunities of disabled people.

Three documents released by the United Nations in 1993 provide a comprehensive framework for governments and disabled peoples' movements to use as the basis for developing appropriate policies and concrete plans for local action.

## **2. Community-Based Rehabilitation**

## **2.1 Definitions & Concept of CBR**

### **2.1.1 What is CBR?**

As many experts and others have noted, it defies definition. It started as a simple idea and strategy to deliver basic rehabilitation services to communities, especially those that were rural and isolated. But as time went, the scope of CBR has widened into a more complex, multi-sectoral strategy, requiring much coordination, collaboration and implementation by various groups and people. There are different approaches and types of CBR services and different models. The type of CBR programme found in a location may vary depending on the resources available, conditions, All this means that it is difficult to identify a model CBR approach and strategy.

Community-oriented programmes have been implemented in developing countries in the 1960s but the CBR approach took off when international groups like the World Health Organisation and international development agencies adopted it to ensure delivery of rehabilitation services in developing countries. The context was that people with disabilities, especially in remote areas, had little or no rehabilitation services.

A International Labour Organization (ILO), UNESCO and WHO joint position paper 1994 states the major objective of CBR is "to ensure that people with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities and achieve full social integration within their communities and their societies." WHO introduced CBR in 1976 as a way to achieved its goal of "Health for all by 2000". CBR received global recognition with the adoption of the World Programme of Action for Disabled Persons, which is a basic document for the United Nations Decade of Disabled Persons.

CBR, some argue, is a way of thinking, not a specific programme. It comprises a lot of different activities, all focused on helping solve disability issues. It looks at solving problems related to disabled people not only from a health perspective but of income and social security, education, legal rights and social participation.

There are different interpretations of what CBR is and means and consequently, it manifests itself in various forms in practice and real life. There are various streams in CBR thinking and practice. One sees CBR as a programme or strategy to empower members of a community and family of the disabled person to perform certain rehabilitation functions. It was simplified so that even an untrained community member could perform some rehabilitation function.

Others see CBR as a means to bring professional rehabilitation services to more disabled persons, especially in remote areas, and also to refer others to more sophisticated services in hospitals and rehabilitation centres. It is also seen as an alternative to centre-based rehabilitation centres in developing countries because the latter had limited impact on large groups of disabled persons due to inaccessibility and other factors. Expensive sophisticated services could only benefit a limited number. It is estimated that as many as 80 percent of disabled people in developing countries live in rural areas.

CBR was seen as a new approach towards a grassroots-type of programme that would bring rehabilitation services to disabled persons, especially in poorer and remote communities. International agencies, NGOs and developing countries were quick to adopt this new strategy. Many governments saw CBR as a cheaper way to help more disabled people in rural communities, and which had the added advantage of increasing a government's presence in such areas.

An essential feature of CBR is its emphasis on partnership and community participation. Its aims are to rehabilitate and train disabled individuals, as well as to find ways to integrate them into their communities. The disabled person, the family, the community, and health professionals collaborate to provide needed services in a non-institutional setting, and in an environment or community where services for disabled persons are limited or absent.

CBR basically refers to rehabilitation within the community and is based on a philosophy that the family and community have a pivotal role in the rehabilitation process. This approach has two major goals:



- *To create a situation where the disabled person can live as fulfilling, self-reliant and whole life as possible.*
- *To help others (family, neighbours, community members) to accept, respect, feel comfortable with disabled persons, provide equal opportunities for, and appreciate the abilities and potential of disabled persons.*

### **2.1.2 Some Definitions**

"A developmental approach towards greater community consciousness and support in reducing the incidence of disability and to sustain a better quality of life. It is an effective entry point to community involvement where the focus is on children and their families with respect to prevention, development and rehabilitation."

"A comprehensive approach which encompasses disability prevention and rehabilitation in primary health care activities, integration of disabled children in ordinary schools, and provision of gainful economic activities for disabled adults."

