SELF-ADVOCACY MOVEMENT IN MALAYSIA: ISSUES, IMPORTANCE AND FUTURE DIRECTIONS

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The self-advocacy movement in Malaysia since the early 1990s has been witnessed in the ability of individuals with learning disabilities to speak out and gain confidence in their individual capacity. The formation of self-advocacy organizations and groups throughout Malaysia has given more opportunities for individuals with learning disabilities to make their stance known in the community. Drawing upon the notion of self-advocacy as an essential ideology for empowering individuals with learning disabilities, this article reviews the issues faced by individuals with learning disabilities in contrasting with the importance of the self-advocacy movement which has affected its development. Issues raised are reviewed as future directions for the movement. Community and government support would provide avenue to realize and acknowledge the meaning of interdependence upon each other in its implication of practice for a holistic development of the individual and the support system.

Keywords: Self-advocacy, learning disabilities, empowerment, support

The self-advocacy movement has developed internationally into a very influential position in the lives of individuals with learning disabilities. Beginning in the 1960s in Sweden, the self-advocacy movement has grown out of deinstitutionalization to the introduction of community care with the concept of normalization (Armstrong, 2002; Callus, 2013). It has provided many platforms for individuals with learning disabilities to become visible in their action and voices when their lives are integrated into the communities with much respect and dignity (Flynn, Grant, & Ramcharan, 2010). For instance, the representation of individuals with learning disabilities at different levels of local government meetings, international conferences and international high-level meetings is in line with the ideology of equality toward an inclusive society for all (Tilley, 2013). The latest Global Report on the Right to Decide has asserted the ability of individuals with learning disabilities to make decisions and have control over their lives in accordance with Article 12 of the Convention on the Rights of Persons with Disabilities (Laurin-Bowie, 2014). Such recognition has made the
effort of self-advocacy movements significant in helping them to be on an equal basis with others in all aspects of life for all individuals with disabilities. As such, the lives of individuals with learning disabilities are empowered with self-confidence and self-identity within a community (Llewellyn & Northway, 2008).

It was debated among the Expert Group Meeting that the genuine achievement of Millennium Development Goals required the inclusion of the rights, well-being, and the perspective of persons with disabilities in development efforts at all levels (Memoire, 2013). Such a notion has been brought for discussion and has resulted in the reaffirmation at the 69th plenary session of the General Assembly on 18 December 2014 for its members to go beyond the agenda for a more universal and inclusive agenda which should include the voice of people with disabilities in every member’s development agenda (United Nations, 2014). The need for capacity development efforts explicitly included empowering persons with disabilities as a new additional plenary action for its member states to continue their effort in the recently implemented Sustainable Development Goals. These development goals are claimed to be a more universal and inclusive agenda for everyone and every country to play their part in developing and achieving a global vision (United Nations, 2015). Inevitably, these goals require much community effort to be realized as we take the stance to observe and reflect upon the self-advocacy movement in Malaysia.

SELF-ADVOCACY MOVEMENT IN MALAYSIA

The self-advocacy movement has been introduced in Malaysia since the early 1990s, specifically to individuals with learning disabilities (Armstrong, 2002; United Voice, 2014). Unlike the birth of the self-advocacy movement in the western countries which came about from the issue of deinstitutionalization, the ideology of normalization and human rights has made its impact in Malaysia. Based on the People First approach, a loose-knit social group at post-school level met up to form United Voice under the supervision of Dignity and Services, registered officially ten years later as a society for and of individuals with learning disabilities in 2005 (Yeo, 2007). Upholding the belief that people are their own best self-advocates, its mission is to empower and enable individuals with learning disabilities to contribute in an inclusive society through the self-advocacy movement (United Voice, 2014). Its right-based movement has impacted the community in birthing more self-advocacy groups so that these young people are trained to speak up and understand their rights as persons.

