

SELF-ADVOCACY MOVEMENT OF PERSONS WITH
LEARNING DISABILITIES: A CASE STUDY
IN THE MALAYSIAN CONTEXT

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Abstract

The needs of persons with learning disabilities (LD) are most effectively addressed when persons with LD advocate for themselves. For this very reason, self-advocacy groups are formed so that persons with LD can unite their voice to represent themselves in society. Self-advocacy movement is considered a civil rights movement for people with LD because it can bring about change in the lives of persons with LD by impacting individuals and changing national policies to ensure the rights of citizens with LD are protected. In this study, factors that affected the movement and the impact of the movement in the lives of persons with LD were investigated. This generic qualitative study uses interviews, observations and document analyses to examine the self-advocacy movement of persons with LD in Malaysia. Participants who were involved in this study include 11 persons with LD and 10 others who are either care givers of persons with LD in a center/organization/family and leaders who are involved in services for persons with LD. The lack of awareness on self-advocacy in general appeared to be the main factor amongst the seven factors found to have affected the slow progress of the self-advocacy movement. Other affecting factors include the lack of support from NGOs involved, structure of self-advocacy groups, family support, intellectual inhibition, public attitude and national policies. The research also discovered that self-advocacy groups have significantly impacted individuals with LD to be aware of their rights, develop confidence to voice up for themselves and take up leadership responsibilities. But, the key concern is many persons with LD in Malaysia are not aware of self-advocacy. It is strongly recommended that self-advocacy should be included in the curriculum of Special Education to ensure that persons with LD are given formal training on self-advocacy.

Abstrak

Pergerakan Advokasi Diri Orang Bermasalah Pembelajaran:

Satu Kajian Kes Dalam Konteks Malaysia

Keperluan bagi orang bermasalah pembelajaran boleh diatasi dengan berkesannya jika individu-individu berkenaan menyuarakan untuk diri mereka. Kumpulan-kumpulan advokasi diri ditubuhkan agar orang bermasalah pembelajaran boleh menyatukan suara hati masing-masing untuk mewakili diri dalam masyarakat. Pergerakan advokasi diri adalah suatu gerakan hak sivil untuk orang bermasalah pembelajaran kerana gerakan ini boleh mengubah kehidupan orang bermasalah pembelajaran secara positif. Pergerakan ini juga ada kesan positif terhadap polisi-polisi nasional untuk memastikan hak-hak warga bermasalah pembelajaran terjamin. Dalam kajian ini, faktor-faktor yang mempengaruhi pergerakan ini dan impak pergerakan ini terhadap kehidupan individu bermasalah pembelajaran telah dikaji. Kajian kualitatif generik ini telah menggunakan temuduga, pencerapan dan analisa dokumen untuk mengkaji pergerakan advokasi diri orang bermasalah pembelajaran di Malaysia. Peserta-peserta dalam kajian ini terdiri daripada 11 orang bermasalah pembelajaran dan 10 orang lagi termasuklah pemimpin, penjaga-penjaga di pusat atau organisasi serta ahli keluarga bagi individu bermasalah pembelajaran. Secara am, kekurangan kesedaran tentang advokasi diri adalah faktor utama antara tujuh faktor-faktor rintangan perkembangan pergerakan ini di Malaysia. Faktor-faktor lain termasuklah kekurangannya sokongan dari pihak NGO, struktur kumpulan advokasi diri, sokongan keluarga, penyekatan intelek, sikap orang ramai dan polisi nasional. Kajian ini juga telah merakamkan banyak impak-impak positif kumpulan advokasi diri terhadap individu bermasalah pembelajaran. Impak-impak utama termasuklah kesedaran tentang hak diri, keyakinan menyuarakan diri dan kebolehan mengambil bahagian dalam kepimpinan. Tetapi,

terdapatnya ramai orang bermasalah pembelajaran yang masih tidak sedar tentang advokasi diri. Cadangan utama ialah menjadikan advokasi diri sebahagian daripada kurikulum Pendidikan Khas untuk memastikan semua orang bermasalah pembelajaran diberi kesedaran dan didikan tentang advokasi diri.

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CHAPTER 1

THE PROBLEM AND ITS SETTINGS

1.1 Introduction

In Malaysia, self-help organisations led by people with disability have a history of about four decades. In 1993, Armstrong (1993:192) already observed that, “Self-help movement has become an important element of response to disability and the advancement of people with disability in Malaysia...” The first Society of the Blind was set up in 1964, followed by the Society of the Orthopaedically Handicapped in 1976, and the Kuala Lumpur Society of the Deaf in 1987. However, there was no society of people with learning disabilities until recently. The first Society of Persons with Learning Disabilities (LD) known as Self-Advocacy Society of Persons with Learning Disabilities Selangor and Kuala Lumpur (United Voice) was registered in July 2005 (Pang, 2005:15).

The late formation of their own self-help organization has deprived persons with LD the opportunity to experience advancement like other disability groups in various aspects of development. For example, in the area of education, as noted by Jayasooria (2000:96), people with LD are the most neglected ones with regard to statutory or government-provided educational and training opportunities. While schools for the Blind and Deaf were set up in the 1950's, formal education for students with LD in the government schools began only in 1988.

Deutsch, (1998:263) noted that most people with LD do not have the experience or opportunity to make their own decisions or be independent. They often do not have a chance to make simple decisions, like what movie to watch, what

restaurant to eat at, or whom to visit. Cognitive impairment and the lack of communication skills, the major handicaps for most persons with LD, could be key reasons that hinder them from speaking up for themselves and experiencing independent living.

To help persons with LD face the challenges in adulthood, opportunities for good basic education, vocational training, employment and social life should be given serious attention by the government as well as the community as a whole. Evidence in the developed countries indicate that person with LD have an important role in determining their own future. Tan (1996:2) explained that, “Self-advocacy is based on the belief that people are their own best advocates. Thus persons with learning difficulties are their best advocates to tell others what they want.” Unless persons with LD learn to advocate for themselves, priorities for their development might not be given much attention as they are contending with so many other social needs especially in a developing nation like Malaysia.

Self-advocacy, a social movement founded in Sweden in the 60’s, has significantly changed the lives of persons with LD in the developed countries where their quality of life has improved through provisions such as Individualised Education Programme, quality vocational training, employment opportunities and supported homes. This movement emerged to give persons with LD a collective as well as an individual voice. A social movement according to Bersani (1998:59), “represents a strong ideological change” which involves the emergence of a new dimension of identity, often portraying a characteristic previously seen as a weakness.

Citing Walmsley and Downer (1997:36), Atkinson (2002:122) explained that self-advocacy is seen to be about people with LD gaining power to speak up for their rights as a group, rather than wait for other people to speak up for them. Goodley

(2000:3) observed that the self-advocacy movement in Britain has “invited people with LD to revolt against disablement in a variety of ways, in a number of contexts, individually and collectively, with and without the support of others. The movement captures resilience in the face of adversity.”

Gray and Jackson (2002:10) argued that advocacy by and for people with LD is based on the belief that all citizens have the same rights, responsibilities and potential for growth. They further stressed that there is a need to combat the exclusion and discrimination experienced by some members of the British society through enabling them to access their human and legal rights. Their view has pointed to the need to strengthen the advocacy and self-advocacy movement of persons with LD who are often excluded and discriminated in all societies.

Self-advocacy movement of persons with disability is affirmed in the Biwako Millenium Framework for Action of Economic and Social Commission for Asia and the Pacific (ESCAP) (2002:5) which stated:

Persons with disabilities are the most qualified and best equipped to support, inform and advocate for themselves and other persons with disabilities. Evidence suggests that the quality of life of persons with disabilities, and of the broader community, improves when disabled persons actively voice their concerns and participate in decision-making. Self-help organisations are the most qualified, best informed and most motivated to speak on their own behalf concerning the proper design and implementation of policy, legislation and strategies which will ensure their full participation in social, economic, cultural and political life and enable them to contribute to the development of their communities.

The Biwako Framework also stressed that it is crucial to recognise the right of persons with disabilities to “self-representation and to reinforce their capacity to take part in the decision-making process.” To bring about development and independent living in their communities and society in general, “persons with disabilities must voice their own issues and advocate for reforms.”

The self-advocacy movement of persons with LD in Malaysia is still in its formative stage. Though two self-advocacy groups of persons with LD were initiated since the early 90's, Bethany Self-advocacy Group in 1993 and United Voice in 1995, it was only in 2005 that the first Self-Advocacy Society of persons with LD was registered with the Registrar of Societies. What are the factors that influenced or affected the progress of the movement? How have self-advocacy groups impacted the lives of individuals with learning disabilities in Malaysia? These are two key questions to be examined in this study.

1.2 The Statement of the Problem

Self-advocacy is an unknown term to many Malaysians. It is not a term used in the legal practice. Neither is it commonly used by laymen. The term is not even found in the Oxford Advance Dictionary.

It appears that many Special Education teachers in Malaysia are not aware of the impact of self-advocacy in the lives of persons with LD. This lack of awareness could be due to the fact that self-advocacy is not formally introduced as a subject in the Malaysian Special Education Curriculum for Primary and Secondary Schools (*Jabatan Pendidikan Khas, 2003; Jabatan Pendidikan Khas, 2004*).

Abidin, a parent who has a child with LD and is also an officer at the Department of Special Education, Ministry of Education Malaysia commented that the curriculum for Special Education in Malaysia is flexible. Teachers who are creative will use the curriculum to teach students many skills to prepare them to be independent young adults. But, she noted that the term 'self-advocacy' is not used in the curriculum and most teachers have no knowledge of the term 'self-advocacy'. As a special educator for the past 10 years and currently pursuing a doctorate degree,

specializing in a field of Special Education, Abidin affirmed that self-advocacy is a very important subject as it will “help students with LD become independent persons and be aware of their rights and teach them to seek help from appropriate channels when needed.” However, she noted that self-advocacy can only be successfully introduced to students when teachers are educated on what self-advocacy is all about. Trained teachers should then organize training for the parents to create awareness on self-advocacy. Parents can provide a strong support to help students practise the lessons learnt on self-advocacy in the community that is closest to them. (N. Z. Abidin, personal communication, September 8, 2005.)

Study shows that students who learnt self-advocacy early in school tend to cope with post school life more confidently (Janipa & Costenbader 2002:465; Test, Fowler, Wood, Brewer & Eddy, 2005:2). Friend (2004:189), who agrees with this view, suggested that students need to be willing to identify themselves and their surroundings. This will help them cope in their education programme which prepares them for independent living and employment. Self-advocacy should be taught in school to instill awareness and build the competence in students with LD to voice up for themselves.

To date, there is only one vocational training center for persons with LD that is run by the government. Most school leavers depend on centres run by NGOs or Community Based Rehabilitation Centres for vocational training or sheltered employment. Observation shows that most service centers for persons with LD are not aware of the term ‘self-advocacy’ though many of them are already empowering their students, clients or members to develop their independent skills. Elsewhere, a study on the Curriculum Strategy of three established centers in Malaysia that provide

vocational training for persons with LD revealed that self-advocacy was not included in the curriculum of these centers (Yeo, 2005:19).

Chang, the Coordinator of Malaysian CARE Services for People with Special Needs, a Non-Governmental Organisation that has helped to establish six Employment Training Centers in Malaysia, confirmed that self-advocacy has yet to be introduced formally in the vocational training programmes used by these centers. Most service centers do not have formal training on self-advocacy skills for students with LD as it is not included as a subject in their curriculum. Chang however, noted that it was only recently that there is more awareness on the urgency for self-advocacy to be taught in a formal approach to equip students to know their rights, to exercise their rights by making decisions and voicing up for themselves to help them live a more independent life. Acknowledging the importance of self-advocacy in the lives of persons with LD, Malaysian CARE is in the process of developing training courses on self-advocacy as part of the curriculum in their Job Training Programme (Chang, F. C., personal communication, September 7, 2005).

Parents are generally ignorant of the self-advocacy concept. Many parents are depending on others to advocate for their children. Only a minority group of parents are actively involved in advocacy (Jayasooria 2000:104-105). Parents in Malaysia are still fighting for basic rights such as medical support, education, employment and living allowances for their LD children. In a report on a seminar entitled Disabled But Not Uneducable – Liberating The Disabled Through Education organised by the Bar Council that was attended by over 200 parents from all over Malaysia, Pang (April, 2005:20), a mother who has a child with LD wrote,

Ten years after the Special Education Department was established, the regulations that discriminate the learning disabled have yet to be amended, as pointed out by the Bar Council in its memorandum to the Government...There are still no early intervention centers for

preschoolers (except those provided by non-governmental organisations) and there are still no trained teachers to deal with specific learning disabilities.

Observation shows that parents who are aware of the importance of self-advocacy are almost insignificant. This could be due to lack of awareness. Some could be apprehensive that their children could be trained to advocate for themselves in this society where people with LD are still deprived of quality education and active participation in the community.

The lack of awareness and education on self-advocacy is obviously shown in the lives of adults with LD in Malaysia. At the 1st National Self-advocacy Conference (2004) organized by persons with LD in Malaysia, it was estimated that less than 15% of the 82 participants representing eight states were familiar with the term 'self-advocacy' prior to the Conference (Yeo, 2005:25). During the Conference, most participants learned for the first time that it is their right to make choices and to speak up for themselves. Many participants learned to share their opinions and make formal public speeches for the first time in their lives. Some teachers or support staffs who came with their youth with LD for this Conference were amazed at the ability of their members to participate in voicing their opinions on issues related to making decisions, relationships, their future and leadership. They began to realize, that when given an opportunity, these students from their centers are able to speak their minds on these issues.

Jamali, a self-advocate and a leader of United Voice expressed that it is difficult to be a self-advocate in Malaysia, "We are not given the freedom to speak up in school and in our community in general. People are not interested to listen to us. People think we are immature and they do not trust us to do things for ourselves. People must learn to trust us." He further stressed that, "We need to speak up so that

the public know us and do not look down on us. The government should hear us and help us in the aspect of education, employment and accommodation.” (J. Jamali, Personal communication, 2005, September, 22)

Support for the self-advocacy movement of persons with learning disabilities is observed to be insignificant within Malaysia though it has been established for more than 10 years. There is no in depth research done on self-advocacy in the lives of persons with LD. In the process of this present study, it was found that the local universities and teachers training institutions have very limited resources on self-advocacy.

If self-advocacy can bring about positive changes in the lives of persons with LD, what are some immediate measures to be taken by all parties (parents, teachers, trainers and advisors) involved in educating and training persons with LD in Malaysia? What action should be taken by the first Self-advocacy Society, United Voice, to further develop the self-advocacy movement? What are some useful researches that will strengthen the self-advocacy movement? These questions will be discussed based on the findings of this study.

1.3 Purpose of the Study

The purpose of this research is to case study the development of self-advocacy movement of persons with LD in Malaysia. By studying the impact of this movement, the researcher aims to examine whether the development of this movement has benefited persons with LD and thus determine the need to further expand the movement nationwide. It will also examine the factors that had affected the progress of the movement so that appropriate steps can be taken to enhance the development of this movement if deem necessary.

1.4 Objectives of the Study

The primary objectives of this study are:

1. To identify the factors which are affecting the progress of the self-advocacy movement of persons with learning disabilities in the Malaysian context; and
2. To examine the impact of self-advocacy groups in the lives of individuals with LD in Malaysia.

1.5 Research Questions

The following research questions are addressed in this study:

1. What are the factors that are affecting the progress of the self-advocacy movement of persons with LD in Malaysia?
2. How have self-advocacy groups impacted the lives of persons with learning disabilities in Malaysia?

1.6 Significance of the Study

There is no absolute statistic to determine the percentage of population in Malaysia that have learning disabilities. According to the Statistic Profile of the Welfare Department 2005, 170,455 persons with disabilities have been registered (Malaysia Community Welfare Department, 2005). Of the above total figures, 57,483 were classified as persons with LD. These figures are probably way below the actual figure of the population with disabilities since it is observed that many people with disabilities are not registered since registration is not mandatory but on a voluntary basis.

In year 2005 (*Maklumat Pendidikan Khas, 2005*), 16,303 students with LD were registered for special education in primary and secondary schools. However,

there is no record of how many children with severe learning disabilities that are not eligible for school as the Malaysian education system does not have provision to support children who are unable to cope with self-help skills as stated in the Regulation 3 of Regulation 1997 (Government of Malaysia, 1997). Many of these children either end up in centers run by private schools, Non-Governmental Organisations (NGO) or become housebound. The government is making efforts to include all students with disabilities in its special education programme. Though the Education Amendment Act 2002 (Government of Malaysia, 2002) has made primary education compulsory, Lim (2005:15) observed that at this stage it is only in theory that “all disabled children whatever their degree of disability, should be able to gain admission into government schools.” The present facilities, she pointed out “are insufficient to cater for the rising populations of pupils with LD”

Unemployment amongst persons with LD remains high. Many do not have opportunity for quality vocational training and therefore are not equipped for open employment. Out of 60 members in United Voice who are of age for employment, only 12 are in open employment. The others are either in sheltered workshops run by NGOs or supported employment. Several remain unemployed and are housebound. (Dignity and Services Review, 2005:2, June-September).

In a case study in Penang (Asia Community Service 2006:2), it was reported that 54.6% of 218 adults with LD who participated in a survey had no work experience at all. There were 24.8% who worked in the sheltered workshops, 5% in family businesses and only 8.7% have worked in the wider community or open employment.

Though the number of persons with LD registered is not an absolute figure, it is significant enough to call for an urgent action to ensure that these special citizens

are given equal opportunities for fundamental human development and also given the best support to improve their quality of life.

As mentioned earlier, it is proven in some developed countries (Janipa & Costenbader 2002:465; Test, Fowler, Wood, Brewer & Eddy, 2005:2) that self-advocacy movement is an effective and essential approach for persons with LD to move forward in a society. This study is necessary to determine the urgency to further develop the self-advocacy movement in Malaysia. If this movement has created a significant impact in the lives of persons with LD, more effort and resources should be invested to encourage the formation of self-advocacy groups and societies for persons with LD all over Malaysia. Support from all sectors involved is then necessary to help them work towards forming a Pan Malaysia Society of Persons with LD. Self-advocacy should also be considered as part of the curriculum of special school and vocational programmes if it is proven to be an effective strategy that can help students be independent and equipped to face life challenges after school and in adulthood.

If self-advocacy is a way ahead for persons with LD in Malaysia, it would be advisable for the Government, and all sectors involved to seriously consider working together in developing a system that will help persons with LD to self-advocate. Conscious effort to empower them to have a significant role in the society will be obligatory. The public need to hear from them about the challenges facing them and their needs. Respect is due to every human being. Persons with LD, though handicapped, should not be deterred from making choices, taking risks, speaking up and taking the lead.

The current study analysed the factors that have strengthened the self-advocacy movement as well as factors that hinder the movement from progressing.

This study strongly recommends that the self-advocacy movement should develop further. Relevant actions for all parties involved to support the movement will be discussed and recommended in Chapter 5. Factors that deter the development will also be addressed. Further research and studies will be recommended to strengthen the movement.

1.7 Limitations of the Study

The current study uses a generic qualitative method which includes observation, interviews and document analysis.

Observation is a very time consuming approach. Rose and Grosvenor (2001:30) acknowledged that, “For small-scale researchers the possibilities of devoting a great deal of time to a direct approach like observation is not possible”. This study did not have sufficient time to study intensively on the factors that affected the self-advocacy movement and the impact of self-advocacy groups in the lives of individuals with LD.

Observation bias and observer expectation could post another limitation in this study. Fraenkel and Wallen (1996:463) cautioned that impartiality and total objectivity is difficult in an observation research. They suggested that researchers should “do their best to become aware of, and try to control their biases”. This advice was carefully observed through out the study. The researcher, being a staff of United Voice has to constantly be cautious of being researcher bias. Her supervisor who is aware of the position of the researcher monitors this aspect carefully.

Any comparison in this study has to be based on research conducted by researchers who are non-Malaysian and of another culture and environment. There may be issues and perspectives observed by researchers of other countries, especially

those from the West, that may not be fully relevant for this current study due to many cultural and environmental differences between the Western developed countries and a developing Asian country, Malaysia. Since there is no earlier study on self-advocacy movement for persons with LD in Malaysia, this study lacks local supporting research.

This being a small-scale research, does not have enough time and resources to conduct an intensive study on the self-advocacy movement in Malaysia. Therefore, this study is only limited to study the factors affecting the progress of the movement and the impact of self-advocacy groups in the lives of individuals with LD.

1.8 Operational Definitions

Below are operational definitions for some of the terms used in this study:

1.8.1 Self-Advocacy

There are many definitions for the term 'self-advocacy' which have been used for more than 26 years. The meaning of self-advocacy has evolved over the years. Balcazar, Keys, Bertram, and Rizzo, (1996:2) defined, "Self-advocacy is a statement by people with developmental disabilities that we want to be seen as people who have something to offer and skills to share, rather than be seen as people with handicaps or limitations." Atkinson (2002:122) noted that self-advocacy is about identity. People in self-advocacy groups, she observed, are more likely to acknowledge their identity as persons with LD, "This can be seen as a celebration of difference rather than a denial of difference..." Self-advocacy, according to Walmsley (2002:29) is about people with LD advocating for their own needs rather than having their needs represented by

others. Self-advocacy has enabled people with LD to speak up and to be heard by others.

Referring to the definition of People First, the only organisation in London that is run and controlled by persons with LD, Aspis (1997:648) noted that self-advocacy includes:

- Speaking up for yourself;
- Standing up for your rights;
- Making choices;
- Being independent; and
- Taking responsibilities for oneself.

Being in agreement with the definition of People First, the First National Self-advocacy Conference by and for Persons with Learning Disabilities in Malaysia (2004) defined self-advocacy as:

- Knowing what you want;
- Making your own choices and decisions;
- Speaking up for yourself; and
- Knowing your rights and responsibilities.

According to Jamali, self-advocacy means “knowing our rights and voicing up for ourselves so that we will not be bullied, humiliated or be taken advantage of by others. Self-advocacy is also about freedom, freedom from our families or guardians so that we may live an independent life.” (J. Jamali, Personal communication, 2005, September, 22).

Test, Fowler, Wood, Brewer and Eddy (2005:6-7) did a comprehensive study on the definition of self-advocacy and aptly concluded that components of self-advocacy include:

- Knowledge of Self;
- Knowledge of Rights;
- Communication; and
- Leadership.

Test, Fowler, Wood, Brewer and Eddy had rightly used the term ‘communication’ instead of ‘speaking up for yourself’ in their definition of self-advocacy. Communication can be expressed verbally or non-verbally and therefore, self-advocacy is not only for LD who have verbal skills but it is also for persons with severe learning difficulties who do not have verbal skills. Tan (1996:3), included persons with severe LD in his definition of self-advocacy:

Given the right, many persons with learning difficulty can and will self-advocate. A person with mild learning difficulty self-advocates by voicing out his or her views. A person with severe learning difficulty self-advocates by his or her presence in a public meeting. Their inherent right to be in and part of society must be seen and upheld by us.

The term ‘self-advocacy’ in this study refers to persons with very mild, mild, moderate or severe LD expressing their thoughts, feelings as well as their views, standing up for their rights, making choices, being independent and taking responsibilities as an individual and as a group.

1.8.2 Self-Advocacy Movement

Self-advocacy movement is considered a civil rights movement for people with disabilities (Test, Fowler, Wood, Brewer, Eddy, 2005:3; Goodley, 2000:24).

According to an encyclopedia, Wikipedia (2005), civil rights movements usually want equal protection of the laws for minorities, as well as new laws outlawing discrimination and its vestiges. A movement can lead to changes that affect a community or a group of citizens and may bring about reform in national policies. The self-advocacy movement is set up to unite the voice of persons with LD to champion against discrimination and to ensure that all civil rights for persons with LD are met.

This current study examined the factors that affected the progress of the self-advocacy movement of persons with LD in the Malaysian context. This study also investigated how self-advocacy groups have impacted the lives of individuals with LD in Malaysia.

1.8.3 Persons with Learning Disabilities

The term ‘learning disabilities’ is defined differently in different countries. According to the Individuals with Disabilities Education Act 2004 (IDEA 2004) of United States, ‘learning disabilities’ do not include persons with mental retardation (US National Center of Learning Disabilities, 2004). Whereas, in the United Kingdom, the government adopts a more general definition for learning disabilities which does not exclude persons with mental retardation:

Learning disability includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development. (Valuing People, 2001)

According to the Ministry of Education in Malaysia, as defined in the *Maklumat Pendidikan Khas* (2004:2), the term ‘students with learning disabilities’ (*pelajar bermasalah pembelajaran*) include students with Down Syndrome, mild

autism, Attention Deficit Hyperactivity Disorder (ADHD), Attention Deficit Disorder (ADD), mild mental retardation and specific learning disabilities such as dyslexia. This definition covers a broad spectrum of learning disabilities. It includes persons with very mild, mild, moderate and severe learning disabilities. However, the very severe or profound LD is not included in this definition.

The term 'learning disabilities' is sometimes referred to as "learning difficulties" or 'intellectual disabilities' by different countries and authors. The operational definition for 'learning disabilities' in this study adheres to the definition used by the Malaysian Ministry of Education. The choice of term is also in alignment with the Malaysian legislature, Section 3 (1) of the Education Act (Special Education) Regulations 2 of the Regulation 1997 which defines "students with special needs" as those with "visual impairment, hearing impairment or with learning disabilities". The main reason 'learning disabilities' is a preferred term for the current study is because United Voice uses this term to describe the medical condition of its members who possess of all the disabilities mentioned in the definition stated by the Malaysian Ministry of Education. Lau, a leader of United Voice expressed, "We do not mind being described as persons with learning disabilities. We have to face it, our learning difficulties are a result of our learning disabilities." (Lau, B. L., personal communication, September 19, 2005).

As agreed by experts in the field of study on LD, individuals with LD are a heterogeneous population. Lerner (2003:14) noted that "Many different characteristics are associated with learning disabilities, but each individual is unique and will present only some of these characteristics". Based on her observation through close interactions with a group of about 70 persons with LD in the passed four years, the

researcher classified the various levels of adults with LD in this study by identifying their characteristics:

1. Very mild:
 - Able to read and write (level of abilities vary)
 - Relatively good in comprehension and communication skills
 - Independent in self-help skills
 - Relatively good in social skills
 - Able to travel independently
 - Capable of working in an open employment

2. Mild:
 - Able to read and write (level of abilities vary)
 - Moderate comprehension and communication skills
 - Independent in self-help skills
 - Inconsistent in social skills
 - Able to travel independently when given the opportunity
 - Not able to work independently in an open employment (in the Malaysian context) because of inconsistency in social skills and inconsistency in work performance (mainly due to mood swing and attention deficit disorder)

3. Moderate:
 - Poor reading and writing skills
 - Poor comprehension and communication skills
 - Inconsistent in self-help skills
 - Poor social skills
 - Not able to travel independently (within the Malaysian environment)
 - Need supervision at work

4. Severe:
 - Can hardly read or write
 - Very poor comprehension and communication skills
 - Weak in self-help skills (need supervision)
 - Very poor social skills
 - Not able to travel independently
 - Need close supervision at work
 - Majority have multiple disabilities

5. Very severe/Profound
 - Very dependent in all aspects of living skills

The term 'persons' is used instead of 'people' to denote a personal reference to a special group of people. United Nations uses the term 'Persons with disabilities' instead of 'People with Disabilities'. For example, the 'International Year of Disabled

Persons' (ESCAP, 2000). United Voice also chose the term 'Persons' instead of 'People' for the name of their Society.

1.8.4 A Case Study in the Malaysian Context

This study does not have sufficient time and resources for an in depth study of the general Malaysian self-advocacy movement of persons with LD. Therefore, this is just a case study that examined only two key issues. Firstly, the factors that are affecting the progress of the movement based on its research on seven out of eight self-advocacy groups within Malaysia.

