

## The Disabled and Their Organizations – The Emergence of New Paradigms

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Given Vietnam's wartorn history, the disabled form a sizeable community. Organized treatment of the disabled was largely in state hands until the 1980s when political reforms enabled a bigger, more proactive role for citizens to organize their own affairs. Part of this self-organization meant contact and interaction with the outside world and the input of foreign ideas and financial resources that in turn challenged the old state-dominant policy, both in terms of assumptions and in practice. In effect, there have been paradigm shifts in governance where the management of the disabled is concerned. This study looks at one such organization that grew up in a time of paradigm shifts. The details provided describe the dynamics of how NGO relate to the state.

This paper is a study on the situation of disabled people in Vietnam that goes beyond statistics on various kinds of disabilities and their health- or rehabilitation-related aspects. Some developments in the disability scene over the past two years justify the author's choice of the present subject for discussion in the context of governance. The point of departure has been the author's first-hand knowledge of a self-help group of disabled people in Hoi An, Central Vietnam, acquired during his stay there between December 1999 and July 2000. Another starting point was the author's friendship with the group's leading member, Le Nguyen Binh, and the latter's involvement with a website created for the Disability Forum, a group of foreign NGOs focusing on people with disabilities in Vietnam. Beyond this, the data is based on on-line resources and e-mail communication. The interviews targeting the Hoi An group, conducted largely by e-mail, followed the ethnographic method of M.H. Agar (Agar 1980). Most documents and data were collected from February through October 2001, without any opportunity for fieldwork. Some of the conclusions in this chapter were checked on the ground during the author's brief visit to Hanoi in December 2001.

### Background

More than three decades of war in the latter half of the 20th century have produced a high rate of war disabilities in Vietnam, including long-term indirect effects after the war caused by land mines, unexploded ordnance and chemicals such as Agent Orange. When the U.S. war ended in 1975, 3 million Vietnamese had been killed and 4.4 million wounded (VNA 5 July 2001). A 1995/ 1996 estimate by Ministry of Health officials puts the total number of people with disabilities (PWDs) in Vietnam between 3.5 and 5 million, or 4 to 7 per cent of the population, with approximately 30 per cent of the total due to war-related injuries." The latest official estimate puts the number of disabled persons at "over 5 million". This number may still not include all disabled people as according to the estimate of the World Health Organization during the International Year of Disabled Persons (1981) the average number of disabled people in any country was as high as 10 per cent of the population. For Vietnam, this would mean some 7.8 million persons. Based on a thorough analysis of all available statistical data from Vietnamese Government as well as foreign NGO sources, a document known as the Kane Report (Kane 1999) stated in 1999 that "the range of estimates cited for the overall prevalence of disabilities in Vietnam is still quite broad (2–10 percent, but most likely 5–7 percent)".

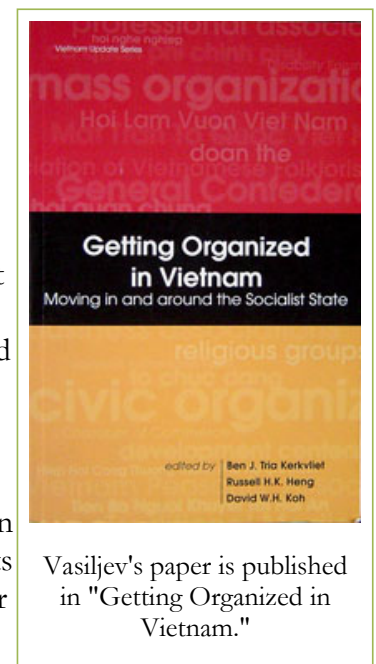
The same imprecision is found in the data on war-related disabilities. According to a survey carried out by MOLISA (Ministry of Labour, War Invalids and Social Affairs) in 1994-95 (Ho Nhu Hai, 1997), war-related disabilities accounted for 19.1 per cent of the total number of disabilities. This stands in contrast to the 30 per cent estimate given by the Ministry of Health, as quoted above. In this case one can assume that, on top of all other possible reasons for statistical discrepancies (e.g., inadequate resources to collect statistics), the gap here is due to a possible difference of criteria used by MOLISA and the Ministry of Health as to what constitute war-related disabilities. Post-war landmine and unexploded ordnance related injuries may not have been included in the MOLISA statistics.

The statistical confusion suggests that the state does not seem very well informed about what must be a major social welfare problem arising from the country's war-torn history. Hence it is difficult to have a reliable understanding of the magnitude of the disability problem. On that count, governance is lacking.

In order to understand the PWD discourse in Vietnam, it is necessary to describe briefly the broad social and economic context in which PWD issues usually overlap with other social problems. These issues, especially with regard to matters of policies, funding or press coverage, are in most cases part of the problems that pertain to larger social groups. Due to this, it is often very difficult to discern people with disabilities from larger social groups in the public discourse.