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

"A term used for situations where resources for rehabilitation are available in the community. There is a large scale transfer of knowledge about disabilities and of skills in rehabilitation to the people with disabilities, their families and members of the community. There is also community involvement in the planning, decision-making and evaluation of the programme. One may call this the democratisation of rehabilitation." (Helander, Mendis, Nelson and Goerd, 1989)

### **2.1.3 Elements of CBR**

Laura Krefting lists some things CBR is not and this includes being high-tech rehabilitation; hospital-based; healing the results of lack of care in community; and being only rural-based (it can be urban-based). According to her, some aspects of CBR are:

- Outreach - professionals going out to home and community to work with families
- Community centre - professionals, disabled persons, families and volunteers coming together
- Mobile rehabilitation units - e.g. van with simple rehabilitation equipment travels to villages for assessment, referrals, awareness.
- Income-generation schemes - training for disabled person; help disabled to set themselves up in the community.
- Increasing social opportunities - help overcomes segregation of disabled person in community.
- Prevention of disability in community - e.g. accident prevention programmes
- Providing special equipment - low cost, low tech. Adapt equipment to local conditions.
- Community education.
- Enabling people with disabilities to help others.
- People with disabilities acting as role models.

### **2.1.4 Strengths & Weaknesses**

Despite problems and doubts, CBR is still considered a viable and valuable option, especially in rural, hard-to-reach and island communities in the Asia and Pacific region. For many in these places, without CBR there is no possibility of any rehabilitation services reaching them.

A major strength is its capacity to provide rehabilitation services with minimum disruption to the disabled person and his or her family. It is also meant to take place within the community where the disabled person resides. Because of the need for community involvement and participation, it can strengthen and develop the community. It also has the capacity to be cultural-sensitive. A 1994 CBR workshop in Kuching highlighted some points showing why CBR was a good approach to solving disability issues. These included:

**Coverage** - services can reach a maximum number of disabled people because it does not depend on a building or highly-trained professionals.

**Cost** - building, equipping and maintaining special rehabilitation facilities and employing professionals are costly. CBR is much less expensive.

**Impact** - Its emphasis on community education, prevention of disability and early intervention, will reduce the number of people with disability, and reduce the degree of handicap in those with disabilities.

**Geography** - it can happen anywhere where there are people who want to help those who are disabled.

**Integration** - because the disabled persons continue to live in the community, they have a better chance of being integrated to it, compared to being sent to an institution outside the area.

**Community education** - it gives the local people a chance to learn about disability, the needs and potential of disabled persons.

**Full participation** - it allows the disabled a chance to be participants in all aspects of the programme, not mere recipients of a service.

**Flexibility** - it responds to the needs of the community and is not a set programme. It can better meet local needs and fit local conditions.

**Community Development** - when the community learns it can help persons with disabilities, it develops into a better

community. It also increases confidence and helps it realise that it can change things for better.

Among some problems and weaknesses identified in CBR are that it is professionally unsatisfactory and that it is difficult to organise as self-sustaining programmes. It can also lack feasibility without major support from the community. And there is no global approach to organising CBR. Others point out that while called CBR programmes, many such programmes lack the essential elements like community participation, awareness and educational components. Although ideal as a strategy and plan, often the implementers and people affected like the disabled people and local community are not properly briefed or understand fully the concept and aims of the CBR programme.

Many CBR programmes still retain a centre-based approach and an emphasis on medical rehabilitation. Some are implemented in a top-down method with little community input, control and participation. Attitudes and values play an important role in the success of CBR programmes and sometimes, there is an attitude of non-acceptance and lack of support from the disabled people themselves and/or the community. In some cases, cultural and social factors are ignored in CBR programmes and result in doubts and lack of context.

The lack of training of grassroots workers and implementers often result in faulty CBR programmes being carried out and the lack of evaluation and monitoring mean that many problems and barriers are not addressed. Other problems identified in some CBR programmes are the lack of trained personnel, poor coordination among groups involved, lack of facilities, no clear Government policies and support, inadequate equipment and supplies, and lack of finances.

## **2.2 CBR in Malaysia**

Community Based Rehabilitation (CBR) has been adopted as a major strategy in addition to the institutional-based approach in Malaysia. It is a programme adapted to fit various local conditions and has been implemented by both Government agencies and NGOs.

It was introduced as a concept to Malaysia in the late 1970's (Ranjit Kaur, 1998) but only took off as a pilot project in

1984. Today, there are numerous CBR programmes carried out at different levels throughout the country. A significant effect of this programme adopted from international aid and health agencies has been that many disabled persons now have a chance and choice to remain at home within the community instead of being placed in residential and other institutions.

CBR was initially promoted as an alternative approach for developing countries so that people with disabilities could have access to more rehabilitation, training and other opportunities to enable them to live as independently as possible. One of its premises is that ordinary people like parents and other volunteers from the community, together with trained staff and rehabilitation and medical professionals could help train, support and encourage the disabled towards self-help and independence. It was envisaged that community resources would be used effectively in this approach. It would also see the community adjusting itself to the needs and aspirations of the disabled persons.