The progress of the movement in this study refers to the number of groups formed thus far as well as the function of the groups in the self-advocacy activities which include training persons with LD to self-advocate, creating awareness, advocating for the rights of persons with LD. The factors could be influences that affected the movement from growing in terms of:

- the numbers of self-advocacy groups;
- the number of persons with LD involving in the movement;
- its strength in informing and teaching the grassroots about self-advocacy;
- and
- the strength of the movement in advocating for people with LD in general.

Secondly, this case study also examined the impact of self-advocacy groups in the lives of individuals with LD in Malaysia based on observations, personal testimonies as well as data collected from interviews with people who work closely with them. The impact may include the way self-advocacy groups have:

- informed persons with LD about their rights;
- trained persons with LD in making choices;
- enabled persons with LD to express or speak up for their rights;
- challenged and equipped persons with LD to take up leadership roles; and
- trained persons with LD to experience independent living.

1.9 Summary

The various comments and reports identified in this current study in the Statement of the Problem (1.2) and Significance of the Study (1.6) suggested that the welfare of persons with LD in Malaysia has to be improved. Self-advocacy is found to have an important role in improving the welfare of persons with LD in other countries. But, to date, the self-advocacy movement of persons with LD in Malaysia seems to be weak and slow as compared to self-help organisations of other disability groups. To address this issue, this study aims to examine the factors that have affected the progress of the self-advocacy movement and the impact of self-advocacy groups in the lives of individuals with LD in Malaysia.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Most of the researches available on self-advocacy movement of persons with LD are conducted either in the United Kingdom (UK) and the United States (US). Reviews on relevant researches have given this study a broader understanding on the self-advocacy movement.

2.2 The History of Self-Advocacy Movement

Goodley (2000:8) who has done extensive studies on self-advocacy movement of persons with LD noted that it is difficult to determine when this movement first started. However, he recorded that the First and Second Swedish National Conferences of Retarded Adults was held in 1968 and 1970. Atkinson (2002:123), an expert in the history of learning disabilities recorded that the self-advocacy movement was founded in Sweden and then in the US in the late 1960's.

The People First of Oregon (2005), a self-advocacy group run by persons with LD recorded that the People First Movement began in 1974 in Salem, Oregon. In 1984 the first International Self Advocacy Leadership Conference was held in Tacoma, Washington. Today, People First and the self-advocacy movement have grown into an international movement in 43 countries, with an estimated 17,000 members or more. In the United States alone, there are more than 800 self-advocacy groups. Citing Simons (1992), Goodley (2000:21) revealed that by 1992 there were about 500 self-advocacy groups in the UK.

In the references that are consulted by the current study, it was observed that there are limited researches of People First or self-advocacy movement in the Asian Region.

In Japan, Tsuda (2005) noted that 130 self-advocacy groups were invited to participate in a research on self-advocacy in Japan. However, not much information could be gathered as this is just a summary of the research that was written in Japanese.

Inclusion Japan (2005) reported that A National Convention is held annually in various places and about 3,000 to 6,000 self-advocates and their families participate in the convention. It also reported that an Interaction programme of self-advocate which is held together with the National Convention is participated by 500-800 self-advocates. Problems and issues discussed by self-advocates will be listed in a resolution at the end of the programme which will then be publicised. The theme varies from the local living support, employment support, protection of rights, community workshops and self-advocacy skills. This report shows that self-advocacy movement is happening in Japan but there was no historical information.

During a recent visit to Japan, the researcher had the opportunity to meet Okikura, an Associate Professor of Taisho University who is an advisor of a self-advocacy group in Tokyo. Okikura reported that the self-advocacy movement in Japan began in 1990 after an Inclusion International Conference that was held in Paris. There are about 230 self-advocacy groups in Japan that are supported by Inclusion Japan, a parents support movement. However, she is not sure how many of these are active self-advocacy groups. Most of these self-advocacy groups are either social groups, centre-based groups or advocacy-supported groups. Okikura observed that many self-advocates have been empowered through these groups in the last 15

years. It was noted that parents are not ready to let go though some self-advocates prefer to be independent from their parents support organization. (Okikura T., Personal communication at Hosei University, Tokyo, Japan, 2006, June, 16).

There are 15 self-advocacy groups under the People First movement in Japan. These are autonomous groups which run independently with the support of some volunteers. But, at present there is no registered society that is run by persons with LD. (Personal communication with Suenaga H., a volunteer of PEOPLE FIRST Higashi Kurume, Tokyo, Japan, 2006, June, 17)

Li (2004:241) gave a glimpse of self-advocacy movement for persons with LD in Hong Kong. According to Li, Chosen Power is the only self-advocacy group that is led by people with LD in Hong Kong. Chosen Power was established in 1995. Li noted that self-advocacy movement is at the beginning phase in Hong Kong. (Li, E. P. Y., Personal communication via email, 2005, October, 10) (Appendix F)

The history of self-advocacy began and concentrated in the European and North American region (Hurst, 1995:529; Kendrick, 2002:189) before moving on to the Asia Pacific region, mainly in New Zealand and Australia (Peter, 2002:207; Imagine Enterprises, 2006). It was only in recent decade that this movement is catching on in a few countries in the East Asian Region as observed in some reports and literature reviews of this study.

2.3 The Models of Self-Advocacy

The following are reviews on the various models of self-advocacy. Self-advocacy can either be carried out individually or as a group. With reference to a number of sources, Goodley (2000:7) concluded that self-advocacy can be practiced by a person individually or in a group.

Before we look at how self-advocacy is expressed individually and as a group, we need to first understand the two main approaches or models of self-advocacy – the Individual Model of Disabilities and the Social Model of Disabilities. Each of these two approaches of self-advocacy determines the liberty given to persons with LD to express themselves and to take the lead. The references for this section will be based mainly on works of two researchers who have done much study in the field of self-advocacy, Atkinson and Goodley.

2.3.1 Individual Model of Disability

Goodley (1997) did a comprehensive critique on two approaches of self-advocacy model, the Individual Model of Disability and the Social Model of Disability. Goodley argued that the Individual Model which focused on the individual's impairment which he described as "personal tragedy" may down grade the meaning of empowerment. Describing this model as pessimistic and that it emphasises on the role of professionals (mainly, the advisors), Goodley (1997:372) expressed concern that advisors or supporters, whether they are professionals or not, may have "prejudiced understandings of disability" that could hinder the development of self-advocacy.

2.3.2 The Social Model of Disability

The Social Model is preferred because it opposes exclusion but asserts that disabled people should go further and take up the challenge of political participation themselves. Goodley (2000:44) concluded that this model promotes an inclusive society which "provides a context in which self-empowerment is located". It also shifts focus away from what people cannot do to what people can do. In favour of this model, Goodley (1997:374) argued that advisors who believe in such an approach will

more effectively empower persons with LD to self-advocate as they are seen as people actively striving for their own self-determination in a society that denies such rights. Goodley aptly quoted a self-advocate, “The biggest disability of all is people’s attitude – it’s not us.”

2.3.3 Individual Self-Advocacy

Individual self-advocacy is defined in many ways. Basically, it means one need not be a member of the self-advocacy movement to engage in individual self-advocacy. Shoultz (2005) described individual self-advocacy as a “lifelong personal pursuit of control over one's own circumstances.” It is the act of advocating for what one wants, for how one desires to live, for how one wants to be treated, within one's family, community and services, and it does not end with one concession or one victory. Individual self-advocacy is continuous, because each triumph creates a new set of issues to be faced. Shoultz (2005) also suggested that everyone, whether or not one has a disability can practise individual self-advocacy. However, she noted that for many people without disabilities, this practice is almost “invisible” because it is taken for granted. Where as, for many persons with learning disabilities, individual self-advocacy is “visible” and has a significant meaning.

At an individual level, Atkinson (2002:122) affirmed that “self-advocacy is seen to be beneficial for the people with learning difficulties involved.” Based on her study on some references she concluded that self-advocacy enhance personal identity, raise self-esteem and support self-determination.

Goodley (2000:7) cited Simons (1992:5) who defined individual self-advocacy as a process of individual development that enable a person to have the confidence and ability to express his or her own feelings and wishes. Referring to his findings

from some researchers, Goodley (2000:7) discovered self-advocacy on an individual level may include the expressions of thoughts and feelings in an “assertive way”, making choices and decisions, knowing ones rights and have control over ones own lifestyle. All these may be expressed in a formal as well as informal context.

2.3.4 Group Self-Advocacy

Atkinson (2002:122) is of opinion that self-advocacy, in practice, often means advocacy in a group. This may mean advocating with and for other people with LD. Atkinson also noted that group self-advocacy has changed the influence of people close to self-advocates, such as parents and staff.

Shoultz (2005) who argued that group self-advocacy is perhaps the most vital form of self-advocacy argued that there would be no national or state self-advocacy organisations without local groups.

Based on his extensive study on the self-advocacy movement, Goodley (2000:15) noted that a great deal of the literature that has explored self-advocacy has done so with reference to the self-advocacy group. In reference to a video produced by Speak for Ourselves of Newcastle on starting a self-advocacy group, Goodley described what a self-advocacy group is like. The following is a summary: The Group meets once a week. A chairperson (a self-advocate) is responsible for conducting the meeting. Topics of discussion are usually decided at the start of meeting and members are encouraged to speak up freely. Self-advocates are involved in the setting up of their own groups. The steps in setting up of a group may include – getting people interested, finding a venue, organising transport, finding an advisor, electing a committee, raising money and making the group aware of what it can do. Goodley noted some vital points in the video:

- Self-advocates themselves are the significant parties. The main focus of the group centers on the interest of its members;
- The group determines their own group membership; and
- It must be clear that the role of an advisor is simply to advise and is not in control of the group.

It was noted that though this particular group has a clear outline of how their group is run and has the basic components of a group, other groups may have different ways of running their group.

Goodley (2000:135-173) conducted a comprehensive study on the different types of self-advocacy groups. He identified four types of distinctly organised self-advocacy groups:

- Centre-based Group;
- Social Group;
- Advocacy-supported Group; and
- Independent Group.

Goodley highlighted the strengths and weaknesses of each of these groups and observed that, the four groups present “four different, albeit overlapping, ways of organised collective self-advocacy, each with advantages and disadvantages.” In his critique on the previous appraisals that have pointed out ‘good’ and ‘bad’ ways of organising self-advocacy, he felt that these appraisals have ignored what self-advocates experienced for being in groups. He pointed out that it is “analytically simplistic” to say that the Independent Group was better than the Centre Group when members of both groups benefited from both approaches to self-advocacy. Disagreeing with the view that a perfect organisational based type of self-advocacy is the right form of self-advocacy, he argued that the “apparently imperfect contexts” often provide space for resistance and self-empowerment to emerge. He analysed that

the four types of groups were “bound together by various intra-group processes and embraced different concerns from social events to formal training programmes.”

2.4 Factors Affecting the Self-Advocacy Movement

The rapid growth in the number of self-advocacy groups in US and UK shows that the self-advocacy movement is well received. Within 30 years, over 800 self-advocacy groups were formed in US. In the UK, 500 groups were formed within 20 years. However, it was argued that the strength of a self-advocacy movement is not measured only by its growth in numbers but its power in changing the society’s mindset about people with LD and influencing policies to protect the rights of persons with LD (Crawley, 1988:47; Aspis, 1997:653; Aspis 2002:5).

2.4.1 Knowledge of Legal Rights

Aspis’ (1997:649) thought-provoking article stressed that self-advocacy should focus on changing policy so that changes become protected rights and not based on the “goodwill” of others. Aspis added that self-advocates should learn what legal rights are because legal rights are not based on goodwill but must be upheld by others. He emphasised that to deny persons with LD the knowledge of legal rights will stop them from gaining real change. He concluded that self-advocacy cannot be a liberating experience if the movement is controlled by people with authority. These people could include care givers, employers or service providers.

In his more recent publication, Aspis (2002:5) suggested self-advocacy is not just about having polite interactions but it should include “direct action, demonstrations, lobbies at full council meetings and how to influence Government legislation. All these approaches are about proactive change...” He further quoted

Dawson and Palmer (1993) who suggested that, in order to advocate, “One needs to resist oppressive practices by challenging people in power.” Aspis explained that this can be demonstrated in having the rights to challenge others, to be angry and even to challenge care givers when necessary. He added that rules, policies and legislation are needed for permanent or long-term change. This approach, he argued is a tool that allows people to speak up about how they understand their lives and enable them to seek changes, including “a shift of power”.

2.4.2 National Policies

There are different levels of self-advocacy. Ramcharan, McGrath and Grant (1997:66-67) revealed in their research that effective self-advocacy depends on the abilities of self-advocates to “pursue the outcomes for themselves through their own actions”. They recognised that persons with LD should be empowered to voice out for themselves. For that reason they stressed that, a process of empowerment in everyday life can only work where the conditions of empowering structures and institutions are in place. The government, they argued owes its disabled citizens a just and impartial society.

In a critique on the European Countries denying people with disabilities their choice and empowerment, Hurst (1995:531) observed that in the developing countries, the voice of disabled people is weak, and is predominantly the voice of the educated, employed disabled person not the person of the grass-roots. A situation similar to the UK and other countries in the 1950s. To change the situation, she suggested that it is crucial for politicians to recognise the necessity for anti-discrimination legislation for liberation (Hurst, 1995:534).

In a report on the 13th World Congress of Inclusion International (2002, September, 22-26) held in Melbourne, Yeo (2002:14) noted a statement made by Brownwyn Pike, the Victoria Minister for Community Services and Housing that the government has the power to instill values amongst the people not only to care but to support people with disabilities by including them. The statement strongly affirmed that the government does not only have the power to change policies but it also has the power to change the mindset of the society.

Recognising the need for global statements of rights, Borland and Ramcharan (1997:93) affirmed that the United Nation's Charter on Human Rights and the Rights of Disabled People provide a powerful incentive for people with learning disabilities in their fight for rights. The UN can be a monitor to ensure that every member country examines its policies and revises its policies if necessary to protect the Rights of the Disabled People.

2.4.3 Empowerment by Families

Families play an important role in empowering persons with LD to be independent individuals who are able to make decisions and participate in developmental responsibilities. Persons with LD are often deprived of control over their adulthood. It was observed that some LD felt held back by parents (Mitchell, 1997:47). They often have to prove themselves before they are allowed to do things. Many are frustrated for being treated differently from siblings. Though most parents want to see persons with LD become more independent, they feel anxious and threatened when they begin speaking up.

Mitchell observed that marriage, divorce and children are some key issues that may have caused parents to be cynical about self-advocacy. The lack of residential

options to allow their children to leave home or to move to when their parents die was suggested by Mitchell as highly significant in influencing parents' feelings about independence. Parents views of self-advocacy were seen by self-advocates in Mitchell's research to have influence in determining their participation in self-advocacy groups. However, she concluded that parents should not be stereotyped. It was briefly mentioned and implied in Mitchell's study that independence from parents and families seems more difficult for Asians as living on their own is not a common cultural practice unless they are married.

In discussing autonomy, interdependence and empowerment, Barnes (1997:73) suggested that self-advocacy which promotes independence should not be misunderstood as being fully independent from family members. The interdependence approach will probably create less deterrence for parents in allowing their children to be involved in the self-advocacy movement.

Processes in transition were considered by Jones and Wallace (1992) as a factor that influences parents' willingness to let go of their children to experience independent living. Their adulthood is only 'socially confirmed' if they are independent of financial support from their families.

The articles and researches referred have given us a glimpse of how families respond to the self-advocacy movement and the influence of their support. Parents who are willing to let go and let their children experiment independence will tend to allow more active participation in self-advocacy activities.

2.4.4 The Structures of Self-advocacy Groups

In the chapter entitled *Inside Self-advocacy Groups: Typologies and Dynamics*, Goodley (2000:135) analysed the study of Worrel (1988:48-49) who used sociograms

(Figure 2.1. and Figure 2.2.) to illustrate two forms of organisation of self-advocacy groups:

Note: M=Members; A=Advisors

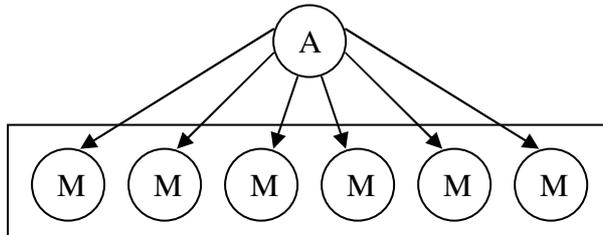


Figure 2.1.: Advisor-oriented group structure (based on Worrel, 1998:48)

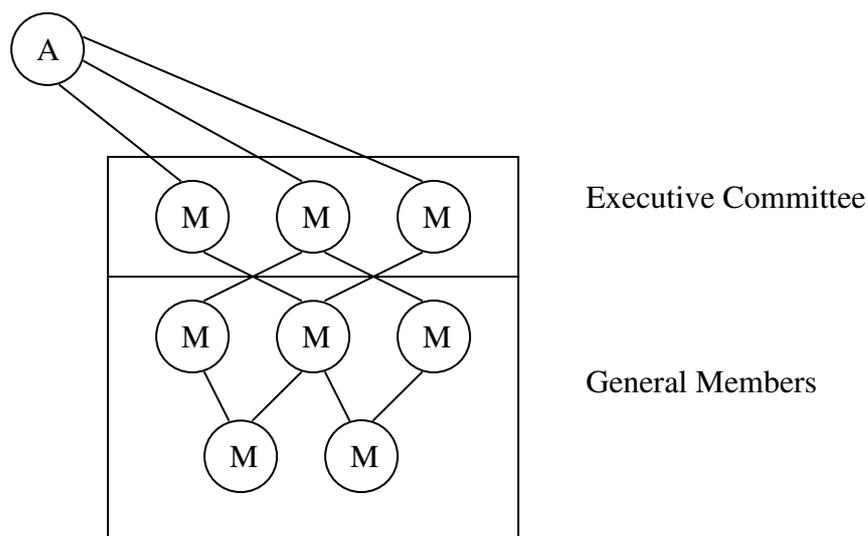


Figure 2.2.: Member-oriented group structure (based on Worrel, 1998:49)

Citing several researchers in this field, Goodley (2000:137) concluded that those who are for the growth of dynamic self-advocacy preferred the Member-Oriented group structure (Figure 2.2.) where self-advocates are in control instead of the advisors as practised in the Advisor-Oriented structure of self-advocacy group

(Figure 2.1.). The Advisor-Oriented groups have the tendency of breeding autocratic, advisor-led environment. Such structure is usually found in service-based self-advocacy groups. This structure may be useful in the initial stages of the setting up of a group but it was noted that a group which continually keeps this structure will limit its growth.

The Member-Oriented group structure which is favoured by most People First Groups promotes interdependent, interactive, cooperative culture which encourages solidarity between members which was noted by Goodley (2000:138) in his research as the key component of the self-organisation of disabled people. Such approach in self-advocacy is vital for a dynamic self-advocacy movement to develop. In another study, Goodley (1998:444) pointed out some positive actions of advisors, for example, helping self-advocates realised that “a person’s abilities are not a mere reflection of some assumed impairment.” Nevertheless, he cautioned the danger of service providers or advisors taking over the role of self-advocates by affirming that “self-advocates are the most important people with respect to the development of their own, and others, individual and collective self-determination.” It was noted that the Member-Oriented structure is usually found in the autonomous group and coalition types group.

2.4.5 Awareness on Self-advocacy

As mentioned in Chapter One, many people with LD in Malaysia are not informed or taught how to self-advocate. They have been depending on others to speak up for them. They do not realise that they have the right to speak up for themselves. Aspis (1997:648) strongly emphasised that in order for people with learning disabilities to advocate they need to learn skills. He noted that courses are now conducted by service

providers, adult training centres, special schools and colleges on how to make choices, taking responsibility and how to speak up.

Though this study does not have any reviews on the influence of formal training on self-advocacy in the self-advocacy movement, it is however strongly suggested by Aspis (1997:647, 2002:5) that in order for self-advocacy to have a lasting impact in bringing permanent change, persons with LD need to be informed of their rights and know how to use their rights. The emphasis on self-determination and self-advocacy in the pre-vocational and transition programmes offered in the US and the UK special education curriculums perhaps have contributed to the rapid growth of self-advocacy in these countries.

Ronald (2000:458) did a comprehensive study on the impact of legislation in the development of persons with LD. He noted that in the US legislation on vocational education and transition for students with disabilities began in the 80's. By 1997, the re-authorisation of the Individuals with Disabilities Education Act requires transition planning to begin no later than age 14.

A review on two most widely used transition curriculum in the US, The Life-Centered Career Education (LCCE) and The Kent Transition Implementation Model showed that self-advocacy is emphasized in these curriculums (Brolin, 1995:64-68).

2.4.6 Summary

The factors highlighted above are identified as the main factors that have influenced the progress of self-advocacy movement from the reviews of this current study. Legislations, National Policies, Empowerment from families and care givers, structure of self-advocacy groups and training or awareness were key factors identified by various researchers as influencing factors to the movement. Most of these factors

though are outside the control of the self-advocacy movement. It was observed that self-advocacy movement that emphasizes on the Social Model of Disability which adopted Member-oriented approach of self-advocacy has the power to change the mindset and system facing persons with LD.

Therefore, it may be concluded here that these reviews implied that in order for self-advocacy movement of persons with LD to advance, there is a need to examine the Model of Disability adopted by the self-advocacy movement and the choice of structure of the self-advocacy groups. The right approaches could strengthen the development of the self-advocacy movement.

2.5 The Self-Advocacy Movement of Persons with LD in Malaysia

As mentioned in Chapter 1, the self-advocacy movement of persons with LD in Malaysia has about 13 years of history. Since there is hardly any research done on this movement, the reviews in this study are based mainly on documentations published in newsletters and other publications of Dignity and Services, the first organisation that took an interest in supporting the development of the self-advocacy movement of persons with learning disabilities in Malaysia.

2.5.1 A Brief History of the Movement

In Malaysia, the self-advocacy movement began with the first vibrant self-advocacy group United Voice (UV) which was founded in May 11, 1995 with only 4 members. Though the Bethany Self-Advocacy group was formed before UV in 1993, it did not take active roles in the movement until recently. Kangaroo Club, another self-advocacy group was formed in Kota Kinabalu, Sabah in 1996 but there was no record

of interaction between these groups until 2003 at a self-advocacy workshop co-organized by UV and Dignity & Services.

UV was first named Self-Advocacy Group and was sponsored by Dignity & Services, a Non-Governmental Organisation that advocates for and with persons with LD. Dignity & Services believes that persons with disabilities have the inherent right to respect for their human dignity. They have the same fundamental rights as their fellow citizens – the right to enjoy a decent life as normal and full as possible. (Dignity & Services, 2001:5). Jayasooria, one of the founder members of Dignity & Services recalled,

People who are blind or in wheel chair are intellectually able and can vocalize their view. But people with LD are not able to verbalise. They need people who support their need to vocalize. People with LD are often pushed aside and not given opportunities to vocalize for themselves. In Malaysia, Peter John Young (Founder and Director of Dignity & Services) was one of the first to speak of Self-advocacy – letting people with LD express their view. (D. Jayasooria, personal communication, 13th February 2006).

A booklet entitled, ‘10 Years On...’ (Dignity and Services, 2001:8) gave an account of the development of the Self-advocacy group sponsored by Dignity and Services. UV was formed as an advocacy-supported group. By early 1996, there were eight members in this self-advocacy group. A committee was formed to allow the members to learn to take leadership roles during meetings. The group members learned to plan meetings and developed skills such as calling their friends, chairing meetings and taking minutes. Their organisational skills began with simple tea parties.

The booklet also highlighted that the group participated in a panel discussion on Personal and Social Relationships with families and service providers in 1998. A year later, a new committee was elected and the self-advocacy group began to take more control of their own affairs. The group started their own bank account and

members are able to sign their own cheques. Their first training camp was organised in June 1999 and their second camp in 2000.

In November 1999 the first book by persons with LD entitled *Difficult but Not Impossible* (Dignity & Services, 1999) was published. Their second book, *My Life* (Dignity & Services, 2001) was launched in February 2001. The contributors to these two books were mainly members of United Voice and their friends from other centers.

At a training session in January 2000, the group decided to name themselves United Voice and also drew up a constitution for UV. The group began to take up more responsibilities by giving talks to local organisations and at conferences abroad.

In July 2002, UV decided to take the bold step to be more independent from Dignity and Services by setting up their own office at their clubhouse (Almeida, 2002:9). The move to be independent from Dignity and Services had a great impact in the group as the committee had more opportunities to take the lead (Yeo, 2004:9).

UV has participated in several forums, dialogues and workshops on disability issues at National level. UV sent a representative to present a short message at the National NGOs pre-budget dialogue with the Prime Minister in year 2003 and 2004. In year 2003, UV participated in a workshop to discuss the draft Bill - Persons with Disabilities Act 2002. This is an act to provide the basis for equalization of opportunities and to avoid discrimination and harassment of persons with disabilities. (Dignity & Services Review, 2003:1).

Yeo (2004:45) noted that UV has proven that persons with LD are capable of participating in national forums and dialogues. She applauded the Malaysian government for opening opportunities for them to participate and to speak up,

They were not sidelined, but were given special recognition of their presence and participation. This was clearly seen in the recent National Forum on Disability Issues with Datuk Seri Shahrizat, the Minister of Women, Families and Community Development. Lau, who

represented UV was specially invited by the Minister to have tea at the VIPs' tea reception.

Yeo also reported that Lau was assured by the Minister that the issues brought up by him in regards to employment opportunities for persons with LD will be given serious considerations. The minister specially requested for Lau's speech to be submitted to her office.

Several UV members have participated in international events. UV had conducted workshops at the 13th World Congress of the Inclusion International held in Melbourne in 2002 and the International Conference of Social Welfare held in Kuala Lumpur in year 2004. Many members in United Voice are active in the Special Olympics. A leader of UV was selected to participate in the Special Olympics World Congress held in the Panama in 2005.

UV co-organized with Dignity & Services a three day workshop on self-advocacy in July 2003. Fifteen self-advocates representing Kuala Lumpur, Selangor, Penang, Melaka and Sabah participated in this workshop. One of the resolutions at the end of the 3 day workshop was for each delegate to return to their own communities and start their own self-advocacy groups (Dignity & Services Review, 2003:3). As a result of this event, two self-advocacy groups were birthed:

1. Dragon Club (2003)
sponsored by Pusat Kanak-kanak Istimewa Kajang, Selangor;
2. Friendship Club (2003)
sponsored by Malaysian CARE, Kuala Lumpur.

In 2004, UV invited Dragon Club and Friendship Club to co-organise the First National Self-advocacy Conference by and for Persons with Learning Disabilities in Malaysia (Yeo, 2005:25). These three self-advocacy groups took the challenge to organise the National Conference with the support of a few supporting friends

assigned by the organisations that sponsor these groups. The Conference was held in December 2004. Those who participated in the Conference included 80 adults with LD from eight states. More than 10 delegates represented Sabah and Sarawak. Two self-advocacy groups, Dayspring Adventure Club, Klang (formed in 1999), and Bethany Self-advocacy Group, Teluk Intan (formed in 1993), were revived after the Conference. One group, Mutiara Voice Club was established in Penang, 10 months after the Conference. Most of these groups are center-based. UV is the only group that is autonomous. Table 2.1 showed that four out of eight groups are located in Selangor.