The situation of war invalids (*thuong binh*) and soldiers with poor health (*benh binh*) is often discussed in the context of preferential treatment reserved for the following groups of people: revolutionary activists, resistance fighters, families of fallen combatants, Heroic Mothers (an honorific conferred on those women who lost all or some of their children in battle) and other "persons who have earned merit for the cause of revolution". All these are usually referred to as people or families "benefiting from priority policy", or in political and journalistic jargon as "policy families" (*cac gia dinh chinh sach*). Identified victims of dioxin poisoning also fall into this category, but post-war landmine and unexploded ordnance victims are not included.

The term *thuong binh* does not include disabled soldiers of the pro-American southern Republic of Vietnam regime. This



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politicized definition means "wounded soldiers who fought for our country." Given this political subtext, in Vietnam, it is necessary to understand the term "war invalids" separately from the term "all individuals disabled because of war". The latter must include, on the one hand, post-war landmines and unexploded ordnance victims and on the other hand, disabled Vietnamese soldiers who fought on the war-time enemy (ARVN) side. All these people can comfortably fit into the category of "disabled people" (ngươi tàn tật), a comparatively new term apparently brought into the public discourse in the late 1970th. Technically speaking, the 1998 Ordinance on Disabled People may cover the veterans of the old southern regime since the act did not specifically discriminate against any group of people.

Another social category in which the disabled are often included, especially when it comes to the distribution of charity funds, are poor people and "other people in difficult" or "very difficult" situation. These comprise old people with no family to support them, orphans, abandoned children, and street children, who sometimes happen to be disabled or sick, or HIV-infected.

### State Policy

Equal rights of disabled people in Vietnam have, in principle, been guaranteed by the Constitutions of 1959, 1980 and 1992. The 1959 Constitution guaranteed citizens basic human rights including the right to employment (Art. 30) and education (Art. 33) and disabled people were covered by this general provision without being specifically mentioned (Constitution, 1960). This is also true for the 1980 Constitution (Art. 53 and Art. 55, respectively), except that government care of orphans, solitary old people, the disabled and other "victims of war and colonialism" was specifically stipulated in Article 68 (Hien phap 1978). However, the implementation of such rights in general, not only with regard to the disabled, depended, and still does, on the capacity of the country's economy.

Nevertheless, it was not before the 1990s that a legal framework detailing specific rights of the disabled was gradually put in place. First it was the Labour Act, adopted by the National Assembly on 23 June 1994, that stipulated detailed provisions for employment of people with disabilities. Then the "Ordinance on Disabled Persons" was adopted by the Standing Committee of the National Assembly on 30 July 1998. It was followed by the Government Decree Detailing the Implementation of a Number of Articles of the Ordinance on the Disabled. The Architectural Barriers Act of Vietnam was prepared in 1998.

These laws represent a long process of increasing awareness within the Vietnamese government of the specific problems of PWDs, a process which began in 1982 when it created a Committee for International Relations of Vietnam's Disabled to take part in the activities of the United Nations International Year of the Disabled. In 1992, the Government committed itself to the Joint Declaration of Countries in the Asia-Pacific Region on Full and Equal Inclusion of People with Disabilities (On Tuan Bao 2001).

However, the main impetus for more specific legislation must have come from within the Vietnamese society as a result of dramatic changes in the transition from a state-controlled economy based on egalitarian distribution to a more laissez faire market model.

Prior to the 1998 Ordinance on Disabled people, only war invalids and soldiers disabled by disease were covered by a specific piece of legislation, the Ordinance on Preferential Treatment of Revolutionary Activists, Fallen Heroes and Families of Fallen Heroes, War Invalids, Diseased Soldiers, Activists in the Wars of Resistance and Persons with Meritorious Activities in Assisting the Revolution. The author was unable to find the date when this Ordinance was passed. The earliest reference to this preferential treatment was found in the draft text of the second Constitution, published in February 1978 (Art. 69). The same article stipulated also that war invalids should be assisted in recovering their ability for normal life (Hien phap 1978). As will be seen below, some practical measures and institutions aimed at such assistance came into being during the 1960s and early 1970s.

Although the war invalids policy covers less than 20 per cent of PWDs (about 1 million persons), it is a convenient starting point for the discussion of several issues related to state policies on disabilities as well as to the socio-economic changes that have created a new environment for the disabled, including war invalids.

First of all, only a small number of war invalids were so severely disabled that they could not work and had to be taken care of in state-run full-time care centers, such as the one in Thuan Thanh, Bac Ninh Province, established in 1965, that caters to nearly 1,000 war invalids nationwide. The more pressing need was to create jobs for those who were able and wanted to work. The best known of state-owned enterprises for war invalids seems to be the July 27 Garment Company, established in 1974 by the Department of Labour, War Invalids and Social Affairs (DOLISA) of Ha Nam Province. It is reported to have created 261 stable jobs for war invalids. Some war invalids went to high schools and universities and have become teachers or other kinds of professionals.