The goal was for the disabled person to live a fulfilling and independent life within the community, without any disruption in terms of relocation to a residential or rehabilitation facility far away. The community would also benefit because more of its resources would be utilised in a beneficial way and disabled members of that community and their families would live more satisfying lives.

Over time, the development of CBR as an approach and programme, together with other national and international initiatives and emphases, has resulted in a more positive atmosphere whereby the disabled can live and progress. While much has been achieved, there is still a long way to go in terms of equalisation of opportunities, attitudinal changes in society, and independence and justice for the disabled.

### **2.2.1 Start of CBR in Malaysia**

Several reasons can be cited for the change in approach by the Government in the way it handled the problem and plight of the disabled. While the dominant approach before the 1980s was mainly residential, institutional and vocational, there was also realisation that these services were

insufficient to meet all the existing and growing needs. Such services were also expensive in terms of infrastructure and manpower. In addition, the disabled who were located in remote areas were to be reached by outreach services which required professionals to travel into these communities. Again, this was not cost-effective and feasible due to lack of follow-up.

The previous approach was also based on a charity and individual model of social work. The disabled were seen and labelled as clients in need of care and services. The community and family members had no part to play in the rehabilitation of these disabled persons. There was also the reality that there are limited places run by Government agencies for the disabled. For example, the Taman Sinar Harapan training centres take in only 800 persons at a time. Even here, the Government faces a problem of trainees who have graduated and yet are unable to return home or are unwanted by their families. Many stay on in these centres and take up places for new trainees. Another 1,041 persons are under the care of institutions run by the Department of Social Welfare. Compared to the estimated

Compared to the present estimated 220,000 disabled persons in Malaysia by the Minister of National Unity & Social Development, formal residential, vocational and institutional centres will never be able to cater for the needs of such a large number of disabled persons. The majority of disabled persons continue to live in the community with their families and guardians. Thus, to cope with the problem of insufficient places for trainees, the department embarked on a pilot Community Based Rehabilitation project in Terengganu in 1984.

Internationally, CBR was being promoted as a viable alternative to the more traditional models of outreach to those in need. It would also use a different approach based on a social model and would involve the active involvement of disabled persons, their families and their communities. The goal was a wholistic and integrated way towards not just physical rehabilitation but also social rehabilitation within the community. This emphasis would be the community as the base for rehabilitation, this the term CBR.

So, after some 40 years with institutional care as the dominant approach since the 1940s, the first CBR

programme was initiated in 1984. Initial guidance and training were provided by World Health Organisation (WHO) consultant Padmini Mendis. And a feature of this pioneer effort was the home-based programmes for each client. As a result of this initial success, CBR was introduced in other places, mainly by the department and then later by NGOs. Some of these CBR projects were new while others grew as an extension of centre-based and other programmes. This community-based approach involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled, and handicapped persons themselves, their families, and their community as a whole (WHO, 1981 : 9). The CBR programmes have not only catered for more service users but the approach has enhanced the potential of disabled people, their families and the community.

### **2.2.2 CBR Models in Malaysia**

The actual implementation of CBR concepts are varied, depending on the agency involved, location and profile of the disabled and community concerned. While the main philosophy of CBR programmes remains the same, there are differences in the way they are initiated and implemented. The varying elements of each CBR programme include (Ranjit Kaur, 1998):

- the rationale for setting up CBR programmes
- the way they are initiated
- the plans
- the management
- funding
- development
- area covered
- type of activities

### **2.2.3 Activities of CBR Programmes**

A typical CBR programme has the following activities:

- Group rehabilitation programmes - in centres
- Individual rehabilitation programmes - at the centre or at home
- Referrals for treatment, education, training, job, etc.
- Recreation and sports

## 2.2.4 Training Workshops

At least four CBR training workshops have been held since 1989, bringing together all the key community workers. It has provided opportunities for staff and volunteers to share experiences and network. In the 1989 workshop on CBR in Malaysia, the participants, using the WHO definition, redefined CBR for application in the Malaysian context. (Ranjit Kaur, Zaliha Omar and Sandiyao Sebastian : 1997). The key points that emerged from this were:

- Ensure the involvement of disabled persons, their families and communities in action taken at the home and community level.
- Prevent the complications resulting from disability.
- Ensure acceptance and integration of disabled persons in the family and community.
- Make available assistance to families of disabled persons.
- Use local resource materials to make aids and appliances for disabled persons.
- Assist disabled persons to achieve their maximal potential to live as independently as possible.
- Ensure prevention of disability by awareness programmes and counselling.