With its stable development for the past twenty years, self-advocates from United Voice have been well-recognized by the local government and international organizations as speakers and resource persons (Osamu, 2013). Eight self-advocacy training and workshops have been organized and run by United Voice funded by Jabatan Kebajikan Masyarakat Malaysia (JKMM) for the Coordinators of Community Based Rehabilitation (CBR) centers throughout
Malaysia since 2012-2014 (United Voice, 2014). These workshops have received positive response with the ideology of upholding self-advocacy. This is proven by the birth of 20 self-advocacy groups throughout Malaysia where individuals with learning disabilities are given opportunity to make decisions and lead activities for the group. According to Maya, the Lead Coordinator from United Voice, the formation of self-advocacy groups is still progressing well with Government support. Following that, United Voice conducted five follow-up regional workshops in 2015 for the Coordinators, parents, and members of CBRs under the sponsorship of JKMM (United Voice, 2015). The workshop has birthed about 40 new self-advocacy groups. To date, there are about 70 to 80 self-advocacy groups in Malaysia (Maya, personal communication, March 3, 2016). The support from JKMM has provided encouragement to the community to understand the importance of the self-advocacy movement in Malaysia.

The development of the self-advocacy movement faces issues and challenges in its practice. It is essential to understand that the increased number of self-advocacy groups is not directly proportional to increased opportunities for self-advocacy. This affects self-determination and societal inclusion of individuals with learning disabilities to be significantly tangible and meaningful (Armstrong, 2002; Fyson & Cromby, 2013). Moreover, it is important to understand that the mushrooming of these self-advocacy groups should be treated as a collective movement giving future directions in framing learning disability services and policy at large (APCD Foundation, 2014; Buchanan & Walmsley, 2006). Group forming may be developed by individuals with potential leadership skills perceived by the service providers, but sustaining the group with a committed mission and vision poses challenges, both individually and collectively. This signals the service providers specifically in re-framing their services, and the community at large in re-thinking their approach of support in achieving self-advocacy to its realistic discourse. This implicates the practicality of self-advocacy in the lives of individuals with learning disabilities, their families and the community. Hence, this involves not only self-advocacy groups in which individuals with learning disabilities participate, but also the disability movement in our local context in pursuit of the common political interests underpinning the rights and empowerment of each individual. It is a matter of collaboration between one another in our social context for us as we look into the lives of individuals with learning disabilities in relation to the impact of the self-advocacy movement.

**IMPACT OF SELF-ADVOCACY ON AN INDIVIDUAL’S LIFE**

In the self-advocacy movement, the impact of the formation of self-advocacy groups in Malaysia on the larger community to accept and understand the capability of individuals with learning disabilities can be seen empirically. Based on personal experience and observation as a service provider and supporting
friend for the past seventeen years, there is an opportunity to critique and reflect on the issues of self-advocacy in the life of the individual with learning disabilities to form its future direction in the self-advocacy movement. We are motivated to scrutinize the impact of self-advocacy and the approaches of behavior management among individuals with learning disabilities from the human rights perspective (Cremin, Sellman, & McCluskey, 2012). This relates to the quality of advocacy support in making self-advocacy effective in its service deliverance, for which we are most concerned. In this paper, we will look into 3 areas of an individual’s life in relation to the self-advocacy movement: the issue of choice and human rights, the dilemma of self-determination, and the role of advocacy support in the context of its issues and future directions.

**ISSUE OF CHOICE AND HUMAN RIGHTS**

Jingree and Finlay (2013) conducted a study on individuals with learning disabilities’ own lived experiences, challenges and how they have suffered failure and frustration rather than empowerment and equity. Individuals with learning disabilities have spoken out on the need to provide more choices and control toward person-centered thinking within service cultures. Such an inclusive perspective has built a more comprehensive appreciation in understanding individuals with learning disabilities and the impact of self-advocacy as a whole picture. In the human rights perspective, the argument should look into and challenge the service cultures, whether to accept the reasoning capacity of individuals of learning disabilities by definition and classification such as the International Classification of Functioning, Disability and Health, or to grant meaningful rights as an explicit expression of human rights in relation to individuals with learning disabilities in our midst (Fyson & Cromby, 2013; World Health Organization, 2015).