Table 2.1:

Self-Advocacy Groups of Persons with Learning Disabilities in Malaysia

Name of Group	Year of Formation	District/State	Type of Group	Sponsor Organisation
Bethany Self-Advocacy Group	1993	Teluk Intan, Perak	Centre-Based	Bethany Home
United Voice	1995	Petaling Jaya, Selangor	Autonomous	Registered with the Registrar of Societies
Kangaroo Club	1996	Kota Kinabalu, Sabah	Centre-Based	Seri Mengasih
Dayspring Adventure Club	1999	Klang, Selangor	Centre-Based	Dayspring Centre
Action Club	2001	Petaling Jaya, Selangor	Centre-Based	Kiwanis Job Training Centre
Friendship Club	2003	Cheras, Kuala Lumpur	Centre-Based	Malaysian CARE
Dragon Club	2003	Kajang, Selangor	Centre-Based	Pusat Kanak-kanak Istimewa, Kajang
Mutiara Voice Club	2005	Balik Pulau, Penang	Advocacy Supported	Asia Community Service

Over the years, United Voice has developed and sharpened its objective as a self-advocacy movement of persons with LD. The objectives of this Society include (United Voice, 2005):

1. To provide a meeting place for persons with learning disabilities where they help and support each other;
2. To develop leadership, independent skills and confidence among members so that they can speak for themselves and make their own decision;
3. To speak and act on behalf of other persons with learning disabilities in Malaysia;
4. To promote self-advocacy and help form self-advocacy groups all over Malaysia;
5. To make the community more aware of the rights, needs and abilities of persons with learning disabilities;
6. To create employment for unemployed members; and
7. To provide an example to the community of a service run well, for and by persons with learning disabilities;

UV is a multiracial society. The membership consists of Malays, Indians, Chinese and other races. Currently (United Voice, 2006:2) there are 30 women and 42 men in the group. The committee has a good balance of gender involvement where there are four women and five men. They are representatives of the three major races in Malaysia. Majority of the committee members are working in a full-time employment.

This is just a brief history of the self-advocacy movement in Malaysia. More research is needed to discover further information from the various self-advocacy groups regarding their contribution to the movement.

Based on this review, the progress of this movement is observed to be in its formative stage. To date, there are only 8 self-advocacy groups spread over 5 states in Malaysia, while there are about 230 groups in Japan, 500 groups in the UK and 800 groups in the US. Compared to the other countries mentioned, the number of groups in Malaysia is relatively small. As in terms of self-advocacy activities, UV seems to be the only active group that has significant achievement in the self-advocacy

movement. However, their achievement is very small when compared with other self-help movements of the blind, the deaf and the orthopaedic in Malaysia. This study investigated the factors that have affected the progress of the other self-advocacy groups and the movement in general.

2.5.2 Factors Affecting the Self-Advocacy Movement in Malaysia

To date, the current study is the only research attempted on the self-advocacy movement of persons with LD within Malaysia. This study as mentioned in Chapter 1 is vital because it aims to examine the factors that affected the progress of the movement. This study will lead to discussions on recommendations that are valuable in helping the movement develop further.

The comprehensive research on Self-Help Organisations in Malaysia by Jayasooria (2000) provides findings that could be valuable insights for the self-advocacy movement of persons with LD. Jayasooria (2000:179) noted though certain Self-help Organisations (SHOs) are active in advocacy issues, the grassroots membership have not developed political-consciousness on the issues and rights of disabled people. He cautioned that SHOs should not focus on enabling care by providing individualised services and lose sight of more urgent matters which are to challenge existing inappropriate approaches. Having the same opinion as Goodley, Jayasooria suggested that the Social Model of Disability should be adopted in order for any change to happen through a SHO. Jayasooria had identified two factors that have deterred a Social Model of Disability to happen effectively in Malaysia. Firstly, “Malaysians tend to be non-confrontational and do not really express how they feel...” He felt that SHOs have not campaigned effectively against the inappropriate services of voluntary organisations or public sector. Secondly, he observed that the lack of

services, provisions and choices has forced disabled people to accept any assistance provided.

Jayasooria (2000:193) concluded that there is urgency for both disabled and non-disabled people to work together to see more positive changes in the system that affect the development of people with disabilities. Three areas essential for this process identified include firstly, more awareness programmes at national level that will change the mindset of society towards people with disabilities. Secondly, there is a need for effective training for a larger pool of disabled leadership. Lastly, he recommended that a strategy and action plan needs to be developed to create equal opportunities for people with disabilities in education, employment and in “developing a society without barrier.”

Recommendations suggested by Jayasooria, though they were derived based on his research on SHO for the Blind, the Deaf and the Physically Disabled, are nevertheless useful insights for the self-advocacy movement of persons with LD. The self-advocacy movement of persons with LD in Malaysia is relatively new compared to the other self-help movements. Thus, it has the advantage of having the privilege of learning from the experiences of other Self-help movement. While the needs for Persons with LD are many, Jayasooria’s findings are a good reminder for self-advocacy groups to play their vital role in identifying and advocating for areas that need improvement so that persons with LD can enjoy a better quality of life.

2.6 The Impact of Self-Advocacy Groups in the Lives of Individuals with LD

There are many testimonies recorded on the impact of self-advocacy in the lives of persons with LD. Reading the contributions of self-advocates in some studies (Aspis, 1997, 2002; Atkinson, 1999, 2002; Goodley, 1996, 1997, 1998, 2000; Beart, Hardy &

Buchan, 2004; Ramcharan, McGrath, & Grant, 1997; Ward, 1998) confirmed that self-advocacy groups had impacted many lives. Self-advocacy has helped persons with LD to be more independent and take up challenges beyond the expectations of their own and others.

Atkinson and Goodley in most of their papers and researches referred to by this study have given life stories of how self-advocacy had impacted the lives of individuals. Many self-advocates learnt to voice out for themselves and develop skills to negotiate with parties involved in their daily experiences – be it at home, in institutions or centres, at work or within the community in general. Independent living became a reality for some after joining a self-advocacy group. The most powerful impact of this movement is raising a group of self-advocates who are able to challenge policies or legislations and take part in policy making that involves persons with LD (Aspis, 2002:5).

Using a grounded theory in their study on the impact of self-advocacy in the lives of persons with LD, Beart, Hardy and Buchan (2004:99) have noted a number of testimonies based on their study on five men and two women who belonged to a self-advocacy group for persons with LD. Their study observed that the positive supportive environment of a self-advocacy group “where participants felt listened to and valued, contributed to changes in individual member’s self-concept.” All participants shared about the changes in themselves since they joined the group. Their findings observed that participants realised the importance of collective action after becoming a member of the group. Therefore, they suggested that recruitment and raising awareness of self-advocacy for persons with LD should be encouraged. They also suggested that self-advocacy groups play an important role in providing emotional support for members who are going through changes in self-concept. Like

all the other research mentioned, this study has again affirmed that self-advocacy groups have significantly impacted the lives of persons with LD.

Atkinson (2002:123) observed that the self-advocacy movement has moved people with LD to the forefront. The awareness of self-advocacy and the training received in speaking up has trained some self-advocates to be effective advocates and valuable resources in the researches on issues related to people with LD.

Goodley (2000:85) highlighted the life stories of five “top self-advocates” which revealed many stories on how involvement in self-advocacy groups impacted the lives of these five persons with ‘learning difficulties’ (a term preferred by most of these five narrators). Lloyd Page shared,

At first it’s difficult, it took me a long time but you need to gain confidence for yourself. You also need to believe in yourself, what you’re saying and what you need to do. I didn’t get the chance to do it before I joined People First – not a chance because I was stopped from speaking out. There wasn’t anybody to listen to you and when I did speak out I was shouted down.

Page testified that his involvement in the self-advocacy movement has given him the opportunities to participate and contribute in organisations and committees such as Central Council for Education Training and Social Work, Equal Opportunities Committee and Open University. He even had the opportunity to be present at the Houses of Parliament to fight for the civil rights of people with LD in UK.

This review has given us a glimpse of how involvement in self-advocacy groups and movements has impacted the lives of individuals with LD from being reserved and shy to being more confident and bold. Some have learned to be outspoken and have been given opportunities to speak their minds in public places. The current study will investigate the impact of the self-advocacy groups in the lives of individuals with LD within the Malaysian context. In Chapter 4, we will examine

some stories and experiences of persons with LD which will help us determine the impact of self-advocacy groups.

2.7 Conceptual Framework of the Study

A conceptual framework is constructed for this study (*Figure 2.3*). The framework shows that the focus of this study is to examine the factors affecting the progress of the self-advocacy movement of persons with LD in Malaysia. The impact of self-advocacy groups in the lives of some individuals with LD was also studied.

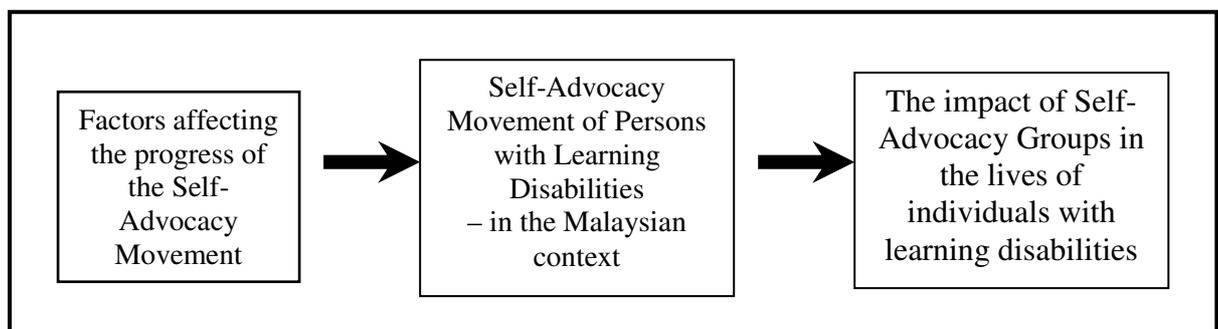


Figure 2.3.: Conceptual framework of the study

The results of this study as analysed in Chapter 4, showed that there are some similarities in the factors that affected the self-advocacy movement which have been found in this review. The key common factors include: awareness of self-advocacy; national policies; family support; and the structures of self-advocacy groups. The result also showed that self-advocacy groups have impacted the lives of individuals with LD as discovered in developed countries shown in this review. Though the self-advocacy groups have impacted the lives of persons with LD in many ways, the significant impacts identified are: the awareness of rights, confident to voice up and ability to take up leadership responsibilities.

2.8 Summary

More than 40 researches, articles, books, papers, and documents were consulted for the review of this study. The findings and researches in this review have helped this current study to have a more in-depth understanding of self-advocacy and the self-advocacy movement. The review of these resources has given this study a framework to work on.

The progress of a self-advocacy movement can be affected by both factors that are inside and outside of the movement. The review on the factors that have affected the self-advocacy movement in other countries has helped this study to examine if there are similarities in the Malaysian context. These resources consulted have enlightened the researcher to realise the importance of examining how the movement has impacted the lives of persons with LD.

This literature review has provided helpful information and guidelines on how to investigate or conduct a research on the related topic. It has pointed out useful insights for the researcher to examine the self-advocacy movement in the Malaysian context. This will be discussed further in the following chapter.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This present study has so far observed in most references that the qualitative method is often used to study persons with LD. Qualitative research is described by Merriam (1998:5) as “an umbrella concept covering several forms of inquiry that help us understand and explain the meaning of social phenomena with little disruption of the natural setting as possible.” A generic qualitative approach is used to conduct this research on the self-advocacy movement of persons with LD in the Malaysian context.

3.2 Design of the Study

The design used for this study as mentioned above is a generic qualitative study, using multiple methods which include techniques such as observations, interviews and documental analyses. These approaches were used to investigate the research questions of the current study.

3.3 Sources of Data

3.3.1 Interview

The main technique used in this present study is interviewing selected participants. This is a useful technique in collecting data for a qualitative study. Citing Fetterman, Fraenkel and Wallen (1996:447) suggested that interviewing is the most important data collection technique in a qualitative research possesses. Rose and Grosvenor

(2001:112) suggested that interviews have the “potential to yield valuable insights into people’s life experiences, attitudes, opinions and aspirations.” Merriam (1998: 72) said that interviewing is essential “when we cannot observe behavior, feelings, or how people interpret the world around them.” She noted that interview is also important in gathering information of past events that are impossible to repeat.

Interviews were used to examine participant’s knowledge or/and involvement in self-advocacy movement of Persons with LD in Malaysia. The data gathered through the interviews includes: information on the factors that affected the progress of the movement, the impact of self-advocacy groups in the lives of individuals with LD and measures that will be taken to strengthen this movement. The participants who were interviewed included:

1. A researcher on the self-help organizations in Malaysia who is also an Executive Staff of an NGO (Non Governmental Organisation);
2. The Leaders/Service Providers of seven Organisations/Service Centers that are involved in the self-advocacy movement of persons with Learning Disabilities. (There are currently eight self-advocacy groups in Malaysia);
3. A Project Coordinator of United Voice;
4. An adult with LD;
5. A care giver (sibling) of a person with LD;
6. A care giver (mother) of a worker with severe LD employed by United Voice;

Semi-structured interviews were used for Participants No.1, 2, 3 and 5. Topics and issues to be covered are specified in advance, in outline form. This helped to

make data collection more systematic for the participants. Interviews were fairly conversational and situational.

Structured interview was used for four of the leaders in Participants No. 2. These four organisations are situated in Sabah (1 participant), Penang (1 participant) and Selangor (1 participant from Klang and 1 participant from Kajang). The researcher gathered data from these 4 participants through email correspondence. A questionnaire was sent to these participants via email. All four participants responded. Further correspondence was used when more probing questions were required to collect more in-depth data. Refer Appendix B for a sample transcript of a structured interview.

Three of the leaders of Participants No. 2 were interviewed face to face using semi-structured interview. These three leaders included an Executive Staff of Bethany Home, Teluk Intan representing Bethany Self-advocacy Group (the first self-advocacy group in Malaysia), a Staff of United Voice (the first Self-Advocacy Society in Malaysia) and a Senior Staff of Malaysian CARE (a key NGO that has helped established a number of centres in Malaysia that provide services for children and youths with LD.)

Since participant No. 4 is a person with LD, both semi-structured and informal conversational interviews were used as a more in-depth study was intended for this participant to examine his view on self-advocacy and how his involvement in a self-advocacy group has impacted his life. In the informal conversational approach, as recommended by Patton, 1990 (cited in Fraenkel and Wallen, 1996:449), “questions emerge from the immediate context are asked in the natural courses of things”. This form of interview used together with the semi-structured interview enabled a more in-

depth collection of data as there is some flexibility to ask questions that emerged from the immediate context during or after the semi-structured interview.

All participants were informed of the purpose of the interview. Verbal consent was obtained before conducting the interview. Permission for audio recording of the interview was also obtained. The researcher was careful not to ask questions that were sensitive to the interviewees. The field notes and audio recording interviews taken were transcribed and re-confirmed by the interviewee before reporting in this study.

Prior to any of these interviews, a pilot structured interview was conducted via email to test if it is feasible. The researcher discovered that some of the responses were well thought through and clearly expressed in writing. However, some answers were superficial and needed further probing questions through follow-up correspondence. This form of interview can only be effective if the interviewee is clear about the purpose of the research and willing to be cooperative.

3.3.2 Pilot Study on Semi-structured and Informal Interview

A pilot semi-structured and informal interview was also conducted with a self-advocate to test if the issues and questions planned to be asked were too difficult for an LD to comprehend. The pilot test has helped the researcher to realise that interview questions for an LD have to be simplified and broken down into many simpler questions which are sub-questions of a core issue. It was also discovered that it is better not to take notes unless necessary. The interviewer should concentrate on the conversation so that effective probing questions could be asked during the interview. Intense listening and eye contact does help the interviewee with LD to realise that the researcher is very interested in what he/she has to say and this will enthuse the interviewee to express his/her views more spontaneously. Being observant of the

facial expression of the interviewee helps the researcher to be more sensitive to the interviewee.

The semi-structured interview questions for the five participants are shown in the Appendix C. These questions were validated and approved by the researcher's supervisor. Since this supervisor has experience in doing in-depth research, her scrutiny of these questions assured their reliability in fulfilling the purpose of this research.

3.3.3 Observation

This study observed how persons with LD practised self-advocacy in a group. Observation data according to Merriam (1998:94) "represent a firsthand encounter with the phenomena of interest rather than a second account of the world obtained in an interview." Citing Kidder (1981:264), Merriam (1998:94) further explained that observation is a research tool when:

- It serves a formulated research purpose;
- It is planned deliberately;
- It is recorded systematically; and
- It is subjected to checks and controls on validity and reliability.

The self-advocacy group that was observed consisted of nine workers with LD who are employed by United Voice to work in United Voice Employment Project. United Voice uses practical approach to instill self-advocacy skills in these workers. These workers are required to have a meeting twice a week at the end of work which lasts for only 10 to 15 minutes. The workers take turn to lead meetings. These

meetings are conducted to evaluate each worker's performance and behavior at work. They are also encouraged to discuss whatever issues raised at the meeting.

The purpose of these observations done by the researcher is to case study the self-advocacy approach taken by this group and how the workers are involved in self-advocacy within their group. The study also observed the factors that contribute to the dynamics of the group and the impact of a self-advocacy group in the lives of these workers.

The group was informed about the intention of this observation and their consent was obtained before the observation began. The researcher used a non-participant naturalistic observation to observe eight sessions (twice a week). A non-participant naturalistic observation involves observing individuals in their natural settings. As described by Fraenkel and Grosvenor (1996:452), "the researchers do not participate in the activity being observed but rather 'sit on the sidelines' and watch; they are not directly involved in the situation they are observing." Field notes (Table 3.1) and audio tape recording were used to record each session to observe how the group operates and how the group members developed in their self-advocacy skills over eight sessions in the duration of four weeks. These notes recorded (Refer sample in Appendix F) were validated by a Project Coordinator of the group who attended every meeting. The Project Coordinator was interviewed at the end of the eight sessions to gather further information especially in regards to his observation of the impact of this self-advocacy training in the lives of these workers in the last four months. This self-advocacy training began in September 2005.

Rose and Grosvenor (2001:30) are of the opinion that observation is a very direct method which provides the researcher with close contact with the subject, behaviours or events being studied, thereby enabling a "real life" picture to be

achieved. They noted that the observation approach when combined with other data collection methods such as interviews and documentary research will enrich the research. However, as mentioned in the limitation of this study in Chapter One, they cautioned that observation is a time consuming approach as the observer needs to be familiar with the environment and the participants. In this study, the researcher has the advantage as she is currently a full-time staff of United Voice and therefore she is familiar with the environment and the participants. However, since the researcher is not a staff directly in charge of the group to be observed, the researcher has to avoid disruption that affects the group's dynamics to ensure a more accurate observation.

Table 3.1:

Field Notes of Observation

Observation No:	
Date:	
Time:	
Side Notes	Observation Dimension:
	<ol style="list-style-type: none"> 1. Setting – the environment and mood of the group 2. How members self-advocate: <ol style="list-style-type: none"> i. Leadership style and abilities of each leader ii. Participation of members in expressing themselves and speaking up on issues raised. iii. Issues raised. iv. Control of the team members in the meeting 3. Involvement of the Project Coordinators in the meeting
Time Ended:	
Reflection:	

3.3.4 Pilot Study on Observation

A pilot study was conducted to test the feasibility of this observation study. The pilot study tested:

1. The possibility of obtaining the consent of team members and the Project Coordinator of United Voice;
2. The flow of meeting with the presence of an observer and audio Recording;
3. The feasibility of the dimension to be observed.

The researcher had no problem obtaining consent from the members and their project coordinator to observe and to audio record the meeting. It was found that the meeting was able to run smoothly and as normal in spite of researcher's presence, audio recording and note taking. The purpose of the observation can be achieved based on the dimension set for the observation.

3.3.5 Document Analysis

The interviewing process of the participants listed will involve some document analysis. For example, besides interviewing the leader of United Voice, the documentary research method to examine the history, organisational structure, events, newsletters, speeches, reports, personal profiles of participants etc, was used to case study the factors that support the progress of United Voice, the first Self-Advocacy Society of Persons with Learning Disabilities in Malaysia.

Document analysis is used in all research projects and it is considered a valuable method for understanding and explaining social relations (Rose and Grosvenor, 2001:50). Rose and Grosvenor classified documentary sources as follows:

- as 'primary sources', that is produced at the time of the event that they describe;
- as 'secondary sources', that is produced after the event;

- as ‘public documents’, generally official records produced by national and local governments;
- as ‘private documents’, produced by individuals not by the state;
- as ‘solicited documents’, produced for a research project; and
- as ‘unsolicited sources’, produced for personal use.

Based on the above classification, this current study used documents of ‘primary sources’ through interviews of individuals; and ‘private documents’ of participants and organisations.

Critical research approach was used to ensure careful evaluation which involves asking questions about the document’s authenticity, credibility, representativeness and meaning (Platt 1998a and b, Scott 1990 cited in Rose and Grosvenor, 2001:51). Citing Froster (1994:155), Rose and Grosvenor listed some useful questions to examine the authenticity of the documents:

- Are the data genuine?
- Are they from a primary or secondary source?
- Are they actually what they appear to be?
- Can authorship be validated?
- Are the documents dated and placed?
- Are they accurate records of the events or processes described?
- Are the authors of the documents believable?

This study used some of the questions listed above when examining documents. The ethic of research in seeking permission of persons or organisation involved before examining any of the documents that are private or confidential was observed.

3.4 Sample Selection of the Study

The participants of this present study included mainly self-advocates, family members, professionals and leaders of service providers. A total of 21 participants were involved in this study. Eleven of them were self-advocates. Two of these self-

advocates were interviewed and nine were observed at meetings. These self-advocates are young adults, whose ages range from 18 to 31 years old.

Purposeful sampling was used to select participants for the interviews conducted in this study. Purposeful sampling according to Merriam (1998:61) “is based on the assumption that the investigator wants to discover, understand, and gain insight and therefore must select a sample from which the most can be learned.” These participants acted as consultants as they are knowledgeable in the issues of this study and are able to provide information-rich cases for the study (Patton, 1990:196).

Seven participants were interviewed for information of their respective self-advocacy groups or society. Most of the participants are leaders or senior staff of the organisations. The majority have served for more than 10 years. Since 7 out of 8 self-advocacy groups in Malaysia were being represented, data collected highly represent the self-advocacy movement in Malaysia.

Table 3.2 listed the Interviewee’s Profile of participants who were interviewed. These participants were selected from five different states (Sabah, Penang, Perak, Selangor, Kuala Lumpur) though the majority (three) were from Selangor (Petaling Jaya, Klang and Kajang) where the self-advocacy movement is most active.

Table 3.2:

Profile of Interviewees (All names are pseudonyms)

No of Participants	Description of participants
1	Participant No. 1: Thomas <ul style="list-style-type: none"> ▪ Executive Staff of Yayasan Strategik Sosial ▪ He is familiar with the disability issues in Malaysia. His PhD. thesis on people with disabilities in Malaysia was

	<p>published in year 2000.</p> <ul style="list-style-type: none"> ▪ Duration of service in the Organisation: 8 years
7	<p>Participant No. 2</p> <p>a. Ravi</p> <ul style="list-style-type: none"> ▪ Executive Staff of Bethany Home, Teluk Intan, Perak ▪ Name of group: <u>Bethany Self-Advocacy Group</u> ▪ The Self-Advocacy Group was set up in 1993. ▪ A centre-based group ▪ Duration of service in the Organisation: 10 years <p>b. Ken Jo (a person with very mild LD)</p> <ul style="list-style-type: none"> ▪ A staff of United Voice, Petaling Jaya, Selangor. ▪ He has relatively good comprehension level and has good command of English ▪ Name of group: <u>United Voice</u> ▪ Set up in 1995 and registered as society in 2005 ▪ An autonomous group ▪ Duration of service in the Organisation: 6 years ▪ 31 years old <p>c. Mei Quin</p> <ul style="list-style-type: none"> ▪ Executive Staff of Pusat Kanak-kanak Istimewa Kajang, Selangor ▪ Name of self-advocacy group: <u>Dragon Club</u> ▪ Set up in 2003 ▪ Duration of service in the Organization: 10 years <p>d. Karen</p> <ul style="list-style-type: none"> ▪ The Principal of Dayspring Centre, Klang, Selangor ▪ Name of self-advocacy group: <u>Dayspring Adventure Club</u> ▪ Set up in 1999 ▪ Duration of service in the Organization: 17 years <p>e. Su Li</p> <ul style="list-style-type: none"> ▪ Executive staff of Seri Mengasih, Kota Kinabalu, Sabah. ▪ Name of self-advocacy group: <u>Kangaroo Club</u> ▪ Set up in 1996 ▪ Duration of service in the Organisation: 15 years <p>f. Suzie</p> <ul style="list-style-type: none"> ▪ A senior staff of Malaysian CARE, Kuala Lumpur ▪ Name of self-advocacy group: <u>Friendship Club</u> ▪ Set up in 2003 ▪ Duration of service in the Organisation: 15 years <p>g. Chui Yee</p> <ul style="list-style-type: none"> ▪ Executive staff of Asia Community Service, Penang

	<ul style="list-style-type: none"> ▪ Name of Self-advocacy group: <u>Mutiara Voice Club</u> ▪ Set up in 2005 ▪ Duration of service in the Organisation: 9 years
1	<p>Participant No.3:</p> <p>Asman</p> <ul style="list-style-type: none"> ▪ Project Coordinator of United Voice. ▪ An Occupational Therapist ▪ Duration of service in the Organisation: 1 ½ years.
1	<p>Participant No. 4:</p> <p>Habib</p> <ul style="list-style-type: none"> ▪ An active self-advocate who has participated in many activities of the self-advocacy movement of persons with learning disabilities in Malaysia. ▪ He has very mild LD – mainly dyscalculia. ▪ He has relatively good comprehension level and has good command of English. ▪ He works as an office assistant in Kuala Lumpur (KL). ▪ Age: mid 20's
1	<p>Participant No. 5:</p> <p>Zaleha</p> <ul style="list-style-type: none"> ▪ The eldest sister of Participant No 4. ▪ Being the oldest in her family, she has been the main support for her brother since their father passed away several years ago. ▪ 30+ years old
1	<p>Participant No. 6:</p> <p>Aishah</p> <ul style="list-style-type: none"> ▪ The mother of Faruq. ▪ Faruq has severe LD and he is one of the workers of UV Employment Project who was observed. ▪ 50+ years old

Participants selected for observation are from one self-advocacy group that is undergoing training to self-advocate. Again purposeful sampling is used for this case study on how self-advocacy can be introduced to persons with LD and how a self-advocacy group can impact their lives. These 9 participants are relevant as they

represent three levels of LD – mild, moderate and severe (the very mild and profound cases were not included). These participants will give us an idea of how people with different levels of LD can self-advocate. Table 3.3 describes the samples. Information regarding these participants was obtained from the Employees' Profile record of United Voice and information from a Project Coordinator of United Voice.