The 1989 CBR Action Planning Workshop which brought together staff from Government agencies, NGOs and others to discuss issues saw plans being charted for the various states. Numerous CBR programmes were initiated at various community levels, with each programme having its own unique features. Almost all the CBR programmes were initiated by an outside agency such as the Department of Social Welfare or NGOs.

However the models used by the department differed from that by the NGOs. The WHO manual and local resources was under-utilised. Therapists and educators were called upon to administer the rehabilitation programmes. Families of persons with disabilities gradually lost confidence in CBR workers and depended heavily upon professionals (Ranjit Kaur, 1998).



### **2.2.5 CBR initiated by the Department of Social Welfare**

Ranjit Kaur describes the way the department initiates CBR programmes in an area. "The staff firstly identify persons with disabilities in their areas using the welfare registration list. They select a community where the number of children with disabilities is larger. The families of these children and local volunteers are contacted and the idea of starting a day care centre (CBR centre) is suggested. The staff and volunteers then identify a local building that they intend to use for implementing the programme.

"The staff then get the assistance of local hospital staff or the nearest therapists who can help assess the children and provide simplified programmes that can be carried out by the carers and local volunteers. As the activities progress, the local volunteers undergo a one-week basic training organised by the department. These volunteers receive a monthly allowance from the department for their work done. The staff of the department play a supervisory and advisory role.

The department then guides and advises the local CBR participants and key persons in the community to form a committee to manage the programme. Gradually they are guided to register with the Registrar of Societies as voluntary organisations. A guideline on staff and administrative matters has been produced by the department for CBR organisations to adhere to."

### **2.2.6 Financial Assistance**

The Department of Social Welfare provides financial assistance to NGOs with CBR programmes. This is in the form of staff allowance, renovation of premises, initial set-up costs and annual running costs. In 1992, the Government began to provide allowances payable to voluntary workers at the rate of RM 300 a month for 36 workers. This was considered a boost and a milestone in the development of CBR programmes in this country. The allocation of such allowances for CBR programmes in the country has increased steadily, in line with the increase in the number of programmes set up. Below is a table with figures from 1992 till 1999.

Year	Allocation (RM)	Number of CBRs
1992	1,129,600	52
1993	1,129,600	75
1994	2,123,000	93
1995	2,661,000	108
1996	2,867,000	158
1997	4,038,640	179
1998	3,280,660	196
1999	3,300,160	203

### 2.2.7 Future Directions

The Department of Social Welfare's Meme Zainal Rashid wrote in 1997 that the CBR programmes provided a viable alternative for cases that could not to be admitted to any institutions for the disabled. Up to June 1997, some 66,859 cases were registered with the department. The breakdown of the registered cases were:

- *Visually handicapped* 11,071
- *Physically handicapped* 23,238
- *Hearing impaired* 12,358
- *Mentally retarded* 20,154
- *Others* 38

The DSW administers five rehabilitation institutions for the disabled known as Taman Sinar Harapan - two in Johor and one each in Selangor, Terengganu and Negri Sembilan with a total maximum capacity of 980. The department is also responsible for the training Centre for the Disabled In Cheras and the Industrial and Rehabilitation Centre in Bangi. These institutions are often full and unable to take in additional cases. They all have long waiting lists of cases for admission. The majority of cases are left in the institutions for care and rehabilitation with no effort on the part of parents to take them back.

Not all cases registered for admission are suitable. Some may just require specific training and rehab programme in mobility, speech, special education and skills in daily living activities which can be best provided through CBR. It is therefore imperative that they be absorbed into the CBR programme where the maximum benefits can be attained at an early stage.

It was observed that children from rehab centres like Taman Sinar Harapan have problems of adjustments during home leave or after being discharged. This was due to the fact that there was no concurrent training and preparation for the families. Prolonged institutionalisation and lack of family involvement have detached them from their families and resulted in greater problems of adjustment during adolescence and often become unmanageable. There was therefore an urgent need to involve family members in the care and rehab of these special children through the CBR programme.

The CBR model that can best be implemented in the districts is one that is both simple and cost-effective. This approach has several distinct characteristics:

- use of a community hall or any building suitable as an activity centre
- CBR programmes to be implemented in places with a high concentration of disabled persons
- parents contribute towards transport expenses for their children to attend the programme
- parents contribute for the running of activities including meals for the children
- active involvement and interaction of parents as a therapeutic group
- progress of the children in the centre and home are recorded
- volunteers are paid an allowance or honorarium'
- after-care supervision is done in the homes from time to time

The department adopted three different approaches: Centre-based CBR; home-based CBR; combination of both where children come to centre three times per week and volunteers make home visits twice a week. The programme has proven effective in helping disabled and families cope and work together towards a better quality of life with the support of the community. Some of the results include:

- Instil an independent attitude among the disabled children
- Parents have acquired knowledge and skills to teach and train their disabled children through direct involvement and participation in activities.
- Disabled children are able to undergo training and rehabilitation tailored to their needs and disability.

