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M. Rezaul ISLAM, Stefan COJOCARU

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# Advocacy for Empowerment: A Case of the Learning Disabled People in Malaysia

M. Rezaul ISLAM<sup>1</sup>, Stefan COJOCARU<sup>2</sup>

#### **Abstract**

The objective of this study was to examine the role of advocacy for empowerment of the learning disabled (LD) people in Malaysia. The study used a qualitative research approach, where multi-method data collection methods such as in-depth case study, focus group discussions, and documentations surveys were employed. Data was collected from the staff members and disabled people from a nongovernmental organization (NGO) named United Voice (UV) working on learning disability in Kuala Lumpur, Malaysia. The results showed that advocacy is a powerful tool towards empowerment at individual, family, and community levels for the LD people. The findings would be important guideline for the government, policy makers, disabled related NGOs, and disabled community.

*Keywords*: disability, learning disability, advocacy, self-advocacy, community force, empowerment, Malaysia.

#### Introduction

Historically, the concept 'disability' remained as one of the most neglected and forgotten development agenda by both the state and the non-state actors (Islam, 2015). The term disability has a generic use and it includes all intellectual and physical impairments that may affect the life of an individual to a greater or lesser degree. People with disabilities (PWDs) in Malaysia can be considered as one of

Institute of Social Welfare and Research, University of Dhaka, Dhaka-1205, BANGLADESH. Department of Social Administration & Justice and Centre for Civilization & Dialogue, University of Malaya, MALAYSIA. E-mail: rezauldu@gmail.com (corresponding author).

<sup>&</sup>lt;sup>2</sup> Alexandru Ioan Cuza University of Iasi, Department of Sociology and Social Work, ROMANIA. E-mail: contact@stefancojocaru.ro

the most vulnerable of the minority group in the Malaysian population (Kamaruddin, 2007). WHO (2011) estimated that 15% of the world population have some form of disabilities. According to the statistics from the Department of Social Welfare Malaysia (2006), the registered number of disabled people in Malaysia is 197,519. The total 359,203 disabled people were registered with the Department of Social Welfare in December 2012. Rashid (2010) mentioned that total number of disabled people in Malaysia is 305640. Among them, 27,363 are visual, 39,303 hearing, 180 speech, 106,252 physical, 117,699 learning, 2,130 mental and 12,713 multiple disabled people. A number of initiatives such as the Federal Constitution (Articles 8 and 12), the Disability rights in PWDs Act 2008, National Plan of Action (2008 – 2012), National Policy for Persons with Disabilities 2007, international conventions, and a number of NGOs are working for the welfare of the PWDs.

The PWD Act protects the rights of persons with disabilities and imposes obligations on government, private sector and non-government organisations in relation to: (a) access to public facilities, amenities, services and buildings; (b) access to public transport facilities; (c) access to education; (d) access to employment; (e) access to information, communication and technology; (f) access to cultural life; (g) access to recreation, leisure and sport; (h) rehabilitation services; i) access to healthcare, health personnel and protection against further occurrence of disabilities; (j) lifelong protection for persons with severe disabilities; (k) access to assistance in situations of risk and humanitarian emergencies (Islam, 2015). There were various services such as legal protection, education, training, employment, social services, cash service, advocacy, etc. are available for the PWDs in Malaysia. There is limited number of scholarly articles published on the rights and advocacy from the international Journals. Undoubtedly, this number will be a handful in Malaysia (Islam et al., 2014). Advocacy is an intervention which has powerful role in order to the access the disabled community to promote and protect, and ensures their full and equal enjoyment of all human rights and enabling community participation. Advocates assist people to participate in decision making and increase their capacity to understand the service delivery options available to enable them to meet their goals. The objective of this paper was to examine the role of advocacy in terms of individual/self-empowerment, family empowerment, and community empowerment in Malaysia.