This experience of state officials in Vietnam, especially the staff of MOLISA, with job creation for, and inclusion of, disabled servicemen must have made them rather receptive to some of the modern trends in the world disability movement as they felt that in some ways they were ahead of the times and had experience of their own to offer. These modern trends were brought to Vietnam by the United Nations and later, by foreign NGOs. Many of these NGOs were from the United States, the centre of the Disability Rights movement, that was spearheaded by disabled Vietnam War veterans. (Sandhu, n.d.).

Most war invalids in Vietnam stayed with their families, often doing odd jobs and receiving a special allowance from the authorities. Their income did not differ much from the wages earned in the egalitarian but generally poor society prior to the 1980s. However, the advent of market forces in the 1980s and the party's doi moi policy, which endorsed market reforms in 1986, brought serious strains and cracks to this society. Market prices soared, in general, ten times higher than the state-subsidized fixed prices of merchandise in the state-owned shops, and so did prices in the as yet limited free labour market. A puzzled receptionist in a state-owned hotel told me in the summer of 1985 that her one-legged husband earned ten times more with his night-time job of looking after bicycles parked on the pavement of a private coffee shop than she did doing her full day job. In no time, most government institutions organized market-oriented production activities outside working hours, totally unrelated to their day-time official duties. This was to enable their staff to survive in the new economic environment. War invalids and revolutionary activists relying on state financial assistance were also on the losing end of this growing socio-economic disparity. From the point of view of governance, this society in transition was an incredible mess although there is no denying that market reforms were needed.

The official budget to disburse aid under the preferential treatment ordinance is 3,000 billion VND (or US\$214.3 million) a year. This is unlikely to give recipients a decent allowance for self-sustenance. The following figures illustrate the financial plight of the seriously disabled. Under the Ordinance on Disabled Persons and related by-laws, the seriously disabled are entitled to government and public support. There are some 1.5 million seriously disabled. The seriously disabled who do not have any income and no alternative means of support are entitled to a monthly government allowance of 45,000 VND [US\$3], if they are staying within the village or ward community; 100,000 VND [US\$7] if they are inmates of a government-



run welfare facility, or 155,000 VND [US\$10] in case of serious mental patients requiring full-time institutional care (On Tuan Bao 2001). Such government allowances are not in keeping with market reality. In the labour market, a low income employee at a workshop in Hoi An is expected to earn no less than 200,000 VND [US\$13] a month. Although seriously disabled people are also entitled to discounts for education, health and rehabilitation expenses and some other benefits, government allowances alone are not sufficient for basic living costs.

Inadequate state welfare is a source of discontent for the revolutionary activists including war invalids who have given the better part of their lives to fighting for the country. It is politically dangerous for the ruling Vietnam Communist Party to so alienate its traditional supporters. One party response to this problem is along habitual lines. It relies on mass mobilization activities organized by the Vietnam Fatherland Front to raise morale. These take the form of “gratitude activities” (den on dap nghia) that seem to have increased in recent years. A Gratitude Fund was established in April 1999, that garnered 134 billion VND (US\$9.6 million) of contributions from individuals and organizations in 2000. Nevertheless, this amount added just 4.5 per cent to the government's annual budget for preferential treatment policies. “Gratitude activities” are also funded from local budgets. This includes the building of “gratitude houses” (nha tinh nghia), “gratitude gardens and gratitude ponds” (vuon cay, ao ca tinh nghia), “gratitude wells” (gieng nuoc tinh nghia), all essential parts of a rural household.

The main emphasis in the government policy of helping “policy families” at present is on promoting the recipients' own efforts in production and business. This is very much a feature of charity programmes of established Fatherland Front organizations such as the Trade Union and the Women's Union when they contribute to the welfare of PWDs. Their contribution is important, but necessarily limited. In a recent gathering with representatives of communes and wards that have a good record of working with war invalids and priority policy beneficiaries, the speakers (who included the Deputy Prime Minister Nguyen Tan Dung and the Minister of MOLISA Nguyen Thi Hang), repeatedly referred to successful families of fallen combatants or to individual war invalids as “outstanding examples of people who surmounted difficulties and affirmed themselves to become excellent producers or businessmen/businesswomen under the market system and bettered their life” (Minister Nguyen Thi Hang). Another example of this self-help emphasis is the many programmes of the Vietnam Women's Union - a member of the Vietnam Fatherland Front - that are aimed at helping “poor families, families of war invalids and fallen combatants, families in difficult situations and [preferential] policy families to develop their family economy in order to add to the quality of their lives”. MOLISA runs two vocational schools for disabled youth in the north and the south who can and want to work but have no skills to earn money. Vocational School number I in Son Tay (Ha Tay Province) trains students in one of the following jobs: repair of consumer electronic or electrical appliances, industrial electrical equipment, cars and motorcycles, as well as plumbing, welding, dress making and using computers, besides general education subjects, including basic English. Most of the graduates end up self-employed, as finding a job is difficult.