In practice, based on our personal observation, self-advocacy is not engaging with the realities of life in individuals with learning disabilities. It is empirically noted that individuals with learning disabilities are being viewed as passive and dependent (Chapman & Tilley, 2013; Jingree & Finlay, 2013). It is hard to identify a space where they have a chance to make their own choices. In most cases, individuals with learning disabilities grow up in a ‘protected’ environment with ‘special’ treatment because of their personal developmental needs. For instance, one of us found that initially in the early years of supporting and training these individuals, the individual training plan was formed in consultation with parents, but decided by staff in its implementation. Many assumptions made are typically against the individual’s choices with false hopes, sadly but unknowingly assumed to be for the well-being of the individual to achieve a promising future. Hence, the experience of professionals has pre-empted the self-advocacy development in engaging individual choice.
Besides this, behavior management strategies used during the individual’s younger years continue to be pursued. Since young, their behavior has been the focus of interventions, and when some measure of strategy seemed to be effective, it would be pursued (Bodtker, 2001). For example, Applied Behavior Analysis is among the most common strategies in dealing with individuals with learning disabilities in Malaysia. This means the practice of reducing bad behavior by using negative reinforcement or rewarding good behavior with a rewards system. It was noted such strategies are still found effective in some young adults with learning disabilities. Even though this strategy in removing inappropriate behaviors in these individuals has been effective when they were young, it was observed to cause them to be static in learning and passive in action when they reach young adulthood. Many still asked for rewards after task completion. They lacked a sense of self-fulfilment.

The issue is there was no opportunity for these individuals with learning disabilities (LD) to speak their mind and express their experience when their behavior was controlled by school teachers, parents, service providers and professionals because of their social cognitive deficit and social conflict on top of their vulnerable sense of self and low self-esteem (Armstrong, 2002; Larkin, Jahoda, MacMahon, & Pert, 2012). When individuals with LD are being arbitrated in their behavior, and when their human rights are being denied, what could be their promising future? The inability to speak their mind often implicates a controlled life without freedom and rights for independent and meaningful lifestyles. Subsequently, they have no platform to develop their sense of self and self-esteem unless it is within the context of self-advocacy when their rights are respected and voices are heard.

To some extent, a critical analysis of the person’s home, family, socio-economic problem and support system tends to be overlooked. For instance, for most individuals with learning disabilities in a home setting, it is rather difficult for them to make their own choices and name their own reality (Aspis, 1997; Fyson & Cromby, 2013). This could be the result of ‘free choice’. For example, an individual with LD chooses to spend each day in front of the computer playing games instead of going to work. This does not only imply the incapacity of individuals to make their own choices, but also the inappropriate guidance in supporting the individuals to make sensible choices for themselves.

Nayor and Loh (2015) did a case study on promoting teacher-parent collaboration during implementation of co-curricular activities for school children with special needs. In our argument, if choices of individuals with learning disabilities are being considered as part of the implementation on top of the teacher-parent collaboration, a more holistic well-being of the individual’s life could be achieved. The argument is that such choices and opportunity underpinning self-advocacy should be promoted in the lives of children with learning disabilities from young in school and family amidst any authority imposed. Consequently, this would empower individuals to be realistic and
practical in making choices in life toward a promising future from young in a progressive way. On the other hand, it is our responsibility as policy makers and practitioners to develop a realistic understanding of the choices imposed on individuals with learning disabilities when offering our services (Fyson & Cromby, 2013). This not only ensures the quality of support to be equitable to the relational understanding of personhood and human rights, but also the elements of choices and self-advocacy to be upheld in its implication for practice for the self-advocacy groups which have been formed.

**DILEMMAS OF SELF-DETERMINATION**

The dilemmas of self-determination often occur in viewing individuals with learning disabilities as rightful citizens with potential and self-worth or with a need to be controlled because of their disabilities (Fyson & Cromby, 2013; Shaw, 2009). In the past, the underpinning principle of long-term individual well-being has been overlooked. According to Karlsson and Nilholm (2006), the dilemmas of self-determination are impossible to avoid completely as we need to understand that we are dealing with the complexity of personhood, specifically in reclaiming the human rights of individuals with LD through self-advocacy movements upholding the ideology of empowerment and choice. In self-advocacy, the ability of being able to explain who they are and what they want is increasingly evident of self-determination. However, many of them are unaware of who they are for various reasons. The dilemmas of self-determination persist in practice because of their inability to communicate and therefore make sound decisions. This renders their voices not being heard notwithstanding their past experiences and present stage of self-determination.

From our experiences of training individuals with learning disabilities beyond school age in Malaysia, we have observed the dilemmas of self-determination having a detrimental effect in their lives beyond school. Emotional stress, misunderstanding, conflict and aggression among individuals with LD persist with different behavior outcomes from similar causes such as school bullying, peer rejection, misunderstanding and personality clashes (Hutson, 2005). Some may be caused by exposure to conflict and violence in the family and school. Often, it appeared to be challenging given the multi-layered underlying issues. Because of the damaging effects of school bullying, even after they have moved on from school, they carry with them the effects in a vicious cycle. It becomes a ripple effect of the dilemma of self-determination in a different context and setting as they move on.