# Literature review: Learning disability, empowerment, advocacy and United Voice

The definitions of disability come in the literature in variety of ways. Bernell (2003) reviewed a wide range of literature to see the definitions of disability from different angles. Through reviewing this literature, he argued that most common definitions of disability used in empirical research involve the functional limitations framework. According to this, an individual is regarded as having a disability if he or she is limited in, or unable to perform, a certain activity or activities. Measures of limitation can be broad or narrow; depending on how the activities are defined and on whether the individual must be simply limited in or incapable of performing the activity. Disability can restrict a person's capabilities in various ways (Mitra, 2006). This may be due to the nature of impairment itself and other personal characteristics, the resources available to the person, and the environment (Palmer, 2011: 212). Louis Harris and Associates (1995) mentioned that an individual reports that he or she has a disability or health problem that prevented him or her from participating fully in work, school, or other activities. There were different types of disability; learning disability (LD) is one of those. Scanlon (2013: 26-27) mentioned that LD is an academic based disorder originating in the central nervous system. Mather and Greg (2006), and Swanson and Jerman (2007) argued that there have always been differences of opinion about the nature of a central nerves system (CNS) disorder, for example what specific processing behaviors define it. On the other hand, Johnson et al., (2010), and Stanovich (2005) argued that there is the question about the legitimacy of LD, whether LD is significantly different from low IQ and/ or achievement or if instead systems variables seek to construct the disorder.

'Empowerment' is a wide and complex concept. It has been used so widely in different disciplines that it now becomes a 'buzzword'. Lord and Hutchison (1997: 7), and Islam (2014) defined empowerment as processes whereby individuals achieve increasing control of various aspects of their lives and participate in the community with dignity. Empowerment as an 'alternative development approach' is now approaching, which allows social aspects of development and of local communities to enhance participation by using local resources (Islam & Morgan, 2012a). Nakanishi (1996) and Lynch (1994) argued that it is not easy in a cultural context, where family members may feel ashamed to have a child with disabilities or reluctant to and afraid of exposing him/her, and thus omission may occur. Whitmore (1988: 13) conceived empowerment as "an interactive process through which people experience personal and social change, enabling them to take action to achieve influence over the organizations and institutions which affect their lives and communities in which they live." Within the field of learning disabilities, one of the ways in which empowerment is believed to be implicated in enabling

people to gain control and to improving their quality of life is through the use of self help a strategy (Jingree, 2009: 16).

Advocacy is a polysemous concept. It has diverse meanings generally captured in dichotomous terms (Chereni, 2015). Garrow and Hasenfeld (2012) mentioned advocacy from 'social benefits' perspective and argued that advocacy activities aim at extending social rights of the disadvantaged groups. Advocates may suggest changes in norms of administration leading to broader societal changes. People with LDs whose communication cannot be understood by others could be included in the permanently vulnerable group (Blackmore, 2001: 222). The Goodbody Report (2004) Vol.1, emphasises that anyone can be an effective self-advocate provided they have the adequate advice, information and support. This is an important engine for equality and participation. There is evidence that selfadvocacy tends to be the preferred form of advocacy for people with learning disabilities. The ultimate outcome of advocacy is self-advocacy whereby ordinary people have been empowered to speak up for themselves or in their behalf as they manoeuvre bureaucracies or interact with state functionaries (Hodgson, 1995; Dalrymple & Boylan, 2013). Advocacy promotes social inclusion, equality and social justice'. This means advocacy helps and improves people's life e.g., disabled in person. UNICEF (2010) mentioned that advocacy is the deliberate process, based on demonstrated evidence, to directly and indirectly influence decision makers, stakeholders and relevant audiences to support and implement actions that contribute to the fulfilment of children's and women's rights. Advocacy involves delivering evidence-based recommendations to decision makers, stakeholders and/or those who influence them. It is a means of seeking change in governance, attitudes, power, social relations and institutional functions. It supports actions which are taken at scale, and which address deeper, underlying barriers to the fulfilment of children's rights. The present role of the advocacy for the LD has come across many movements by the international organisations. Disability advocates and their organizations are exploring these emerging issues, taking stock of their membership, and evaluating their advocacy strategies.