Nevertheless, state efforts at promoting self-help are far from adequate. The two MOLISA vocational schools can take only a few hundred students, which is only a small fraction of disabled young people. Central Vietnam has only small private training centres. On the national scale, according to MOLISA surveys, 97.64 per cent of PWDs are unskilled. The rest who have some form of training are: 1.22 per cent from vocational schools, 0.53 per cent from technical high schools, and 0.61 per cent from college or university. Unemployment among the disabled who are able and willing to work is 30.43 per cent (On Tuan Bao 2001).

These figures point to a need for more action not only by the state but also by non-state actors wanting to help the disabled. As part of its doi moi policy, Vietnam is opening its doors to foreign NGOs as well as allowing the growth of domestic NGOs ( see chapter 6). This development has seen significant changes in the policy on PWDs. In a nutshell, the thinking on PWD welfare has experienced a paradigm shift. But these changes are not only confined to the nuts and bolts of how to improve the lot of the PWDs. Embedded in them are larger milestones of social and political changes that tell of the shifting dynamics of state-civil society relations. This raises some pertinent questions. For example, in a society that has habitually been wary of any free association of its citizens, how does the state respond to the emergence of NGOs, both foreign and domestic? How effective have these NGOs been? To excavate these issues, what follow are two case studies: one of a domestic group and its self-help philosophy and the other of a foreign-initiated forum for NGOs working on disabled welfare.

### **Progress of Disabled People of Hoi An Group**

This case study provides an example that may be contrary to a popular view that has highlighted the difficulty of organizing representation for personal interests in a one-party dominated authoritarian polity like Vietnam. The literature on civil society in Vietnam tends to focus on the issue of whether NGOs enjoy a meaningful level of independence from the state. Linked to that issue of independence is the question of whether an NGO in Vietnam can function effectively if it is subject to state control or patronage (Nguyen Ngoc Giao 1995, p. 16; Nguyen Ngoc Truong 1994, and Tran Thi Lanh 1994). That debate has not been settled yet and this study shows how an individual quite effectively organized a group of disabled people to look after their own interest within an environment where the state has not adequately provided for the disabled. Such an NGO has to work within the parameters of the Vietnamese system, negotiating issues like registration, access to information, networking with foreign organizations and the support of officialdom. In describing the growth of this organization for the disabled, this article hopes to shed some light on the possible space for NGO activities in Vietnam.

Progress of Disabled People of Hoi An (Tien Bo Nguoi Khuyet Tat Hoi An) is based in Hoi An. Hoi An with its 79,000 population is an old town in Central Vietnam that is popular with foreign backpackers. The tourist traffic generates a high demand for Internet facilities, which in turn raises locals' awareness about the English language and computer usage. Mr. Le Nguyen Binh, 37, the author's key respondent, was born in North Vietnam. His parents were both teachers and the family was much respected for their moral integrity in Hoi An, where they settled and taught upon their demobilization from the army after 1975. In 1979, at the age of 15, Binh became victim of a medical accident that left his lower body paralyzed. For the next three years, he was hospitalized. This involved much mental suffering, doubts about the meaning of human existence, and despair. At the hospital, he observed with compassion the suffering of many victims of landmines and unexploded ordnance, particularly numerous in Central Vietnam in those years. This, together with his family upbringing, his independent spirit and efforts to find answers about the meaning of life in books, gave Binh a new purpose in life. “The answer came to me as a deliverance – as something I felt was compelling me to live for, to overcome my unfortunate destiny. I hoped to do something for people who were struck with the same misfortune as myself and to find new joy in my life.”

The next challenge was how to be more independent of a loving family who had taken care of everything and thus excluded him from social life. He rebelled and in 1983 went alone for a one-year tour of eight provinces in Central and South Vietnam, including several months in Ho Chi Minh City, equipped only with his identity card, a file with his medical history and addresses of his parents' friends and relatives. Through this experience he forged new relationships and discovered the meaning and importance of “integration” or “inclusion” (hoa nhap) for disabled people to become full members of society.

After this self-discovery trip, Binh took evening classes to further his education, while during the day he made a living by raising and selling goldfish. He graduated from a two-year general education course and a three-year English course. He also took two six-month courses in computing in Da Nang City. With his knowledge of English and access to the Internet, he acquired tools for life-long learning, making up for his lack of formal higher education. He firmly believes that life-long learning is an absolute necessity especially for people with disabilities.

Through his efforts Binh created a niche for himself. In 1997, he opened an IT training centre called Tien Bo (Progress) in his mother's house. By 2000, he was teaching as many as 70 students at a time, some of whom became his assistants. In September 1999 he married Quyên, his former student, who became his closest associate in his endeavours. Through personal experience, Binh demonstrated that the more educated and skilled disabled people are, the more self-confidence they have and the better their chances to create job opportunities by and for themselves. This is important in towns like Hoi An where job opportunities are limited even for young people in good health.

In 1987, together with some other enthusiasts in the local branch of the youth union, Binh started teaching groups of orphans and disabled children in the Orphans Camp of Hoi An. In 1988 an informal group, Compassion (Tinh thuong), evolved from these activities. At first, it consisted mostly of non-impaired people. Gradually, more young people with disabilities joined, organized outings and excursions, and increasingly felt that they needed an organized group to solve some common problems such as vocational training and job acquisition.

