



**Disabled Peoples' International Asia Pacific
(DPIAP)**

Report

**The Independent Living Seminar Workshop
for Persons with Disabilities**

**7 – 11 March 2010
Ho Chi Minh City, Vietnam**

By

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Abbreviation

ASEAN	Association of Southeast Asian Nations
CRPD	the Convention on the Rights of Persons with Disabilities
CSOs	Civil Society Organizations
DPI/AP	Disabled Peoples' International Asia-Pacific Region
DOLISA	Department of Labor, Invalids and Social Affairs
DRD	Disability Resource and Development
DS	Down Syndrome
HCMC	Ho Chi Minh City
GOs	Government Organizations
IL	Independent Living
ILC	Independent Living Center
MD	Muscular Dystrophy
NCCD	National Corporation Committee on Disabilities
PA	Personal Assistant
PC	Peer Counseling
PWDs	Persons with Disabilities
SCI	Spinal Cord Injury
TNF	The Nippon Foundation

Contents

Opening remarks and guest speeches	4
Introduction of Lecturers	6
History and Philosophy of IL Center	6
What is Independent Living/Independent Living Center?	7
• Activity Report from Hanoi, Q and A	
Closing remarks	7
Independent Living Workshop	7
Orientation (1) (Purpose of workshop, self-introduction, reminder)	
Concept of Independent Living/ Comments and Q and A on IL Seminar on March 7 th	8
History of activities by PWDs	
• Feedback from participants	11
• Q and A	
What is Independent Living Center? (Philosophy, role, service) / Q and A	13
New & Good/ What is peer-counseling (1) (history/purpose)	13
User centered personal assistance service	13
Different types of disabilities/ What personal assistants need to remember	15
• Feedbacks from participants	
Assistance method (assist of wheelchair)	15
Assistance method (assist of dressing)	16
Independent living program/ Role-playing (1)	16
Role-playing(2)	17
How to make a program/ Good and learned	18
Activities in Thailand	19
• Feedbacks from participants	
Activities in Hanoi/ Role of PWDs	19
Review/ Q and A /Closing Ceremony	20
Annex 1 Program	25
Annex 2 Handouts	28
Annex 3 List of Resource Persons	41

Report of the first Seminar on Independent Living (IL) in Ho Chi Minh City was held on 7th–11th March 2010 at the First Hotel, 18 Hoang Viet Street, Tan Binh District, Ho Chi Minh City, Vietnam. The seminar was organized by Disabled Peoples' International Asia-Pacific Region (DPI/AP) with the support of the Nippon Foundation (TNF).

Monday 7th March 2010 Morning Session

Opening remarks and guest speeches

At the opening remark Mr. Nguyen Xuan Lap, Director of NCCD stated that Vietnam committed to the Convention on the Rights of Persons with Disabilities (CRPD). In order to achieve the ultimate goal of disability development that is full participation and equal opportunity, the government of Vietnam has a new policy on disability to include IL in national policy. This affects the positive attitude of society towards persons with disabilities. He thanked for technical and financial support from DPI/AP and the Nippon Foundation respectively.



Mr. Gong , Vice Director of DOLISA expressed his appreciation to the cooperation between Disability Resource and Development (DRD) and IL Hanoi to empower persons with disabilities to live independently. The national policy to include persons with disabilities in activities at all levels need to be changed. By this way, the visibility of persons with disabilities and their own voices will be increasing more opportunity to join society activities.

The participant at the opening ceremony.

Mr. Shoichi Ohno, Executive Director of the Nippon Foundation, as a sponsor, stated that persons with disabilities are able to be agent of change through IL seminar. In collaboration with DPI/AP, IL Hanoi, DRD, DOLISA and TNF, he additionally insisted the gradual change of the policy on PWDs Program as ILC will be established throughout ASEAN state member. With ASEAN motto “Building Caring and Sharing Society,” Vietnamese government as the chair of ASEAN can take this opportunity to build up a society for all.



Mr. Shoichi Ohno gave his opening speech at IL Seminar in HCMC.



Mr. Tadoshi Kikuchi, Consul-General of Japan gave an opening speech.

Mr. Tadoshi Kikuchi, Consul-General of Japan insisted the continuous relationship between Vietnam and Japan through business investment. IL seminar builds up a new development on disability for Vietnam.

Mr. M. Rajaretnam, Special Advisor on Community building and Outreach of ASEAN referred to the importance of socio-cultural pillar which includes disability issues. Moreover, everyone should learn more ASEAN and ASEAN Socio-cultural pillar. ASEAN charter purposes to enhance the well-being and livelihood of the peoples of ASEAN by providing them with equitable access to opportunities for human development, social welfare and justice; to promote a people-oriented ASEAN in which all sectors. It, therefore, is very important to understand well being, welfare and livelihood that are center of ASEAN. IL is giving an answer to it.



Mr. M. Rajaretnam, Special Advisor on Community building and Outreach of ASEAN gave his interesting speech on the ASEAN IL project.

Through IL seminar, Vietnamese government can take this opportunity to promote a program for all PWDs in ASEAN state members. Five areas of support by strategic partnership between TNF and ASEC office are Leprosy, traditional medicine, maritime safety, human dignity and PWDs promote cooperation with GOs and civil society organizations. He recommended 6 steps to mainstream disability in development policy.

1. Working at regional level.
2. Getting a positive outcome by working together.
3. Coordinating among ASEAN and CSOs at regional and national levels.
4. Learning from other countries' best practices.
5. Setting up ASEAN disability laws or common policy.
6. Taking advantage of ASEAN and TNF to promote disability issues.

Finally he addressed the strong partnership between ASEAN and TNF in order to develop and to promote the right of PWDs and establish ILC in ASEAN within three years.

Introduction of Lecturers, Ms. Vo Thi Hoang Yen

Ms. Vo Thi Hoang Yen, Director of DRD referred to her memory of IL conference in Hawaii twenty years ago. She said with her happiness that there were a lot of persons with disabilities at the seminar today. IL improves the quality of life of people with disabilities and pointed out the outcome of IL concept to persons with severe disabilities as an example of the Japanese experts - Mr. Shoji Nakanishi and Ms. Hiroko Akiyama who are the speakers of the IL seminar in Ho Chi Minh City. Both of them can live independently and work for the world of disability.

History and Philosophy of IL Center, Mr. Shoji Nakanishi

In this session, Mr. Shoji precluded the history of the situations of persons with disabilities in Japan over twenty years ago. Discrimination against persons with disabilities could be seen generally in hospitals and community. He became a person with disability when he was an undergraduate. At that time, there was not any service for persons with severe disabilities. So, he and his friends tried to set up a small group of persons with disabilities who ran services for persons with disabilities. This is a new model of service for persons with disabilities by persons with disabilities.



The local government visited his office and the first ILC in Japan founded by him and his friends became well known. The government supported ILC and expanded ILC throughout the country. He also mentioned his ambition to establish ILC in every ASEAN country.

Mr. Shoji Nakanishi, Chairman of DPI/AP gave an information of ILC to the participants.

Ms. Liu T. Anh Loan, Facilitator of the opening ceremony requested the participants to hold their questions to the afternoon session as for lunch time.

Monday 7th March 2010 Afternoon Session

What is Independent Living/Independent Living Center?, Ms. Hiroko Akiyama

Ms. Hiroko Akiyama gave her personal information to participants. She has muscular dystrophy and became a person with severe disability when she was a student in the university. She was hopeless and her daily activities were relied on her mother. She was afraid that one day when her mother die, she would not be able to live alone. So she would like to have a person who is not her family member to assist her in all kinds of activities. Finally, she received the information about ILC from a personal assistant (PA). She still remembered the first time she met Mr. Shoji Nakanishi at ILC and at this place, she decided to use IL services to live independently and beneficially in the community.

Her life was gradually changed through many services of ILC such as IL program, experienced room, peer counseling (PC), rental house service for PWDs, wheelchair service, etc. Also how to empower persons with disabilities can be done by role play in peer counseling program. All participants could see necessary assistive devices to transfer persons with disabilities from wheelchair to bed by one PA. Experienced room was important for persons with disabilities who would like to live independently.

Her presentation also revealed the life of a person with disabilities on a VDO. He used respirator and wished to rent an apartment room. He came to ILC for ILP training and because of IL concept and ILC services; he can live independently with PA and assistive devices.

Activity Report from Hanoi by Ms. Nguyen Hong Ha

Ms. Nguyen Hong Ha, IL Project Director presented ILC in Hanoi. It was founded in 2009. This project has been running for three years. The main objectives of ILC Hanoi are persons with severe disabilities can live independently and they can have services i.e. PA, PC and ILP.