The goal of advocacy can be to address imbalances, inequity and disparities, promote human rights, social justice, a healthy environment, or to further the opportunities for democracy by promoting children's and women's participation. Advocacy requires organizing and organization. Disability advocates, including those who are trained as researchers, have had a significant impact on disability research during the past 20 years. The most significant contribution has been to promote a shift away from a medical model of disability and toward a sociopolitical model that stresses the interaction between the person with the disability and his or her environment (O'Day & Goldstein, 2005: 240). This socio-political model has been named as the Social Model of Disability that was initially introduced in the mid-seventies by a 'disabled' lecturer Mike Oliver. He adapted it

from a booklet published by the Union of Physically Impaired against Segregation (UPAIS) titled Fundamental Principles of Disability (Brainhe, 2006). The social model is mostly accepted in developing countries like Malaysia where the disabled people are structured with the socio-political and cultural contexts. In this regard, Yokotani (2001) mentioned that the social model puts emphasis on the socio-political context, and strongly suggests that problems are situated in the social structure which tends to exclude disabled people (Fig. 1). It is because of both physical and institutional inaccessibility and altitudinal segregation with prejudicial views underpinned by cultural and religious beliefs.

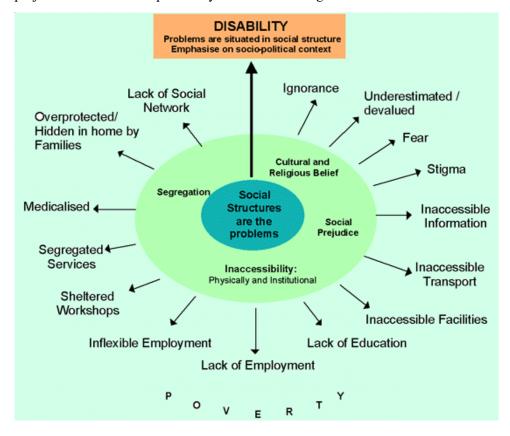


Figure 1. Social model and disability Source: Adapted from Yokotani (2001)

The non-governmental organizations (NGOs) are providing a variety of services such as vocational education, advocacy and counselling, etc. for the disabled people, but these are not at a satisfactory level (Islam, 2015). United Voice (UV) is the first society in Malaysia that is led by persons with learning disabilities

which was registered in July 2005. The members of UV include persons with Down syndrome, autism, attention deficit disorder, global developmental delay and other specific learning disabilities. Since UV became a registered society, it has grown rapidly. More parents are beginning to realize the need to expose their children with learning disabilities to the self-advocacy movement activities so that they learn to be more independent and develop skills to voice up for themselves. The core objectives of UV are to provide a meeting place for persons with learning disabilities where they help and support each other to learn more about their rights and become more responsible in the community; develop leadership, independent skills and confidence among members so that they can speak for themselves and make their own decision; speak and act on behalf of other persons with learning disabilities; provide training on self-advocacy for persons with learning disabilities all over Malaysia; make the community more aware of the rights, needs and abilities of persons with learning disabilities; create employment for members; and provide an example to the community of a quality service run by persons with learning disabilities. UV has a number of programmes such as learning to speaking up, public awareness, employment generation, social gathering and outings, sports, overnight stays, networking, promoting self-advocacy, interacting with other young people, and participating with the dialogue, forum, and workshops. UV pioneered the self-advocacy movement in Malaysia to reduce the isolation of people with LDs and give them the tools and experience to take greater control over their own lives and be integrated in the community. The organisation has been actively collaborating with Malaysia Welfare Department, Malaysia Special Education Department, Japan International Cooperation Agency (JICA), local universities and NGOs to organize awareness events on the importance of self-advocacy. United Voice's effort in developing the self-advocacy movement in Malaysia has been commended by UNESCAP, UNDP, APCD and JICA Malaysia.

