

Testimony by:

**Mary Eileen Dolan-Hogrefe
Vice President and Senior Advisor
National Organization on Disability**

**June 4, 2009
House Committee on Foreign Affairs
Subcommittee on Asia, the Pacific and the Global
Environment**

Mr. Chairman, members of the Committee, my name is Mary Eileen Dolan-Hogrefe, and I serve as Vice President and Senior Advisor of the National Organization on Disability – a non-governmental disability organization founded in 1982. I would like to thank you for the invitation to testify at this important and timely hearing. Mr. Chairman, I ask for my full statement to be entered in the record.

The National Organization on Disability (NOD) is one of the longest running cross disability organizations in the country. We focus on the number one issue facing our constituency which is employment and economic self-sufficiency for people with disabilities. We work in partnership with the United States Army to conduct the Army Wounded Warrior Careers Project which serves the most severely wounded Army soldiers in three demonstration sites in the US. Funding for NOD comes from individuals, foundations and corporations, and from time to time from government.

In December 2007 I was named a member of the US –Vietnam Dialogue Group on Agent Orange/Dioxin, a citizen bilateral group addressing two dioxin related humanitarian issues from the Vietnam War – environment and disability. Since that time I have traveled twice to Vietnam. My purpose is to provide insight and information on disability issues.

My statement is based on my two trips to Vietnam – in February 2008 and April 2009 as well as on the myriad of conversations I have had over the past year and a half with experts and others who have worked on this issue far longer than I. In my travels to Vietnam, I have done site visits and met with a number of ngo's and other experts.

The level of commitment within and outside of Vietnam on environmental and landscape issues has been great. The dioxin at DaNang airbase is being contained, and other hotspots identified. The Bill and Melinda Gates Foundation and the Atlantic Philanthropies, along with the Government of Vietnam are funding the development of a \$15 million lab that will be a state of the art scientific facility to test soil for toxins. This all bodes well for cleaning up the environment.

I applaud this focus of resources on environmental concerns, yet as *the* disability person on the US side of the Dialogue Group, I would like to see an increase in attention and commitment to disability issues.

Given the limited resources available at present, there are many worthwhile projects on the ground in Vietnam that are helping to improve the human condition such as those being carried out by Vietnam Veterans of America Foundation, East Meets West Foundation, and Children of Vietnam. These projects follow the principles of Community Based Rehabilitation, which was established in the 1980's by the World Health Organization as the guiding principle that individuals benefit most when care and rehabilitation are conducted within their own communities. These organizations are establishing protocols and procedures for the care of people with disabilities in their own communities and I applaud their efforts, that of their dedicated staff and the funders who are devoting resources.

The human health and disability issues in Vietnam are quite severe. Poverty compounds the problems. Access to health care, transportation, school, employment, isolation are all challenges that people with disabilities face. These are not particular to Vietnam, for they are universal gaps for the disability community all over the world.

Despite the fact that some much needed attention is being directed to the disabilities in Vietnam, I would like to highlight some areas where improvements are urgently needed. I do not do this for purposes of embarrassment but rather to shine a light on the great need for additional resources to improve what is being put in place, and to deepen and strengthen the impact. Furthermore, I am concerned that sustainability for these programs currently under development will be threatened without the following being adequately addressed:

1. On the Ground Assessment and Limits of Community Based Rehabilitation

Well intentioned efforts are being taken by both American and Vietnamese organizations to identify people with disabilities, assess their disability, determine needed therapies and/or interventions, and then carry out those therapies or interventions in home or within the commune environs. However, there is no nationwide application of universal disability assessment standards, and there is a desperate lack of expertise in early detection and intervention for infants and toddlers with disabilities. The efforts now occurring are largely implemented by people with limited to no specialized training be they the commune health workers, or family members.

As for medically assessing disability when assessments are done, it is usually by someone without truly sufficient training. This risks failure to identify non-apparent disabilities, as well as increases the chances of mis-categorization of disabilities.

The other concern is the implementation of therapy plans using the Community Based Rehabilitation (CBR) model. CBR can be appropriate and when applied accurately has many positive effects. However, for CBR to be effective, adequate training must be conducted with adequate supervision. Effective and safe treatment must be the goal. This can occur within CBR and the programs on the ground now can benefit from a strengthening of the cadre of individuals working for these programs.