This ILC has recruited more male PA in Hanoi via media to advertise for the position. Moreover, its activities are broadcasted on television and written in articles. Through many kinds of media, PA are proud of their career.

There was a presentation about the life of a person with severe disabilities who once could not leave home and depended on his family members. Because of IL services, he is now a manager of a newspaper whose PA are students assisting him in writing articles.

Q and A

There was an interesting question about the service of the ILC serving cross disability. Ms. Nguyen Hong Ha, responded that ILC provided services for all kinds of disabilities and she requested Mr. Shoji Nakanishi to explain in details.

Closing remarks, Ms. Vo Thi Hoang Yen

Ms. Vo Thi Hoang Yen, Director of DRD gladly recited at the closing remarks that she was confident that the knowledge of IL can change the lives of persons with disabilities in Vietnam. This is a new pace of development on disability that the government of Vietnam has better to design the national policy for all walks of life. Persons with severe disabilities in communities will be mainstreamed by ILC. She hopes to see increasing network of government organizations and organizations of persons with disabilities in order to reach the quality of life for all.

Tuesday 8th March 2010 Morning Session
Independent Living Workshop
Orientation (1) (Purpose of workshop, self-introduction, reminder), Mr. Shoji Nakanishi



Mr. Shoji Nakanishi and Ms. Hiroko Akiyama were in the IL workshop.

Mr. Shoji Nakanishi welcomed the participants, told them the objective of IL workshop and the situation of Vietnamese persons with disabilities. They are kept in their families and cannot join social activities because of the lack of accessibility and the social attitude. The benefit of IL workshop will change the lives of persons with disabilities of the next generation in Vietnam. After that he asked other speakers and participants to introduce themselves. The participants expected to learn about IL, to be employed and to further their education. Some would like to participate in activities of persons with disabilities. One is a blind man who is conducting a research on disability and works for DRD. Another would like to be a peer counselor and to utilize the knowledge to help their friends who are persons with disabilities. The team of experts from Hanoi introduced themselves, following by the team of experts from Thailand. Before break, Loan, IL workshop coordinator announced the 83rd anniversary of the international day of women and gave away some presents to female participants.

Concept of Independent Living/ Comments and Q and A on IL Seminar on March 7th, Ms. Hiroko Akiyama

Ms. Hiroko Akiyama asked the participant's opinions about IL. Her question is "What is the meaning of IL?" and she asked each participant to answer the question.

1. Mr. Tran Quang Bach, Youth Club for People with Disabilities, gave his opinion to the workshop about decision making by persons with disabilities being the main concept.
2. Mr. Ha Van Than, Spinal Cord Unit, would like to bring IL knowledge to enhance the potential of persons with disabilities in the hospital.
3. Ms. Nguyen Thi Xuan Thao, Disabled Youth Association, said that IL means persons with disabilities can make decisions by their own. It doesn't mean that persons with disabilities are separated from the society. PA can help persons with disabilities doing many activities. The situation of persons with disabilities in Vietnam is worse than Japan and Thailand. Persons with disabilities should be agent of change.
4. Ms. Ung Thi Phat Loi, Disabled Youth Association, expressed that PA service is a new and good thing. She faces environmental barriers and asks for help from her brother.
5. Ms. Pham Thi My Tien needs PA to assist her. The public transportation in

Ho Chi Minh City should be improved so that persons with disabilities can participate in activities in society.

6. Ms. Ngo Thi Nang, student, hopes her dream of ILC establishment would come true.
7. Mr. Le Minh Duy, student, shared her knowledge from the opening ceremony. Firstly, persons with disabilities want to have PA. Secondly, persons with disabilities can have IL skill training. Finally, persons with disabilities can have full participation and equal opportunities.
8. Ms. Tran Thi Dieu Linh, Youth Club for People with Disabilities, revealed that this is the first time for her to know about IL. She has lived with her parents. The Vietnamese society has discrimination against persons with disabilities. Her difficulty is transportation that is not equipped with accessibility.
9. Mr. Tran Vu Hoai Phuong, Youth Club for People with Disabilities, thinks that persons with disabilities can do many things when they have their own equipped rooms.
10. Mr. Le Dan Bach Viet, Nguyen Dinh Chieu School for the Blind, told that he would like to know about IL and apply it in his daily life.
11. Ms. Nguyen Thi Tu, said that she is happy to attend the workshop. Also, she has transportation difficulty.
12. Ms. Lieu Thi Ngoc Hieu, Former of DRD staff, thinks that persons with disabilities can live independently and this will increase their responsibility. Consequently, the IL concept can be included in the movement of social development.
13. Ms. Tran Thi Hong Ngoc, suggested that there should be a meeting of the parents of children with disabilities on IL.

Ms. Hiroko Akiyama said that all participants understand IL. IL does not mean that persons with disabilities can do everything by themselves but they can participate in many activities non-disabled persons can do. She could not answer the question about the percentage of the knowledge of participants about IL. However, she mentioned about the old idea of the lives of persons with disabilities who can live by themselves are those who passed the process of rehabilitation and can earn their lives. IL means that persons with disabilities manage their lives by themselves. People think that persons with severe disabilities cannot make any decision on their lives. She gave an example about the education issue. Persons with disabilities are blamed if they want to go to school or even disabled graduates cannot find jobs. IL is a tool for persons with disabilities to erase social perception on discrimination against persons with disabilities.

There was a question about persons with disabilities who use PA would rely on PA in doing everything or not. Mr. Shoji Nakanishi answered this question by using himself as an example. PA helps him in daily activities before he goes out to work. For persons with severe disabilities, most of their time are spent on routine activities at home and do not have time for others. Because of PA, he can go out to work for persons with disabilities and change the society to be barrier-free. Additionally, Ms. Hiroko Akiyama responded to this question that persons with severe disabilities can design and manage their lives by using PA in each activity. The most significant concept of IL is that the decision makers are the persons with disabilities not PA. She gave her example of giving orders towards PA who just follow them. Persons with disabilities have better

know ordering skills so that PA who follows their orders will not make mistakes. She designs her activities with PA in twenty four hours.



The atmosphere in the IL workshop.

A Vietnamese participant gave his opinion about the meaning of IL.



Tuesday 8th March 2010 Afternoon Session

History of activities by PWD s, Mr. Shoji Nakanishi

Before starting the next topic, Mr. Shoji Nakanishi and Ms. Hiroko Akiyama said about the rules of PA. They insisted that persons without severe disabilities have to learn what they can and cannot do. They should use PA in activities they cannot do.

The time spent on daily activities can be saved by the help of PA. Both speakers think that all participants do not have much experience in using PA so that they do not clearly understand about this. After the explanation of both Japanese experts, one participant gave an opinion about the need of PA for accompanying him to the IL seminar. The other participant told that we use PA only in necessary activities as PA's wages are high.

Mr. Shoji Nakanashi talked about the IL workshop in Japan twenty five years ago. Japanese persons with disabilities had the same perception as the participants in Ho Chi Minh City today. He gave his personal information about his disability. During his early twenty years of age, he had a car accident and people thought that he couldn't do anything. His parents were very old and could not take care of him. He also had two choices. One was to stay in the hospital and the other was to live on his own. He spent his life about one year and a half in the rehabilitation center. He faced poor living condition and could not have any permission to go out. So he decided to live by himself. He had an opportunity to go to meet with government officers and revealed about the living condition of his friends in the rehabilitation center. He wished to see many friends leaving there and enjoy their lives in the society. It took him two years to find a rental house where nobody wanted to live in due to the suicide incident in the house. He had his house renovated and cleaned up. Because of there were many things needed to be done, so he wanted some help. He decided to go to the university to find PA. Then six students took turn to help him with his daily activities. He gave them some food in return. He thought that this would not be possible in Vietnam. He could drive but it took time to get in the car. After the graduation of six students, all of them found permanent jobs so he thought that there should be PA service for persons with disabilities.

Mr. Shoji Nakanashi shared his IL experience to the participants.

At last, he made a meeting with students who would like to be his PA but most of them refuse to get up early in the morning to help him. So he thought of a better way to solve this problem by creating PA service. He thought that this service should not be voluntary works. PA should have salary like other careers. Some persons with disabilities used PA service running by Mr. Shoji Nakanashi, but they could spend small amount to him. At that time the Japanese society could not accept the money from persons with disabilities. So recruiting PA was very difficult because they could work with persons with disabilities and living in the same community and must be willing to receive the money in return. He spent high expenses at the first stage of running his ILC. Not long after that, his ILC became renowned – media, academic persons, government officers came to his ILC. Also, he collected fees from these visitors so at the end, he had more budgets to support IL services.