Table 3.3:

Profiles of Participants in Observation (All names are pseudonyms)

Disabilities	Name & Code	Description
Mild Learning Disabilities	Rashid (MA)	<ul style="list-style-type: none"> ▪ Rashid (23) has difficulties in reading, writing and arithmetic. ▪ He is an artist and he enjoys drawing cartoons. ▪ He can work independently with minimal supervision. ▪ His social skill is affected by his mood swing. ▪ He speaks mainly Bahasa Melayu.
Mild Learning Disabilities	Zi Ai (WH)	<ul style="list-style-type: none"> ▪ Zi Ai (32) has difficulties in reading and writing. ▪ She is an efficient worker and is able to supervise the weaker ones in the team. ▪ She works slowly but independently with minimal supervision ▪ She speaks English, Cantonese and Bahasa Melayu.
Mild Learning Disabilities	Yakob (IS)	<ul style="list-style-type: none"> ▪ Yakob (23) has autism. ▪ He can read, write and count. ▪ He travels independently by public transport to work. ▪ However, he has poor concentration span and is easily distracted at work. ▪ He needs supervision to ensure quality work. ▪ He speaks fluent Bahasa Melayu and fairly good command of English

Mild Learning Disabilities	Qassim (IH)	<ul style="list-style-type: none"> ▪ Qassim (25) can read, write and count. ▪ He has good leadership skills. ▪ Able to work with very little supervision. ▪ However, his social skill is often affected by his mood swing. ▪ He speaks fluent Bahasa Melayu and fairly good command of English
Mild Learning Disabilities	Sakira (JO)	<ul style="list-style-type: none"> ▪ JO (24) can read and write simple sentences. ▪ She is weak in social skill because she is extremely shy with strangers and people in authority. But, with her friends she can be completely different. ▪ She does her work well though at a slower pace because she is meticulous. ▪ She needs minimal supervision at work ▪ She speaks English and Bahasa Melayu fairly well
Moderate Learning Disabilities	Samy (AT)	<ul style="list-style-type: none"> ▪ Samy (22) has William's Syndrome. ▪ He can express himself verbally though he has limited vocabulary and comprehension skills. ▪ He can read and write very simple words. ▪ He is unable to travel by himself. ▪ He has weak motor skills. ▪ He needs supervision at work. ▪ He speaks basic Bahasa Melayu and Mandarin
Moderate Learning Disabilities	Kah Chung (WL)	<ul style="list-style-type: none"> ▪ Kah Chung (18) is autistic and does not have verbal skills. ▪ He sometimes uses facial expression, makathon and makes sounds to express himself. ▪ He is diligent and a very fast worker ▪ He needs supervision at work. ▪ He can write (incomplete sentences) in Bahasa Melayu or Chinese.
Severe Learning	Faruqh (BK)	<ul style="list-style-type: none"> ▪ Faruqh (24) has Down's Syndrome. ▪ He is not able to walk or talk.

Disabilities		<ul style="list-style-type: none"> ▪ He has low comprehension skills though he is capable of basic self-help skills. ▪ He is able to work with close supervision and improvised tools. ▪ He communicates with basic Bahasa Malaysia
Severe Learning Disabilities	Sandra (SL)	<ul style="list-style-type: none"> ▪ Sandra (27) has Down's Syndrome. ▪ She has a very soft voice that can hardly be heard. ▪ She can read and is able to pronounce words with clear diction even with her very soft voice but has low comprehension level. ▪ She is very slow in her movement but capable of basic self-help skills. ▪ She works with close supervision. ▪ She communicates with basic English

3.5 Data Recording and Analysis

A record file was used during the field study to write up observations made during the field visits. Notes taken were revised to maintain an accurate recording of information. Key points were taken during interviews besides tape recording interviews that were done face to face. Data were transcribed after each session. (Sample Transcripts: Appendix D, E, F)

Data analysis in qualitative studies is an ongoing process. Findings are generated and systematically built in the process of gathering data (Mertens, 2005). Mertens (2005:421) emphasised that data analysis includes “reflective activities that result in a set of notes that records the analytic process, thus providing accountability.”

The data analysis was done manually by comparing and matching the findings from different data sources. This study adopted the following steps in qualitative data

analysis suggested by Miles and Huberman (1994) as cited in Mertens (2005:423); and Meriam (179:181):

1. Give codes to first set of field notes drawn from observation, interviews, or document reviews;
2. Note personal reflections and other comments in the margin;
3. Sort and sift through the materials to identify similar phrases, relationships between variables, patterns and themes;
4. Category Construction (Meriam 179:181) was used after all the transcripts were compiled. Categories construction was done through the constant comparative method of data analysis to draw out information, remarks and stories that are linked to the core categories. The core categories in this study are:
 - Factors that are affecting the progress of the self-advocacy movement
 - Impact of self-advocacy groups in the lives of some individuals with LD
 - Implications
 - Recommendations
5. The transcript has two side columns for Sub-topics and Emerging Themes. The Sub-topics were derived from the comments of interviewee. Emerging Themes were categorised based on the four core categories listed above.
6. The researcher synthesised the data analysed to draw some conclusions to the study.

3.6 Data Validation

To avoid any biased influences in the data collection, all data collected were verified by participants of this study after the field notes and recordings were being transcribed.

The Triangulation approach was used to verify the data collected from different sources to identify the factors that have affected the self-advocacy movement and the impact of self-advocacy movement. Mertens (2005:255) explained that “Triangulation involves checking information that has been collected from different sources or methods for consistency of evidence across sources of data.” In

this study, triangulation that involves the convergence of multiple data sources was used. These data sources which were collected from interviews and observations were being triangulated by analysing emerging themes of the different sources. Emerging themes that appeared in more than two sources were studied to examine its validity.

An auditor (supervisor) was consulted to examine the fairness of the research process and accuracy of the data in the process of data analysis.

3.7 Duration of the Study

This research required three and a half months of study and analysis, using the various approaches of data collecting or accessing information and recording of observation. The schedule planned for this study is shown in Table 3.4.

Table 3.4:
Research Schedule Plan

Date	Research Process
1 st week January	<ol style="list-style-type: none"> 1. Began observation of a self-advocacy group – United Voice (twice weekly). 2. Transcribed field notes from observation after each session. 3. Project coordinator of United Voice validated transcribed data. 4. Interviewed Participant No. 3. 5. Contacted participants No 2 and sent structured interview questions to participants. 6. Contacted Participant 1, 4, 5 and 6 made appointment for interview.
1 st week February	<ol style="list-style-type: none"> 1. Interviewed Participant 1, 4, 5 and 6. 2. Transcribed interviews
2nd week February	<ol style="list-style-type: none"> 1. Compiled email data from participants No. 2 and followed-up with more questions for 3 of the participants. 2. Interviewed three of the participants in No. 2 face to face. 3. Transcribed data collected from interviews. 4. Interviewees re-confirmed data that had been

	transcribed.
4 th week February – 3 rd week March	<ol style="list-style-type: none"> 1. Analysed data collected 2. Began writing first draft of report 3. Auditor (Supervisor) reviewed the data analysis procedures and results 4. Edited report Consulted auditor again for final approval
4th week March	<ol style="list-style-type: none"> 1. Final editing of dissertation
2nd week April	<ol style="list-style-type: none"> 1. Submit dissertation

3.8 Summary

The design of this study is found to be appropriate for the study. Data collected from structured and semi-structured interviews, observations and documents were able to provide reliable findings to the research questions. The research has successfully met the objectives of this study.

Being a qualitative study, the researcher had to be well organised and disciplined in contacting and following up with participants, transcribing data and ensured that transcripts are audited. The data analysis was tedious. It required focus and understanding of the issues to accurately analyse the data collected with category construction and triangulation. The discussions of the findings required skills to synergise the results of data collected with reviews of this study and current issues that are related to the self-advocacy movement of persons with LD. The writing of report required analytical reflection and careful choice of words to avoid biasness.

The researcher is thankful to have an experienced supervisor to critique her work at every stage of the research. The careful auditing of this study by the supervisor who is an expert in research and knowledgeable of the issues in this study has helped to strengthen credibility and authenticity of this study.

CHAPTER 4

RESULTS

4.1. Introduction

The data collected in this study has provided insights about the self-advocacy movement of persons with LD in Malaysia. The 21 participants selected have contributed much useful and in-depth information for the purpose of the current study. This chapter reports the findings and analysis of the data that have been transcribed and validated by the participants. Based on the analysis, the researcher attempts to answer the research questions:

1. What are the factors that are affecting the progress of the self-advocacy movement of persons with LD in the Malaysian context?
2. How have self-advocacy groups impacted the lives of persons with LD in Malaysia?

This research has discovered some of the factors that have influenced the progress of this movement in the past 10 years. These findings are reliable as the data were collected mainly from interviewees who have many years of experience in the field of persons with LD from five different states within Malaysia, namely, Selangor, Federal Territory (Kuala Lumpur), Perak, Penang and Sabah. The factors derived from the analysis showed that there is much to be done to ensure that the self-advocacy movement of persons with LD in Malaysia continues to advance. However, these may not be the only factors that have affected the progress of the movement since this small scale research has limited resources and time for an in-depth study.

In studying the impact of self-advocacy groups in the lives of persons with LD, the researcher has discovered some strong evidences that involvement in self-advocacy groups can indeed have many positive impacts in the lives of persons with LD. This study has discovered that the self-advocacy group has also impacted not only those with very mild LD but it has impacted those with moderate as well as severe LD.

4.2 Factors that are Affecting the Progress of the Movement

The general consensus from the data collected observed that the self-advocacy movement of persons with LD in Malaysia is slow in its progress in terms of the growth in numbers of the self-advocacy groups and its impact in the lives of persons with LD throughout Malaysia. Ken Jo, a staff at United Voice who has been an active self-advocate for the last six years observed that the progress of self-advocacy movement in Malaysia,

...was slow at the beginning but it is picking up now. With the formation of Self-Advocacy Group in Perak, Penang, Selangor, Kuala Lumpur, Sabah things are moving but are a scattered fragment. But we need to spread to other states and districts with no Self-Advocacy Group yet so that we can form a National Body.

Asman, another staff of United Voice observed that, “In Malaysia, I feel the progress is still very limited and small. Only in UV it has grown more significant.” Suzie observed that many persons with LD whom she observed have not fully understood the concept of self-advocacy, “Though some of them are beginning to understand, they have not fully internalized.” In agreement with Ken Jo and Asman, she observed that the self-advocacy movement is limited and is affecting only a small group of adults with LD.

The analysis of the data collected derived several factors that have contributed to the slow progress of this movement. The factors include:

- Awareness of self-advocacy
- Support from NGOs
- Structure of self-advocacy groups
- Socio-economic background and family support
- Intellectual inhibition
- Public attitude
- National Policies

4.2.1 Awareness of Self-Advocacy

Almost all participants agreed that the lack of awareness of self-advocacy by persons with LD themselves is the key factor that affected the progress of this movement. Ravi, Suzie, and Mei Quin expressed that the progress of their group is slow and marginal. One of the major reasons they agreed that has affected the progress of the self-advocacy movement is the fact that many persons with LD in Malaysia themselves are not ready to take up the task to self-advocate. They were not taught to self-advocate in school. Self-advocacy is a new concept to many of them. Suzie commented that persons with LD are slow in their participation and contribution to the self-advocacy movement because,

They have not fully understood the concept of self-advocacy. They also do not know how to see that self-advocacy is an empowerment tool for them. The leaders, I think, don't quite fully grasp their roles and responsibilities.

In Kota Kinabalu, Su Li from Seri Mengasih reported that their self-advocacy group, Kangaroo Club is also progressing very slowly as a result of lack of awareness,

At the moment there is no real awareness of self-advocacy in the minds of the member.... The dependency syndrome is real and a huge big block of obstacle in the minds of not only persons with LD but their families too. The centre had tried to “let go” but the Club merely stopped its activities.

Ken Jo, testified that it took ten long years of training before the first self-advocacy Society in Malaysia, United Voice was formed because,

If we have been a Society earlier, we would not have been ready to take lead. Too few members who were able to lead. It would have to depend too much on the able-bodied. But now... we have better leadership skills after years of leadership training and hardcore training.

Thomas thinks that if persons with LD are aware of self-advocacy and are taught to self-advocate when they are young, the scenario could have been different,

I think if there is early intervention for persons with learning disabilities and appropriate programme for every stage, then they would have better abilities in self-achievement. If there are proper training programme they can be more independent.

As pointed out in Chapter 1, self-advocacy is not in the curriculum of the Malaysian Special Education for LD. Subjects related to Pre-Vocational Training and Transition has yet to be introduced. These are key subjects where self-advocacy can be introduced and taught. Ken Jo stressed on the need to formalise self-advocacy training in school and Community Based Rehabilitation (CBR) Centres to change the misconception on what self-advocacy is about,

There is no word of self-advocacy taught in school. Only a few CBR centres are open for ideas about self-advocacy whereas majorities are not interested due to the lack of knowledge what self-advocacy is. Some have the misconception that self-advocacy is about fighting against the government.

Habib, another self-advocate and a leader of UV observed that not many persons with LD in Malaysia know how to self-advocate. He thinks that self-advocacy

should be taught in school. Recalling the quality of his early education in England, he suggested that more professionally trained teachers are needed, “When I was in England at five to eight years old, I learnt to speak up in school. I hope there will be more professional teachers who are trained overseas.”

Ravi suggested that self-advocacy should be taught formally in secondary school but, education on making choices should begin even in primary school. He advocated for change to the current scenario in most Malaysian schools, “In our school system, teachers tell them exactly what to do...If choices are given from early stages they will be able to be where UV members are.”

Thomas also suggested that a change in teaching approach is necessary though he thinks that the change in approach will take a while to develop because we are faced with situations where services are not comprehensive enough. Lack of expertise and funds are observed to be reasons that the special education programmes are not carried out effectively. Thomas suggested,

People may still be thinking of helping them in basic independent skills...I think they should teach them to vocalize to speak up for themselves. Personal Advocacy to voice your views and know your rights is important... There is lack of well-trained people.

The fact that self-advocacy is not a formal subject in school has affected the ability of students with LD in voicing up or negotiating for themselves while in school and in life after school. Self-advocacy should be taught formally in school because it is a skill that can be learnt. Karen of Dayspring Centre for Persons with LD in Klang observed that with consistent training, role plays and practices the members in their group who did not understand the concept of self-advocacy gradually learned to voice their opinions, make decisions and take up responsibilities. Karen commented,

We did see them improving, starting to talk and make conversation... Later, they were able to form a committee and elect their own leaders...We could see them being very responsible in carrying out their duties.

This experience shared by Karen has given us a glimpse of how education on self-advocacy can train persons with LD to self-advocate and to take up leadership responsibilities. The process may be slow but it is possible. The trainees at Dayspring Adventure Club may need a lot of guidance at this stage but with more practices they can one day take charge of their self-advocacy group independently. As Thomas has suggested, persons with LD could be better self-advocates if they had been taught to speak up at a young age. Early intervention has proven to be an effective approach in educating persons with LD. The Malaysian Special Education may have lost many precious years by missing out self-advocacy in its curriculum but it is not too late to begin creating awareness on self-advocacy in school.

4.2.2 Support from NGOs

To date, only eight organisations working with persons with LD have caught on the vision to support the self-advocacy movement. The lack of awareness, expertise and focus are observed to be the main causes of the poor support from NGO's. This could be the main reason why many centres failed to emphasise on self-advocacy training and forming self-advocacy groups. Most of the Centres that provide multiple services explained that the lack of staff and resources are main reasons why a self-advocacy group is not a priority in their programmes. Mei Quin realised that their self-advocacy group, Dragon Club, would have progressed faster if they had a full-time staff. However she expressed, "We are not ready to employ full-time staff for the self-advocacy group as our organization provides a very, very wide range of services and we need to balance our activities to meet the group of varying range."

Ravi acknowledged that his organization, Bethany Home, has so many other things that bog them down. Advocacy is just one little option at their centre. However, things are beginning to change now as the organisation has recently appointed a full-time staff to focus on supporting the self-advocacy group.

The majority of the groups that are centre-based hold their self-advocacy meetings on a working day due to lack of staff support. Those who have graduated from these training centres or sheltered workshops are unable to join the group since meetings are held on working days. Suzie's organisation is beginning to give more emphasis in supporting their self-advocacy group. They realized that there is a need to hold the self-advocacy group meetings during the weekends. This step is indeed necessary so that trainees who are trained to self-advocate can continue to learn and contribute to the group after they have moved on from the centre to work in an open employment. Otherwise, the centre will only be providing short term self-advocacy experience which may not be effective in impacting the lives of persons with LD.

United Voice was an advocacy-supported group sponsored by Dignity & Services (D&S) for 10 years before they became a registered Society. Ken Jo appreciated the support provided by D & S. The board of D & S employed a full-time staff to specially support UV. Recognising the fact that members of UV need support in running their organization, Ken Jo shared,

When UV was under the sponsorship of D & S, they employed a full-time supporting staff for UV. The role of the staff is to assist us and help the committee in whatever support needed to run the group....

Ken Jo felt that the support and space given to UV to run their own office and group has helped UV to be where they are today. Though Ken Jo acknowledged the

importance of having support in running a self-advocacy group, he advised persons with LD,

Give your supporting friends limited roles to play in the committee meetings. They can advice but the ultimate decision is yours. Choose supporting friends who are patient, tolerant, understanding, honest and loyal. Fall short of these values may mean trouble.

The lack of support from NGOs for persons with LD in the self-advocacy movement is partly due to the lack of know how. Ravi suggested, “In Malaysia, we are lack of resources in the know how. We know Self-advocacy is important but we don’t know the formal way of training.”

Suzie revealed that many centres have difficulty employing trained staff. Though in recent years, graduates from the field of psychology have increased, Suzie noticed that,

Many of these graduates are not interested to play supporting role or be involved in services...because there is no prospect and there is lack of incentives. Low salary is another main factor that deters professionals from joining the services to support persons with LD. We may have to revise the salary.

The NGOs play a very important role in supporting the self-advocacy movement in Malaysia. However, only a few are actively involved in supporting this movement. Many are still unaware of the importance of self-advocacy. For those who are involved, their resources seem limited. Constraints of funds, manpower and expertise have limited their effort to help the self-advocacy groups advance more progressively. The future of the self-advocacy movement depends very much on the government’s effort in collaborating with these NGOs by giving them full support in terms of finance and training for trainers to help this movement progress further.

4.2.3 Structure of Self-Advocacy Groups

The structure of self-advocacy groups is found to be another factor that has affected the progress of the self-advocacy movement. United Voice, which followed the social model in its operational approach all through its development, has seen the effect of this model in impacting the growth of the group. UV began as an advocacy supported group and later became an independent or autonomous group. Ken Jo explained, “UV is run by persons with LD. In UV, the nine committee members are in charge...”

The advocacy-supported or autonomous groups seemed to be more independent and taking more initiative. While most of the interviewees from the centre-based groups felt that their self-advocacy group members need a lot of prompting and support in carrying out their responsibilities and running their group activities, the advocacy-supported group, Mutiara Voice Club (MVC), has a different outcome though the group is located in a non-urban district and in a relatively lower socio-economic community. MVC is situated in Balik Pulau, Penang, a district which is in the outskirts of the city.

Chui Yee, the executive staff of Asia Community Service (ACS) which is the sponsor of MVC testified when asked why her organization forms a self-advocacy group,

ACS did not form the group. The effort was by the members at the workplace themselves after being motivated by a visiting self-advocate from UV.... ACS has always supported the philosophy of people centred and people first.

Chui Yee thinks that the advocacy-supported group is a better approach. Centre-Based Groups and Social Groups are somewhat controlled or bound by the Organisation’s rules and regulations that “persons with Intellectual Disabilities cannot

fully be empowered.” The MVC has learned to plan, organize, and arrange meetings and their own activities. Chui Yee shared,

They hold monthly meetings in various venues in the community (i.e. community hall, coffee shops, at the centre, individual homes etc..) and have organised their own outings and carried out the activity without the need for support... Yes, all action at their own initiative, we merely offered suggestions.

Though the findings of this factor may not be conclusive, it appears that an advocacy-supported group can have more opportunity to be independent, make decisions and take initiative. Being given the authority to make decisions helps persons with LD to take control and not depend on others to decide for them. The group is not restricted to the rules and regulations of the organisations which may confine their activities to suit the centres set up and environment. The advocacy-supported group such as MVC has the liberty to decide what they want for their group. Ken Jo testified that, “Advocacy or autonomous groups like UV is run by the self-advocates. This is a good place for them to discover their leadership potential & other abilities.”

MVC could be an isolated case being located in a smaller community and given good leadership training at their work place. However, Chui Yee who has been involved in services for persons with LD for more than 20 years could also have made a relevant observation that an advocacy-supported group can be more effective and appropriate in training persons with LD to run their group independently. UV has also proven that the advocacy-supported group can go very far in developing their own group and eventually their own organization.

Perhaps, each supporting organisation involved should re-examine their support for the self-advocacy groups. Is there a need to change the approach for a

better outcome? Is the group ready to move a step closer to the advocacy-supported approach?

4.2.4 Socio-Economic Background and Family Support

The socio-economic status, according to Thomas can affect the self-advocacy movement. The fact that more self-advocacy activities are clustered in the Klang Valley, raised a question: Why is self-advocacy more active in the city and its peripheral towns as compared to smaller towns and districts?

Thomas noted that, there are differences in socio-economic status between people living in Petaling Jaya, a city, and those living in a more rural area. There is also a difference between people living in group homes, institutions or within their own families. The environment they live in will determine the opportunities given to them to self-advocate. He suggested that the level of resources within families can also affect the opportunities given for self-advocacy. Ravi agrees with Thomas's opinion and shared his experience in Bethany Home,

Persons with learning disabilities in the Estate quite often don't participate in the community. They don't have the opportunity to be independent. People always tell them what to do...they don't know how to communicate, they get violent, loud and aggressive...they try to fight the system by behaving like that.

In Friendship Club, Suzie observed that the educated parents understand the importance of self-advocacy whereas those from the lower socio-economic background have no awareness of what self-advocacy is. The educated parents tend to be more supportive of their children participating in activities related to self-advocacy and they enhance what is taught at self-advocacy meetings. Mei Quin observed that some parents are very receptive but not many have knowledge of what self-advocacy means.

Lack of awareness seems to be a common reason to deter parents from allowing their children to participate in self-advocacy groups. Su Li, a supporting friend of Kangaroo Club, finds that parents underestimate their children and they do not trust that any good can come out of a meeting of a club without teachers around. One self-advocate of Kangaroo Club revealed that, “Some families disagree because they don’t understand what Kangaroo Club is all about, and members don’t know how to explain...”

Ravi is of the opinion that the mindset of parents can be a hindrance. In his observation, many parents are not willing to let go of their child and as a result become over protective.

...What they are doing is they are keeping them in cages- beautiful cages - some are air conditioned cage, with all the electronic stuff etc. But, that is not the world. We have to educate parents to let go... When they let go, then they will support their child doing things by themselves.

Ken Jo on the other hand observed that parents in the Klang Valley who are more aware of the importance of self-advocacy are supportive because, “They know they can’t be there all the time. They have to let go...”

Though socio-economic background seemed to be a possible factor that may have affected the ability of persons with LD to self-advocate because of the environment and opportunities, it is not conclusive. A more in-depth research is needed to certify this suggestion.

The MVC members seemed to prove that those from a lower socio-economic background are able to be effective self-advocates. The majority of the members of MVC are from lower socio-economic background but the group showed more independent abilities compared to other groups observed in this study. Being in a non-urban district may provide them a safer environment and more accessibility to public

facilities. They may have the advantage of living in a smaller community where people may have a better awareness of their existence and needs.

Awareness on the importance of self-advocacy and the mindset of families seemed to be influencing factors on parents' support for self-advocacy. Some parents from lower socio-economic status who are aware of self-advocacy may be more open and willing to let go than those from the upper socio-economic background. It appeared in this research that awareness and the mindset of the parents is a stronger factor than socio-economic background in determining the support given for their child to be involved in the self-advocacy movement.

The parents of UV members showed support in the self-advocacy movement though they represent the various socio-economic backgrounds. Perhaps being in the urban districts these parents have a better awareness of self-advocacy movement as a result of more opportunities for exposure and information. Awareness of the importance of self-advocacy would be necessary to change the mindset of parents who are apprehensive or ignorant.

4.2.5 Intellectual Inhibition

Interestingly, Thomas has the opinion that people with LD may not necessarily be in a worse condition when compared to other disability groups in general. He noted from his research that though other disability groups may be intellectually more able, there are many barriers for them to be independent. The dynamic of the scenario, the dependency, the feeling of inferiority might be very similar. People with Learning Disabilities might actually be very lovable and have more opportunity to go everywhere. They might be happier persons.

Nevertheless, in terms of running an organization, Thomas observed that the other disability groups are more advanced because they do not have intellectual inhibition. They are

...very well organized groups. In this case, they are able to take their agenda further... As a movement, they are ahead of persons with LD. They started earlier and they have the funds...they do not have intellectual barrier.

Sharing the same opinion, Suzie explained further that the self-help or self-advocacy movements of other disability groups are way ahead of the movement of persons with LD because "...quite a lot of them completed tertiary education in the universities and hold degrees, etc. They also have their own vocational training centres."

The inhibition of the mind is a major factor that has caused persons with LD in Malaysia to lag behind in developing their self-advocacy movement when compared to other disability groups. But, given opportunities and support, persons with LD can also organize and run their own self-help movement. Several participants of this research who have had exposure overseas testified how capable and independent persons with LD can be when given the relevant education, support and opportunities. Ravi observed,

In the Special Olympics World Congress in Panama City, the persons with LD there are so independent and capable. They are much better than our "cream". They are independent, confident and outspoken. I believe they are more able because they have better education.

Suzie shared what she saw in Australia 20 years ago:

...their Self-Advocacy movements were so advanced. They have several autonomous groups who were affiliate members of National Government Bodies. They were able to do so because they were given support and opportunities.

Intellectual inhibition and the lack of quality education seem to cause persons with LD to be less progressive when compared to persons with LD in some developed countries where quality education, support and opportunities were available.

It is time for all parties involved in Malaysia to give persons with LD better education, exposure, support and opportunities to be independent and to voice their opinions. Such move can help them develop their full potential to represent themselves and stand up for themselves in the society in spite of intellectual inhibition.

4.2.6 Public Attitude

Public attitude could be a key factor that affected the development of the self-advocacy movement of persons with LD. Thomas commented,

I think one large factor would be public attitude. They think People with Learning Disabilities are incapable. How can they run a society? How can they drive a car? They might let go of people who are more able to articulate.

Ravi expressed his observation and frustrations based on his many years of intense involvement in the developing and running a school for students with LD who are unable to fit in the local school system:

The mindset of people must change and it must begin with the ministries concerned.... Only the loud people get what they want. But, persons with LD are treated as nobody. It is time for them to speak up.

Again Suzie suggested that the public attitude is due to lack of awareness. She believes that awareness is very important for all levels, including the government and the public in general. She suggested there should also be more training and awareness for the leaders of NGOs and the authorities who can make policy change.

Suzie and Ken Jo were very upset that persons with LD were not represented in a recent workshop (23-25th February 2006; in Kuala Lumpur) on the drafting of the Disability Act organised by the Ministry of Women, Family and Community Development. Suzie raised a pertinent question, “How can the drafting of the Disability Act enhanced Rights-based and Protection for all disability groups when persons with LD were not given a platform to voice their issues, needs and concerns?”

Chui Li implied that she too agrees that the public’s attitude towards person with LD should be addressed. When asked if she thinks that the voice of MVC is important in changing policies that will affect the life of persons with LD, Chui Li replied, “Yes, it is important but it will take a long, long time, I guess. Changing policies may be a dream for now, but creating awareness and changing attitudes on individuals may be a more realistic goal.”

Being a person with LD and believing in the power of the self-advocacy movement, Ken Jo felt strongly that persons with LD should join force to break down discrimination, “We need to unite the voice of more persons with learning disabilities so that we will be seen and heard by the general public and society... we need to break down discrimination at every level.”

From the various opinions and expressions, it is clear that the public attitude does affect the self-advocacy movement. The public attitude will determine the opportunities given to persons with LD to represent themselves in all sectors. The apprehension towards their ability will deter opportunities given to persons with LD to voice up for themselves. To counter this attitude problem, more awareness regarding persons with LD is needed for “all levels” as emphasised by Suzie.