In 1998 they established themselves as a self-help group for PWDs and changed the name of the group to Progress of Disabled People of Hoi An (PDP of Hoi An), echoing the name of Binh's company. The idea was to link PWDs with their peers in order that they could help each other and share experiences to improve their living and working conditions. They also set out to promote more understanding within society for the creation of accessible environment for PWDs. In 2000 the group had 15 members, most of them young. Only one member of the group is a war invalid, entitled to priority treatment. The rest are children of local craftsmen, businessmen and farmers.

Between 1998 and 2000, PDP acquired 14 wheelchairs, which they distributed to disabled people in the Hoi An area. supplied by an Overseas Vietnamese charity, the Social Assistance Program for Vietnam (SAP-VN), a non-profit NGO in California. Contributions by Overseas Vietnamese charities along with other foreign NGOs through various channels (mostly Fatherland Front organizations, or local administration bodies) have been encouraged by the Vietnamese government since the 1990s. SAP-VN has been targeting disabled people in Central Vietnam.

An impetus for a higher level of activity came in March 2000 during Le Nguyen Binh's interview for the job of Project Coordinator of the Disability Forum. The latter is an informal grouping of foreign NGOs. Though Binh did not get the job, he offered his skills to create a website for this group. The website was launched on 12 September 2000.

A Workshop on Employment for the Disabled was jointly organized in Da Nang by MOLISA and an American NGO, the Office of Disability Technical Assistance (ODTA) of the Vietnam Assistance for the Handicapped (VNAH). The workshop was supported financially by another American NGO, the Health Volunteers Overseas (HVO). Binh was invited as representative of the PDP group, along with representatives of other PWD groups from Hanoi, Ho Chi Minh City, Da Nang and two other provinces. The workshop concluded with a number of policy recommendations, which included views expressed by the various groups of PWD. In one of the PDP proposals for government agencies, Binh suggested that a larger Internet website should be created in Vietnam to connect all disability-related agencies and services and people with disabilities and their families.

As a spin-off of the Da Nang workshop, the PDP group set out to “provide vocational training courses for PWDs to widen their employment opportunities and create other services that facilitate integration into the community.” Its first such project was a four-month course of applied IT and English for ten disabled young people from Hoi An, funded by HVO. By the end of the course in October 2001, five of the participants had found employment. Two had already been working since March with a monthly wage of 450.000 VND, one in charge of a five-computer Internet centre at a local hotel and another staying with Binh's Tien Bo IT training centre. One participant opened a shop at home, using e-mail and the Internet as a new tool to communicate with distant customers. The parents of the most heavily impaired participant in the class bought her a computer to do typing for customers from home. One young man works in Da Nang for a private IT services business.

But the results went beyond job creation. This was a course for the disabled by the disabled. It gave the participants a feeling of extraordinary accomplishment. They saw, in fact, that computing is an activity that disabled people can do as well as people without handicaps and gained self-confidence. They could also gain community recognition: one of the graduates was elected secretary of a local Youth Union branch, upon graduation. There was a clear feeling that if funding were available, such courses should continue to draw students from the larger region of central Vietnam. However, up to the end of 2001 no such funding was forthcoming.

After the completion of the computer class, the group initiated its second project, which was a shop selling souvenirs produced by the handicapped at their homes and partly at the shop itself. An application for a license was sent to the Hoi An Municipality's Department for Commerce and Tourism on behalf of the PDP and signed by Le Nguyen Binh on 10 March 2001. He wrote: “Statistical data show that there are at least 500 disabled people of working age in Hoi An, most of whom do not have jobs or have no possibility of vocational training;...It is important to create suitable jobs for them and an outlet for selling their products.” The authorities responded promptly, most likely because the project did not involve any controversial use of public space and because of the validity of Binh's case: the license was issued on 20 March.

The shop opened on 9 April in a small private house situated in the town's heritage area. By September 2001 the revenue of this business was sufficient to cover all its operating costs including wages of four PWDs working at the site. The shop has long-term contracts with four PWD workshops from various parts of Vietnam and buys products of dozens of individuals working at home. Neither the IT centre, nor the shop gets any funding from any foreign NGO or individual.

The self-help concept came to Binh and his friends as a real revelation. They had previously no knowledge of such concepts as independent living, community-based rehabilitation, peer support, barrier-free environments, emphasis on abilities rather than disabilities, disabilities created and perpetuated out of prejudice, and some other contemporary ideas about disabilities. With hindsight, Binh understands that his earlier years of anguish were partly caused by the fact that there was little information in Vietnam on how PWDs can deal with their condition. That paucity of information was caused by the long years of the war and its aftermath – the U.S. trade embargo and the mistrust by the Vietnamese government of anything coming from a hostile United States. Overcoming these political hurdles has enabled groups like the PDP of Hoi An to serve as a conduit for ideas that were previously unthinkable. Such changes point to the role an NGO can play in a situation where the state has monopolized the governance of PWDs for a long time.