The government did not want him to continue ILC for the government wanted to run this service. His ILC provided very good services for persons with disabilities and had a lot of customers. He went to the government to negotiate for the budget of PA service. In those days, the government had only the budget for the elderly persons but did not have the budget for persons with disabilities. He concluded the difficult situation when he started ILC. He believed that this will happen in Vietnam and other countries in Asian Pacific as well.

Last year there were twenty persons with disabilities in IL seminar workshop. They were empowered to be IL leaders. There were Korean persons with disabilities who studied about ILC in Japan. Nowadays, over one hundred ILC have been established in Korea. The rights of persons with disabilities must be equally accepted especially persons with disabilities in rural area in Vietnam. There is a tragic incident in Japan about a mother of a child with disability killing her own baby, whereas in Korea, ten persons with disability fell into the train tracks. All of them were killed from this accident. The Korean government did not show any responsibility to their families. Persons with disabilities in Korea and in Asia Pacific protested against Korean government. A long time ago, this similar tragic story happened in Japan also but we have been fighting for the new generation even though some leaders have left the movement of disability.



DPI/AP team observed the workshop.

Feedback from participants

Ms. Hiroko Akiyama asked the participants' opinions.

Ms. Nguyen Thi Xuan Thao gave her feeling about the good understanding of IL concept and history. She hoped that it would take less time in Vietnam to set up ILC than in Japan.

Ms. Shoji Nakanishi added that most of the people in the society think of the financial support for ILC establishment in the first step but the first thing to do is to raise awareness about the lives of persons with disabilities. He thinks that it takes a long time to cultivate society in disability issues. Such as an example of married women with disabilities can now give birth to babies with disabilities as according to their human rights. ILC not only change the live of disabilities but also change the society.

Q and A, Ms. Nguyen Hong Ha

Ms. Nguyen Hong Ha explained about IL to answer some participants who still did not understand clearly. She said that there is the environmental barrier in Vietnam, so that persons with disabilities can not enjoy their lives in all participation. We as a person with disability should have knowledge about ourselves so that we can give information to the government officers. Referring to Mr. Shoji Nakanishi's presentation on PA, she added that PA is a person who supports persons with disabilities in doing activities they cannot do due to their physically limitation. Only accessible environments and PA, we cannot live independently since the society still has discrimination against persons with disabilities. Therefore, raising awareness towards disability issue is a challenge that persons with disabilities must be undertaken.

She addressed the Article 9 under the Convention on the Rights of Persons with Disabilities (CRPD) that persons with disabilities as the citizens of the countries who have the rights to live independently and to be included in the community. Since the government cannot support persons with disabilities, there has been a case of a mother willing to leave her child at ILC. Actually ILC is not the place for persons with disabilities to live in but it supports persons with disabilities to be integrated them in the society. Persons with disabilities can exercise their rights to receive all kinds of services – transportation, infrastructure, accessible environment.

She asked an interesting question to participants about IL and human rights. “If all participants do not enjoy living independently, are they still considered citizens of Vietnam?”

One participant answered her question that persons with disabilities should form up their self-help organizations like ILC to negotiate what they want with the government. At ILC, we provide ILP to empower persons with disabilities about their own rights. We are non-profit organization. In fact, ILC must support and provide services for cross-disability. PA services can enhance their potential. Moreover, they can be advocate to promote and protect their human rights. ILC leaders must be persons with disabilities. ILC members should be fifty one percentages of persons with disabilities. It provides core services such as PA, PC, ILP and advocacy.

She gave more information about core services. PA and PC services serve persons with disabilities individually. ILP is like daily planning and social skill program. There are IL skill training courses. We also need the support from the government in some activities.

She told the participants about the differences between IL and CBR. IL increases persons with disabilities social skills, giving vocational training and building capacity. All IL services are for persons with disabilities by persons with disabilities. CBR services are formed by the government and NGO. CBR services do not include PA service. She ended with her presentation would be shown on March, 11th.

What is Independent Living Center? (Philosophy, role, service) / Q and A, Ms.

Hiroko Akiyama

Ms. Hiroko Akiyama pointed out that ILC is not the living place of persons with disabilities but it is the place for persons with disabilities to increase their skills and knowledge in order that they can live independently. Here, persons with disabilities can join many activities with eagerness. There is no place providing services for persons with disabilities like ILC. She talked about PC that changed persons with disabilities to have self-esteem. In fact, the potential and self-confidence of persons with disabilities still exists in them but the disability conceals this. ILC is the place where persons with disabilities can bring out their potential to develop self confidence, self reliance and self esteem. Moreover, ILC supports persons with disabilities to go out. If there are a lot of persons with disabilities wish to go out into the society, we will see the change of the society especially public transportation. She also gave an example of environmental barrier to persons with disabilities like ten storied building that has no elevator. She compared persons with disabilities to non-disabled persons who wish to go up top. Even non-disabled persons are exhausted to walk up there no matter how strong they are. ILC is the place persons with disabilities can meet their needs in order to change their lives. Before closing this session, Mr. Shoji Nakanishi added that the questions of most participants were clarified by Ms. Hiroko Akiyama.

Wednesday 9th March 2010 Morning Session

New & Good/ What is peer-counseling (1) (history/purpose), Ms. Hiroko Akiyama and Ms. Nguyen Bich Thuy

The Japanese experts conducting this session did not allow participants from Thailand to be participated. There was the other parallel session on PA conducting by Mr. Shoji Nakanishi and two Japanese PA.

User centered personal assistance service, Mr. Shoji Nakanishi

Mr. Shoji Nakanishi gave the definition of PA and his experience in using PA. From his experience, PA should be students and they should have good foreign language skills. He told the participants that when we work in the community, we will learn more about using PA. He asked each student who would like to have PA training to introduce himself. Most of all are studying in the Faculty of Social Work from Opening University. Some used to work as PA for persons with disabilities; however, all of them would like to have PA knowledge and work for persons with disabilities. After that DPI/AP staffs from Thailand introduced themselves.



Mr. Shoji Nakanishi and Vietnamese students in PA workshop.

Mr. Shoji Nakanishi said that there are differences between PA service for persons with disabilities and caregivers for the elderly. By using PA, persons with disabilities can join social activities. Since persons with disabilities can not go out so that they are excluded from the community.

IL concept can support the lives with disabilities so that they can lead their lives with self-confidence. As a good PA, you must follow the order of persons with disabilities.

Since you are students, please do not use your own decisions to accomplish all tasks ordered by persons with disabilities. In order to reach the goal of IL, you must support persons with disabilities in their activities so that they can make decisions by their own. PA is a person who gives opportunities of decision making to persons with disabilities. For example, PA must support persons with disabilities who want to go out their houses even though their parents do not want them to go. In this situation, PA must try hard to persuade their parents to allow persons with disabilities to complete their wishes. There is not PA service in any rehabilitation center. Persons with disabilities in the rehabilitation center are reluctant to ask for help from other persons. Persons with disabilities can use PC service at ILC. This service will bring out their self-confidence. ILC has ILP that requires PA in many activities so that persons with disabilities can learn and practice how to use PA. The language you use may hurt the feelings of persons with disabilities as well as you keep quiet.

In order to be a good PA, you need to be punctual. If you came late, the whole schedule of the persons with disabilities must be changed. Persons with disabilities cannot follow their daily planning because of PA's lack of responsibility. If you know you will come to meet persons with disabilities late, you must contact them urgently.

Mr. Shoji Nakanishi asked all students to attend the workshop of persons with disabilities in another meeting room at First Grill after the break.

After the students met persons with disabilities, they came back to the meeting room and attended another session.

Different types of disabilities/ what personal assistants need to remember,

Ms. Mami Ogino

Ms. Mami Ogino taught all students about three kinds of disabilities. The first one is spinal cord injury (SCI). The second one is Down Syndrome (DS). The last is muscular dystrophy (MD).