4.2.7 National Policies

During Thomas' visit to the UK in the mid 90's, he observed that adults with LD were living independently in group homes provided by the government. He recalled that Britain has a system in which people with LD can make certain claims for self-support. Many of them are employed and they have housing allowance. Support from the government helps them to be independent. Persons with LD and other disabilities as a whole in Malaysia, have yet to realise such privileges. We are still fighting for more allocations to improve the education of persons with LD, a basic need.

Thomas observed, "In terms of impact of modernity, Malaysians are moving from basic poverty and basic survival skills to other issues". However, through his active involvement in social movements, Thomas noticed that in most social economy discussions,

...disability issues don't surface yet...the focus is much more on racial comparison. Until and unless disabled people get into the planning process of national development plans such as the 9th Malaysian Plans,... it will not be in the mainstream.

The self-advocacy movement has yet to realise its full potential because the support given by the government for the development of this movement is marginal. Suzie is optimistic that persons with LD in Malaysia will one day have their own National body and will have more networking with the government agencies and ministries, "but it is going to be a long journey to reach that level". Suzie pointed out the self-advocacy movement in Malaysia is far behind when compared with the self-advocacy movement in other developed countries. In Malaysia, the awareness of the existence of the self-advocacy movement of persons with LD is insignificant. The self-advocacy movement has only recently begun to participate in National Bodies

like Malaysian Council for Rehabilitation (MCR) and Malaysian Confederation of the Disabled (MCD).

To make themselves known to the government and the public, the self-advocacy groups should find more platforms to voice their views. Thomas suggested,

Don't make disability issue the concern of just the Welfare Department...It could be Education, Housing, Health or whichever public space that provides an opportunity...Link up with think tank groups to know the process that is going on... Make your presence felt.

The self-advocacy movement could be more effective in its nationwide development when there is recognition and support from the government. To create a better awareness of the self-advocacy movement, more effort has to be made for the movement to enter into the discussion of disability issues as well as general issues at the local and national level. The self-advocacy groups have to make their presence felt in public events.

To date, the Education Act and Regulations has not mandated for Pre-Vocational Training and Transition to be included in Secondary School Curriculum as practised in some developed countries like the US as discussed in Chapter 2. As pointed out earlier, these are two important subjects where self-advocacy can be introduced to students with LD. There is a need for policy change to enable the implementation of training on self-advocacy in school nationwide. The self-advocacy movement in Malaysia has to realise this issue and urge the Ministry of Education to explore positive changes to the current curriculum for students with LD.

4.3 Reflection on the Factors Affecting the Self-advocacy Movement

The lack of awareness on self-advocacy by persons with LD, their families, NGOs, the government and the public as a whole, seems to be the main factors why the

progress of the self-advocacy movement in Malaysia is progressing slowly. Being persons with LD, they need support from their families and all sectors involved to move on progressively. But, due to the lack of awareness on self-advocacy, support given to persons with LD to develop this movement is marginal.

That awareness on self-advocacy should begin with the education system was strongly recommended by most of the participants in this study. This can be an effective strategy. The students with LD, their parents and teachers as well as other authorities involved would have awareness of self-advocacy through the education process and system. Education on self-advocacy should be implemented not only in government schools but all other training schools and centres run by NGOs. The school is the most effective platform to reach the grassroots. In years to come, the public's attitude towards persons with LD will change. For the self-advocacy movement to progress nationwide, the Ministry of Education, the Ministry of Women, Family and Community Development and the NGOs should work hand in hand to help create a greater awareness on the need for persons with LD to self-advocate. The National Policies related to Special Education have to be studied carefully and revised where necessary.

The government has to invest more funds for research and training to build a team of expertise who can help develop the self-advocacy training programmes both for the students as well as the trainers. Since Malaysia has very limited research and resources on self-advocacy, expertise from overseas should be consulted.

The task to educate all persons with LD to self-advocate is enormous. The implementation involves many sectors and requires a lot of funds. Unless, the government is convinced that this is an important move and is willing to invest, the

development of the self-advocacy movement will probably remain slow and not be able to reach the grassroots effectively.

4.4 The Impact of Self-Advocacy Groups in the Lives of Individuals with LD

The impact of the self-advocacy groups in the lives of individuals with LD was examined through interviews and observations. The data collected indicated that involvement in a self-advocacy group is an effective way to train persons with LD to become more independent. It has impacted persons with LD in many ways. Three most significant impacts include:

- Awareness of rights;
- Confident to voice up; and
- Ability to take up leadership responsibilities.

Most of the leaders and the staff of the various organisations who were interviewed observed that the self-advocacy group activities have provided opportunities for those involved in the self-advocacy groups to develop independent and leadership skills.

Ken Jo testified,

UV has encouraged me to freely express myself, change my leadership capacity, sharpen my thoughts, taught me to work with others and plan for the group which has now become a Society. If I am not involved in UV, I would probably be stuck at home and miss out all the opportunities. I would not have so many friends that I do now.

Suzie, Mei Quin and Chui Li shared how their trainees and workers are impacted by self-advocacy as a group. Suzie observed many changes in Friendship Club,

Self-advocacy has taught them to speak up, gain confidence and help them to also feel a sense of achievement... This has enabled them to be more pro-active. They have also learned to challenge or 'argue' with the trainers. It is no longer 'you say, I do'. Now they can express

their opinions and say their mind. Before, they were timid. Now they have developed better communication skills.

This is what Mei Quin noticed in the Dragon's Club,

The self-advocacy group has developed ability to make choices, decide for themselves...developed better self-esteem. They also learned how meetings are conducted which have not happened before.

In Mutiara Voice Club, Chui Li commented,

The group is independent in making their own decisions and capable of seeking for advice and assistance where needed. They have taken more responsibilities and developed a sense of belonging and pride to have formed the group. They have learned to plan, organise and arrange their own meetings.

The feedback from the participants on the impact of self-advocacy groups is very positive especially in cases where appropriate environment and support are given. Being involved in self-advocacy groups has helped persons with LD develop communication, leadership and independent skills.

This study also examined the impacts of a self-advocacy group, United Voice, in the lives of two individuals with LD. These two individuals are Habib, a person with very mild LD and Faruqh, a person with severe LD. Both of them showed progress in their independent skills after joining a self-advocacy group.

4.4.1 The Story of Habib

Habib, a young man in his mid twenties hails from a town in Selangor. He joined UV in 2001. It has been five years since he joined UV. Habib shared how his involvement in this self-advocacy movement has changed his life. In a nutshell, Habib summed up that UV has helped him to speak up for himself and be more independent. Habib tells his story:

Independent and social skills

“UV has motivated me to take public transport to KL or anywhere outside KL by myself... I have also learned to go for movies by myself instead of following my family all the time. At UV, I learned to speak up.... UV has given me opportunities to mingle with people – with members, parents, other people like volunteers.

Sense of belonging

I have many friends at UV. These friends are open and fun. We celebrate one another’s birthdays and make everyone feel important. Some are my close friends. UV supporting friends and volunteers are nice. It is easier to accept their advice. They treat us like friends. They accept us and give us good advice. There are no parents and teachers at UV meetings. We can share secrets. We can have guy’s talks – personal stories. I can express freely.

Working Life and Awareness of Rights

In all my jobs, most of the employees are nice to me but I did meet some weirdoes. I had some bad experiences like being harassed, given names and asked for money. I was afraid. I think there should be laws to protect people with disabilities - Laws about their work place and laws to protect their rights. I have heard about such laws in other countries. Ya, in a movie – ‘Loretta Claiborne’ which I watched at the 1st NSAC (1st National Self-Advocacy Conference for and by persons with Learning Difficulties in Malaysia, 2004). She was bullied by her school mates and colleagues but she fight back. She was brave. Loretta is from America. She spoke up for herself and about her life in public. She made her own decisions. In America, the public and the government allow them to speak up. The people there are more open.

Relationship with Family

My family... How they treat me now? Er..., when I was a kid, I like to go out, they won’t allow me. Now, things have changed. They have changed. But, I wish my family won’t be a shame to talk about certain things. I wish... we can have open talk about problems or anything... Er...especially between man and woman relationship. They won’t like it. I can only comment about their (women) looks but not more than that. Can only be friends. I wish my family will allow me to get married. They think financially, I can’t afford. The government should provide houses for persons with LD like the develop countries. They should learn from other overseas countries.

Exposure

Through UV, I learn to speak up, I learn to be a leader, to run a society...I learn about my rights and speak up for the rights of persons

with LD. I spoke in conferences and public meetings. Eh...it has changed my thinking...encourage persons with LD to speak up for their rights... I have been to conferences like ICSW (International Conference of Social Welfare)... I was a participant and I also conducted a workshop...on Self-advocacy Movement for persons with LD in Malaysia. I was elected to join the Special Olympics World Congress in the Panama. I met many people from all over the world. They are very independent. They spoke up a lot.

Advocacy

I met with the former PM (Prime Minister) – Dr Mahathir twice. In 2003, I spoke up for persons with LD. I talk about education for persons with LD. It was a pre-budget forum with NGOs. I said that the government should not have too much reading and writing in Special Schools for persons with LD... giving too much pressure. The schools should use Fun ways. Ask them what they like and what they want. The school in Malaysia doesn't teach much about vocational skills, not much.

I attended other meetings... We discussed about the Disability Act - A law to protect people with disabilities in Malaysia. We discussed about education, employment and housing for people with LD. I suggested to them that students with LD should not be locked up when they are in school. ...But, not much changes yet. They are taking a long time to change.

Habib's story indicated that UV has impacted his life in many ways. Being a person with very mild LD, Habib has the potential to learn and experience new challenges. Though he has learning disabilities, his personality shows that he is relatively mature and sensible. What he needs is opportunities and guidance. He has developed many independent and interpersonal skills.

He comes from a family that is supportive of his involvement in a self-advocacy group. His family allowed him to experience new challenges, for example by traveling independently to places outside the Klang Valley. However, he seems to expect more independence from them especially in regards to relationships and marriage.

Through UV, he has become more aware of his rights and learned to speak up for himself. Being a leader in UV he has learned how to run a society. He has opportunities for exposure within the country and outside Malaysia. With such exposures, he has developed critical thinking, learns to evaluate the situation in his own country and motivated to advocate for persons with LD in Malaysia. He has developed the courage to advocate for persons with LD even amongst politicians. Habib has learned the skills to speak up in forums and dialogues with NGO leaders and officials from the government sectors.

The exposures at UV helped Habib discover his potentials in leadership and in career advancement. Habib's sharing clearly showed that UV, as a self-advocacy group, has impacted his life. He has discovered potentials in himself which perhaps he never thought he could achieve (Refer Appendix E).

4.4.2 A Sibling's Observation

The researcher spent about three hours chatting with Zaleha about Habib's involvement in UV. Her stories had enlightened the researcher on the importance of the commitment of the family in supporting a person with LD to be involved in a self-advocacy movement. Zaleha saw many positive changes in the life of her brother through his involvement in the self-advocacy movement, "He has become more responsible and mature." The following are some snippets of her story about Habib:

Sense of Belong

...UV is a Club. Habib feels he is part of a something important to him. Before UV, he hardly had any friends. But, now we have to remind him not to spend so much on his SMSes.... I think he has also learned to accept himself better after he joined UV. This has helped him to feel less deprived when compared to what his siblings are experiencing in live.

Change in Ambition

UV has changed his career path...He saw a UV friend working in an office and he told mum "If he can do that, so can I". That became his dream, to work in an office. Finally, after a few years of waiting, his dream came true....

Learned to Verbalise his Feelings

Before, when he was angry with mum he would take it out at other things. For example, he would pour out Mum's shampoo in the toilet bowl and refilled the bottle with water instead. That was his non-verbal form of expressing his anger. Now, he has learned to verbalise his anger and would say to mum, "Stop treating me like a child. I'm not a baby...!"

Family Support

A lot of credit goes to mum. Initially, mum was not too confident about him joining UV. Firstly, UV is so far from home and secondly, we do not know if it is a good Club. He kept pestering mum until she gave in. Mum was the one who taught him how to take public transport for UV meetings. He can't count. Training him to have exact change for his travels was a challenge. A lot of hard work for mum but she was willing.

Parents and siblings play an important role to help open opportunities for them. We need siblings to push their siblings. Somehow, some parents go into denial mode. My dad was totally in denial. Though mum noticed the difference in Habib and realised he needed help. Dad denied that.

Independent

He used to ask for permission to go for UV events like seminar, camp, etc. But, eventually he doesn't ask for permission anymore. He just informs mum, "I have a conference in such and such a hotel this weekend. I am going." Before, we used to ring people in charge of these events "When, Where and How". But now, he is the one giving us all these information. We have learnt to trust him that his information is reliable. Now that we know who he goes around with - we know he is safe. Mum is beginning to treat him as an adult.

If Habib did not have the opportunity to be part of UV, he probably won't have the opportunity to express himself. He probably would still pour Mum's shampoo into the toilet bowl when he is upset with mum. Now that he can self-advocate he can express himself so much better.

The Role of Religion

His exposure to religion does help him grow as a person. It instilled values in him...He knows his limits. He learned to differentiate between good and bad. I think religion does play a role in helping him... He holds to his religious beliefs.

Difficult but not Impossible

He might need more time to express himself but when allowed to do so he can.

Zaleha has observed many positive impacts the self-advocacy movement has contributed to her brother's life. UV has given him a sense of belonging, helped him develop his independent skills as well as career path. He has developed self-confidence to verbalise his thoughts and feelings. However, through Zaleha's sharing it was noted that the impact of self-advocacy can only be effective with appropriate support from the family. Her family, in particular her mum, was willing to let go and took the risk to allow Habib to experience new challenges. Zaleha also shared that Habib's exposure to religious teachings has instilled good values in his life.

4.4.3. The Story of Faruqh

The mother of Faruqh shared how her son's participation in a self-advocacy group in the last 3 years had affected his life. Can someone with severe LD like Faruqh self-advocate? Aishah's opinion is "Yes, of course!" Without doubts she testified that Faruqh is motivated by UV to be more expressive in non verbal forms since he has no verbal skills. She noticed that often "...we are the ones that need to learn to understand people like Faruqh. They can self-advocate but the question is, are we willing to give him an opportunity." Here is her story:

Learned to Socialise

How has his involvement in a self-advocacy group impacted his life? A lot! He has learnt to socialise. He has become more interested in mixing with others. He used to be so anti social and would not accept others to come near him. But now he is different. His acceptance of others, especially the UV members is probably because he feels belonged to the group.

Sense of Belonging

He used to feel very threaten by other people around him due to a traumatic experience. But, now I think he feels that he is being treated like a person. This I believe is due to the fact that he is being accepted and cared for by the group. He is not being made fun of in spite of his limitations and his inability to walk.

Developed Self-Confidence

He has progressed a lot in the last three years... He is a very much happier person, less tantrums. He has learnt not to reject people or things given to him as often as before. He has developed better self-confidence. He has learned to negotiate – using more signs, facial expressions and gestures to communicate when he wants something....

At UV, he has actually learnt to travel for the first time without support from the family for a holiday. I think such an exposure is very good. As a parent, I have to learn to let go....

Persons with Severe LD can self-advocate

Would I encourage other parents to allow their children to join a self-advocacy group like UV? Certainly, I believe persons with severe LD like Faruq can also self-advocate when given a chance. It is in a self-advocacy group like UV where there are opportunities and training that are affecting him positively.

Aishah's sharing is eye opening. Many would think persons without speech and with very low intellectual abilities would not be able to self-advocate. But, her sharing has provided evidences that when given an opportunity and a supportive environment, persons with severe LD can also self-advocate – not verbally but with other expressions with which they are familiar. The fact that Faruq has developed

self-confidence, become more open to befriend others and happier as a person tells a lot about the impact of a self-advocacy group in his life.

4.4.4 Self-Advocacy Group in Practice at United Voice

The eight sessions of self-advocacy meetings observed by the researcher at United Voice has given some firsthand witness on how persons with various levels of LD learn to self-advocate in a group. However, the eight sessions were insufficient for the researcher to have in-depth observation on the impact of a self-advocacy group in the lives of the participants. Therefore, the observations are supported by the input of Asman, a Project Coordinator of United Voice. Asman worked closely with this group and has observed them since the training started four months ago. The observations in this formal self-advocacy group noted a number of findings on the impact of a self-advocacy group. Refer Appendix F for sample notes and reflections.

From the eight sessions of observations, the researcher observed that a self-advocacy group is an effective approach to develop independent skills in persons with LD. The following are some of skills identified during the observation sessions that could possibly develop over time through such group dynamics:

1. Learn to speak up;
2. Develop self-confidence and self-esteem;
3. Develop leadership skills;
4. Improve communication skills;
5. Raise issues and discuss issues;
6. Learn to be more aware of themselves. This awareness includes their behaviour, productivity at work, abilities to communicate and abilities to lead;
7. Learn about their rights by:

- expressing their likes and dislikes
 - making complaints when bullied or upset
 - negotiating with person in charge
8. Learn to respect one another by taking turns to speak;
 9. Learn to accept one another's strengths and weaknesses;
 10. Learn to understand one another by solving conflicts and misunderstandings;
 11. Learn to ask questions to their peers as well as to the person in authority (the Project Coordinator, in this case); and
 12. Persons with LD can learn to take charge of their own meetings by:
 - setting up the meeting room
 - decide who to lead
 - chair the meetings

4.4.5 Asman's Observation on the Impact of a Self-Advocacy Group

Being an occupational therapist, Asman has made some objective observations on how self-advocacy group training can help develop self-advocacy skills for persons with LD of various levels. He thinks that the self-advocacy training provided at UV is an initial stage for the group to learn about themselves and to know what it means to self-advocate. He testified, "In the last four months, I observed they have improved a lot...." Asman shared:

They were very inexperienced initially. But, now some of them are able to lead a meeting, more aware of their rights, more alert of their environment, more brave and confident to speak up.

Qassim

Qassim, for example, is relatively more mature than others in the group but he had no clue as how to lead a meeting initially. But, after a few months of training, he is beginning to gain confidence and he

knows how to lead an evaluation meeting in their group quite effectively.

Sakira

Sakira, though very shy is beginning to pick up courage to speak up. Peer influence is very important. It has helped her to develop her self-esteem and self-confidence.

Samy

Samy, still needs a lot of support and help, I believe he will improve when given more opportunity. The fact that he is given opportunity empowers him. But, maybe for some of them, we have to accept their limitation in leading a group.

Faruqh

Faruqh would not even join the meeting initially, but after some persuasion from his friends he gradually joins the meeting and seems to look forward to it. He might not be able to say anything to contribute to the group but his presence helps the group understand him. It also shows that he has developed self-confidence by the fact that he is willing to join the group. He expresses himself when he is happy or upset by his facial expressions and sounds that he knows how to express. His friends are beginning to understand his expressions better.

The Group

As a group, they are beginning to correct one another's weaknesses such as teasing others or taking other people's things. They also learn that when they are not happy with something or someone they can speak up. This is an initial stage of understanding their basic rights. They learn to complain when they or someone else are being bullied.

An Effective Training Approach

I think this is an effective training approach for them to learn self-advocacy. I would recommend schools and training centres to consider this self-advocacy group training approach to instill independence, communication, social and leadership skills in their students or trainees. Persons with LD need real life experiences and time to learn new concepts.

The eight sessions of observations and the interview with Asman has concluded that a self-advocacy group can be a very effective way to teach persons with LD to develop independent, interdependent, social, communication and leadership skills. It can also help persons with LD to be more aware of themselves and to develop self confidence. It is an effective way to help train persons with mild

LD to take up responsibilities. The self-advocacy group in UV has a very natural setting to teach the members to be aware of their rights and to speak up for their rights. The group has provided an environment whereby persons with very mild, mild, moderate and severe LD can learn self-advocacy, though each at their own pace and capacity.

4.5 A Reflection on the Impact of a Self-advocacy Group

The sharing of Habib, Zaleha, Aishah and Asman and the eight workers at UV has given so many insights on the impacts of a self-advocacy group in the lives of persons with LD. Self-advocacy has impacted persons with very mild, mild, moderate and severe LD. Given the right environment, training and empowerment, persons with LD can indeed learn to self-advocate. The impact may vary from person to person as there are other factors to consider. These factors of influence may include family support, the environment, the training approaches used and the abilities of the individual to learn. Though the impacts are many, the three significant impacts identified include awareness of rights, confidence to voice up and ability to take up leadership responsibilities.

4.6 Summary

The results of this current study have identified the factors that have affected the self-advocacy movement of persons with LD in the Malaysia. It has also discovered the significant impacts of self-advocacy in the lives of individuals with LD. The progress of the movement is reckoned to be slow due to several factors that have been discussed. The impact of self-advocacy groups is found to be significant. These results provide a strong reason for the self-advocacy movement of persons with LD to

develop more intensively nationwide. The next chapter will discuss recommendations to make this a reality.

This small scale study did not have sufficient time and resources to have a more in-depth study on the self-advocacy movement in Malaysia. Further research is necessary to examine why the movement has only reached five states thus far. Why are the other states not responding to the movement?

CHAPTER 5

DISCUSSION AND CONCLUSIONS

5.1 Summary of Findings

The self-advocacy movement of persons with LD is still at its formative stage though it has a history of about 13 years in Malaysia. It was discovered in this present study that only a small fraction of people who are involved in the education and services for persons with LD are aware of the self-advocacy movement. Many persons with LD, their parents, caregivers and practitioners in the field of LD are not aware of self-advocacy and its positive impact in the lives of persons with LD. Seven factors were found to have affected the progress. These factors include: awareness of self-advocacy, support from NGOs, structure of self-advocacy groups, family support, intellectual inhibition, public attitude and national policies.

This study also showed that self-advocacy groups have impacted persons with LD to be aware of rights, develop confidence to voice up and be able to take up leadership responsibilities. Self-advocacy is proven to be an effective approach to train persons with LD to be independent and to voice up for themselves. But, the key concern is that many persons with LD in Malaysia have yet to learn to self-advocate.

Though several individuals with LD are already involved in advocating for the rights of citizens with LD in Malaysia, their involvement in advocating for persons with LD is minimal. Aspis (2002:5) has suggested that the most powerful impact of the self-advocacy movement is to raise a group of self-advocates who are able to challenge policies or legislations and take part in policy making that involves people with LD. It is observed that only a few self-advocates in Malaysia have such exposure

and their involvement at this level is minimal. Therefore, the impact of self-advocacy in the lives of individuals that are already involved in the self-advocacy movement has yet to reach its full potential.

The negative mindset of our society has affected the quality of life of persons with LD as discussed in Chapter 1. To improve the quality of life of persons with LD, it is necessary for them to learn about their rights and speak up for their rights. They have to be seen and heard in public to change the mindset of our society about them. The Biwako Millenium Framework for Action of Economic and Social Commission for Asia and the Pacific (ESCAP) (2002:5) stated:

Persons with disabilities are the most qualified and best equipped to support, inform and advocate for themselves and other persons with disabilities. Evidence suggests that the quality of life of persons with disabilities, and of the broader community, improves when disabled persons actively voice their concerns and participate in decision-making....

To date, the education for persons with LD for all levels, from early intervention to vocational education is still far from satisfactory. Pre-vocational Training and Transition has yet to be introduced in the curriculum of Special Education for students with LD. There is only one vocational training school run by the government that offers training courses for persons with LD. Employment opportunities for persons with LD are way below the needs. There is little effort to provide adequate housing for adults with LD who are interested in independent living. For a better future, it is vital for persons with LD in Malaysia to stand up for their rights and make their voice heard.

This study showed that persons with LD can voice up and represent themselves when given the support, exposure, training and opportunities. Education on self-advocacy should be emphasised in the Special Education for children, youth

and adults with LD. Such a move will gradually help them strengthen their voice for an inclusive society.

5.2 Discussion

This chapter discusses the seven factors that have affected the development of the self-advocacy movement. The implications of each of the seven factors are examined. Recommendations to improve the situation are discussed.

5.2.1 Awareness of Self-advocacy

In Chapter 2, Aspis (1977:648) strongly emphasised that persons with LD need to learn skills to advocate. Aspis (1997:647, 2002:5) also stressed that for self-advocacy to have a lasting impact in bringing permanent change, persons with LD need to be informed of their rights and know how to voice their rights.

At present, self-advocacy is neither taught in the government run Special Schools nor in Private Schools or Centres run by NGO's. Jelas's (SUHAKAM, 2004:200-205) paper, Access to Quality Education for the Disabled was informative about the current situation of the Special Education in Malaysia. Much emphasis was on Inclusive Education. In her attempt to report on the teaching programmes of Special Education of all the various disability groups, there was no mention at all on Pre-vocational Training, Transition and the need to introduce self-advocacy.

Though United Voice has existed for more than 10 years and progressed actively as a self-advocacy group, no effort has yet been made to challenge that self-advocacy should be taught in school. This is due to the fact that even within UV there is limited knowledge about how self-advocacy should be taught and at what age persons with LD should learn about self-advocacy. Lack of research, exposure, man-

power, resources could have led to this delay in discovering this urgent need. As Thomas has pointed out that the journey for change will be long because, "...The Special Education System in Malaysia is not comprehensive enough." Issues on Special Education are still focusing on improving the basic curriculum of Special Education and the environment of Special Schools. The need to introduce self-advocacy in the curriculum has yet to surface.

As Malaysia progresses in modernity, greater emphasis should be given to improve the education for persons with disabilities. Chiam (2004:32) aptly quoted The Convention On The Rights of The Child (CRC) Article 23, and emphasized:

Children with disabilities have the same right as children without disabilities. They have the right to non-discrimination, the right to development, freedom of expression, the right to healthcare and so forth...a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.

To help children with LD to enjoy the right to development, freedom of expression, self-reliance and active participation in the community, it is urgent to teach them self-advocacy skills in school. Education on self-advocacy will help them to be aware of their rights and equip them to express or voice up for themselves, be self-reliant and participate in the community.

The Human Rights Commission in Malaysia (SUHAKAM, 2004:309) in its observation on the Proceedings of the Conference on Human Rights and Education held on Malaysia Human Rights Day 2002 stated that, "Human right education should be targeted to vulnerable and minority groups and aims at changing their human rights situation. The minority groups could be...people with disabilities..."

The above statement clearly supports the idea of teaching persons with LD to self-advocate while they are still in school. The school is the best place to educate the

grassroots on human rights. The school is thus the best place to teach the grassroots about self-advocacy. The school can also educate the educationists and parents about self-advocacy when the subject becomes part of the system.

5.2.1.1 Implications

To improve the quality of life of persons with LD, self-advocacy must be introduced to persons with LD in school to ensure that all persons with LD are taught to self-advocate at a young age. Such practice will help persons with LD assimilate this independent skill in their daily life so that they can become more self-reliant and have more active participation in the society. When self-advocacy becomes a formal subject in school, the public, including the parents and practitioners will also gradually be educated to give persons with LD their rightful place in the society.

5.2.1.2 Recommendations

The Ministry of Education has to first of all recognise the importance of self-advocacy being introduced and taught in school. When support from the Ministry of Education is approved, forming a think-tank group is essential to study the strategy of introducing self-advocacy in school. A decision has to be made as at which level should self-advocacy be introduced.

Training programmes for special education teachers trainees in the universities and colleges have to be revised to include self-advocacy as a subject. Postgraduates programmes in Special Education should also introduce self-advocacy as a subject so that practitioners under training will be informed and educated on the importance and the know-how of self-advocacy.

Research to develop a syllabus on self-advocacy that can be introduced in the curriculum of Special Education is vital. Consultation with special educationists from overseas who are experts in this area is needed to help facilitate this research. There should also be consultations with local NGOs that are experienced in this field. They can share their experiences in the Malaysian context.

Sufficient funds should be allocated to carry out the necessary research, consultations, training and developing the syllabus and materials necessary to teach self-advocacy in school.