In actual fact, concepts such as “self-reliance” (tu luc canh sinh), “self-nourishment” (tu tuc) or “self help” (tu luc) are

compatible with the ideological sentiments of the Vietnamese state and have, for decades, dominated the political and economic discourse. However, these concepts had never been applied, perhaps understandably, to the severely disabled (for example, those unable to move without a wheelchair, a relatively new device, in Vietnam).

It took the severely disabled people themselves to realize that “self-help” is the only way to their inclusion into mainstream society, to their “salvation”. (Binh has been usually using the term “self-salvation” (tu cuu), though other similar groups seem to prefer “self-help” (tu luc). This and other associated conceptual inventions of the American and world “disability revolution” (e.g., independent living) were imported into Vietnam and disseminated by governmental and non-governmental channels through UNESCAP and some other United Nations agencies, by foreign (including American) NGOs and by international organizations of disabled people in the 1990s, and increasingly, through the Internet.

Although established national Fatherland Front organizations (especially the Vietnam General Confederation of Labour and the Vietnam Women’s Union) do much for the disabled and other underprivileged people, their focus is on charity, care and support, their contributions are important, but necessarily limited. Full inclusion of the disabled into mainstream society is impossible without their own intense and organized efforts similar to those of the PDP of Hoi An. Such organizations are, however, still a missing link in the system of social organizations in Vietnam. The total membership of active self-help groups associated with the Disability Forum, Vietnam (apart from the established Vietnam Association of the Blind with 261 local branches and 31,895 members nationwide – On Tuan Bao 2001) was 365 persons in 8 groups (5 in Hanoi and 2 in Ho Chi Minh City). However, the majority of people with disabilities, more than 87 per cent, reside in rural areas (Ho Nhu Hai, 1997).

What does the setting up of the PDP of Hoi An tell us about the issue of governance and NGOs? First, there was the issue of registration. PWD self-help groups in big cities like Hanoi and Ho Chi Minh, acquire legal status by accepting the patronage of an existing and recognized organization, thus becoming one of its branches.

An example of such an organization is the Association for Support of Disabled Children and Orphans (Hoi Bao Ho Cac Tre Em Tan Tat va Mo Coi), which has branches in some localities. However, there was no such branch in Hoi An. Hoi An only has a branch of the 1969-constituted National Association of the Blind, which is a member of the Fatherland Front. (On Tuan Bao 2001). But the chairman of that Hoi An association refused, apparently on the grounds that his association charter allowed only for membership of the blind, while PDP members were movement-impaired. Up to the time of writing, PDP has been given no assistance either by Hoi An local government agencies or by the local branch of the Fatherland Front. The probable reason was the limited scope of public activities in the group's initial stages and the fact that the members of the group, though severely disabled, do not fit exactly into target groups of charity as their families are not poor.

Thus the PDP of Hoi An has not formally constituted itself as an association. On the other hand, nobody ever stopped its members from what they were doing. PDP attends nationwide workshops where state officials are present and its credentials were never questioned by central or local authorities. There are a few explanations for this tacit acceptance of an association without bona fide credentials. First, Binh's family background or personal political history provides no a priori reason for the authorities to be suspicious of him. Second, the group evolved around a legally set up business that was providing a useful social service. Proscribing such an entity risks alienating the public. Third, the boundary between “association” and “business” in Vietnam has become rather fuzzy, as there are many businesses run by various associations. Fourth, the launching of PDP came at a time when a vast number of associations were being set up in Vietnam. Similar self-help groups for disabled people had existed in Hanoi and Ho Chi Minh City before PDP. For example, Bright Future, an 18-member group of Hanoi, was constituted in 1988 and received the required patronage of the relevant Association for Support of Disabled Children and Orphans in 1995.

There are indications that central authorities may be re-considering whether the fact of being covered by an “umbrella” organization is that essential for efficient public control. A party official in a private interview with the author pointed out, that the situation on the ground has become quite complicated. An “umbrella” association can now be several times removed. In local parlance, the “umbrella” association has evolved from a hoi me (mother association) status of being the direct overseer of an NGO to becoming a hoi ba (grandmother association) or even hoi cu (great grandmother association) as its “daughter” association becomes an “umbrella” for new associations. According to that same official, there were only three conditions for setting up an association and they were “to have an organizing/preparatory committee, to draw a charter of the association, and to pledge that the organization would not require any state subsidy”. However he added that many associations, after their approval, were not sticking to the last commitment. In the case of NGOs for PWDs, the state does not want to create more hardship for them by obstructing their work. The state, however, is concerned to see that aid money is used properly and not undermine the trust of donor organizations. Taken at face value, this describes a form of minimalist governance to ensure that no financial irregularities occur. However, the official was speaking informally. While his words hold some validity, the rights of NGOs are not sufficiently institutionalized as yet, not least because many people seem not to have an exact knowledge of the boundaries between the permitted and the forbidden.

