

# Self-Advocacy Movement of Persons with Learning Disabilities in Malaysia

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## *The Beginning*



In Malaysia, the self-advocacy movement began with the first vibrant self-advocacy group which was founded in May 11, 1995 with only 4 members. The group was named Self-Advocacy Group.

## *Dignity & Services Pioneered this Movement*

The Self-Advocacy Group was sponsored by Dignity & Services, a Non-Governmental Organization 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. Denison 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 learning disabilities are not able to verbalise. They need people who support their need to vocalize. People with learning disabilities are often pushed aside and not given opportunities to vocalize for themselves. In Malaysia, Peter Young (Founder and Director of Dignity & Services) was one of the first to speak of self-advocacy – letting people with learning disabilities express their views.”*

## *Leadership Roles*



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.

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## *Learning to Self-Advocate*

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.

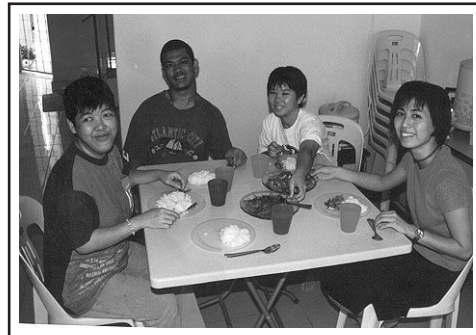
In November 1999, the first book by persons with learning disabilities entitled “*Difficult But Not Impossible*” was published. Their second book, “*My Life*” was launched in February 2001. The contributors to these two books were mainly members of United Voice and their friends from other centers.

## *United Voice*

At a training session in January 2000, the group decided to name themselves “*United Voice*” and also drew up a constitution for UV. The name United Voice represent a collective voice of persons with learning disabilities. The group began to take up more responsibilities by giving talks to local organisations and at conferences abroad.



## *Being Independent*



In July 2002, UV decided to take the bold step to be more independent from Dignity & Services by setting up their own office at their Clubhouse in Shah Alam. 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.

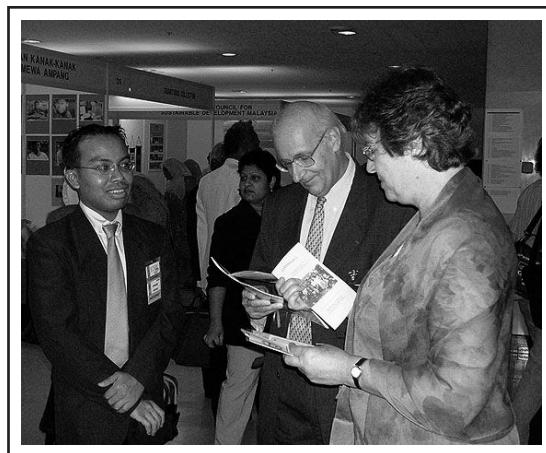
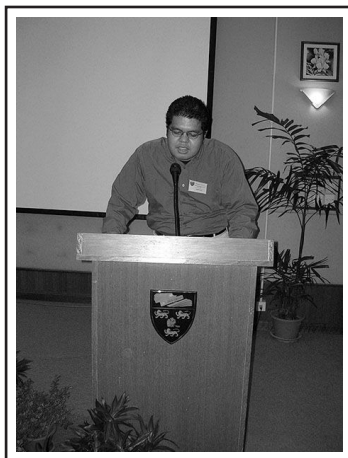
## *Speaking Up*



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. UV has proven that persons with LD are capable of participating in national forums and dialogues.

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## *Participation in Local and International Conferences*



UV members had participated in local and international conferences. UV had conducted workshops at the 13<sup>th</sup> 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. The President of UV, Johari Jamali was selected to participate in the Special Olympics World Congress held in the Panama in 2005.

## *Promoting Self-Advocacy*



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. 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.

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## *1<sup>st</sup> National Self-Advocacy Conference for and by Persons with Learning Disabilities*



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. These three self-advocacy groups took the challenge to organise the 1<sup>st</sup> National Self-Advocacy Conference with the support of a few supporting friends.

The Conference was held in November-December 2004. Eighty adults with LD from eight states participated in the event. 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 birthed in Penang, 10 months after the Conference. Most of these groups are center-based. UV is the only group that is autonomous. The table below shows that four out of eight groups are located in Selangor.

### *Self-Advocacy Groups of Persons with Learning Disabilities in Malaysia*

<b>Name of Group</b>	<b>Year of Formation</b>	<b>District/State</b>	<b>Type of Group</b>	<b>Sponsor Organisation</b>
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
Aktion Club-KJTC PJ	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, Selangor
Mutiara Voice Club	2005	Balik Pulau, Penang	Advocacy Supported	Asia Community Service

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## *The 1<sup>st</sup> Self-Advocacy Society*



The last ten years of training, exposure and experiences in the self-advocacy movement have equipped UV to become a full fledged Society. On July 12, 2005 UV created history in Malaysia for being the first society led by persons with LD that is recognized by the Registrar of Societies in Malaysia. The group decided to maintain the name United Voice. UV is officially known as *Self-Advocacy Society of Persons with Learning Disabilities Selangor and Kuala Lumpur*. The membership of UV grew to 70 members by end of 2005.

### *United Voice Committee 2006*

Johari Bin Jamali	President
Deerick Lim Kay Huat	Vice-President
Christina Yeow Chor Keen	Secretary
Cynthia Joann A/P Thomas Raju	Assistant Secretary
Teoh Hooi Ting	Treasurer
Aslam Bin Sulaiman	Ordinary Comm. Member
David Foo Khee Choong	Ordinary Comm. Member
Esther Moo Shook Leng	Ordinary Comm. Member
Alexander Tang Wing Cheong	Ordinary Comm. Member

### *The Objectives of United Voice*

Over the years, United Voice has developed and sharpened its objective as a self-advocacy movement of persons with learning disabilities. The objectives of United Voice:

- 1. To develop leadership, independent skills and confidence among members so that they can speak for themselves and make their own decision;*
- 2. To speak and act on behalf of other persons with learning disabilities in Malaysia;*
- 3. To provide a meeting place for persons with learning disabilities where they help and support each other;*
- 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;*

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## *United Voice Members*

Currently UV has about 80 members. UV membership include persons with Down Syndrome, Autism, Attention Deficit Hyperactivity Disorder, Cerebral Palsy and Global Developmental Delay.



UV is a multiracial society. The membership consists of Malays, Indians, Chinese and other races. Currently there are 31 women and 44 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. All committee members are working in Open Employment.

## *The Progress*

The progress of self-advocacy movement of persons with learning disabilities in Malaysia is observed to be in its infancy stage. To date, there are only 8 self-advocacy groups spread over 5 states in Malaysia, while there are about 150 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 in Malaysia such as self-help movement of the blind, the deaf and the orthopaedic.

To strengthen this movement, the existing groups have to play a more active role in advocating for persons with learning disabilities. Adults with learning disabilities throughout Malaysia should be encouraged to form their own self-advocacy groups. Self-advocacy should be introduced in school so that persons with learning disabilities are exposed and trained to self-advocate at an early age.

## *Trail Blazer*



United Voice is the trail blazer for the self-advocacy movement in Malaysia. The unity of all the self-advocacy groups to stand up for the rights of persons with learning disabilities can bring about change to the lives of persons with learning disabilities in Malaysia. The support from all parties involved in assisting them and providing them the opportunities to be included in the community can spur them on to greater heights.