# Methodology

The nature of this study was a qualitative case study. Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This kind of research involves the studied use and collection of a variety of empirical materials – in-depth case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts - that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand (Denzin & Lincoln, 1994). The case study research design has evolved over the past few years as a useful tool for investigating trends and specific situations in

many scientific disciplines (Cojocaru, 2010). This study used in-depth case study method for collecting detail information from one NGO- United Voice (UV) from Kuala Lumpur, Malaysia. The rationale behind to select this NGO was that the activity of this NGO has good relevancy with our study objective. Secondly, we thought that this case study would give detail information which would help to understand the advocacy programme it Malaysia and its effectiveness for the welfare of the PWDs.

We collected data from the staff members of UV who are working on advocacy programme for the LD people. We used three qualitative data collection methods e.g., in-depth case study, focus group discussions (FGDs), and documentation survey. We developed three sets of data collection instruments. One is unstructured in-depth case study questionnaire consisted open ended questions. We arranged one in-depth case study with the Coordinator of UV and one FGD session with the relevant staff members. The in-depth case study session continues two hours in two sessions. In FGD session, we considered 12 staff members who had long experience to work with the advocacy programme. This session took nearly one and a half hour time. The Research Assistant (RA) assisted to arrange this FGD session and took all notes. After finishing the session, he transcribed all recoded information and prepared FGD report. We also collected necessary data from UV's official records, relevant files, annual reports, and other relevant documents as part of our documentation survey. We also searched the internet sources and government documents such as law, policy and international conventions related disability rights in Malaysia. We strictly follow the research ethical guidelines provided by the University of Malaya. Data from unstructured in-depth interview, FGD, and documentations survey transcripts and research memos were entered onto an Excel database, to provide structure and flexibility to the management and integration of different types of data (Bazeley, 2010). The research questions and conceptual framework had generated an initial start list of analytical codes, which were developed during data analysis. Triangulation permitted the search for convergence and divergence in the multiple sources of information gathered, in order to develop and confirm (or disconfirm) the analytic themes (Creswell, 2003). We used descriptive data analysis technique to present our findings.

#### Results and discussion

## Individual empowerment

The complexity of the attitudes towards disabled persons and the sublimation of these attitudes have created a variety of perspectives and theories, ranging from how people develop and change their attitudes, to the impact of those attitudes on their behaviour in interactions with other people. In this regard, advocacy has a

crucial role towards individual empowerment. A good number of literatures showed how a LD person can be empowered through this advocacy. The Speaking Up and Speaking Out (1985: 9) mentioned that self-advocacy is important because it makes a LD person independent and helps his/her personal growth. It makes feel welcome. It makes a LD person such a way so that s/he feels that s/he is doing something for himself/herself. This is the ability to express their thoughts, feelings and rights about things that are important to them. At an individual level, selfadvocacy is seen to be beneficial for the people with learning difficulties involved. It helps to enhance personal identity, raise self-esteem and self-determination. It enables a person to have the confidence and ability to express his or her own feelings and wishes (Goodley, 2000; Simons, 2000). It may include the expressions of thoughts and feelings in an 'assertive way, making choices and decisions, knowing ones rights and have control over one's own lifestyle (Goodley, 2000). A LD person may gain open and permissive communication with persons who have experienced the same problem or condition and societal reactions. This gives plenty of opportunities to enhance socialization for the individuals who are isolated and or/alienated; and who have lack of coping abilities from peers. In an in-depth case study, the Coordinator of UV mentioned that thought self-advocacy the members learn the right to self-determination, the right to speak out and be heard, the right to choice-making, the right to services, the right to consumer control, and the right to citizenship.

Our finding 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. Atkinson (1999) found 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. Three most significant impacts include: awareness of rights, confident to voice up, and ability to take up leadership responsibilities. Most of the staff members observed that the selfadvocacy group activities have provided opportunities for those involved in the self-advocacy groups to develop independent and leadership skills. Some staff members mentioned that they found most of the leaders and the staff of the various organisations reported them self-advocacy group activities have provided opportunities for those involved in the self-advocacy groups to develop independent and leadership skills. Now they can express their opinions and say their mind. Before, they were timid. They have now developed better communication skills, developed ability to make choices, decide for themselves, and developed better self-esteem. They also learned how meetings are conducted which have not happened before. 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.