Arguments and violence continue to build tension and conflicts, resulting in assaults and sometimes destructive outcomes such as aggressive behaviour on each other (Bodtker, 2001; Larkin, Jahoda, & MacMahon, 2013). At times, the individuals with learning disabilities become the perpetrators, doing what they
have experienced as victims and become commonly being viewed as ‘problems’ (Flynn et al., 2010; Shaw, 2009). In most cases, their voices were unheard or the message was interpreted wrongly by themselves or other supporting parties (Karlsson & Nilholm, 2006). This is common in individuals with speech difficulty in expressing their views. The dilemma of self-determination deprives them of the opportunity to enhance their self-advocacy skills. Such dilemma is compounded by suspension as the most common consequence executed for the welfare of other members during conflicts, after warning has been given by the authority-in-charge in the training center or representatives from their family members (Tobin & Sprague, 2000). As a result, these individuals would be oppressed in their self-advocacy skill and conduct when the circumstances deprive them from being heard. Henceforth, their representation in a self-advocacy group would be deprived.

The argument is that developing self-determination in an individual’s life is important in enhancing the self-advocacy movement as an ongoing process to achieve a promising future. It is best learned through real life encounters with sufficient support and on-going guidance according to the individual’s level of understanding. For instance, such support could come from motivational courses and prolonged counseling sessions to enhance their self-determination to live independently (Khadijah Rohani, Abu Bakar, Sharifah Norul Akmar, Rohaida, Noraini, & Hidayah, 2014). The point is, they need to realize and accept their own disabilities, and move on from their own past experience of false hope which may be detrimental. Moreover, if the learning of self-determination relates fully with respected choices and timely opportunity, we believe the life of individuals with LD would be empowered with much confidence and determination toward a promising future. Karlsson and Nilholm (2006) conclude that the self-determination dilemma could be handled with understanding and support from the service culture with increased opportunity for self-advocacy as an expression of democracy in its implication for practice. Such a suggestion should underpin self-advocacy as its fundamental agenda compatible to the personhood development and systemic empowerment at large in the self-advocacy movement in Malaysia.

importance of advocacy support

Both the issue of choices and human rights, and the dilemma of self-determination have highlighted the critical needs for advocacy support in its implementation. From the onset, a person’s ability to speak up is being emphasized and measured in terms of its success or failure of self-advocacy. But the argument is the ability to speak up lies in the advocacy support provided. For instance, the notion of lack of self-confidence acknowledged by individuals with disabilities to sustain a job and achieve independent living (Khadijah Rohani et al., 2014), critically
implies the need to have quality support in developing their self-confidence as individuals. On the other hand, for those who have speech and communication limitations, their presence and action imply that the practice of self-advocacy is their protective right (Fyson & Cromby, 2013). Such notions should be notified by the advocacy support in the practice of self-advocacy. The approach of advocacy support determines the practice of self-advocacy in making its impact. In other words, it is the relational understanding of personhood which should serve as the fundamental basis in achieving self-advocacy, be it in an individual capacity or as a collective body and movement.

This highlights the critical importance of self-advocacy support for individuals with learning disabilities. Chapman and Tilley (2013) in exploring the role of support workers in self-advocacy identified some complex ethical issues with the pursuit of social change and the attainment of rights for people with learning difficulties (Caldwell, 2010). According to Caldwell (2010), the role of support workers in understanding the ‘ethic of care’ is essential to support self-advocates to be more self-directed, both individually and collectively underpinning the issues of relational power in shaping self-advocacy support and its movement for a promising future.

In Malaysia, lack of knowledge and skills in self-advocacy and lack of quality support have been the issues in guiding and providing counselling to students with learning disabilities in schools (Hanani, Hasnah, & Salleh, 2012). Moreover, it requires the notion of working with and alongside the reality of the difficulty in conceptualizing and understanding by individuals with learning disabilities upon the multi-faceted interactions between emotion, feelings and the complexities of everyday life. This challenges the support workers as ‘neutral facilitators’ in believing in the potential and ability of individuals with learning disabilities in providing insights, care and support in the process of self-advocacy in the professional practice model. Hence, it is critical to note the “voice” of individuals with learning disabilities featured over their problems and experiences in advocacy support (Armstrong, 2002; Chapman & Tilley, 2013). The argument is the need for effective advocacy to happen which does not only rely on individuals with learning disabilities but the understanding and support from the surrounding services including their family and the service providers. It is a critical call for the service culture to take responsibility for the choices imposed upon individuals with learning disabilities where hope is being developed into a promising future.