2. Need for Capacity Building for People with Disabilities and Organizations of and For People with Disabilities

The mantra in the disability community around the world is nothing about us, without us. This needs to be the case in Vietnam, and I encourage the direction of resources toward empowering people with disabilities, and growing their own organizations.

A critical part element to empowering the community is to ensure accurate data collection. Disability survey research is just one of many areas where the US can provide technical assistance.

Opportunities for economic self-sufficiency need to be improved and updated. Vocational training should be expanded to include training for the new industries coming to Vietnam – high tech for instance. People with disabilities should not be relegated to subsistence level trades of years gone by. The business community – investors in Vietnam – both foreign and Vietnamese - should invest in this community. American businesses that invest in Vietnam and employ Vietnamese need to follow the Americans with Disabilities Act especially when it comes to employment and accommodations and put to use the abilities of people with disabilities.

3. Need for Professional Knowledge Exchange and Capacity Building for Medical and Rehabilitation Community

Vietnam needs expertise in disability treatment and rehabilitation. While there have been several visits by US medical professionals to share knowledge and expertise in Vietnam, a comprehensive and coordinated approach is needed.

The disability need far exceeds the supply of medical personnel and other disability related resources. There is a great need for people trained in therapies that help improve the lives of people with disabilities, such as physical, occupational, and speech therapists for instance. Dr. Phuong, the distinguished member of the Dialogue Group on the Vietnamese side, and noted ob-gyn, shared with me her concern for the lack of early detection and intervention specialists in Vietnam. A comprehensive plan is needed for technical support and knowledge exchange. The US can be a great resource and should be.

In the February 2008 Dialogue Group meeting in Hanoi, when I was asked to comment on disability issues in Vietnam, I called for a focus on the following:

1. advocacy and awareness for and by people with disabilities themselves, their families and ngo's
2. improving and/or creating systems of service delivery and case management
3. training medical professionals and paraprofessionals
4. education for people with disabilities
5. improve job training and provide opportunities for a life of economic self-sufficiency
6. need for respite care and long term care facilities
7. alleviate immediate suffering through medical attention

I still believe these points to be critical for Vietnam and encourage attention by all those working on these issues to find ways to devote resources to help people with disabilities and enhance their potential through a multidisciplinary approach to disability.

The disability community is extremely thankful to Senator Leahy who single handedly ensured the two separate appropriations of \$3 million each for Vietnam. Due to the scale of the problem and what should be a non-partisan humanitarian issue, I am surprised there are not more champions.

The US needs to commit resources and expertise to Vietnam to continue resolving the environmental problems caused by Agent Orange, and to help create a disability movement which would improve medical attention, and offer capacity building. And, as we in partnership with the people of Vietnam help resolve war legacy issues, let us show our leadership here at home by resolving Agent Orange legacy issues for our US Vietnam Veterans and their affected family members.

I was involved in the research and writing of the paper by the National Organization on Disability titled: "US Vietnam Veterans and Agent Orange – Understanding the Impact 40 Years Later". It is clear that the US has fallen short in what we should and should have provided to our US Vietnam veterans. And, there is compelling information that many families have also been affected and continue to be affected.

I ask for the NOD paper to be submitted as part of the record.

The paper calls for the following action steps to help US Vietnam veterans and their families affected by Agent Orange and dioxin:

1. Provide outreach to all affected veterans and their families
2. Provide outreach to health practitioners and disability-related service agencies
3. Make available medical care for affected children and grandchildren
4. Have a fresh approach to research including:
 - a. A scientific consensus on unanswered questions related to Agent Orange and dioxin and means of addressing them.
 - b. Broad, well-supported use of existing data for further research — particularly information from the Ranch Hand study and the industrial worker data collected by the National Institute for Occupational Safety and Health.
 - c. Expansion of the Agent Orange Registry into a complete database of affected veterans and their offspring.
 - d. Coordination of Data Across the Whole Spectrum of Veterans Services:

And finally,

5. Provide direct service to veterans and their families, in their communities: which proved its merit and need through the Agent Orange Class Assistance Program in the 1980's and early 1990's

In closing, I wish to thank you again Mr. Chairman and the Committee for its attention to this issue. I thank my fellow members of the Dialogue Group for their partnership and leadership, and the Ford Foundation for convening the Dialogue Group and its commitment to this issue.