The feedback from the participants on the impact of self-advocacy groups was very positive especially in cases where appropriate environment and support were given. The following are some of skills identified during the FGD sessions that could possibly develop over time through such group dynamics: learn to speak up, develop self-confidence and self-esteem, develop leadership skills, improve communication skills, raise issues and discuss issues, learn to be more aware of them. This awareness includes their behaviour, productivity at work, abilities to communicate and abilities to lead. They can learn about their rights by: expressing their likes and dislikes making complaints when bullied or upset negotiating with person in charge, learn to respect one another by taking turns to speak, learn to accept one another's strengths and weaknesses, learn to understand one another by solving conflicts and misunderstandings, learn to ask questions to their peers as well as to the person in authority, and persons with LD can learn to take charge of their own meetings by: setting up the meeting room decide who to lead chair the meeting. Our findings are supported with other previous studies. For example, Gray and Jackson (2002) mentioned that advocacy by and for people with LD are 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.

## Family Empowerment

Families play an important role in empowering persons with LD to make their decisions and participate in developmental responsibilities. UV observed that most parents do not know the rights of their children in Malaysia. UV thinks that family is the most important when a LD person can be more empowered as because s/he stays most of his/her time with family members. In this case UV invites the family members specially parents to participate in different events such as parents gathering, workshops, training, counselling, etc. They should be informed and be encouraged to teach their children about their rights. Parents should also be informed how self-advocacy can improve the quality of life for persons with LD. They should know the purpose of self-advocacy groups and the possible outcomes, and impact the group can have on their children. One staff members told us that awareness on the importance of self-advocacy and the mindset of families seemed to be influencing factors on parents' support for selfadvocacy. They observed that 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. This is our observation that 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. Awareness of the importance of self-advocacy would be necessary to change the mindset of parents who are apprehensive or ignorant.

In a group environment, all members share their feelings, ideas, and experiences. Here 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. Being involved in self-advocacy groups has helped persons with LD develop communication, leadership and independent skills. Some staff members and some LDs argued that parents are generally ignorant of the self-advocacy concept. Many parents are depending on others to advocate for their children. Parents in Malaysia are still fighting for basic rights such as medical support, education, employment and living allowances for their LD children. Mitchell's (1997) 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. Lan (2007) in this regard argued that since the mindset of parents or guardians is discovered to be a big influence in supporting their child's involvement in selfadvocacy 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. A number of LDs confirmed that they were able to benefit from their self-advocacy groups because their family is supportive of their involvement. Parents have to be educated on the importance of allowing their children who have LD to voice their opinions. As suggested by Barnes (1997), 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.

## Community empowerment

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 (ESCAP, 2000). As a long-term process, it enables people to take collective action to achieve their common goals; as a participatory method it leads to improved resource allocation and sustainable outcomes, to increase the negotiation power of poor people, and mobilises greater local resources to be reinvested locally; as a programme it gives communities a sense of responsibility, authority and control over the development decision-making process, the set-up of the development agenda and thus in the process of resource allocation (Islam & Morgan, 2012b). The literature shows that self-help organisations plays significant role to speak on their own behalf concerning the proper design and implementation of policy, legislation and strategies which ensure their full participation in social, economic, cultural and political life.

UV sees the social model in the way that 'disability' is the result of the interaction between people living with impairments and an environment filled

with physical, attitudinal, communication and social barriers (Fig. 1). The principle UV follows is that people with disability are not 'objects' of charity, medical treatment and social protection but 'subjects' with rights, capable of claiming those rights, able to make decisions for their own lives based on their free and informed consent and be active members of society. UV believes that the Social Model of disability is a civil rights based approach to disability. It focuses on challenging and removing barriers which prevent disabled people from living full and active lives. The staff members and Coordinator of UV argued that the social model can achieve equality for disabled people; not by medical interventions, miracles or acts of charity but by: creating buildings that are accessible, producing information in accessible formats, challenging stereotypes and assumptions, ending segregated services, disabled people are doing things for themselves and disabled people having full civil rights under the law.