### **The Disability Forum**

Developments in PWD welfare in the United States and elsewhere and the revolution in thinking about how the disabled can lead independent lives had a definite impact on Vietnamese NGOs like PDP. Hence, it is essential to look at how the state regulates the relationship between foreign and domestic NGOs (For a discussion on the role of international donors, see chapter 7 in this volume). This is the reason for taking a closer look at the Disability Forum.

All foreign NGOs engaged in development or humanitarian assistance activities in Vietnam require permission from its government in the form of “Permit for Operation, Permit for the Establishment of Project Office, or Permit for the Establishment of Representative Office”. To this end, Vietnam has established a Vietnam Union of Friendship Organisations (Hoi lien hiep cac Hoi huu nghi Viet Nam) or VUFO that oversees “issuance, extension, amendment or withdrawal” of the said permits. VUFO has established an agency Committee for Non-Governmental Organization Affairs, usually referred to, in NGO parlance, as PACCOM, which stands for People's Aid Co-ordinating Committee, the name of a past organization replaced by this new Committee for NGO Affairs.

VUFO/PACCOM participates in the evaluation of NGO projects or programmes and advises the government on policies, but the job of monitoring the “implementation of approved aid” lies with the respective ministries, ministerial-level agencies, government departments, people's committees of provinces and centrally managed cities and central bodies of civic organisations in whose jurisdiction the project or programme is conducted.

Partners of the NGOs implementing disabilities-related projects include MOLISA, the Ministry of Health, the Ministry of Education and Training and the individual people's committees of provinces and cities where the assistance projects are implemented. Most of the projects are highly technical in nature, comprising the production and fitting of artificial limbs, improvement of rehabilitation services, training of Vietnamese rehabilitation technicians and medical staff. The funding for



these projects comes both from government and private sources. The main donor behind the American NGOs is USAID's Patrick J. Leahy War Victims Fund (Kane 1999).

This arrangement seems straightforward enough but in reality, the process is compromised by delays and lack of coordination. PACCOM's regulations stipulate that approval for projects will take 30, 60 or 90 days depending on the type of operation yet the approval "can be a time-consuming and difficult process". Foreign donors have also been concerned at the lack of coordination among NGOs working in different parts of the country thus leading to unnecessary replication and wastage. The data collected by the NGOs often differed from each other (Kane 1999). The NGOs themselves and the government are anxious to make sure that projects are sustainable and can multiply. The situation points to a need for better tripartite coordination between the government, NGOs, and foreign donors.

The Disability Forum grew out of this need for better coordination. Initially, the idea was to borrow the Cambodian model of setting up a Disability Action Council but skeptical Vietnamese officials dragged their feet on this. Then Larry Wolfe of Health Volunteers Overseas (HVO) found an unexpected opportunity. At the VUFO – NGO Resource Centre in Hanoi, a facility provided by PACCOM for the numerous UN and other non-governmental organizations to have their meetings, there was a planned, but inactive discussion group called the Disability Forum. Its meetings also involved government departments, mass organizations, professionals and the media, Larry Wolfe used this to invite fellow NGOs, government agencies and groups of PWDs for regular discussions. The idea of the Disability Forum was endorsed, in October 1999, by the Kane Report, with its conclusion that "support should be provided to disseminate and share disability data collected by various ministries and NGOs. The NGO Disability Forum may be able to play a facilitating role in this regard." (Kane 1999).

"I had sometimes the feeling that we were moving slightly off limits," recalled Wolfe. This statement can be understood as meaning that Larry Wolfe's actions, in this case, did not exactly fit the description of the initially approved project of his NGO. However, the discussions answered practical needs, generated by the overall results of assistance projects after several years of their implementation. Subsequent participation of MOLISA (discernible, for example, through the regular presence of high-ranking MOLISA officials at the Disability Forum's nationwide workshops) has shown that the innovation was not only approved by PACCOM but also fully endorsed by its government partner organizations, beginning with MOLISA and the Ministry of Health. The Disability Forum became operational in June 2000 and opened an office in August.

The new Disability Forum set out to "promote co-operation, collaboration and better communications among NGOs, organizations for PWDs and relevant government ministries. The issues addressed by the Forum include rehabilitation and health services, employment, inclusive education, consciousness-raising and barrier-free access to public places. Country-wide workshops are conducted approximately every six months... Smaller meetings are held in Hanoi on an ad hoc basis." The Disability Forum consists of twenty foreign NGOs and eight Vietnamese PWD groups. The primary movers behind the Disability Forum's nationwide workshops on the foreign NGO side have been, apart from HVO, the Vietnam Assistance for the Handicapped (VNAH) through its Office of Disability Technical Assistance (ODTA) and its Director John Lancaster. John Lancaster, former Coordinating Director of the U. S. President's Committee on the Employment of People with Disabilities, is also acting in a consulting role to the government.

The Disability Forum runs a website, which is useful for providing information to PWDs on the Ordinance on Disabled Persons and other legal documents and government policies related to the disabled.