1. SCI can be found in persons with severe disabilities who cannot move their bodies since shoulders down. They cannot sense in the parts of the body where are paralyzed. Because of this, they cannot move and cannot sense. So they might be pressure sores. PA must inform them to see doctors to check their skins. Skin diseases can be generally founded because of their paralysis. These persons with disabilities usually ask PA to check up their skins. Moreover, they cannot control both the upper and the lower muscular in the bladder. So they sometimes leak urine automatically. Some persons with disabilities have to use medicine to help them move liquid waste out of their bodies. This kind of persons with disabilities cannot sit in balance.
2. Down Syndrome (DS) is a kind of intellectual disability that can be found in new born babies. There are many levels of this disability. Some can move their bodies while some cannot. Most of them cannot understand what we talk to them. They usually ask questions. Because of their communication difficulty, it takes time for us to understand them. PA must have strong endurance in interaction with them. PA must not ask them questions. However, please ask them what they want. When this kind of persons with disabilities turns forty, they will be physically weak.
3. Muscular Dystrophy (MD) causes muscular weakness until they cannot move their bodies. They cannot do any activity. They need the assistance of PA all the time, so you must inform them before going anywhere. Due to their physically

weakness, they usually catch a cold easily. PA must have good hygiene. PA must have endurance in working for them by following their orders all the time and do not think that they are patients. Please do not treat them as children and direct them to do according to your own decision.

Before she ended, she recited that PA is a person to support persons with disabilities in many activities to live independently. So, PA must understand IL concept that insists the decision making of persons with disabilities by their own. PA must follow orders of persons with disabilities even though these orders are incorrect. For example, a person with disability would like to prepare her meal by the assistance of PA. PA must not give any comment to the taste of her dish. This is her own decision to cook the food whatever way she wants.

She concluded the qualification of PA. Firstly, PA must be punctual. Secondly, PA must not make decisions for persons with disabilities. Thirdly, PA must not reveal the secrets of persons with disabilities to others. Fourthly, PA must be reliable. PA must avoid the issue of religion. Finally, there should be intervals between PA and persons with disabilities.

Feedbacks from participants

The first student asked about the difference between the wages of male and female PA. Ms. Mami Ogino said that there is no difference between the wages even their works are different. No matter how hard you work, you cannot choose your customers.

The second student asked about the relationship between PA and the family members of persons with disabilities. Ms. Mami Ogino answered that it depends on the situation. There should be an interval between PA and persons with disabilities so that PA can work smoothly. However, PA can develop relationship with the family members of persons with disabilities.

Wednesday 9th March 2010 Afternoon Session

Assistance method (assist of wheelchair), Ms. Mami Ogino and Mr. Atsuo Takagi



Mr. Atsuo Takagi, Japanese PA, introduced each part of a wheelchair to Vietnamese students.

Mr. Atsuo Takagi introduced and explained how to use each part of the wheelchair to the students. After that, he invited a student to sit in the wheelchair and asked another student to wheel her. He asked the students to find a partner in order to practice wheeling wheelchair at the steps and the slope in front of the meeting room. He gives more information about how to control wheelchairs. After finishing this session, all students had a break.



Vietnamese students took turn to practice wheeling their friends in the workshop.



A Vietnamese student practiced wheeling her friends outdoor.

Assistance method (assist of dressing), Ms. Mami Ogino and Mr. Atsuo Takagi

Both Japanese PA taught all students how to dress up persons with disabilities in bed and in wheelchairs. He showed the techniques how to move the body of a person with disabilities and how to insert the dress under the body. He gave information about cautions when PA have to transfer a person with disability from the wheelchair. After that they asked all students to practice.

A Vietnamese student practiced dressing her friend on a chair.



Vietnamese students practiced dressing her friends lying on the floor.

Thursday 10th March 2010 Morning Session

Independent living program/ Role-playing (1), Ms. Hiroko Akiyama and Mr. Yoshihiro Mitsuoka

The two Japanese experts asked the participants about New and Good. Each participant shared their New and Good. New and Good is a technique to acknowledge new and good experiences daily. This helps them to enjoy lives and find the value of being persons with disabilities. Ms. Hiroko Akiyama asked the participants, “What is PC?”

ILC gives information to persons with disabilities and they have to make decisions based on correct information. Peer counselors can support persons with disabilities in planning their lives and using services of ILC. Peer counselors are not persons who make decisions for persons with disabilities. They are not teachers. Peer counselors gave choices and persons with disabilities are the ones who select their own choices. ILP consists of two styles. One is individual program provided for meeting the specific need of each person with disabilities. The other is group program. This program is organized for the group with specific topics. Participants can exchange information and encourage each other. Persons with disabilities leaders and sub leaders conduct the program.

ILC provides an experienced room for persons with disabilities under the training of ILP. There are assistive devices and more spaces for persons with disabilities who want to live independently and using PA. Persons with disabilities will recognize what they can do and what they cannot do by using this room. Especially, persons with severe disabilities who use experienced rooms must request PA to practice living independently. For example, some persons with severe disabilities want PA to assist them during sleeping and having meals. ILP helps persons with disabilities to bring about their self-confidence in doing activities. PA supports persons with disabilities to do what they have never done before. PA and PC services are important. We perform a role play to illustrate conflicts' solutions.

Ms. Hiroko Akiyama assigned a participant to be a PA who has a conflict with the family of a person with disability. During the role play, all PA cannot attend this session.

After the role play, there was a question about the duration of PC. "Is it possible to use over one hour for PC?" Ms. Hiroko Akiyama responded that people in general can concentrate on the topic within one hour.

Another question was about equal allocation of time. "What is the importance of equal allocation of time?" Ms. Hiroko Akiyama responded that persons with disabilities lack time of expressing their feelings. Especially persons with disabilities who live with their families cannot reveal their desires to their family.

Thursday 10th March 2010 Afternoon Session

Role-playing (2), Ms. Hiroko Akiyama and Mr. Yoshihiro Mitsuoka



Ms. Hiroko Akiyama and Mr. Yoshihiro Mitsuoka explained the significance of the role play.

Both Japanese experts divided the participants into two groups and each group selected the topic for their own role play. After that each group also selected the persons who will be the characters in the role play. Both groups had one hour to finish the first round. Then the rest of the members in each group gave opinions to the person with disability who cannot solve the problem. Next, persons with disabilities played the second round and had to find the way out for the same problem by their own. This role play benefits persons with disabilities in developing their skills to find the solution. Each role play was conducted in privacy and cannot be written in this report.

How to make a program/ Good and learned, Ms. Hiroko Akiyama and Mr. Yoshihiro Mitsuoka

Ms. Hiroko Akiyama explained how to make a planning of independent living program. Firstly, persons with disabilities have to set a goal in a short time or in a long time but for the participants she suggested setting a goal in a short time. After the participants



Ms. Hiroko Akiyama and Mr. Yoshihiro Mitsuoka taught the participants about planning IL program.

have to set the goals, they make a list of what they have done and what they have not done to achieve the goal.

A participant wanted to change the public transportation to be accessible for persons with disabilities. He tried to make his planning of independent living. However, Ms. Hiroko Akiyama thought that this example is too big for one person with disabilities. She asked him to change the topic but he still insisted to use this one. He explained each step according to the guideline in the handout. Then he could not make it done due to the lack of experiences. By the way, Ms. Nguyen Hong Ha informed him about how to work and negotiate with the local government in order to provide persons with disabilities accessible public transportation.

Ms. Hiroko Akiyama recited that persons with disabilities have to think about what they have done and what they have not done. She asked them to set up priority for each step. After that she explained the question in the handout to the participants and asked them to fill it. Only some can complete their planning of independent living programs. Therefore, Ms. Hiroko Akiyama asked all participants to send the handout to the director of DRD who will pass all papers to her.

Friday 11th March 2010 Morning Session

Activities in Thailand/ Ms. Supattraporn presented on her independent living, Ms. Supattraporn Tanatikom

Ms. Supattraporn Tanatikom gave her personal information before she became a person with severe disabilities. She showed how she lives independently and how she works with an assistive device at the computer. She has involved in IL movement since 2002 and studied PC at Human Care Association in 2003. Next, she told about the history of IL in Thailand, IL pilot project, Thailand Council for Independent Living Centers (TIL).



Ms. Supattraporn Tanatikom, Regional IL project manager, DPI/AP, presented IL movement in Thailand.

The expansion of TIL network during 2006-2009 resulted in 11 self-help groups who joined the IL network in Thailand and took the concept of IL to improve the lives of persons with disabilities. Moreover, twenty organizations in twenty provinces of Thailand have requested to participate in the training of IL concept and observe the IL management. The presentation also addressed the issue of ILC services and the achievement of ILC in Thailand. Additionally, she showed two case studies. One is IL concept that changes the life of a young person with disabilities. Another one is the activity on advocacy of an ILC. She ended her presentation with a VDO about her life and the importance of PA.