5.2.2. Support from NGOs

Established NGOs that provide services for persons with LD are observed to focus on early intervention and vocational training programmes. However, their lack of awareness on the importance of self-advocacy and the lack of know-how about self-advocacy was indicated in the result of this study. There isn't any strategy just yet on educating persons with LD on self-advocacy. Some effort has been made by UV to promote self-advocacy groups but there are hardly any adequate manuals and teaching tools available for those who are interested to form their own self-advocacy groups. There are only two basic manuals that are produced by Dignity & Services:

- “Self-advocacy” (Tan, 1996:5-7) - A brief introduction on self-advocacy and basic guidelines on forming a self-advocacy group.
- “Meeting” - A basic guide about organising a committee meeting and running a committee meeting.

The lack of training materials, resources and know-how, as pointed out by Ravi and Suzie has affected the growth of the movement. The lack of knowledge on what is

self-advocacy and how to teach persons with LD to self-advocate hinders the self-advocacy groups from progressing effectively.

The effort given by NGOs to support the self-advocacy groups organized their 1st National Self-Advocacy Conference for and by Persons with LD held in 2004 (Yeo, 2005:25) was a good move to create awareness and to provide training for persons with LD. But, more road shows, workshops and training seminars are necessary to spread this vision and practice to every district so that it can benefit a wider group of people. Awareness programmes and training should reach persons with LD, their parents or family, service providers and volunteers.

Persons with LD should be consulted and be involved in organising as well as conducting these awareness programmes, trainings and conferences for better effect and impact.

5.2.2.1 Implications

Lack of strategy and know-how in emphasizing self-advocacy in their teaching programme indicates that NGO centres are lack of knowledge on the importance of self-advocacy. Besides financial constraints, the lack of expertise and training materials are the main reasons that have hindered support from NGOs in this movement. Self-advocacy is an unheard of or new concept to most caregivers and practitioners. Training manuals and practical training are needed to equip more NGOs to teach self-advocacy at their centres, to establish self-advocacy groups and to be involved in supporting self-advocacy groups effectively.

5.2.2.2 Recommendations

NGOs that are already actively involved in the self-advocacy movement should network with one another to share notes on supporting self-advocacy groups, discuss strategies to promote the formation of self-advocacy groups for school-leavers or adults with LD throughout the country. They should work together to develop materials that are suitable to educate persons with LD at different level on self-advocacy. They should source funding to invest in resources available from overseas.

NGOs should place more emphasis not only in the self-advocacy groups they are supporting but they should introduce self-advocacy in their training programmes to the students or trainees in their centres. Full-time staff should be employed to develop self-advocacy training programmes and to support the self-advocacy groups.

Collaboration between the Ministry of Higher Education, Special Education Department, the Social Welfare Department and the NGOs is necessary to improve on the above situation. The Ministry of Higher Education has to include training programmes that will prepare educationists to teach self-advocacy in schools and in Community Rehabilitation Centers (CBRs). The Ministry of Education and the Social Welfare Department can work together to organize courses to train trainers at CBRs and NGO centres. More investment is needed in research and in equipping trainers.

Joint effort of the above parties is also necessary to work on training manuals on self-advocacy that are useful for all levels. Training manuals should be available not only for trainers but also for self-advocates. There should be manuals that can help them understand what self-advocacy is and how to practise self-advocacy which could include independent skills, communication skills, public speaking and leadership skills.

Training seminars and conferences should be organized periodically to create awareness and educate parties involved in educating persons with LD. Parents should be included in such training as self-advocacy is practised in daily living. What is learned in school or training centre should be enhanced at home.

5.2.3 Structure of Self-Advocacy Groups

Jayasooria (2000:179) in Chapter 2 noted though certain Self-help Organisations (SHOs) in Malaysia are active in advocacy issues, the grassroots membership have not developed political-consciousness on the issues and rights of disabled people. Goodley (1997:374, 2000:35-44) and Jayasooria (2000:178-179) suggested that the Social Model of Disability should be adopted in order for meaningful impact in the lives of persons with LD to happen through the self-advocacy movement. The Social Model of Disability which promotes an inclusive and right-based society empowers persons with learning disabilities to have an active participation in the society.

The structure of self-advocacy groups has to be explored by NGOs that are interested to support self-advocacy groups. Due to the lack of training and awareness of the various structures of self-advocacy groups, most centres would naturally adopt a pattern of support with which they are familiar. Without knowledge of the difference between the Advisor-Oriented group structure and the Member-Oriented group structure as discussed in Chapter 2, most groups tend to follow the set up of a service center which is more of a teacher-student approach or Advisor-Oriented structure.

The dependency attitude is unsurprisingly created in a group that is held within a centre that runs a school or a training programme. Unless the group had exposure on running their own group independently or had been taught to do so, they

will tend to be dependent because the education approaches in most schools and centers have not emphasised on self-advocacy or Member-Oriented structure.

It is important for NGOs such as UV to take the lead to inform other self-advocacy groups of the various approaches in running a self-advocacy group, so that an appropriate approach is adopted for each group. Groups should also be aware that the approach can evolve from Advisor-Oriented group structure to Member-Oriented group structure as the group matures and become more independent as suggested by Goodley (2000:171-173).

The Advocacy-Supported approach as practised by United Voice (before being independent from Dignity & Services) and Mutiara Voice Club seemed to be more effective in helping persons with LD develop independent skills. Groups that have the potential should be encouraged to work towards becoming Advocacy-Supported or Autonomous. Such a goal will give both parties an aim to work towards. Those giving support should gradually work themselves out of a supportive role and the persons with LD, who are in charge, should eventually take up more responsibilities in running the group.

The different models and structures of self-advocacy groups as discussed in Chapter 2 should be studied carefully and be made known in the training on Forming and Running Self-advocacy Groups. The strengths and weaknesses of each model or approach should be discussed so that groups are aware of the effect of the approach they choose to adopt.

Chapter 2 noted Aspis's (2002:5) advice that rules, policies and legislation are needed for permanent or long-term change. He suggested that self-advocacy is not just about having polite interactions but it should include "direct action,

demonstrations, lobbies at full council meetings and how to influence Government legislation. All these approaches are about proactive change...”

Such awareness should be introduced to all types of self-advocacy groups. Self-advocates should be aware of their rights and be encouraged to speak up for their rights. They have to learn about policies and legislations that affect people with disabilities and persons with LD in particular. As this has already been practised by a few self-advocates in Malaysia, they should represent persons with LD to voice up against systems, policies and legislations that discriminate people with disabilities. They should learn to critique the existing education and employment policies to ensure that the welfare of persons with LD is protected. Their involvement in the drafting of the Disability Act should not be overlooked.

Malaysia, being one of the nations that supports the Biwako Millenium Framework for Action of ESCAP, 2002, which advocates for an inclusive and right-based society should move towards enabling persons with LD to have an active participation in the society. The Malaysian society owes persons with LD their rightful place to make their presence felt and be heard in the society. The development of self-advocacy movement should be strengthened to support this move.

5.2.3.1 Implications

The awareness of Social Model of Disability in impacting the disability movement is generally weak in Malaysia. The Social Model of Disability approach which is often adopted by advocacy supported and autonomous groups has proven to have a greater impact in developing an inclusive society as seen not only in the developed countries but also in United Voice and Mutiara Voice Club in Malaysia. This indicates that

Social Model of Disability is applicable if persons with LD in Malaysia are given an opportunity and an environment that adopt an inclusive setting. But, much work is needed to educate the public in general and those involved in services for persons with LD on the concept of Social Model of Disability. The society has to change their attitude towards persons with LD. They need to accept their disability and acknowledge their rights to have an active participation in the society. Creating a right-based and inclusive society requires a national reform.

5.2.3.2 Recommendations

It is only in recent years that there is more awareness on human rights in Malaysia. SUHAKAM the initiator of the first Malaysian Human Rights Day on the 9th of September 2001, has made many efforts in educating the public about Human Rights. One significant move was to promote human rights awareness to young children and students in general through school. Through the education on Human Rights, the rights of persons with disabilities must be discussed. This will create the awareness and respect of the rights of persons with disabilities. A national reform towards an inclusive society may eventually be cultivated.

SUHAKAM has also played an important role in promoting the rights of persons with disabilities. However, more effort is needed on the part of SUHAKAM to include persons with LD in round table discussions, dialogues and forums. It is observed that persons with LD are often represented by the non disabled. Persons with LD should be invited to represent themselves on disability issues. SUHAKAM plays an important role in influencing the government, the NGOs and the public in general to include persons with LD in public discussions and dialogues.

NGOs should awaken to the fact that the way forward for persons with LD is to equip them to stand up for themselves. The Social Model of Disability should be practised to promote empowerment. Training manuals on self-advocacy should include information on the models of disability and the structure of self-advocacy groups. This will help educate those who are involved to know the effect of the various approaches and will perhaps influence their choice of approaches that best suit each group.

National bodies for the disabled such as the Malaysian Council of the Disabled should educate NGOs that are involved in advocating or providing services for persons with LD to equip persons with LD in voicing up for themselves and taking up leadership responsibilities. Persons with LD should be represented in public meetings. Individuals that are invited to represent organizations for persons with LD should make it a point to ensure that persons with LD are included. Inclusion should begin with the movements advocating for persons with disabilities. This effort, together with active promotion on self-advocacy will eventually encourage more self-advocacy groups to develop throughout Malaysia.

5.2.4 Family Support

Mitchell's (1997:47) observation that independence of persons with LD from parents and families seems more difficult for Asians appeared to be true in Malaysia as observed in this case study. Habib's sharing on his family's objection for him to consider marriage at this point due to lack of financial independence confirmed the suggestion of Jones and Wallaces (1992), that the adulthood of persons with LD is only "socially confirmed" if they are independent of financial support from their families.

Since the mindset of parents or guardians is discovered to be a big influence in supporting their child's involvement in self-advocacy groups, more effort should be made to educate parents and guardians on self-advocacy. The right information and life stories will help parents see the relevance of self-advocacy groups. Habib and Faruq for example, are able to benefit from their self-advocacy groups because their family is supportive of their involvement.

In our Asian culture, speaking up is sometimes seen as being rude. Parents have to be educated on the importance of allowing their children who have LD to voice their opinions. As suggested by Barnes (1997:73), the interdependence approach should be encouraged to help parents realise that self-advocacy is not promoting rebellion and alienation from families, but promotes an interdependence culture. This may encourage parents who have difficulty in letting go to see the positive outcome of self-advocacy.

It is observed that most parents do not know the rights of their children. They should be informed and be encouraged to teach their children about their rights. Parents should also be informed how self-advocacy can lead to policy change that can improve the quality of life for persons with LD. Parents should know the purpose of self-advocacy groups and the possible outcomes and impact the group can have on their children.

Parents support organisations can play an important role in the development of the self-advocacy movement. As practised in Japan, self-advocacy groups were established with the support of a parents support movement, Inclusion Japan. It was reported that the self-advocacy groups compiled a resolution at the end of each annual conference to be submitted to the Welfare Measures of Tokyo Metropolitan Government (JICA Rehabilitation Course Report, 2006). Their resolution implied that

self-advocates in Japan are informed of their rights and the national policies for persons with disabilities. Nevertheless, support from parents support movement will better enhance the self-advocacy movement if self-advocacy groups that have the potential are eventually given the liberty to become an independent bodies or societies of persons with LD.

There is currently no national parents support movement for persons with LD in Malaysia. As noted by Jayasooria (2000:104-105), only a minority group of parents are involved in advocacy. Many parents are ignorant on the rights of persons with disability and their family. They lack knowledge on how advocacy can improve the current situation of persons with LD in Malaysia. Such ignorance could have contributed to the slow development in nearly all sectors for persons with LD in this country.

5.2.4.1 Implications

Family support is important for the development of self-advocacy movement. The support from parents for the self-advocacy movement is generally weak due to lack of awareness on advocacy and self-advocacy. The absence of active parents support movement could be one of the reasons self-advocacy movement in Malaysia is slow in its progress.

5.2.4.2 Recommendations

More awareness campaigns for parents regarding the importance of self-advocacy are necessary. Parents of school-going children, school-leavers or adults should be educated on the role and impact of self-advocacy.

If self-advocacy is introduced as a subject in school, parents will be more aware of the importance of self-advocacy. Parents-Teachers Associations in schools are good platforms to educate parents on this subject.

Training should be provided for parents to know how to enhance what their children have learned in schools or centres or groups regarding self-advocacy. NGOs should conduct workshops and seminars to create awareness amongst parents on the need to strengthen the self-advocacy movement and their role in strengthening this movement.

Parents need to be concerned about what life is after school for their children. They need to be informed that self-advocacy groups provide social and moral support for school leavers. It is also a place where they can unite their voice and make their presence felt in the society.

Parents should understand the importance of forming a strong national support movement for parents to discuss issues and advocate for the rights of their children and their family. Perhaps bodies such as SUHAKAM and the Bar Council should have more seminars and dialogues to help parents be aware of their role in forming and changing policies to improve the services, provisions and benefits for their children.

5.2.5 Intellectual Inhibition

Intellectual inhibition can pose hindrances to the achievement of persons with LD. However, it can be overcome by employing personnel to assist them in issues or matters that are beyond their grasp. Often, it is a matter of simplifying the text or interpreting the text or documents to help them understand. Chapter 4 noted that United Voice is for the idea of self-advocacy groups employing full-time supporting

staff to assist them in running their organisation as testified by Ken Jo, “We employ an accounts manager...and coordinators.... They can advise but the ultimate decision is ours.” Recognising their intellectual inhibition Yeo (2004:46) suggested,

...their intellectual handicaps should not be seen as incapability but be recognised as their special needs for support... support given is merely as a means to help them achieve their full potential. It is not meant to take over their rights to make decisions and choices....

For the advancement of the self-advocacy movement, a supporting organisation should see it as a commitment to employ staff to specially be available to assist the group when necessary as practised by organizations of persons with physical, visual or hearing impairment. With support, they can participate in any forums, dialogues and discussions that require intellectual skills. Persons with LD can prepare speeches before events and be guided to focus on issues to be discussed. They might take a longer time to understand issues and to express themselves, but they can. Ken Jo and Habib have proven that they can handle forums, dialogues, workshops and conferences at national and international level when appropriate support is given. What they really need is motivation and opportunity. They often use assistive technology such as power point presentations with projected notes, graphics or photographs to present their speeches.

The report of the 1st National Self-Advocacy Conference for and by Persons with LD in Malaysia 2004 recorded the proceedings of the workshops conducted at the Conference. Many persons with LD raised issues that include employment, family, transportation, bullies, relationships, housing, government subsidy etc. Given the opportunity and practice, they can speak their mind.

5.2.5.1 Implications

Intellectual inhibition will remain a factor that hinders the development of self-advocacy if persons with LD are not given the support to overcome this challenge. It has been proven that with appropriate support, intellectual inhibition should not deter persons with LD from being actively involved in an inclusive society.

5.2.5.2 Recommendations

Personnel involved in supporting persons with LD should be trained to draw out their potentials instead of merely teaching them basic skills. More creative and dynamic teaching approach should be adopted to help persons with LD develop their skills to be more independent and to be confident to speak up. For example, they can be taught to travel by public transport so that they can travel independently to work or for social activities. They can also learn to use the computers to help them present their public speeches more effectively.

More professionally trained persons who understand the psychology of persons with LD should be employed to help persons with LD overcome their fears, apprehensions and low self-esteem which often affect their confidence to discover their hidden potentials.

Persons with LD should be given opportunity to participate in the society. Their presence and contributions when acknowledged will help them be more confident to take more challenges. They should be seen in making more public speeches and represent themselves in public meetings or events. Persons with more severe LD should also be seen and heard in public places. Acceptance of the public will help boost their confidence to participate in society.

The public in general should also see that it is the right of persons with LD to be given necessary support when needed to help them overcome their handicaps that are caused by intellectual inhibition.

5.2.6 Public Attitude

Public attitude is a big obstacle for persons with LD to integrate in society. The government is required to play an important role in changing this attitude and create an inclusive society. As suggested by Ravi, Suzie and Ken Jo in Chapter 4, positive public attitude towards persons with LD should begin with the government.

SUHAKAM (2004) has compiled several papers that are focused on Human Rights and Education. It was strongly advocated that Human Rights should be taught in school to change the mindset of our society towards the underprivileged. Wu (2004:25), from Hong Kong observed student's attitude towards disabilities,

On disabilities, students tended to pay attention only to the constraints and held erroneous perceptions of person with disabilities. Persons with disabilities were perceived as pitiful, deviant, accident prone and appropriate for repetitive work...

Such attitude is observed to be true in the Malaysian schools and in the general public. Public awareness through media, public meetings and campaigns will help educate the public and change mindsets. But, a more effective approach for long-term change would be to educate students about human rights and social responsibilities. Wu (2004:26) further emphasised,

Many persons with disabilities are still largely excluded socially from the mainstream, and students viewed this exclusion as normative. This leads to a vicious cycle of further misunderstanding and hesitance to treat them equally as members of society...education must be built on diversity and equality. People are different but they are equal; and education and textbooks must act as catalysts for change.

Wu's suggestion is vital if a society desires to see a change of mindset and attitude towards people with disabilities. Such a view should be seriously considered taken into serious consideration by the Ministry of Education. Inclusive Education should be adopted which promotes integration of students with and without disabilities. SUHAKAM (2004:316) applauded the view of the former Prime Minister of Malaysia, Mahathir Mohamad that the school environment plays a critical role in students' understanding of human rights and their belief that human rights is an essential element to the quality of life.

Public attitude towards persons with LD can change through education and public awareness. School plays an important role in educating students about persons with LD. Students should be encouraged to include students with LD in school activities. Such interaction can create a better awareness and understanding of persons with LD. Attitude towards persons with LD may change when there is a better understanding of their needs. With better awareness people might be more willing to listen when persons with LD speak up.

NGOs in Malaysia play an important role in creating public awareness. Nadason (2004:179) observed that NGOs in Malaysia have undertaken various programmes to enable the masses to understand human rights and increase their awareness about these rights.

Jayasooria (2000:193) suggested there is a need for a strategy and action plan to create equal opportunities for persons with disabilities in education, employment and in developing a society without barriers. NGOs such as UV should make every effort to work together with their counterparts to create more public awareness about persons with LD and their potentials. UV (United Voice, 2005) used various ways to create awareness, including Medias like airing through radio station for nationwide

publicity. Publicity for persons with LD should be strengthened through visual medias such as internet, television and promotions through VCDs (Video Compact Disks).

As noted by Yeo (2002:14) in Chapter 2, the government has the power to change the mindset of the society through awareness campaigns and policies. The Malaysian government has developed pro-active campaigns such as “A Caring Society” to promote awareness and care for persons with disabilities. However, such a campaign has to be ongoing and creatively presented to create an impact.

5.2.6.1 Implications

Public prejudice towards persons with LD can be changed by creating awareness to help the public understand persons with LD and to see their potential instead of focusing on their disabilities. The role of the government in changing public attitude towards persons with LD is vital.

5.2.6.2 Recommendation

The Ministry of Education should speed up effort on educating students about persons with LD in schools to clear misconceptions. Campaigns that help students to be aware and understand the characteristics of LD will help students appreciate their school-mates with LD better. A healthy integration environment should be fostered through school activities.

More educational TV and Radio programmes should be produced to help the public understand persons with LD. NGOs should be encouraged to create informative websites and produce brochures to educate public about LD.

The public should be aware that persons with LD can contribute in the society when necessary support is given them. Publicity that focuses on their contributions and abilities should be promoted.

Employers should be encouraged to hire persons with LD by giving them guidebooks that will help them understand persons with LD and ways to assist them work more effectively. Corporate Social Responsibilities (CSR) campaigns should highlight not only contribution on monetary support but should also motivate community to include persons with LD in society. Corporate companies and the government sector should take the lead in creating employment for persons with LD within their set-up.

A Discrimination Act that protects persons with disability from public discrimination is urgently needed.

5.2.7 National Policies

Chapter 2 suggested that the government owes its disabled citizen a just and impartial society. The government can strengthen the national policies to protect persons with disabilities from discrimination. Hurst's (Hurst 1995:534) suggestion for anti discrimination legislation for liberation should be considered. Thomas raised the fact that disability issues are often not discussed in detail in the Malaysian five-yearly Plan. The former Prime Minister of Malaysia, Mahathir bin Mohamad (2004:10) stated at the Conference on Human Rights and Education, 2002,

...Under the Eight Malaysia Plan, more school and special classes in mainstream school will be established for children with other abilities. The ministry of Human Resources has established a code of practice on the hiring of disabled workers in the private sectors. Employers have been urged to employ the disabled to provide them the opportunity to develop their full potential and lead a dignified and fruitful life.

To date, there is no legislation that provides specifically for the protection of the rights of the disabled. The provisions in the existing laws are inadequate. Issues of disability are not dealt with comprehensively. NGOs have been pressing for legislation that covers comprehensive guidelines to ensure that all forms of discrimination against disabled people are eliminated. A proposed People with Disabilities Act was drafted in 2002. This Act includes the protection on specific needs in education, employment, rehabilitation, accessibility, support services, social security and prohibition of discrimination. It was reported (STAR, 2006:26) that in the recent Ninth Malaysian Plan, the government will enact The People with Disabilities Act to,

... promote and protect the rights of the disabled to live with dignity and self-respect...The ACT will ensure the rights of the disabled to an inclusive society, greater access to education and vocational training, employment, barrier free environment and access to Information and Communication Technology.

At a press conference represented by a few NGOs, The Malay Mail (2006:11) reported, "Some of the handicapped feel the Ninth Malaysian Plan is too general when it comes to addressing the needs." The researcher, who was present at the press conference, noted some comments from the representatives. V. Murugeswaran, the president of Damai Disabled Peoples' Association of Selangor commented that, "persons with disabilities are not invited for dialogues on the Malaysian Plan." He felt that their presence in such planning dialogues is important as they know best what their needs are. Murugeswaran's concern confirms Thomas's observation that persons with disabilities are not involved in the Malaysian Plan. The government should take into consideration to include persons with disabilities in the planning of the next Malaysian Plan and any plans that involve policies related to people with disabilities. Murugeswaran also commented that the implementation of the promises for persons

with disabilities in the 8th Malaysian Plan is weak. The Malay Mail (2006:11) quoted Murugeswaran's statement, "We hope that the Plan, when translated into policies, will address the needs of the handicapped. We all want to contribute effectively to the realization of Vision 2020."

At present, support by the government for the self-advocacy movement is minimal. The researcher is confident that the government is open to know more about self-advocacy and support the move if it is clear to them that such a movement will enhance the quality of life of persons with LD. The promises made in the 8th and 9th Malaysian Plan give hope to people with disabilities that the government is making an effort to improve their quality of life. The government seems interested to help persons with disabilities to reach their full potential and to live a dignified and fruitful life.

Plans however are proven effective only when they are being realized. As observed by Ravi, the implementation of good strategies is observed to be generally weak due to lack of awareness, training and commitment of those who are reaching the grassroots. The government should ensure that the implementation of these plans is carried out effectively to benefit people with disabilities. Perhaps the government needs expertise to study the current situation and strategise plans. Plans that are decided should be disseminated effectively to the trainers or officers who are reaching the grassroots.

Chapter 2 noted Ronald's (2000:458) comprehensive study on the impact of legislation in the development of persons with LD. The US legislation on vocational education and transition for students with disabilities began in the 80's. By 1997, the re-authorisation of the Individuals with Disabilities Education Act requires transition

planning to begin no later than age 14. Such a move could be considered to improve the Malaysian Special Education Curriculum.

5.2.7.1 Implications

Legislation to include Transition and Pre-Vocational in the special education curriculum will strengthen the self-advocacy movement in Malaysia. A national policy that protects the rights of persons with disability is desperately needed by persons with LD in Malaysia so that their quality of life will improve with better education, better opportunity for employment, housing and benefit provision that enable them to live an independent life.

5.2.7.2 Recommendations

The government should endorse the proposed Disability Act. Further delay will only hamper the advancement of persons with disability in Malaysia.

The Ministry of Education should invest more in researches that will strengthen the Special Education. More collaboration between the government and NGOs is necessary to synergise the available expertise and resources. In the implementation of introducing self-advocacy in school, more funds would be needed to build up the necessary resources.

More study and consultation are needed in regards to introducing Pre-Vocational Training and Transition in the curriculum of Special Education in Malaysia. These are two important subjects that include vocational skills and self-advocacy as key focus. The right expertise from within the country and overseas should be consulted for strategy planning, action plan and training. More research is needed for fruitful planning.

The legislation of Transition and Pre Vocational Education to be taught in school should be included in the section on Education for persons with LD of the Disability Act.

5.3 Suggestions for Further Research

This small scale research has only touched the tip of the iceberg on issues related to self-advocacy movement in Malaysia. More research is required to look more in-depth into the factors that are affecting this movement. Research on the other nine states of Malaysia that have yet to respond to the self-advocacy movement is necessary to examine the situation. Research on the materials suitable for the Malaysian use is necessary to develop good resources that will enhance the progress of this movement. The feasibility of education on self-advocacy in primary, secondary and vocational centres should be studied to strengthen the implementation of self-advocacy in schools and institutions. Gender involvement in self-advocacy could be explored.

5.4 Conclusion

The welfare of persons with LD in Malaysia is observed to have improved over the last 10 years. As of 2004, the Special Education for persons with LD is reaching out to 16,657 students with LD in the primary and secondary schools.

However, more efforts need to be made to improve the education system for persons with LD in order to help them “live with dignity and self-respect” as pledged in the 9th Malaysian Plan. The welfare of persons with LD is still lacking in basic need for quality education, employment and housing as discussed in Chapter 1. As a caring nation, we should strive for the best for persons with LD. Young, P.J., the founder of

the self-advocacy movement of persons with LD in Malaysia advised in response to this study,

The stories of Habib and Faruq confirmed that self-advocacy plays an important part in providing both dignity and well-being for persons with learning disabilities. Therefore, every effort should be made to encourage existing self-advocacy groups and to promote self-advocacy both to the government and to all those involved in the welfare of persons with LD. (Young, P.J., personal communication, March 26, 2006)

Self-advocacy may not have the answer to solve all the needs of persons with LD. But, the testimonies of Habib, Ken Jo, Faruq and their friends in UV showed that persons with LD can advance in independent skills with the awareness on self-advocacy. Self-advocacy has helped them to have more friends, to improve in their communication skills, to make choices, to stand up for their rights, to take up leadership responsibilities and to move towards independent living. We would deny them a great opportunity to develop themselves if we do not teach them to self-advocate. They could be deprived of good moral support and social life by not being part of a self-advocacy group as Ken Jo testified, “If I am not involved in UV, I would probably be stuck at home and miss out all the opportunities. I would not have so many friends that I do now.”

Based on the findings of this study, awareness and education on self-advocacy is strongly proposed to be introduced in school. More self-advocacy groups should develop in every district in Malaysia to empower and impact more persons with LD. Collaboration between the government sectors and NGOs should be strengthened to support the self-advocacy movement.

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Appendix A

Sample Letter and Statement of Consent

Letter of Consent from UV

A sample Statement of Consent of a Participant

Appendix B

A Sample Correspondence and Structured Interview

A Sample Email Correspondence with a Participant of a Structured Interview:

1st February 2006

Dear XXXX,

Thank you for your response.

I need to ask you further questions to discover more about your group. I hope you don't mind. Would appreciate if you could respond to this one by end of next week :) The follow-up questions are in brown fonts.

Thanks very much.

sweelan

----- Original Message -----

From: XXXX

To: [Yeo Swee Lan](#)

Sent: Monday, January 30, 2006 11:13 AM

Subject: Re: May I have an hour of your time?

This e-mail was scanned by TM Net E-Mail Virus Shield.