The Disability Forum involves organizations of Vietnamese PWDs for whom it creates for the first time, the opportunity to learn more about the social implications of their condition and about their rights. Moreover, it provides them with a possibility to propose policies to the state that will serve their needs more effectively.

Prior to the Disability Forum taking on this task, the work was done largely by the foreign HVO in the form of workshops to promote the reintegration of PWDs into society. HVO had organized these workshops in conjunction with the Ministry of Health and over a period of time, HVO had shifted the focus from talking about health issues related to PWDs to larger and more politicized topics that involved giving PWDs a greater role in shaping policies that affect them. For instance, a series of workshops starting in March 1998 with one entitled "Workshop on the Rehabilitation and Reintegration of People with Mobility Impairment and other Disabilities", made these recommendations in their final report:

- To include people with disabilities (PWDs) in the decision-making process
- To increase the number of associations for people with disabilities and their family members
- To form a national association of PWD to organize self-help activities and lobby the government on policies that affect PWD; and
- To have a representative of PWD in policy-making government bodies.

Another HVO-sponsored workshop was to respond to the Ordinance on Disabled Persons. As of June 2000, HVO transferred the responsibility for organizing the workshops to the Disability Forum. Thus the Disability Forum became a platform to encourage, step by step, the empowerment of people with disabilities and their effective inclusion into society at all levels.

This consensus between the government and the Disability Forum group of NGOs must be seen in the context of Vietnam's 1992 commitment to the Joint Declaration of Countries in the Asia-Pacific Region on Full and Equal Inclusion of People with Disabilities (On Tuan Bao 2001).

To this end, a National Coordination Committee of Disability (NCCD) was formed in March 2001. It is a Government body based at MOLISA and presided by Dr. Dam Huu Dac, Vice Minister of MOLISA, with Dr. On Tuan Bao, a MOLISA official, serving as Director of its office. These are the same officers who represented MOLISA at a Self-Help Leadership Training Seminar for Disabled Activists in Ho Chi Minh City in August 2001, jointly organized by the Asia – Pacific Regional Council of the Disabled People's International, the NCCD and VNAH-ODTA. A document called "Recommendations Towards Full Participation and Equality of Disabled Persons" was adopted by the participants who expressed "resolve to constitute ourselves into the coordination group of majority of people with disabilities and their supporters" and called the government to "encourage and facilitate the formation of self-help organizations of women and girls, men and boys with disabilities at all levels in order to form a National Coordinating Body".

The latter would be totally different from a government body. It may take time before such an organization emerges, but it seems that developments are moving towards such a goal and are quietly encouraged by MOLISA officials. At least, the NCCD enlisted several disabled activists from the Disability Forum's PWD member associations, such as Bright Future and others, featured them prominently during the December 2001 Hanoi leg of the Campaign to promote the Asian and Pacific Decade of Disabled Persons, and continued to work with them even after the event.

## Conclusion

The experience of the PDP of Hoi An shows that the full inclusion of PWDs into mainstream society is impossible without their own intensive and organized efforts. These can never be fully substituted by the charitable activities of other people and organizations. Thus the new, emerging paradigms, as far as Vietnam's disabled people are concerned, are an emphasis on self-help rather than charity, on action by the disabled rather than for the disabled, and on the equal participation of people with disabilities with the rest of society in all activities and sectors.

However, the scope of the Disability Forum and its activities shows that there are still too few such organizations in Vietnam. Though the Disability Forum has helped these local groups establish contacts with each other, with the government and the foreign NGOs on the national level, they are still far from having set up a solid nationwide network or a national union which they seem to perceive as one of their goals in order to better serve their specific needs. Their associations also tend to be urban-based thus neglecting the majority of PWDs who are found in rural Vietnam. Clearly, it will take many more years of efforts and enormous investment before a system of good governance over millions of Vietnam's people with disabilities and their problems can be achieved.

How do the experiences of the author's two case studies relate to the issue of governance in Vietnam in general? Both the locally-initiated Progress of Disabled People and the foreign-sponsored Disability Forum do not suffer from long-abiding differences with the Vietnamese state to make a working relationship impossible. On the contrary, the working relationship gets better with time and the NGOs enjoy progressively greater space. This is not to say that state-NGO dynamics always run smoothly. The relationship requires initiative and some patience on the part of the NGOs. It is also a complementary relationship. While professing to provide for the welfare of PWDs, existing state institutions lack the resources to do an adequate job. In that sense, governance has its shortcomings and requires the supplementary effort of civic organizations, both foreign and local. In order for these civic organizations to be effective, the state has to be more accommodating of their initiatives. These developments have taken place against a background of the country's political leadership re-examining its old paradigms of governance. It has spawned a climate of reforms within which many sectors of society can also seek out new paradigms of operation. The PWD community is no exception. It has made use of the more open climate of doi moi to engage the outside world, absorb new ideas and lobby for policy improvements. In that sense, NGOs that have spearheaded these changes for PWD welfare have, first, been able to exert themselves in matters of governance and second, contributed to better governance.

## Note

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