Feedbacks from participants

A participant was interested in the computer technology for persons with severe disabilities. She asked about the control system and its function. Ms. Supattaporn Tanatikom explained her mouthpiece and the software to access the information through the internet. Because of this assistive device, she can create her own job and produces to pocket books. Moreover, it assists her to complete Master's.



The participants paid attention on the presentation about IL in Thailand.

Another question from a participant was about her independent living. How she lives by her own decision making such a big surprise for not only persons with disabilities but non-disabled persons. She planned to live by her own since she decided not to rely on her family and asked her friends to find an apartment. Finally, she met her ex-boss at a farewell party. This has been changing her life to be in IL movement.

Activities in Hanoi/ Role of PWDs, Ms. Nguyen Hong Ha, Ms. Hiroko Akiyama

Ms. Nguyen Hong Ha presented the picture of ILC Hanoi. She said about her office that it is small because of a ramp and an elevator. Bright Future is now managing this ILC project. There are two aims. The first one is individual support for persons with disabilities. The second one is advocacy on accessibility in the community. She tried to raise fund from the government projects. It takes time for persons with disabilities to live independently. ILC leaders must be persons with disabilities. Also, ILC must provide services for cross-disability.

She is now the director and Ms. Nguyen Bich Thuy is the manager. ILP services at her center supports persons with disabilities to have more social skills and increase their potential. For information support, her center also has information for persons with severe disabilities. For persons with disabilities, their family thinks that the place for their children with disabilities is their home. Thus, persons with severe disabilities lack participations in community. ILP, PC, PA and advocacy are main core services. At ILC, persons with disabilities can make their planning on ILP, use PA, increase social skills, find conflict solution and negotiate with the government.



Ms. Nguyen Hong Ha, the Director of ILC Hanoi presented the activities of ILC Hanoi.

PA is not volunteers because volunteers do not work as hard as PA. PA is a career which is very important to persons with disabilities. PA coordinator at ILC was trained by Japanese experts to have more education on disability. So, they can create good relationship with persons with disabilities. Besides, they know how to transfer persons with disabilities correctly. There are at present forty three PA. Some work part-time and others work full-time.

ILC Hanoi has good relationship with the media. The media plays a role to help ILC find more PA and disseminate articles of ILC.

A participant asked Ms. Nguyen Hong Ha about the difference between PC by persons with disabilities and PC in general. PC conducted by persons with disabilities, the counselor must not give any suggestion to solve the problem whereas PC conducted non-disabled persons the client is the receiver who follows the suggestions of her counselor. This participant wants to be a counselor but now the ILC does not have any course for training person with severe disabilities.

Ms. Nguyen Bich Thuy added that peer counselor is a career for persons with disabilities and the ILC provides vocational training for persons with disabilities. Ms. Nguyen Hong Ha added that ILC in developed countries receive fund and welfare from the government. In Vietnam, persons with disabilities use resources of the family so they cannot live independently.

Review/ Q and A /Closing Ceremony, Ms. Hiroko Akiyama

Ms. Hiroko Akiyama asked the participants to give their opinions about IL.

Ms. Lieu Thi Ngoc Hieu answered that IL can help persons with disabilities to make decisions on their own issues. There are necessary services for persons with disabilities at ILC.

Ms. Hiroko Akiyama asked the participants, “Why non-disabled persons cannot run ILC for persons with disabilities?” She clarified that services for persons with disabilities at ILC should be conducted by persons with disabilities because we as persons with disabilities know our disabilities and our needs very well. Non-disabled persons do not have disability, so they cannot provide services that are suitable for us. If persons with disabilities in Vietnam start to establish ILC as soon as possible, it will benefit the new generation of persons with disabilities. Like Japan thirty years ago,

persons with disabilities led their lives difficultly. However, some persons with disabilities devoted themselves to improve the lives of persons with disabilities by ILC. It takes time for persons with disabilities in Vietnam to live independently. She gave an example about the seminar here can change the attitude of the hotel staffs because of our visibility; they can serve us according to our needs such as providing ramps and utensils.

Ms. Tran Thi Hong Ngoc said that she has known how to use PA. She hopes that she can live independently. Everyday persons with disabilities should be aware of new and good things. Moreover, she learned about making a planning of IL and rules of PC.

Ms. Ung Thi Phat Loi understood PC for persons with disabilities by persons with disabilities. She knows the difference between PC of ILC and PC in general. Because of this, she has positive view on IL.

Ms. Pham Thi My Tien told that she gained a lot of IL knowledge during the five day seminar. Moreover, this ILP training gave her more self-confidence.

Ms. Nguyen Thi Xuan Thao thinks that persons with disabilities can change the society. Persons with disabilities are able persons. Do not judge them from their disability but look at their capability. Persons with disabilities have equal rights as the non-disabled persons do.

Ms. Ngo Thi Nang believes that persons with disabilities are able to conduct PC. They can freely express their feelings.

Ms. Liu T. Anh Loan learned a lot about IL from the Japanese experts. She used to feel inferior to others but right now she has more confidence.

Ms. Nguyen Thi Tu gained the ILP knowledge from the Japanese experts for the past five days. She will share what she has learned to her friends.

Mr. Tran Quang Bach said that she learned many knowledge of IL and understand her disability. He wanted to thank the Japanese speakers who made his have self confidence.

Ms. Tran Vu Hoai Phuong thinks that role play will give more understanding about persons with severe disabilities. She is aware of persons with severe disabilities living with the family.

Ms. Tran Thi Dieu Linh understands PC clearly and appreciates the Japanese experts for helping persons with disabilities in Ho Chi Minh City.

Mr. Ha Van Than felt that he was lucky to attend this seminar. He received IL knowledge from Thailand and Japan. Besides, he believes that it is not difficult to set up an ILC in Ho Chi Minh City.

Mr. Le Minh Duy said thanks the Japanese, Thai and Hanoi team.

Ms. Nguyen Hong Ha thanked all participants. She said further that the participants in Ho Chi Minh City are younger than those in Hanoi.

Ms. Nguyen Bich Thuy said that all participants are very active and the questions they asked are the same questions as the participants last year. She believes that participants in Ho Chi Minh City would have more opportunity to exchange experiences with her. We do not know the future. However, she believes that ILC might be formed up in many places in Vietnam.

Ms. Saowalak Thongkuay said she was happy to see different situations of persons with disabilities in Hanoi and in Ho Chi Minh City. Even though the participants in Ho Chi Minh City are younger than those in Hanoi, she believes that the participants can learn about IL quickly. Since the first day till today, the participants understand IL very well because you are open-minded to new things. She also learned about disabilities in Ho Chi Minh City and hopes to see another ILC in Ho Chi Minh City that provides services for persons with disabilities. She also thanked the Japanese experts and took this floor to announce that ASEAN wants to expand ILC in ten country members. The best practices in ASEAN will be role models as same as the Japanese experts who help many countries in Asia and the Pacific to establish ILC. She thanked again for all and hopes to have a good collaboration in the future. She also prepared ASEAN bags for all participants.

Mr. Paradorn Kumpsab said that he understands different kinds of disability and the situations of persons with disabilities in Vietnam. He exchanged his IL with all participants and the knowledge gained from this seminar will help him in other IL seminar workshop.

Ms. Supattraporn Tanatikom said about the roles of givers and receivers in five-day activities. The Japanese experts used to be the receivers from many Japanese leaders of the IL movement. Now, they become the givers for ILC establishment in Asia and the Pacific. The participants repeat their history as the receivers before being the givers finally.

Mr. Yoshihiro Mitsuoka said that he sees the endurance of the participants. When persons with disabilities firstly fought for something, they must face many barriers. The endurance is the strong point of persons with disabilities. He insisted his commitment to devote himself for IL movement in Vietnam.

Ms. Hiroko Akiyama said that the participants would like to fight for IL movement. It is quite new in Vietnam. Japan is a developed country where persons with disabilities can live independently. However, persons with disabilities around the world would like to help each other.

Before the end of this session, there was a certification ceremony. Then all of participants and experts took a group photo.



Ms. Saowalak Thongkuay, DPI/AP Regional Development Officer, Ms. Hiroko Akiyama and Mr. Yoshihiro Mitsuoka at the certification ceremony.



Japanese, Thai and Vietnamese team and all participants took a group photo at the closing ceremony of IL workshop.