If they were given the necessary skills to enhance their own life, there is hope to witness the responsibilities of the support system to work in collaboration with individuals with learning disabilities as partners for a new direction of system change (Armstrong, 2002). Implicitly, to provide quality advocacy support, the support workers’ sense of self is pivotal in shaping the relational autonomy and reciprocal relationship in the interdependent roles of self-advocacy support (Fyson & Cromby, 2013). As a support worker, relational autonomy and reciprocal relationship take place through effort and time from
both parties in a self-advocacy group. Sharing from our personal experience, there is a paradigm shift within us as support workers in accepting and embracing the diversity of each individual with learning disabilities. This might seem overwhelming at times but such a paradigm shift is built upon ongoing personal reflection of our own services and practice in relation to the social model of disability and self-advocacy as opposed to the charity model. In practice, we need to minimize our own subjectivity, experience, influence and power as support workers to facilitate independence and self-determination, and ultimately, to make self-advocacy prominent in the lives of individuals with learning disabilities as a movement.

As argued by Chapman and Tilley (2013), it is a form of partnership with individuals with learning disabilities in providing self-advocacy support as opposed to services provided for them. Subsequently, it aims to set a role model for individuals with learning disabilities to be developed for leadership roles through the self-advocacy movement. Hence, in our personal capacity and partnership with individuals with learning disabilities, advocacy support challenges our practice to be reciprocal and responsive, with the principle of interdependency upon each other toward a promising future.

**IN ACHIEVING A PROMISING FUTURE**

In achieving a promising future, self-advocacy is essential in seeing individuals with learning disabilities to be resilient in managing their daily challenges. With the issue of choice and human rights, individuals with learning disabilities should be given the opportunity to make choices in their own respect from young. The dilemma of self-determination could be managed with maximizing different learning opportunities, beginning with each individual’s life in his or her family. We believe the ripple effect of self-advocacy when practiced at home would gear individuals with learning disabilities with self-determination in making their choices. This belief is based on the life testimonies shared by self-advocates from Malaysia after learning about self-advocacy (United Voice, 2012, 2015). Both testimonies have shown the impact of self-advocacy in their lives, and highlighted the needs to live interdependently in a community. Moreover, the importance of self-advocacy has given them direction and hope for a meaningful life. Subsequently, this should be carried on as a movement in the self-advocacy groups in Malaysia.

With the assumption and declaration of seeing individuals with learning disabilities take control of all aspects of their lives, the use of self-advocacy in their daily lives is increasing. By enforcing self-advocacy skills, they would be encouraged to speak up for their rights and be more responsible persons. On the other hand, without self-advocacy, practically most of them would remain with their issues as there would be no opportunity to speak up. Hence, this clearly
indicates the critical need for a structured and constructive system in managing their lives to achieve a promising future underpinning self-advocacy. We believe this could be achieved beginning from home including their daily living environment. This demands the need to strengthen self-advocacy skills in a progressive and structured manner for long-term development in achieving effective management and community support.

This is clearly depicted in the 4th goal of the Incheon Strategy of “Make the Right Real” for Persons with Disabilities in Asia and the Pacific (United Nations, 2012). The argument is that individuals with learning disabilities require a support system to realize their potential through emancipation of self to social empowerment when services and programs are enhanced for them to live independently in the community, as depicted in Figure 1. Beyond the ideology of empowerment in the self-advocacy movement, let us consider the practicality of self-advocacy within the complex dilemma of each other’s roles as partners, in acknowledging the importance of interdependence within the self-advocacy support system with the elements of engaging with individuals with learning disabilities. Issues should be viewed and treated as a challenge in the support system in its transition toward a promising future with the emancipation of individuals with learning disabilities through opportunity, understanding and support from one another in the movement.

Figure 1. A summary chart on the support system for individuals with learning disabilities
REFERENCES