Dear Swee Lan

Gong Xi Fa Cai. Thousand apologies..... for overlooking your matter. Surprised you didn't "chase" or send me a reminder !!! So sorry... anyway attached is the response to your questions. Hope they are ok.

cheers

XXXX

----- Original Message -----

From: [Yeo Swee Lan](#)

To: XXXX

Sent: Tuesday, January 10, 2006 12:45 AM

Subject: Re: May I have an hour of your time?

Hi XXXX,

Thanks for your willingness to help out. Much appreciated. Your response to those questions is important for my research :)

Looking forward to read your response.

sweelan

----- Original Message -----

From: XXXX
To: [Yeo Swee Lan](#)
Sent: Sunday, January 08, 2006 11:14 PM
Subject: Re: May I have an hour of your time?

This e-mail was scanned by TM Net E-Mail Virus Shield.

*****_*****

Hi Swee Lan

Got your mail. Great progress, huh?! Well done. Will have a word with XXXX ... shouldn't be a problem.

cheers
 XXXX

----- Original Message -----

From: [Yeo Swee Lan](#)
To: XXXX
Sent: Saturday, January 07, 2006 1:50 PM
Subject: May I have an hour of your time?

Dear XXXX,

Happy New Year to you!

I am now in the final stage of my studies at UM. It has been a very good time of learning. This semester, I will be spending time writing my dissertation. I have completed Chapter 1 to 3. In the next 3 months I have Chapter 4 & 5 to complete. These two chapters will include the description and analysis of my practical research.

Part of my research is to examine the factors that have influenced the progress of self-advocacy groups in Malaysia. I need approval from you and XXXX (the President) to select Mutiara Voice Club as one of the groups for my research.

If you and XXXX agree, please kindly help me by taking some time (probably about an hour) to answer the questions in the document attached. Please be informed that names of groups and participants will be replaced with pseudonyms .

I would very much appreciate if you could respond by 20th January, 2006. If necessary, I will ring you for a follow-up interview.

Thank you very much.

Regards,

Swee Lan

A Sample Structured Interview with a Participant

This interview was conducted via email. The following is a transcript of two interview sessions. The follow-up interview of the first is indented. The italic texts are response of participant to the interview questions.

Background information:

Name: XXXXX

Age: 42

Gender: Female

Organisation: Asia Community Service, Sponsor of Mutiara Voice Club

Duration of involvement in the Organisation: 9 years

Position in the Organization: Executive Director

Interview:

1. What is your involvement in the self-advocacy group/society of your organisation?

ACS provides as an umbrella body to Mutiara Voice Club.

2. When was your self-advocacy group established?

July 2005

How long did the group take to decide to have their own self-advocacy group? When did they first thought of and talk about having a self-advocacy group?

The group got more formalized after the visit from the team from United Voice in May 2005. Prior to that, there were small groups that do activities together (makan out and go pasar malam) on their own accord anyway.

3. Why does your organisation form a self-advocacy group?

ACS did not form the group. The effort was by the members at the workplace themselves after being motivated by another visiting self-advocate. I believe it was the idea and sense of belonging that motivated the formation.

Why does your organization decide to support the formation of this self-advocacy group?

ACS has always supported the philosophy of people centred & people first. But from the beginning, we were aware and cautious NOT to start the group ourselves, but instead focused on building the foundation – leadership, responsibility etc. through the workplace. Therefore when they were challenged to start the group by others, they were ready to make that decision themselves. That is more fulfilling for the realization of self-advocacy movement. Therefore, I think it is only natural that ACS provides the support until they choose otherwise.

4. What is the operational approach of your group?

- ~~i. Centre-based Group (with full support and supervision)~~
- ~~ii. Social Group (with full support and supervision)~~
- iii. *Advocacy-supported Group (with support when needed)*
- ~~iv. Independent Group (autonomous)~~

Do you think this is a good operational approach for MVC?
Why?

Yes, after all that is what self advocacy is all about!! Centre based Groups and Social Groups are somewhat controlled / bound by the Organisation's rules and regulations that PwID cannot fully be empowered. But it is our hope that one day they will be able to move towards being an independent group when they are able to determine that themselves.

5. In your opinion, how has this self-advocacy group benefited the members of the group?

They have taken more responsibilities. Developed a sense of belonging and pride to have formed the group.

What are some specific responsibilities that the committee, in particular, is participating in?

For example, organising, planning and arranging for their own meeting.

Why do you think they (the committee? members?) felt belonged to the group?

The whole idea of exclusiveness and eliteness-lah!!! Honestly speaking, not sure if it's good or bad. For the moment, it's ok I guess.

6. How is the progress of the group since it was formed?

They hold monthly meetings in various venues in the community (i.e. community hall, coffee shops, at the centre, individual homes etc..) and

have organised their own outings and carried out the activity without the need for support.

How do they fund their meetings – eg: for refreshments, use of community hall?

They collect RM5 from each member at each meeting. Refreshment is sometimes bought (cakes from the centre) or they will take turns themselves to bring their own kuih muih.

Was it their initiative to apply to the community hall for permission to use the venue?

Initially they met at the ACS centre over the weekend; but one time, staff was not available to “open up” the centre. Options were suggested to them to either change the day or meet somewhere else. They choose to meet at the coffee shop and then investigated the availability of the meeting room of the district library. (BTW, they were rejected). Then after that they approached the Pengerusi of the local JKKKK who offered them the use of the UMNO hall and other community hall. Yes, all action at their own initiative, we merely offered suggestions.

7. What are the factors (positive as well as negative factors) that affected the progress of the group?

Positively – group is independent in making their own decisions and capable of seeking for advice and assistance where needed. Negatively – group is currently confined to a few selected members. Can be viewed as an “elite” group if too exclusive.

Why was the group not formed earlier?

Answer as per Q3 above.

Why is the group confined to a few selected members?

The present members themselves have not decided to expand.

Does the group intend to enlarge their membership? Do they have ideas on how they can increase the membership of the group?

We have hinted many times, and offered several ideas but

8. What are some developments you would like to see in the group?

- *Include all members and open up to others in the district / state.*
- *Work towards an “autonomous” (independently registered) status.*

Bravo!!! 😊

9. How can these developments be achieved?

More exposure to widen the scope beyond the workplace and area.

In what ways does your organization helped in informing, educating and guiding them on this matter?

Nothing formal such as training session etc.. at the moment. But offer suggestions and options; help them make informed decisions. Let them know that they can always approach us on any matters.

10. In what ways can your group contribute to the development of the self-advocacy movement of persons with learning disabilities in Malaysia?

- *Demonstrate self-advocacy in practice.*
- *Host events such as Dinner and Dance; Meetings etc...*

Do you think the voice of your group is important in changing policies that may affect the quality of life of persons with learning disabilities in Malaysia? Appreciate your comment on this issue.

Wah!! Will keep this very short and sweet. Yes, it is important but it will take a long, long time, I guess. Changing policies may be a dream for now, but creating awareness and changing attitudes on individuals may be a more realistic goal.

Appendix C

Core Questions for Semi-Structured Interviews

Questions for Participants No: 1

An Expert in Social Work within Malaysia.

Background information

Name

Age

Gender

Organisation

Duration of involvement in the Organisation

Position in the Organisation

1. In comparison with other disability groups, what is your opinion of involvement of persons with learning disabilities in Malaysia, in championing for their own development and their rights?
2. What is your observation of the self-advocacy movement of persons with learning disabilities in Malaysia?
3. What are some of the significant achievements of this movement?
4. In your opinion, what are the positive factors that have supported the progress of the self-advocacy movement of persons with learning disabilities in Malaysia?
5. Can you identify some factors that have hindered the self-advocacy movement from progressing more effectively?
6. What roles can the government play in supporting such a movement?
7. To what extent is the government in Malaysia supportive of such movement?
8. What are some recommendations you would like to suggest for the development of this movement?

Questions For Participant No.2

Leaders of self-advocacy groups.

Background information

Name

Age

Gender

Organisation

Duration of involvement in the Organisation

Position in the Organization

1. What is your involvement in the self-advocacy group/society of your organisation?

2. When was your self-advocacy group established?
3. Why did your organisation form a self-advocacy group?
4. What is the operational approach of your group?
 - i. Centre-based Group (with full support and supervision)
 - ii. Social Group (with full support and supervision)
 - iii. Advocacy-supported Group (with support when needed)
 - iv. Independent Group (autonomous)
5. In your opinion, how has this self-advocacy group impacted the members of the group?
6. How is the progress of the group thus far?
7. What are the factors that affected the progress of the group?
8. What are some improvements you would like to see in the group?
9. In what ways can your group contribute to the self-advocacy movement of persons with learning disabilities in Malaysia?

Questions For Participant No.3

A Project Coordinator of United Voice

Background information

Name

Age

Gender

Organisation

Duration of involvement in the Organisation

Position in the Organization

1. What is your involvement in the self-advocacy group/society of your organisation?
2. In your opinion, is the self-advocacy training provided by United Voice for their Employment Project workers effective?
3. In the last 5 months, what are some of the impact you have observed in the lives of these workers through this training?
4. What are the factors (positive as well as negative factors) that affected the progress of the group?

5. Do you think self-advocacy should be taught through a formal subject in special education? Why?
6. At what age do you think self-advocacy should be introduced to students with LD?
7. What are some improvements you would like to see in this self-advocacy group?
8. How can these be achieved?
9. In what ways can United Voice contribute to the development of the self-advocacy movement of persons with learning disabilities in Malaysia?

Questions For Participants No. 4

An adult with LD

Background information

Name

Age

Gender

Profession

Marital Status

1. How long have you been involved in United Voice – Self-advocacy Society of Persons with Learning Disabilities in Malaysia?
2. Who recommended you to the group?
3. Why do you decide to join this group?
4. What is your opinion of United Voice when you first joined the group?
5. How are you involved in this society?
6. What do you like about United Voice?
7. How has United Voice changed your life?
8. Where do you work?
9. Does United Voice support you in any way in your career?
10. What are some of your achievements through your involvement in United Voice?
11. How has United Voice supported other members of the society?

12. Do you think every adult with learning disabilities should participate in a self-advocacy group? Why?
13. In your observation, how successful is the self-advocacy movement of persons with learning disabilities in Malaysia?
14. What are some positive factors that have supported this movement?
15. Are there any negative factors that have hindered this movement from progressing more effectively?
16. What further achievement would you like to see in the self-advocacy movement of persons with learning disabilities in Malaysia?

Questions For Participants No. 5

A care giver (Sibling) of Habib (Participant No. 4)

Background information

Name

Age

Gender

Profession

1. How long has your brother been involved in United Voice?
2. How is your brother involved in this organization?
3. What is your opinion of this self-advocacy society?
4. What are some impacts you have seen in him since his involvement in this society?
5. What is your recommendation for a parent who is considering sending his or her child to join a self-advocacy group?
6. In your observation, how successful is self-advocacy movement of persons with learning disabilities in Malaysia?
7. What further achievements would you like to see in the self-advocacy movement of persons with learning disabilities in Malaysia?

Questions For Participants No. 6

A care giver (parent) of a United Voice member (Faruqh) who has severe LD

Background information

Name

Age
Gender
Profession

1. How long has Faruq been a member of United Voice?
2. Is he happy working at the Employment Project of UV?
3. Do you think Faruq has learnt to express himself since he joined UV?
4. How has self-advocacy impacted Faruq's life?
5. At what age should a person with LD be taught to self-advocate?
6. When did you first learn about the importance of self-advocacy?
7. Are parents in Malaysia aware of the importance of self-advocacy?

Appendix D

A Sample Transcript of a Semi-Structured Interview

Self-advocacy Movement of Persons with Learning Disabilities:
A Case Study in the Malaysian Context.

Transcript of Interview with Participant No. 1

Date: 13th February 2006

Background information:

Name:	XXXXXX
Age:	50's
Gender:	Male
Organisation:	Yayasan Social Strategik
Duration of involvement in the Organisation:	8 years
Position in the Organization:	Executive Position
Professional Training:	PhD in Social Studies

Appendix E

A Sample Transcript of a Semi-Structured and Informal Conversational Interview

Self-advocacy Movement of Persons with Learning Disabilities:
A Case Study in the Malaysian Context.

Transcript of Interview with Participant No. 4 – A person with LD

Date: 3th February 2006

Background information:

Name:	XXXXXX
Age:	mid 20's (participant prefers not to reveal exact age)
Gender:	Male
Organisation:	United Voice
Duration of involvement in the Organisation:	4 years
Position in the Organization:	XXXX (participant prefers not to reveal)
Occupation:	Office Assistant and Receptionist

Note: "XXXX" in transcript are scripts censored by participant for this publication.

Appendix F

Sample Notes and Reflection of Observations

Sample 1:
Leading a Self-Advocacy Meeting for the First Time

<p>Observation Session II:</p> <p>Date: 3.1.2006 Time: 4.20 pm</p>	<p><u>Setting:</u></p> <p>Members voluntarily arranged the meeting room with chairs for everyone. Most people sat in the same position as previous meeting. Zi Ai was the chairperson for today. She seemed a little nervous. This is her first experience chairing a meeting.</p> <p><u>Self-advocacy in practice:</u></p> <p>Zi Ai greeted the group “Good Evening”. Rashid requested Zi Ai to speak in Malay. Zi Ai paused. Rashid prompted Zi Ai to proceed. Zi Ai asked Kah Chung, how many cards he made today. Kah Chung has no verbal skill, so he signed with his fingers the number of cards he made. Zi Ai asked him “Is everything ok for you today?” Kah Chung was frustrated because he can’t respond. He expressed with some sounds. Zi Ai tried using Cantonese but it didn’t help. Kah Chung did not respond. Zi Ai then moved on to ask Samy, how many cards he has made today? Samy had difficulty expressing himself. But, finally uttered “One Bookmark” Yacob said Samy made many cards but only one was not rejected. “I made 200 centre folds.” Zi Ai affirmed him “Good” and moved on to ask Rashid about his work. Rashid reported that he drew three girls. Sakira reported she made 22 cards. When it was Sandra’s turn, she could hardly be heard. She managed to whisper softly. Others interrupted when they can’t hear her. Yacob laughed rudely. Zi Ai then asked, “Who else would like to speak?” Rashid reported that he drew a picture of Zi Ai, a car and a motorcycle at home. Anyone else wants to speak? Zi Ai asked. Others responded “Takda”(No)</p>
<p>Time: 4.28 pm</p>	<p>Meeting ended</p> <p>-----</p> <p>Reflection:</p> <p>Zi Ai seemed to lack confidence since this is her first attempt as a chairperson for a meeting. Others sensed her lack of confidence, tried to help her out. She managed to get the meeting going. It was frustrating for those members who were unable to speak when she kept pressing them to respond to her questions. Though she knew they are unable to speak, she</p>

	<p>was at a lost as how to lead them on when they did not respond to her question. Kah Chung expressed his frustrations by making some noise. She skipped when it was Faruqh's turn. Maybe, to avoid embarrassment in case she can't handle his response. Generally, those who could speak up expressed themselves quite spontaneously. Meeting was a little tense. Asman, the UV Project Coordinator did not make any comment at all today.</p>
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Sample 2:
Leading A Self-Advocacy Meeting After Four Months Of Training

<p>Observation Session VI</p> <p>Date: 24.1.2006</p> <p>Time: 4.10pm</p>	<p><u>Setting:</u></p> <p>Meeting began earlier than usual. Qassim is leading again. He was absent for two meetings. Setting is as usual. Everyone takes their place and joins the meeting happily. Due to his inability to walk, Faruqh is usually slightly late. But, he joined the group eagerly. A seat nearest to the door is always reserved for him.</p> <p><u>Self-advocacy in Practice:</u></p> <p>Qassim spoke in Malay and asked “Hi, How is everyone?” Others responded and said they are “Ok, Good”. Yakob said work is good today but he doesn’t like Saori weaving. Qassim asked “Is it difficult?” Yacob said it is not difficult but, troublesome. Tread got entangled all the time. Samy reported that work was good. He made 3. Actually, he made more than three but he has difficulties with numbers. Qassim asked Sakira, “How are you?” Sakira said she is fine. Qassim asked if she likes weaving? Sakira did not respond. She just smiled. When Kah Chung was asked what he made today he did not respond. Qassim assured and said “Never mind if you can’t speak. You can use signs - use your fingers.” Kah Chung tried to express with some signs. But, I didn’t understand his signs. Qassim praised him and said “Good”. Zi Ai reported that she made 36 boxes today. Qassim exclaimed, “Very good!”. Rashid said he made airplane. Qassim corrected him and said “You drew airplane”. Rashid acknowledged his mistake and added that he made 8 cards today. Qassim then asked Faruqh, how was work today. Faruqh pointed at John who was sitting behind him. Suggesting that Qassim should ask John first. John is part of the work team but not a participant in this observation. John could not respond to Qassim. Zi Ai spoke on behalf of John who has no verbal skills. Qassim asked Faruqh to say something. Asman, the project coordinator explained to Qassim and the team that Faruqh has no verbal skill. He encouraged Faruqh to use signs. Qassim then said, “You can’t speak, it’s ok. Like Samy, John and Kah Chung. I don’t mind. You can use sign language.” When it was Sandra’s turn to report Qassim went close to Sandra trying to hear what she has to say. But, could not hear her. Asman reported on Sandra’s behalf and said</p>
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<p>Door bell rang. Some parents have arrived.</p> <p>Time: 4.30pm</p>	<p>she made teddy bears. Qassim reported that he made many caterpillars. He then asked “Anything else?” Yacob asked why didn’t Qassim turn up last week. Qassim explained that his mum Mum was sick. Rashid asked why Qassim has grey hair? Qassim said he is like my dad. Jet Lee another worker at UV, but not a participant of this study told Qassim that he thought he pasted lady birds. Qassim replied “Oh ya, I forgot” He sounded a little mixed up. Asman signed to Qassim that time is up. Yacob questioned why is Vincent not working anymore? Qassim who sounded concerned asked “What’s wrong with him?” But, because time is up he said. “OK, never mind, we have to go home.”</p> <p>Meeting ended.</p> <hr/> <p>Reflection:</p> <p>Qassim led the meeting successfully. He managed to get more conversation going. The group was relaxed. He is good in asking and probing – getting people to talk. He has also learned to be more sensitive to those who are not able to speak or have no verbal skills. He acknowledged their presence and made them feel accepted. But, he seemed to have forgotten that Faruq is unable to speak. The other group members, the more vocal ones seemed to notice the good examples he has set. Asman made comments only when necessary.</p>
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Appendix G
Sample Correspondence

Sample Correspondences

Email Correspondences with Professor Dorothy Atkinson.

School Health and Social Welfare
The Open University,
Walton all, Milton Keynes, MK7 6AA, U.K

October 16, 2005

Dear Prof Atkinson,

Thank you for your reply. I have written to Prof Li, Eria Ping Ying , Hong Kong Polytechnic University and Prof Tsuda, Eji, Faculty of Human Development University of Kobe. These are two researchers I have come across so far who made brief mentioned of self-advocacy movement in their countries. But, I have yet to receive any response from them.

I have learned to understand self-advocacy much more in the process of my research. Thank you once again for introducing those informative resources to begin my search.

Regards,

Swee Lan

----- Original Message -----

From: D.M.A.Atkinson

To: Yeo Swee Lan

Sent: Thursday, October 06, 2005 10:49 PM

Subject: RE: Self-advocacy movement in Malaysia

This e-mail was scanned by TM Net E-Mail Virus Shield.

Dear Swee Lan

Yours is the only research on self-advocacy that I have come across in Malaysia – but I haven't studied the Asian region in any detail. I think you are far better placed to know what else, if anything, has been done in your area.

Good luck with completing your studies.

Best wishes

Dorothy Atkinson

From: Yeo Swee Lan [mailto:ysweelan@tm.net.my]

Sent: 01 October 2005 04:59

To: D.M.A.Atkinson

Subject: Self-advocacy movement in Malaysia

Dear Prof Atkinson,

I have been spending some time looking at the self-advocacy movement in the Asian region. From my study thus far, the research on this issue in this region is rather limited. In your observation and study, what is your impression on the self-advocacy movement in the Asian region? As far, as I know, the current study that I am attempting is the first research in Malaysia on self-advocacy movement. Reading your findings and many others have helped me to see the urgency for us in Malaysia to invest time, effort and resources to further research on this issue.

Have you any record of History of development on self-advocacy movement in the Asian Region? I checked out the People First Oregon's international directory on SA groups in the East Asian region - and I have only found three countries mentioned - Hong Kong, Japan, Malaysia. I managed to obtain only a few research papers/articles about SA movement in Hong Kong, Japan and Korea.

I would very much appreciate your response.

Thank you.

Regards,

Swee Lan

Email Correspondence with Professor Eria P.Y. Li

Department of Rehabilitation Sciences
The Hong Kong Polytechnic University
"Eria Li [RS]" <rseriali@inet.polyu.edu.hk>

Dear Yeo Swee Lan,

In Hong Kong, there is only one self-advocacy group that is organized by people with intellectual disabilities. The name of this group is "Chosen Power" which was established in 1995. For detail, you can view the file attached.

The self-advocacy movement is at the beginning phase in Hong Kong. Since 2003, we have every two years the local conference for people with intellectual disabilities. For the first conference held in 2003, please access the website: www.hkmh.org/hk_conf.htm You will find this website very helpful.

I shall give you the website of the second conference in July 2005 later.

The second conference was organized by people with intellectual disabilities. They were the chairpersons of the various working groups. They demonstrated to the public that they have leadership and self-confidence. Their performance is very impressive.

Eria Li

>>> Yeo Swee Lan <ysweelan@tm.net.my> 10/07/05 9:01 AM >>>

Dear Professor Eria,

I read you study "Self-perceived equal opportunities for people with intellectual disability" and I am glad that you noted the importance of self-advocacy.

I am currently a full-time staff of the first Self-advocacy society in Malaysia, United Voice and I am also pursuing M.Ed, majoring in Special education. My thesis topic is "Development of self-advocacy movement of Persons with Learning Disabilities in Malaysia."

I have written to Chosen Power for some information regarding self-advocacy movement in Hong Kong, but I have not received any response from them.

I would be grateful if you could provide me some information about self-advocacy movement in Hong Kong.

1. How many self-advocacy groups are there that are run by people with Learning Disabilities in Hong Kong?
2. When was the first self-advocacy group formed? What is the name of the group

and how it first started?

3. In your opinion has the development of self-advocacy movement for persons with Learning Disabilities been well received? Why?

4. How has self-advocacy movement impacted the lives of persons with LD in Hong Kong?

I will appreciate very much if you would help provide me some information by answering these questions. I believe we have much to learn from the self-advocacy movement in Hong Kong.

Looking forward to hear from you.

Thank you.

Regards,

Yeo, Swee Lan
(I am a Malaysian)

Email Correspondence with Hjh Noraini B. Abidin

Currently pursuing PhD. in a Special Education field in University of Warwick, England.

----- Original Message -----

From: [noraini zainal abidin](mailto:noraini_zainal_abidin)

To: [Yeo Swee Lan](mailto:Yeo_Swee_Lan)

Sent: Thursday, September 08, 2005 3:00 AM

Subject: Re: Ok

This e-mail was scanned by TM Net E-Mail Virus Shield.

Yeo Swee Lan <ysweelan@tm.net.my> wrote:

Hi Hjh Noraini,

How are you?

I need some info from you for my dissertation. My topic is:

Development of Self-advocacy Movement for Persons with Learning Disabilities in Malaysia.

I noticed from the national curriculum for special education in the secondary level there isn't any topic on self-determination and self-advocacy.

I would appreciate if you would also help me by responding to the following questions:

>>To what extent does our national curriculum for special ed in secondary level touch on self-advocacy?

You must get the "Sukatan Pembelajaran Pendidikan Khas Bermasalah Pembelajaran Sekolah Rendah & Menengah". The book is in pink colour, Ask Zaiton borrow from her school. If you go through this book, I think it quite thorough including the teaching method like mastery learning and so on. But our problem is the way and creativity of the teacher in implementing it. Basically, the word self-advocacy is not exist, but under kemahiran bersocial the teacher is free do teach it. Since our curriculum is flexible, so the teacher can teach many thing including the skill on how to become an independent young adults. When you ask me to what extent, my answer is not sure, because I myself is still not know about self advocacy very well.

Why? Lack of knowledge about advocacy. The word self advocacy itself is not really clear to me and maybe other teachers. You must provide the definition of the word clearly first before you ask further question. (Since this is your research project, I would like to give you some advise: If you have to interview teachers regarding this matter, sometimes you cannot get the answer in direct, so you must play with your words. It just like when you ask to mother from rural area about kurikulum sekolah, they all not really understand apa tu kurikulum, so you kena tanya...apa yang anak makcik belajar si sekolah, nanti bila makcik tu cerita pasal apa yang anak dia belajar, then you can interpret it as curriculum. ok)

>>Do you personally think this is an important topic to address in school?

Yes, it is very important,

Why? Because this topic will lead into the development of the student with learning disabilities towards become independent person in future through know their right being a disabled person, know what action they (or parent) should take if the problem arise and know the proper channel to refer to.

>>At what age do you think self-advocacy should be taught?

It depends, for more bright students you can start at the second year of secondary school, because the first year is a transition period for them in the secondary school environment. For moderate and severe student you can start when the teacher think the student is capable in receiving information. I suggest 3 years before they leave the secondary school.

>>In your experience as a parent and a teacher of special ed, how will the parents in Malaysia response to self-advocacy being taught in school?

Firstly, it would be better if you could foster the skills and knowledge to the teachers and parents regarding self-advocacy. Provide them with positive sample from existing students with LD who has the skills. I think it will be no objection from them if they know it really give a positive benefit for students and their child.

>>I know you must be busy but, I would very much appreciate if you could take some time to respond to the above questions.

Thank you.

Best Regards From



Noraini Zainal Abidin

Do You Yahoo!?

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<http://mail.yahoo.com>

		Sub-topics	Emerging Themes
1.0	Were you involved when the Self-Advocacy Group started by Dignity & Services?		
1.1	When it was set up I was one of the Directors at D&S.	Director of D & S when the Self-Advocacy Group was set up.	
1.2	What were the reasons / vision to begin the Self-Advocacy movement?		
1.3	<p>People who are blind/in wheel chair are intellectually able and can vocalize their view. But people with Learning Disabilities are not able to verbalize – they need people who support their need to vocalize. People with Learning Disabilities are often pushed aside that they can vocalize for themselves.</p> <p>Peter Young was one of the first to speak of Self-Advocacy- letting People with Learning Disabilities to express their view.</p> <p>Solomon & Kay were the first to put it into practice. They were at Bethany Home.</p> <p>I also looked at the self-help group home concept instead of keeping the institutional approach. That was the initial stages - the model of People with Learning Disabilities was at the early stage of development. There was no model for us to follow. But we were more keen on the social model.</p> <p>I had exposure to 2 Self-Advocacy groups when I was in UK. These were Self-Advocacy Groups of People with Learning Disabilities- they learn to do their own things for their own club. They were living in group homes or on their own.</p>	<p>People with LD are deprived of opportunity to voice up for themselves.</p> <p>Peter Young – founder of Self-Advocacy</p> <p>Bethany Home – started first self-advocacy group Prefer Social Model</p> <p>Exposed to self-advocacy groups in UK</p>	<p>Concerns</p> <p>History</p> <p>History</p> <p>Approach</p> <p>Approach</p>
1.4	Why UV went ahead of Bethany Home in its' Self-Advocacy Group?		