Annex 1-Program

Agenda of Independent Living Seminar in HCMC

March-10

		Independent Living Seminar		
3/7	Sun		Venue: First Hotel, Hoa Su I (Ground Floor) 18 Hoang Viet, Tan Binh District, Ho Chi Minh City Tel: (848)-3844-1199/1175/1167 Fax: (848)-3844-4282	
		8:30-9:00	Reception	
		9:00-9:40	Opening remarks and guest speeches List of expected speakers: Mr. Nguyen Xuan Lap (Director of NCCD) Mr. Gong (Vice-Director of DOLISA) Mr. Shuichi Ono (Executive Director of the Nippon Foundation) Guest from Consulate-General of Japan	
		9:40-9:50	Introduction of Lecturers	Vo Thi Hoang Yen
		9:50-10:50	Lecture (1): History and Philosophy of IL Center	Nakanishi, Shoji
		10:50-11:20	Tea Break	
		11:20-12:30	Lecture (2): What is Independent Living/Independent Living Center?	Akiyama, Hiroko
		12:30-14:00	Lunch	
		14:00-15:00	Activity Report from Hanoi	Nguyen, Hong Ha/Nguyen Bich Thuy
		15:00-15:30	Tea Break	
		15:30-16:30	Q&A	Nakanishi/Akiyama/Hong Ha/Thuy
			Closing remarks	Hoang Yen

			Independent Living Workshop	
3/8	Mon		Venue: First Hotel, First Grill (First Floor) 18 Hoang Viet, Tan Binh District, Ho Chi Minh City Tel: (848)-3844-1199/1175/1167 Fax: (848)-3844-4282	
		9:30-10:30	Orientation (1) (Purpose of workshop, self- introduction, reminder)	Nakanishi, Mitsuoka, Loan
		10:30-11:00	Break	
		11:00-12:00	Concept of independent living / Comments and Q&A on IL Seminar on March 7	Akiyama
		12:00-13:30	Lunch	
		13:30-15:00	History of activities by PWDs	Nakanishi
		15:00-15:30	Break	
		15:30-16:30	What is independent living center? (Philosophy, role, service) / Q&A	Akiyama
		17:00-18:30	One to one interview to trainees (1)	Nakanishi/Akiyama/(Mitsuoka)

3/9	Tue	9:30-10:30	New&Good/What is peer- counseling (1) (history / purpose)	Akiyama
		10:30-11:00	Break	
		11:00-12:00	Peer-counseling (2) (rules / why peer-counseling is exclusively conducted by PWDs)	Mitsuoka
		12:00-13:30	Lunch	
		13:30-15:00	Nature of human beings / Discharge of emotion	Akiyama
		15:00-15:30	Break	
		15:30-17:00	What is disability? / Good and learned	Mitsuoka
		17:30-18:30	One to one interview (2)	Nakanishi/Akiyama/Mitsuoka

3/10	Wed	9:30-10:30	New&Good / Q&A	Mitsuoka/Akiyama
		10:30-11:00	Break	
		11:00-12:00	Independent living program / Role-playing (1)	Akiyama/Mitsuoka
		12:00-13:30	Lunch	
		13:30-15:00	Role-playing (2)	Akiyama/Mitsuoka
		15:00-15:30	Break	
		15:30-17:00	How to make a program / Good and learned	Akiyama/Mitsuoka
		17:30-19:30	Fellowship party	

3/11	Thu	9:30-10:30	Activities in Thailand / Ms. Supattraporn's presentation on her independent living	Saowalak / Supattraporn
		10:30-11:00	Break	
		11:00-12:00	Activities in Hanoi / Role of PWDs	Hong Ha / Akiyama
		12:00-13:30	Lunch	
		13:30-15:00	Review / Q&A / Closing ceremony	Akiyama

			Training for Personal Assistants	
3/9	Tue	9:35-10:25	User centered personal assistance service	Nakanishi
		11:05-11:55	Different types of disabilities / What personal assistants need to remember	Ogino
		13:40-14:50	Assistance method (assist of wheelchair)	Takagi / Ogino
		15:40-16:50	Assistance method (assist of dressing)	Takagi / Ogino

Annex 2-Handouts

What is Independent Living Movement?

Emiko Nakahara
Human Care Association

1. Independent living movement in the United States

- It is conceived that this movement began when Ed Roberts, who is called as “father of independent living,” entered University of California, Berkeley in 1962. Roberts became polio victim at the age of 14. He had severe paralysis below his neck and, hence, used motorized wheelchair equipped with respirator.
- It was the period of active minority movements for rights, such as, by African American or women, in the United States. In 1964, civil rights bill was signed. Students with disabilities had influence and lunched “program for physically disabled students” at UC Berkeley in 1970.
- In 1972, Roberts could no longer use on-campus supports for disabled students such as personal assistance and housing because of his graduation. Hence he established Center for Independent Living (CIL) in community with support of family and friends. This was the beginning of the independent living center. The CIL in Berkeley had four principles:
People with disabilities:
 - (1) belong in the community, not the convalescent home.
 - (2) are neither patients to be cured, children to be taken care of, nor brave souls to be admired.
 - (3) should be in charge of the assistance they may required, that is, free to be independently dependent.
 - (4) are victimized by a prejudiced society, not the disabilities they happen to have
- “Independent” means that one can quest for one’s own life through self-choice and self-decision. This “independent” necessitates self-responsibility.
- In 1976, Roberts was appointed as the director of California Department of Rehabilitation. Because of the amendment of Rehabilitation Act in 1987, partially a result of independent living movement, independent living centers began to receive subsidies from the Federal Government. Currently, there are more than 400 IL Centers, including small ones, in the United States.
- In 1979, Gerben Dejong, up-and-coming sociologist in the United States, published *The Movement for Independent Living*, and theoretically proved effectiveness of support from IL center in the comparison with rehabilitation.
- In 1990, IL movement proposed ADA (Americans with Disabilities Act), the first legislation to eliminate the discrimination of PWDs, and succeeded its enactment.

- In Canada, its first IL center was open soon after the establishment of DPI in 1981. In 1989, IL centers succeeded in establishing Self-managed Care and Direct Founding System in every Canadian state.
- In the United Kingdom, the parliament passed Direct Payment Bill as Community Care Act. The national government consigned to IL centers the promotion of Direct Payment at local municipalities.
- In Sweden, with support from personal assistance user's coop, IL centers have taken in charge of self-managed personal assistance services. PWDs themselves assess the services.
- Independent living movement did not stay a mere movement in society, but altered conventional medical and rehabilitation models for better support of PWDs.

2. Independent Living Movement in Japan

- In the early 1970s, severely disabled persons began to try live independently in community.
- Since 1960s, Aoi-shiba ("Blue Lawn"), a movement organization of persons with cerebral palsy, had insisted that PWD had rights to live in community as a human being even though he/she had difficulty in working. In its movement, *Aoi-shiba* made argument that "disability is personality" and, in fact, had commonality with philosophy of independent living movement.
- In May, 1970, a mother killed her two year old disabled child in Yokohama-city, Kanagawa prefecture. Soon after this affair, associations of parents of disabled children and neighborhood associations made a plea of commutation of punishment. But, Kanagawa chapter of *Aoi-shiba* took actions of opposing to the plea.
- Previously, there were only two options for life of severely disabled persons: one was life in residential institutions. The other was to live under protection from family. However, some severely disabled persons began to seek for "the third way" in which PWD rent a room in community and live by arranging the rotation of 24-hour assistance by students or workers.
- In 1972, the first national conference of wheelchair users was held in Sendai-city. The conference led to the installation of ramps on a street and promoted movement for community building. Since then, the national conference has been held in every two years and contributed to community building.
- Corresponding to the appearance of activities for community building, Tokyo metropolitan government established a board on community development in 1973. Some PWDs participated as board members. This led to improvement of the means of transportation. In 1977, a welfare foundation by major Japanese newspaper *Asahi Shinbun* donated 50 foreign made electric wheelchairs to PWDs. This donation stimulated the metropolitan government to set the committee for studying electric wheelchair.
- *Human Care Association*, the first independent living center in Japan, was established in June, 1986. After this, IL center spread nation-widely. In November

1991, “Japan council on Independent Living Centers,” umbrella organization of IL centers, was established. In May 2006, JIL has 128 member organizations.

What is Independent Living Center?

Human Care Association/CIL Hino

Independent Living Center

1. Back Ground

Once there had been a belief that only expert such as doctors, occupational therapists, physical therapists or councilors could understand and help PWDs. However, PWDs claimed that it was PWDs themselves who best understood PWDs’ need and were the experts on disability. In 1972, they established and managed the first independent living (IL) center in Barkley, California, and provided services for PWDs. Establishment of IL centers occurred in every state of the United States, and then happened in Canada and Europe. In 1986, “Human Care Association” – the first IL center in Japan – was established. Now, establishment of IL centers is occurring in several Asian countries, such as, Korea, Thailand and Pakistan.