At community level, this self-advocacy group bring a lot of changes. We observed that UV made a number of social networks with the local community and local institutions e.g., clubs, local NGOs and GOs. These networks are working as social capital through building societal relations and successfully working together. UV successfully created such an environment which creates an 'enable environment' working for the advocacy support for the LDs people who are socially excluded. In a nutshell, we have got that a self-advocacy group is an effective approach to develop independent skills in persons with LD, family and community. The following skills were identified during the FGD e.g., learn to speak up; develop self-confidence and self-esteem; develop leadership skills; improve communication skills; raise issues and discuss issues; and learn to be more aware of them. This awareness includes their behaviour, productivity at work, abilities to communicate and abilities to lead; learn about their rights by: expressing their likes and dislikes, making complaints when bullied or upset, and negotiating with person in charge; learn to respect one another by taking turns to speak; learn to accept one another's strengths and weaknesses; learn to understand one another by solving conflicts and misunderstandings; learn to ask questions to their peers as well as to the person in authority; and persons with LD can learn to take charge of their own meetings by: setting up the meeting room, decide who to lead, and chair the meetings.

# Conclusions and policy implications

This study presented insightful and detail findings based on a case study method which covered a number of areas of self-advocacy programme of the NGO- United Voice. Due to its lack of statistical analysis, it was difficult to test theories with large participant pools. Time consuming and personal biases increased the tensions in qualitative research approach (Islam et al., 2013; Islam &

Banda, 2011). We faced a number of commune level limitations and challenges such as lack of research knowledge and research orientation, lack of gaining access, cultural barriers, political issues, lack of social trust about the research findings, subjective sensitivity, and non-cooperation from the operating organizations (Islam *et al.*, 2014; Islam & Siti Hajar, 2013). With considering these limitations, we would say that our study presented some contextual findings on the role of self-advocacy towards individual, family and community empowerment. We have seen that the UV took three types of programmes towards self-advocacy e.g., training, income generation programmes, and workshop. The training and workshops were two important areas where UV took different activities for self-advocacy such as disability equality training, leadership training, income generation training, management training, empowerment training, short and long-term workshop, etc. This package helped LDs in learning to speaking up, public awareness, employment generation, social gathering and outings, networking, and interacting with other young people.

To consider the overall comments from three types of stakeholders, we could realise that still both GO and NGOs are not much aware about the importance of advocacy programme in Malaysia. The literature review makes clear that the progress of self-advocacy in Malaysia is slow and limited. Even many persons with LD are not fully understood about the concept of 'self-advocacy'. The factors include lack of awareness, lack of GO-NGO support, faulty structure of self-advocacy groups, lack of socio-economic background and family support, intellectual inhibition, negative public attitude, and lack of national policies. The lack of government initiatives, lack of financial support, shortages of qualified staff members, and staff turn-over were frequently mentioned by all stakeholders in our study. Due to financial shortage, UV could not take any long-term activities such as training, motivation and campaigning, self-employment projects, etc. The low salary of the staff members was one of the principal barriers to recruit a qualified staff member for counselling, advocacy, training, and so on.

The finding of this study has significant policy implications in both Malaysia and South East Asian countries. The important reality is to consider advocacy as an important intervention for the LD person's empowerment at their individual, family and community levels. Indeed, there is not much research conducted on LD in South East Asia and the role of advocacy is still unknown to the policy makers and academicians. As we mentioned earlier that like many other Asian countries, the disability issue in Malaysia is a highly prioritized policy concern at both global and international levels, though the concept 'disability' remained as one of the most neglected and forgotten development agenda by both the State and the non-state actors (Islam, 2015). The government should take further consideration for modifying existing laws, action plans, and disability related policies. The most important issue is to give more power and opportunity to the NGOs who

can play significant role like other Asian countries especially on the advocacy issue where grassroots level movement is crucial.

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