	Could it be the difference in approaches of these 2 groups? One is centre-based and the other is advocacy-based?		
1.5	<p>I think you'll have to look at the socio-economic factor- whether- people living in a group home/centre/ family, or level of resources they have in their home.</p> <p>There are differences between people with living in PJ & Bethany Home.</p> <p>I think the people in charge are important- what their vision is- their focus.</p> <p>When living in an institutional based - the child grew up in the centre. People in charge of them are like parents to them- they could be treated as children - protected. Less opportunity to Self-Advocate.</p>	<p>Socio-Economic factor</p> <p>Vision of people in charge</p>	<p>Factor</p> <p>Factor</p>
1.6	In comparison to other disability groups- how far have they moved on?		
1.7	<p>Though the disability may defer- the inhibition they experience is quite similar. They may be more vocal- example for the blind and wheel chair bound because no inhibition to the mind.</p> <p>But the question of whether they are more independent or not is debatable. In some cases the blind can be so dependent on the people around them. This kind of dynamic is quite the same as People with Learning Disabilities-they are dependent on their family.</p> <p>Though they may be intellectually more able there are many barriers for them to be independent.</p> <p>The dynamic of the scenario, the dependency, the feeling of inferiority might be very similar.</p> <p>People with Learning Disabilities might actually be very lovable & more</p>	Inhibition of the mind	Factor

	<p>opportunity to go everywhere. They might be far more happier person.</p> <p>But they are very well organized groups. In this case, they are able to take their agenda further. It also depends on how many are empowered to do it. They have more opportunity for education.</p> <p>But the bulk of them are quite similar. They might be isolated.</p> <p>May not be able to do anything unless given the opportunity. The dynamic might be similar- the feelings wise- some blind people may be worse off- can be depressing & suicidal. A person is able to vocalize- we think they are more able. But, most Malaysians don't vocalize.</p> <p>In term of their movement- As a movement they are ahead they started earlier- they have the funds. People with Spinal injury –they do not have intellectual barrier.</p>	<p>Other disability groups are very well organized and able to take the agenda further because they do not have intellectual barrier.</p> <p>Most Malaysians do not vocalize.</p>	<p>Comparison with other disability groups.</p>
1.8	What are some factors that affected the movement of Self-advocacy of People with Learning Disabilities?		
1.9	I think one large one would be public attitude- they think People with Learning Disabilities are incapable- how can they run a society, how can they drive a car. They might let go of people who are more able to articulate.	Public Attitude	Factor
2.0	Do you think education could be a factor?		
2.1	I think so. I think if early intervention for People with Learning Disabilities and if there is appropriate programme for every stage, then they would have better abilities in self-achievement- they can be more independent. If there	Lack of quality education due to lack of funds	Factor

	<p>are proper training programme they can be more independent.</p> <p>Those who go to Community-Based Rehabilitation are more being in a day care. There is lack of well-trained people.</p> <p>I don't think Government has enough funds for institutions to run a good educational programme. Even for the blind people training is out-dated.</p> <p>But more people who have gone to normal school and they can achieve more. For People with Learning Disabilities Government needs to invest more for their education.</p>	<p>Lack of well-trained people</p> <p>Lack of funds for quality educational programme</p>	<p>Factor</p> <p>Concern</p>
2.2	If there is formal teaching in school will it help to train People with Learning Disabilities to be able to Self-Advocate?		
2.3	<p>To develop their skills is certainly important. People may still be thinking of helping them in basic independent skills.</p> <p>But, I think they should teach them to vocalize to speak up for themselves. Personal Advocacy to voice your views and know your rights is important - need to be introduced to children without disabilities too.</p> <p>But, I think that part will take a while to develop because we are faced with situations where services are not comprehensive enough.</p> <p>We have to take one step at a time. The position is not extensive enough.</p> <p>If we take Self-Advocacy & political right then you have a long way to go.</p> <p>I think overall in Malaysia in terms of impact of modernity, people are moving from basic poverty and basic survival skills to other issues- but it will still be quite a long way.</p>	<p>Self-advocacy should be introduced in school.</p> <p>Lack of comprehensive services</p> <p>Generally, all disability groups lack of awareness and focus on political right</p>	<p>Factor</p> <p>Concern</p> <p>Concern</p>

	<p>Even within the disability movement there I don't think there is enough consciousness amongst the blind and the deaf to ensure their voice is being heard. You might have a blind advocate who might feel that the Learning Disabled are not capable to vocalize.</p> <p>But because of movement like United Voice there is greater consciousness.</p>	<p>Self-advocacy movement like United Voice can create greater consciousness on political right.</p>	<p>Recommendation</p>
2.4	Can you recall how the Self-Advocacy is like in UK?		
2.5	<p>They were older groups that are living on their own. Britain has a system in which they can make certain claim, for self support, they are working, they have housing allowance; they are quite independent.</p> <p>They come for meeting on their own and they have good time with each other. They are expressive. This was in '94, 95.</p>	<p>Financial support from government enabled persons with LD in UK to be more independent.</p> <p>They are more expressive</p>	<p>Comparison with developed country</p>
2.6	How can the Government support the Self-Advocacy Movement?		
2.7	<p>In most social economy discussions, disability issues don't surface yet. Like working towards the 9th Malaysian Plan, while disability could be treated as an area for funding, it doesn't enter into mainstream of discussion.</p> <p>The focus is much more on racial comparison.</p> <p>Until & unless disabled people grow & get into the process, like Professor Ismail has attempted to - like getting into the budget discussion, it will not be in the mainstream.</p>	<p>Disability is not in social economy discussions</p> <p>Persons with disabilities need to be involved in policy making.</p>	<p>Concern</p> <p>Concern</p>

<p>But, nonetheless there is enough commitment from the Government to make allocation of the budget for People with Disability.</p> <p>It is now to make sure when there is public policy forum example the police issue, national unity & integration, they have a committee & the able people from the public.</p> <p>Until & unless, like United Voice participate in discussions on 9th Malaysian Plan & integration, then UV should write a note to the Prime Minister to relevant body to make an appointment to voice your view. If you are persistent, you'll be given an opportunity.</p> <p>Example with the police, if People with Learning Disabilities has a particular problem in the related issue then they could make appointment to meet the authorities involved & voice up your views.</p> <p>You should see where is the public opportunity to express views then you should enter the discussion. Like UV is in the Majlis Perbandaran Petaling Jaya area, then it would be good to get involved with the local authority in their Agenda 21. MPPJ will invite people to comment on the budget. This is what I call the public space. Public space to voice opinion. It can be formal like select committee on national unity & integration.</p> <p>Let's say UV, see the committee & request for time to present your view, you will be given about 10 to 15 minutes to present. Then your presentation will be recorded.</p> <p>You should utilize public not just on issues on disabilities but general topic. Then disability is integrated into the community.</p> <p>MPPJ is one, where the disabled people can voice up about transport, at Agenda 21 – if it is not good, etcetera. Can request for allocation in 2007</p>	<p>Self-advocacy groups should be persistent in finding a platform to voice up concerning policies</p> <p>Seek and seize opportunities to voice up concerning policies.</p> <p>United Voice should find public space to express views on policies.</p> <p>To integrate into the community disability groups should speak up not only on disability issues but also on general topics.</p>	<p>Recommendation</p> <p>Recommendation</p> <p>Recommendation</p> <p>Recommendation</p>
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	<p>budget - then you are making a contribution.</p> <p>Don't make disability issue the concern of just the welfare department because it cuts across a cross-sectional area- could be education, housing, where a public space is an opportunity to monitor.</p> <p>UV can link up with MCA think tank or other group so you know the process is going on. Need to monitor the paper to know where are the public spaces to voice up local or international issue.</p> <p>If there is a disaster then UV can also participate in raising funds. If there is a family in need- UV can contribute - get the news to cover story- you become a higher profile.</p> <p>You then are not just recipient. There will be greater awareness.</p> <p>Example when there is Hari Raya open house, go to the Menteri Besar's house or Prime Minister's house. Bring UV members.</p> <p>This is increasing your profile to get into the public space discussion on local issues. I think people will listen. Politicians are interested in media coverage.</p> <p>The outcome has to be monitored over-time.</p>	<p>Disability issue should be cross-sectional.</p> <p>Be well informed about local news to seek platform for local and international public space.</p> <p>Be a contributing party and not just recipient.</p> <p>Make your presence felt at distinguish host's open houses.</p> <p>Monitor outcome.</p>	<p>Recommendation</p> <p>Recommendation</p> <p>Recommendation</p> <p>Recommendation</p> <p>Recommendation</p>
2.8	What do you think the Self-Advocacy movement can do for People with Learning Disabilities in Malaysia – in long term?		
2.9	<p>I think it is enlarging the outreach - how do you get similar groups in different district.</p> <p>How to move across to other areas where you integrate the grassroots and cover the development in some other areas and convincing people because</p>	<p>Self-advocacy can impact the grassroots by enlarging its outreach</p>	<p>Recommendation</p>

	there is a long way to actually display the model. To touch the grass root will make a longer impact.		
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		Sub-Topics	Emerging Themes
4.0	How are you?		
4.1	Good		
4.2	How did you come here today?		
4.3	By train		
4.4	How long have you joined UV?		
4.5	Since 2001		
4.6	Why do you join UV?		
4.7	It was Ms XXXX's idea. Ms XXXX from PKIK	Informed by someone from a NGO center.	Factor: Awareness
4.8	What did she tell you about UV?		
4.9	She showed me UV's newsletter.	Newsletter of United Voice	Factor: Awareness
4.10	Did she explain why you should join UV?		
4.11	I can't remember – too long ago.		
4.12	Who is XXXX?		
4.13	She is the director of XXXX.		

4.14	What is XXXX?		
4.15	A school and centre for persons with learning disabilities.		
4.16	Were you a student at XXXX then?		
4.17	Ex student		Background
4.18	How long were you a student at XXXX?		
4.19	Two years		Background
4.20	So, because XXXX recommended, you decided to join UV?		
4.21	Yes		
4.22	Was your family happy that you join UV?		
4.23	Yes	Supportive Family	Factor: Family Support
4.24	Why did they agree?		
4.25	No idea. I never ask them.		
4.26	You joined UV since 2001. It has been 5 years. In these 5 years what have you learnt from UV?		
4.27	To speak up for myself and be more independent.	Learned to speak up and be more independent	Impact: Able to speak up and more independent
4.28	What is UV?		

4.29	It is a Self-advocacy society for PWLD	Knowledge of United Voice	Impact: Knowledge of Self-advocacy Society
4.30	What is Self-advocacy?		
4.31	Speak up for yourself.	Definition of Self-advocacy	Impact: Knowledge of Self-advocacy
4.32	Besides speaking up for yourself, is there other meaning?		
4.33	Make your own decision. Have the rights to speak up. Know your rights.	Definition of Self-advocacy	Impact: Knowledge of self-advocacy
4.34	Do you think self-advocacy is good for persons with learning disabilities?		
4.35	Yes!		
4.36	Are you able to accept that you are a person with learning disability?		
4.37	(Paused)... Kind of.		
4.38	How has UV changed your life?		
4.39	I learn to speak up. Eh...it has changed my thinking.	Learned to speak up and changed in thinking.	Impact: Changed mindset
4.40	Any example?		

4.41	Exposure. I have been to conferences like ICSW (<i>International Conference of Social Welfare</i>) held in KL.	Exposure to International event	Impact: More Exposure
4.42	What did you do at the conference?		
4.43	I was a participant and I also participated in a workshop.	Promoted Self-advocacy movement in a Workshop at an International Conference	Impact: Active involvement in public speaking
4.44	What was the topic of the workshop?		
4.45	Self-advocacy Movement for persons with learning disabilities in Malaysia.		
4.46	What do you think UV has helped you in terms of your own independence? Before you joined UV were you independent?		
4.47	Almost.	Already quite independent before joining UV	Personality: Quite independent
4.48	After joining UV are you more independent?	More independent after joining UV	Impact: More independent
	Yes.		
4.49	Can you tell me some examples/things you do now that you did not do before?		
4.50	I can take public transport to KL or anywhere from Kajang by myself. I can travel by bus, LRT or the commuter. I don't have to depend on my family for transport now.	Able to travel independently.	Impact: Learned to travel independently
4.51	How has your ability to travel by yourself changed your life?		

4.52	I know I can't depend on my mum and sibling all the time. Now I can travel wherever I want to go. I go to work by myself in KL from Kajang. I travel to UV office for meetings and for Special Olympics games every once a week. I come up to KL when there is something on like a bazaar, seminar or meetings. I have even traveled by bus to Teluk Intan by myself! I go for movies by myself instead of following my family all the time.	Able to travel near and far and be involved in activities independently.	Impact: Developed independence skills and developed self-confidence
4.53	I would like to ask you about your involvement in UV. What was your involvement when you first joined UV?		
4.54	I was just an ordinary member.		
4.55	How did you feel when you first joined?		
4.56	They speak up a lot.		
4.57	What did you do as an ordinary member?		
4.58	I kept quite and just looked at what they do. Then, I joined a Special Olympics event and there I saw a girl Marina. She made a speech in public. I was impressed. That encouraged me to speak up.	Peer Influence and Inspiration	Impact: Developed courage through peer influence.
4.59	What are some things that you do in UV which you think are important?		
4.60	I mingle with people – with members, parents, other people like volunteers. I also meet with people from other organizations and other countries in conferences.	Social and interpersonal skills	Impact: Developed social and interpersonal skills
4.61	How does mixing with so many people affect you?		

4.62	Getting more exposure.		
4.63	Can you give some examples?		
4.64	In school – I saw parents who left their child and never come back for the child.	Awareness of social ills	Personality: Felt sorry for abandoned children
4.65	How does that affect you?		
4.66	Er, I was shock.	Affected by social ills	Personality: Self-awareness and expressive
4.67	Did that experience make you want to speak up for PWLD?		
4.68	Yes.		
4.69	How do you think by speaking up you can help them?		
4.70	Er.. talk to the parents – ask them don’t neglect people like us. Encourage PWLD to speak up for our rights. I would like the government to give us opportunity to speak up for our rights. I want the public to know more about us – some of us are unemployed, stuck at home.	Awareness of rights and government’s responsibilities	Impact: Awareness of rights
4.71	Do you think the government and public should provide more opportunities for them?		
4.72	Yes.		

4.73	Can you share about your work experiences. What was your first job?		
4.74	I was a trainee at a bakery. Then, I joined Metro in but only for 2 weeks. In 2001 I joined Sugar Bun – a fast food restaurant. I worked there for 3 years and then resigned because of some wackos.	Experience at work - harassment	Personal Experience: awareness of environment
4.75	Who are these wackos?		
4.76	Weirdos. (Chuckled). They disturbed me all the time.		
4.77	So you moved from Sugar Bun... What did you do then?		
4.78	I worked at Mc Donald's I was a crew member – mop the floor, clean the windows...	Work experience	Personal experience: Work experience
4.79	How long were you at Mc D?		
4.80	1 ½ years		
4.81	What is your current job?		
4.82	I work at an accounting firm.	Work experience	Personal experience: Change working environment
4.83	Is it an office job?		
4.84	Yes.		

4.85	Why did you change from a fast food restaurants to an office job?		
4.86	It has been a long time I work in the food industry. So, I decided to join the private sector.	Upgrading job experience	Personality: Awareness of need for personal development
4.87	Are you happier in this new job?		
4.88	Yes.		
4.89	Why are you happier in this current job?		
4.90	I meet other people – professionals. I learn new things.	Work assessment	Personality: Self-awareness
4.91	Have you learned a lot?		
4.92	Yes, except the computer.	Work assessment	Personality: Self-awareness
4.93	What are some of the things you have learned?		
4.94	I mix with clients.	Confident to mix with clients – non disabled people	Impact: Independent and social skills developed through self-advocacy activities can equip oneself for more challenges at work.
4.95	In your work places so far, do you think the employers and workers		

	treat persons with learning disabilities well?		
4.96	Yes, with me yes. They are nice.		
4.97	Were there any bad experiences?		
4.98	Er...(Chuckled) Should I or should I not tell.... (Smiled).	Apprehension in revealing negative experiences at work	Personality: self-awareness
4.99	Well, it is up to you. If it is too personal, you can choose not to tell me. Do you think your friends with LD have bad experiences at work?		
4.100	Yes		
4.101	Can you share some examples of bad experiences your friends have gone through?		
4.102	Like harassing. Give names. Asked for money.	Types of harassment at work	Personality: Able to identify harassment
4.103	Your friends told you these stories?		
4.104	Er... it was me.	Revealing personal experience	Personality: Self-conscious.
4.105	I see, it was your own experience. How did you feel?		
4.106	I was afraid.	Fearful	Personality: Lack ability to protect self from

			harassment
4.107	What do you think you can do to make sure things like that don't happen to persons with learning disabilities?		
4.108	They should have some laws for persons with learning disabilities – to protect them. Laws about their work place and laws to protect their rights.	Advocating for Laws to protect LD	Personality: Awareness on the influence of laws
4.109	Have you heard about such laws in other countries?		
4.110	Ya, in a movie – Loretta Claiborne at the 1 st NSAC (<i>1st National Self-advocacy Conference</i>).	Learned about Laws that protect LD at self-advocacy conference	Impact: Awareness on the influence of laws
4.111	From a movie?		
4.112	Ya, she was bullied by her school mates but she fight back. She was brave.	The right to protect oneself from harassment or bullied	Impact: Knowledge on right to protect one self
4.113	So, you feel that persons with learning disabilities in Malaysia should learn to protect themselves?		
4.114	Yes.		
4.115	Where is Loretta from?		
4.116	America.		
4.117	What else did she do in the movie?		

4.118	She spoke up for herself and about her life in public. She made her own decisions.	Courage to speak up in public	Impact: Peer influence
4.119	So, you were impressed with person with learning disabilities like her. Do you think persons with learning disabilities in countries like US (<i>United States</i>) have more opportunity to speak up?		
4.120	Yes		
4.121	Why do you think they have more opportunities to speak up?		
4.122	(Paused)... the public and the government allow them to speak up.	Awareness of the influence of public and government	Impact: Awareness of public security
4.123	Do you think in the US persons with learning disabilities have more freedom to speak up?		
4.124	Yes. They are more open.		
4.125	What about in Malaysia?		
4.126	Malaysians, they are a bit, lots of traditional beliefs – shy, pantang, looking down on persons with learning disabilities. Giving names.	Personal experience as a Malaysian LD	Impact: Aware of community attitude
4.127	How has self-advocacy changed your relationship with your family?		
4.128	How they treat me now?.. (chuckled)...wow... (chuckled). Er, When I was a kid, I like to go out, they won't allow me. Now, things have changed.	Family trust and expectations	Impact: Gained family trust.

	They have changed, but I wish they have more westernized thinking. That we can have open talk about problems and anything without saying pantang. I wish my family won't be a shame to talk about certain things. But... XXXX (certain comments were censored by the participant for this publication)		
4.129	You mean because of their culture?		
4.130	Yes		
4.131	What are some changes you would like to see in your family?		
4.132	I wish my family will XXXX – like being more open.	Desire more freedom from family to make personal decision or views	Impact: Awareness of need to be independent
4.133	Can you be more specific?		
4.134	So many...		
4.135	Would you like to give just one example.		
4.136	XXXX Er...(paused)...especially between man and woman relationship. They won't like it	Deprived of freedom to have relationship with the opposite sex	Impact: Ability to express sexuality issues
4.137	You mean, they won't allow you freedom to have a relationship with women?		
4.138	I can only comment about their looks but not more than that. Can only be friends.		

4.139	What do you wish your family will allow you to do?		
4.140	Get Married.	Desire to get married	Personality: Conscious of marital status
4.141	Your family won't allow you to get married?		
4.142	No, they think financially, I can't afford.	Financial factor	Personality: Aware of financial needs
4.143	What is your opinion to this issue?		
4.144	The government should provide houses for persons with learning disabilities like the developed countries.	Awareness on social security in other countries	Impact: Awareness of social security
4.145	You feel if the government provide such support you and your friends with learning disabilities can consider getting married?		
4.146	They should learn from other overseas countries.		
4.147	What are some things you have done through UV?		
4.148	I met with the former PM (Prime Minister) – Dr Mahathir twice. I spoke up for persons with learning disabilities.	Advocating for persons with LD	Impact: Able to advocate for others
4.149	What did you tell to the former PM?		
4.150	I talked about education for persons with learning disabilities.	Education for Persons with LD	Impact:

			Awareness on the Educational needs of LD
4.151	At what event did you meet him?		
4.152	It was a pre budget forum with NGOs. I was invited by D&S to make a speech in front of the PM at that time.	Pre-Budget Forum	Impact: Awareness of pre-budget forum
4.153	What did you say/tell the PM?		
4.154	I said that the government should not have too much reading and writing in special schools for persons with learning disabilities.	Advocating for better education for persons with LD.	Impact: Speak up objectively
4.155	Why did you suggest that?		
4.156	Giving persons with learning disabilities too much pressure.		
4.157	What do you suggest that the school should teach?		
4.158	Fun ways. Ask them what they like and what they want.	Positive Recommendation on education persons with LD	Impact: Able to voice constructive opinion and ideas
4.159	Do you think the special schools in Malaysia teach the students with learning disabilities vocational skills?		
4.160	No, not much....		
4.161	Where did you have your vocational training?		
4.162	At a NGO centre in my hometown.		

4.163	You met the former PM only once?		
4.164	No, I met him twice. Also at a National pre budget forum.		
4.165	What did you say the second time you met him?		
4.166	(Paused)...can't remember...I think it was about financial help for persons with learning disabilities...		
4.167	You kept your speeches? Can I have a look later...		
4.168	Yes...		
4.169	Besides the pre budget forum have you been to any other meetings organized by the government ?		
4.170	I attended another meeting organized by the Ministry of welfare. We had a meeting.	Aware of the various governmental ministries	Impact: Knowledge of national system
4.171	What was the meeting about?		
4.172	We discussed about the Disability Act.	Aware of Disability Act	Impact: Aware of need for policies and legislations
4.173	What is the Disability Act?		
4.174	A law to protect people with disabilities in Malaysia.		
4.175	What did you talk about at the meeting?		

4.176	We discussed about education, employment and housing for people with learning disabilities.	Discussed about education, employment and housing for persons with LD	Impact: Able to discuss issues affecting persons with LD
4.178	Who were there with you?		
4.179	A supporting friend from UV and Nazmi, my UV friend. I also suggested to them that PWLD should not be locked up when they are in school.	Persons with LD should not be locked up in school	Impact: Able to verbalise concerns
4.180	Do you think after meeting the PM and participating in those forums you mentioned have changed the situation for persons with learning disabilities in Malaysia?		
4.189	No, not much. They are taking a long time to change.	Not much changes	Impact: Learn to analyse and critic
4.190	How do you feel?		
4.191	Disappointed.		
4.192	Why do you think that changes are happening so slowly?		
4.193	They are too busy.		
4.194	Do you think you'll continue to speak up for the rights of persons with learning disabilities?		
4.195	Yes		
4.196	Would you encourage other persons with learning disabilities to join a		

	group like UV?		
4.197	Yes, because there are so much opportunity to learn about our rights and make decisions.	Self-advocacy – knowing ones rights and learning to make decisions	Impact: Awareness of impact of self-advocacy
4.198	Do you think many persons with learning disabilities in Malaysia are able to self-advocate self-advocate?		
4.199	No.		
4.200	Why is it so?		
4.201	Because most of them are not taught how to self-advocate in school.	Many persons with LD are not able to self-advocate because they are not taught about Self-advocacy in school	Implication: Many LD are not able to self-advocate because it is not taught in school.
4.202	Do you think self-advocacy should be taught in school?		
4.203	Yes. Questions which they can't ask their parents, they can ask in school. So school must give them opportunity. School should have more professional teachers.	Self-advocacy should be taught in school.	Recommendation: Self-advocacy should be taught in school
4.204	Do you think persons with learning disabilities should learn to self-advocate when they are young?		
4.205	Yes. When I was in England, 5 to 8 years old, I learn to speak up in school.	Learned to speak up at 5 years old	Personal Experience: Learn to speak up at a young age.

4.206	You said that not many persons with learning disabilities can self-advocate. What can UV do to change the situation?		
4.207	Encourage them to speak up.	UV should encourage other persons with LD to speak up	Recommendation: UV to encourage other LD to speak up.
4.208	What else can you do all do?		
4.209	Encourage them to form their own self-advocacy groups – all over Malaysia. Eg, Mutiara Voice Club, Penang. UV encouraged them and helped them to form their group.	UV should encouraged more self-advocacy groups to be set up.	Recommendation: Form more self-advocacy groups.
4.210	What else did UV do to promote self-advocacy?		
4.211	UV organized the 1 st National Self-advocacy Conference in Malaysia.	1 st National Self-advocacy Conference	Implication: A national movement
4.212	Were there many people who participated in the conference?		
4.213	Yes, persons with learning disabilities came from Melaka, N. Sembilan, Perak, Penang, Sabah, Sarawak, KL and Selangor.	Eight states participated in the Self-advocacy Conference	Implication: A national movement
4.214	Was the conference successful?		
4.215	Yes.		
4.216	What did you all learn at the conference?		

4.217	We learn to make decision and how to form self-advocacy groups, how to lead a meeting and public speaking.	Learn to self-advocate and form self-advocacy groups	Implication: Self-advocacy can be learned
4.218	In your opinion, who supported UV to become such a successful SA group?		
4.219	The public, parents, NGO like D & S – they help us financially and gave us training.	UV is given financial support	Implication: Self-advocacy groups need support
4.220	Are there many NGOs like D&S?		
4.221	No, I don't think so.	Not many NGOs are like D & S that supports self-advocacy.	Factor: Lack of support from NGOs
4.222	How does the public support UV?		
4.223	They gave us donations and sponsorship and be our volunteers...	Support from Public	Implication: Need support from public
4.224	In what ways do parents encourage UV to progress?		
4.225	They provide transport. They allow their children to attend UV meetings and activities.	Support from Parents	Implication: Need support from parents
4.226	Do you think all parents are supportive?		

4.227	Some yes, some no.	Not all parents are supportive	Factor: Not all parents are supportive.
4.228	Can you give an example of a supportive family?		
4.229	My family... they encouraged me to be involved – especially my mum. They helped me with transport initially, my siblings help edit my speeches and articles. But, some parents think their child is not confident. They do not allow them to take public transport. They nag... Treating their adult son/daughter like a child... no respect in public. Embarrass their child.	Family support: support from parents and siblings	Factor: Support from parents as well as siblings is important
4.230	What are some of your achievement by joining a self-advocacy movement like UV?		
4.231	I learn to be a leader, to run a society... I learn about my rights and speak up for the rights of PWLD. I spoke in conferences and public meetings. I was elected to join the Special Olympics World Congress in the Panama.	Learned about leadership, rights and speak up at local and international events	Impact: Learn to be a leader, aware of rights and voice up
4.232	Are you very involved in Special Olympics (SO)?		
4.233	I am an athlete and a council member of SO Malaysia. I am the only learning disabilities in the council. Maybe, Marina is also a council member, I am not sure.	Participate in council meetings with non disabled persons	Impact: Developed leadership skills & work with persons without disabilities.
4.234	What did you learn when you were in the Panama?		
4.235	I met many people from all over the world. They are very independent. They	Inspired by peers at international	Impact: Self-

	spoke up a lot. I learnt about leadership and about our rights. I also met the first lady of the Panama. Yes. She came for the congress.	event	advocacy provide opportunities for exposure and learn from peers who are more advanced
4.236	What other progress would you like to see in the self-advocacy movement in Malaysia ?		
4.237	I hope we will become more professionals. More professional in the way they speak, act, think.... I want to see more self-advocacy groups – more persons with learning disabilities can speak up all over Malaysia. I hope there will be more professional teachers who are trained overseas.	Develop self-advocacy movement and have more trained teachers.	Recommendation: More self-advocacy groups and better trained teachers in schools.
4.238	Thank you very much for your time and your willingness to be interviewed.		
4.239	You are welcome.		