Persons with disabilities, even with severe one, can live in community independently by using services from IL centers. As the most effective organizational system to realize philosophy of independent living, IL center has dual functions as service provider and social movement body at the same time.

2. Philosophy

Under the concept that persons with disabilities know the best of own needs, Independent Living has been turned into reality by the paradigm shift that the persons with disabilities once were recipients become providers for own issues according to their own experiences. It is IL center that support the persons with disabilities those who exercise self-determination and self-choice for own life to live with self-responsibility.

IL center has two aspects that is an agent of service provision to provide persons with disabilities with necessary services to live in community, and is also an agent of social movement. The inclusive society in which persons with severe disabilities can enjoy living with quality of life is really inclusive society for all. To appeal actively to the society is one of important activity towards the inclusive society.

3. Conditions of Independent Living Center

- (1) President and secretary of General must be persons with disabilities.
- (2) More than 51% of board members must be persons with disabilities.
- (3) Cross-disability service provision.
- (4) Information referral and advocacy are the basis of services.

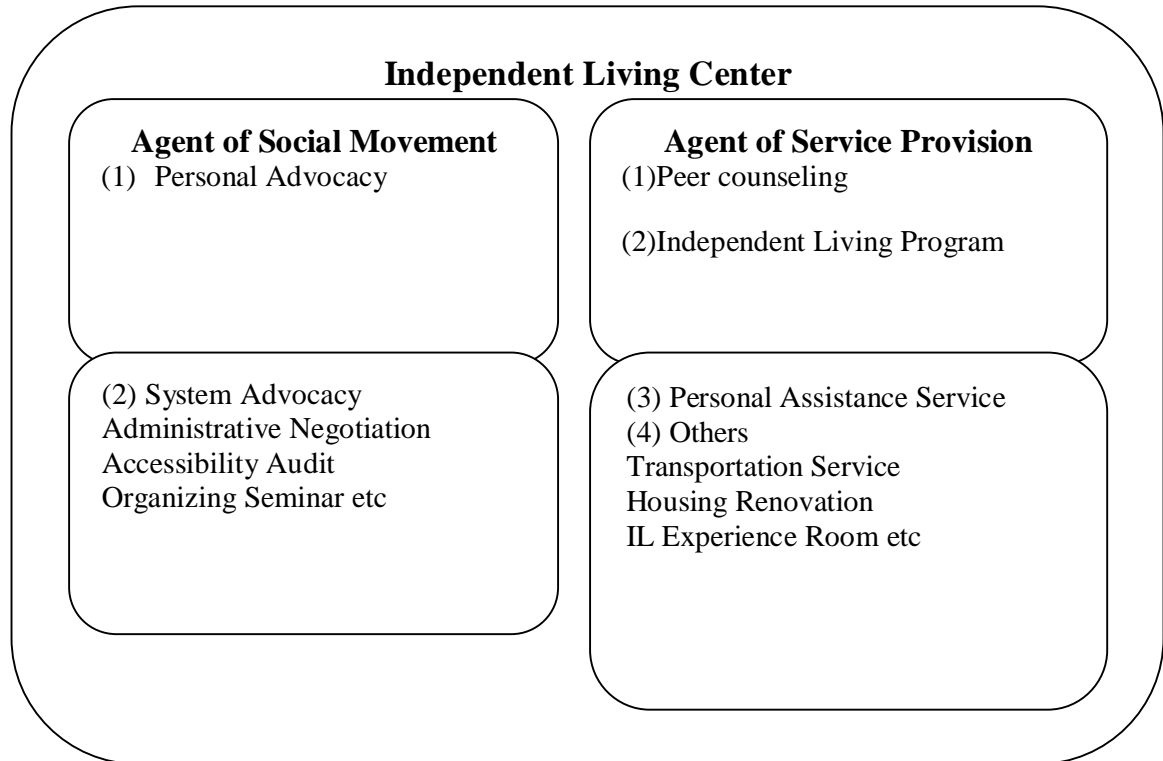
4. Services

- (1) Peer-counseling

- (2) Independent Living Program
- (3) Personal Assistance Service
- (4) Housing Renovation
- (5) Transportation Service
- (6) Independent Living Experience Room etc

6 Advocacy

All activities of Independent Living Center are implemented on the basis of advocacy.



What is Independent Living Program (ILP)?

Human Care Association / CIL Hino

1. What is independent living program (ILP)?

ILP is the program in which persons with disability learn necessary knowledge and skills for independent living, such as, relationship building, management of expenses, cooking and so on which they cannot experience at residential institutions or family's home.

ILP is an opportunity of experiential empowerment. Experiences in ILP help persons with disability to solve one's anxiety and problems, encourage them to retain confidence for independent living, and enrich their life.

2. Difference between ILP and peer-counseling

ILP: Information referral and training. Experiential empowerment.

Peer-counseling: Approach to psychology. Psychological empowerment.

* ILP and peer-counseling are "two wheels of one cart" of support

3. Origin of ILP (Pre-IL center period)

(1) Transfer of experience from senior to junior PWDs

How to find an apartment, how to find personal assistants, how to persuade family, etc...

(2) Relation between senior and junior PWDs is not one way

Transfer to experiences to junior PWDs also enriches life of senior ones.

4. Involvement of persons without disability

ILP is exclusively conducted and participated by persons with disability as same as peer-counseling:

(1) To be free from oppression

(2) To be free from dependence

(3) To know mutual support of PWDs

Some programs, such as cooking or field trip, however, need personal assistants. Same can be said on interpreters. Leader of ILP flexibly consider and decide the participation of personal assistants or interpreters into programs.

5. Themes of ILP (examples)

(1) Objective setting, (2) self recognition, (3) health management and emergency, (4) personal assistances, (5) relationship with family, (6) management of expenses, (7) housing, (8) menu, shopping, and cooking, (9) sexuality, (10) social interaction and information

6. Styles of ILP

(1) Individual program: This program is organized for individual. Program is made based upon specific needs of that person and conducted along with one's pace and condition.

(2) Group program: This program is organized for group with specific theme. Participants can exchange information and encourage each other. PWD leader and sub-leader conduct the program.

(Examples of group program themes) "Relationship with Family" –each participant practices how to explain one's will to family members. "Personal assistance" – participants learn how to use personal assistance (e.g. how to give instruction to PA).

7. Necessary conditions and knowledge for ILP leader

- (1) Must be a person with disability
- (2) Must be living independently
- (3) Can be a role model
- (4) Listen to other people attentively
- (5) Divide time equality
- (6) Not to deny or criticize
- (7) Keep confidentiality

8. Leader's duty

- (1) Prepared an interesting program
- (2) Know participant's preoccupation and anxiety, and work to release these
- (3) Introduce his/her own themes to program if necessary
- (4) Be aware leader is a role model for participants

9. Sub-leader's duty

- (1) Pay attention to leader and support him/her
- (2) Intervene into leader's pattern. But do not evaluate leader in front of other participants.
 - (3) Follow each participant who needs special support (e.g. one who tends to go into one's shell, one who begins to express emotion desperately). (Leader takes care of whole situation of program.)

Human care Association and Its Core Activities

Shoji Nakanishi

Chairperson of DPI Asia-Pacific
President of Human Care Association

Principle of Human Care Association and Case of its User

On the administrative board of Human Care Association (HCA), more than 51% of board members should be PWDs in principle. President and secretary-general should be PWDs, too. This principle is also applied to about 200 IL centers in Japan, which are established modeled after HCA. Being PWDs the board members and president means that those who have been the recipients of welfare services become the providers. This also means that, if they provide good services, the quality of their life will be improved because they are service users at the same time. If not, they have to bear the low quality of life. Hence, they have to make effort for better services. As a result, local municipal and other PWDs evaluate IL centers as very fine service providers.

The first user of our PA service was a woman with amyotrophic lateral sclerosis (ALS). When I met her at the first time, her disease often made her tumble. Soon, she became not to be able to stand up. Half a year, she became even not be able to speak. Thus, HCA set up a team of 20 personal assistants, and began 24-hour support for her. With the support, she enjoyed life in community with reading Holy Bible and writing her autobiography.

Because of the progress of her disease, she even needed 2 hours to drink a glass of water. There was a high risk that she would be choked by food. HCA, however, strongly hoped to respect for her will and support her as long as she enjoys current life in community.