- Awareness on the part of parents that their children have the ability to develop given the proper training and guidance.

The department planned to upgrade current activities of CBR to higher level of technology - production of simple utensils and assistive devices used in CBR like modified eating utensils, modified wheelchairs and other devices. Some CBRs with suitable personnel and trained disabled participants can be used as a base to mass-produce such devices for use of other CBR projects.

In 1997, DSW had 167 CBR projects with 3,000 children and 318 workers or teachers. The Government approved RM2.6 million that year to subsidise payment of workers' allowances and rental of premises. An additional RM1.056 million was approved for setting up of 20 CBR projects and RM500,000 for purchase of training materials and rehabilitation equipment for CBRs. The CBR approach should not deviate from its fundamental principles of cost saving, optimal resource mobilisation and utilisation, full participation of parents and their immediate families and empowering the members of the community to manage and take responsibility of the CBR programme through establishment of ad-hoc committees.

The department also feels that CBR has been an effective alternative in the rehabilitation of the disabled. It is also less expensive compared to the cost of the Government-run Taman Sinar Harapan centres. For example, the cost of CBR programmes for 240 disabled persons was RM209,160 per year (or RM2.40 per day per disabled person). In comparison, the cost in the Taman Sinar Harapan programme was RM1,228,905 for the same number of disabled persons (or RM14 per day per disabled person). The saving per day per disabled person was RM11.60.

In addition to help given to the disabled person, the CBR teachers can also do home visits to teach the parents rehabilitation skills at home. CBR is also able to optimise the involvement of the parents and local community. The problems of running a CBR programme and those of the disabled are shared and they look for solutions together. This will increase the awareness of parents and the community about the needs of the disabled.

In 1994, the department committed itself to developing this approach and their target is to set up at least one CBR programme in each and every district in Malaysia by 1995. There are 86 districts in Malaysia. By the end of 1995, there were 135 CBR programmes run by the department, providing services to 1,770 disabled people at the cost of RM 2.123 million (Rahman, 1995b:12). The department plans to improve and widen the centre-based CBR programmes to every district. For the year 2000, 20 new CBRs will be set up to meet the training and rehabilitation needs of the disabled. To improve the effectiveness of the programmes, the department plans to set up three levels of CBRs. These are Level 1 - Early Intervention (0-7 years); Level 2 - teenagers (8-18 years); Level 3 - small industries involving the disabled and local communities.

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

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

In 1998, there were 196 CBRs serving 3,779 disabled persons. By August 1999, there were 213 CBRs with 4,781 clients and 453 staff. The breakdown for 1998 were:

	Number of Clients		Number of CBR's	
	1997	1998	1997	1998
Perlis	4	4	53	86
Kedah	11	12	188	243
Pulau Pinang	17	17	181	201
Perak	17	20	358	307
Selangor	21	28	433	567
Kuala Lumpur	2	2	30	30
Negeri Sembilan	18	23	379	502
Melaka	8	10	203	270
Johor	18	24	308	499
Pahang	19	20	291	317
Terengganu	8	10	134	162
Kelantan	15	15	282	299
Sabah	5	6	92	148
Sarawak	3	4	57	136
Labuan	1	1	11	12
<b>Total</b>	<b>167</b>	<b>196</b>	<b>3,000</b>	<b>3,779</b>

### 2.2.8 CBR initiated by NGOs

There are basically two types of CBR programmes implemented by NGOs. NGOs that have institutional services or special education programmes have extended their programmes by introducing CBR in their areas. Newly set-up NGOs have also formed to provide CBR programmes. These NGOs are set up by local persons such as local community leaders, professionals, parents of persons with disabilities and interested persons.

The day care centres or CBR centres are located in various premises, from existing community buildings to rented or owned premises. Some of these NGOs conduct home visits where the persons with disabilities undergo home-based rehabilitation programmes. Since the Government through the Department of Social Welfare does not provide all the funding, NGOs often have to seek their own funds, through such activities like:

- *charity dinners and concerts*
- *donations from corporate companies and Foundations*