We went to see her doctor for consulting her condition. The doctor told us his wish that HCA continue her support. He said that her will to live in community sustained her life. She made efforts to open pages of Bible and to operate word-processor by hanging her arms with ropes from ceiling. Her efforts maintained her muscle.

However, if she dies when she is using her personal assistant, police would have to investigate for her death. Hence, in case of her death, HCA consulted with a lawyer and decided to make written contract. In the contract, it was written that HCA would owe responsibility if she die from assistance.

We asked her whether she wants to continue to live in community. She answered, "Yes". She could understand her situation and make her own decision. Her will to live in community was her self-decision. It was she to have sovereignty to herself. Hence, they trusted her and decided to continue her support.

More than 51% of board members of HCA are PWDs. This meant that if she had to be hospitalized, so we were. This is the reason why fundamental principle of ILC that more than 51% of board members should be PWDs is significant. Persons without disabilities give priority to the protection of organization. But, we are not. We do not mind the dissolution of our organization. We believe that the society would support us

even if the dissolution happens. If there were ILC that does not respect for PWD's will. It is better such ILC be dissolved.

Core Activities of HCA

HCA provides services of peer-counseling, independent living program (ILP), personal assistance (PA), and housing information. Courses of peer-counseling and ILP are held several times in a year. The purpose of peer-counseling is provision of psychological support for PWDs who have had to bear prejudice and discrimination.

ILP is support in which PWDs learn necessary skills and know-how for independent living. Many PWDs have difficulty in expressing their wants, hopes and dreams even to their parents and siblings because they are too much conscious about relations with surrounding persons. Thus, through ILP, they acquire skills to communicate with others persons. For example, using role-playing in ILP, they learn how to tell their will to get married.

PWDs who only stayed home before can go out and have experience to learn necessary skill, such as, asking a favor, for independent living in ILP. For example, a senior PWD took out to a woman to a department store as a part of her ILP. The woman could not go out before because she worried about her toilet. However, she could learn how to ask for assistance for toilet by looking at behavior for her senior PWD. Of course, she could not make it at a once. But, 6 months later, she phoned us that she could ask for assistance for toilet by herself.

Through programs on shopping and cooking in ILP, PWDs learn how to give instruction to personal assistants. ILP for such purpose is conducted in actual living area, and use roads and shops they may use. This is because they can directly connect their experience into their life in community. Therefore, ILP cannot be conducted at institutions, such as, rehabilitation center, which are remote from living area. In fact, ILP that was organized by a rehabilitation center of Tokyo metropolitan government did not work at all.

As to PA service, HCA provided 125,800 hours in total amount in 2010. 1200 persons are registering to HCA, and about 400 of them are actively working as personal assistants. About 400 persons with disabilities are using our PA service. HCA now employs 26 staffs in the office-12 PWD staffs, 11 PA coordinators, and 3 other staffs.

Another service by HCA is provision of housing information. PWDs often cannot rent a room. Therefore, HCA cooperates with real-estate agencies for information of available housing. We also tie up with carpenters, and support to remodel rooms and houses.

Along with these services, HCA has activities of advocacy, provision of information, and negotiation with local municipal. We also provide service of free personal consultation, which is consigned by local municipal. We have about 100 consultations per month. We also have activities to check the accessibility of train stations by joining a committee for accessibility, and to negotiate for subsidies to IL centers.

What is Peer-counseling?

Human Care Association / CIL Hino / IL Minami Tama

1. History and Outline of Peer-counseling

“Peer” means “colleagues” or “persons who have similar background”. We call mutual support of persons with disability (PWDs) through listening each other as “peer-counseling”.

In the 1970s, effectiveness of mutual support by persons with disability was widely recognized in the independent living movement in the United States. Each independent living center in the US used peer-counseling with its own method.

Peer-counseling in Japan based upon the method of re-evaluation counseling.

Significant point of this method is reverse of roles between counselor and client and sharing of same amount of time.

“Peer-counseling” in our use means not only mere counseling but also general peer support activities to realize independent living. The meaning includes whole activities by peer-counselors to disseminate their experiences and information as PWDs, such as, individual counseling, study activity for independent living, utilization of social resources, seeking for house, and various advocacy activities.

By learning peer-counseling and providing detailed supports, PWDs assist the realization of independent living in community.

2. Purposes of Peer-counseling

Goal of our activity is independent living of persons with disability. To achieve this goal, peer-counseling has three purposes:

- 1) Recovery of self-reliance
- 2) Rebuilding of human relationship
- 3) Social change

3. Basic Method of Session

- 1) Equal allocation of time
- 2) Mutual listening

We rotate the roles of counselor and client, create the environment that encourages client to speak, and let participants know how comfortable to be listened quietly.

4. Rules of Session

- 1) Equal allocation of time
- 2) Confidentiality, protect privacy
- 3) No denial, no criticism
- 4) No advice

Plus 1: If possible, do not smoke, nor drink beverage containing alcohol or caffeine. Also do not eat sweets during peer-counseling course period.

5. Role of Counselor in Session

- 1) Listen attentively
- 2) Trust client
- 3) Intervene into clients patterns
- 4) Encourage and accept client's discharge of emotion
- 5) Do not give advice
- 6) Do not get involved into problems of client

6. Role of Client in Session

- 1) Be aware of that time is totally for yours
- 2) Be aware of that time and place are safe
- 3) Carefully consider to recognize your problems and patterns
- 4) Discharge a lot of emotion

7. Reason Why Peer-counseling Is Exclusively Conducted by PWDs

- 1) To be free from oppression
- 2) To be free from dependence
- 3) To know persons with disability can support each other

8. Terms often Used in Peer-counseling

New and Good

Work to find out new and good in life.

Session

Counseling each other under equal allocation of time

Tension back

Brief question from counselor to client to return client's attention normal after a session.

(e.g. What did you eat this morning? Please name your telephone number from the tail.)

Think and listen

More than three participants speak one's feeling one by one based upon given themes. Time is equally allocated among participants. When one speaks, others listen attentively with supportive response and do not intervene by opinions or questions.

Discharge

Release of emotion to outside. Crying, getting angry, shaking, sweating, laughing, yawning, and so on.

Demonstration

Work in which one of pairs demonstrates session in front of other pairs for improvement of counselor's skill.

Appreciation

Work to appreciate one by one

9. Consultation Service Adapting Peer-counseling Method

In consultation, we take position of “attentive listening” that is fundamental element of peer-counseling. “Confidentiality” and “no denial and no criticism,” which are rules of peer-counseling, are also important. We also must not forget one of clauses of counselor’s role in session: “Do not give involved into problems of client.”

Difference of consultation from peer-counseling session is that counselor does not reverse the role with client and not share equal amount of time at the work of general consultation. What important for peer-counselor during consultation is to take posture of attentive listening and carefully watch client get solution by oneself.

Rule of peer-counseling session says “does not advice to client”. However, in consultation, counselor should provide necessary information appropriately. Counselor is also necessary to give positive words to some client who always denies oneself.

Training for Personal Assistant
What is independent living center and independent living movement?

Why Persons with Disabilities Are Persons with Disabilities?

The fact is not only because persons with disabilities have physical, mental and intellectual disabilities.

How the people around persons with disabilities, community and society have been related with persons with disabilities?

- The period of when person with disabilities were not seen in communities, that is around 30 or 40 years ago, where the persons with disabilities were living?
- Why institutions for persons with disabilities were in need?
- The goal was to overcome disabilities and go back to society of able-bodied society. Everyday persons with disabilities had to commit to rehabilitation.
- What does independent means? It is not to do everything by alone.

What did persons with disabilities want to speak out?

- Fuchu Medical Center for the Severely Disabled Conflict
- *Aoi Shiba no Kai (Green Lawn Grass Association of Persons with Cerebral Palsy)*
Campaign against communication on murder case of children with disabilities.
" To restore human rights of persons with disabilities

Independent Living Movement in the United States

- Persons with disabilities
 - (1) are to live in _____, not in “segregated institution”.
 - (2) are not _____ to be cured, are not _____ to be protected and are not _____ to be worshiped.
 - (3) are in the position of _____ assistance.
 - (4) Are victim of _____ by society rather than by “disability” itself.

**We spend our own life, hiring personal assistants, determined by ourselves
without being force by those around one.**

Independent Living Movement in Japan, Independent Living Center (IL center)

- In 1986 Human Care Association, first Independent Living Center in Japan, as established.
- Independent Living Center is;
 - (1) that the person in charge is _____.
 - (2) that the majority of the executive board members are _____.
 - (3) that provides services for cross _____ etc.
- The characteristics of Personal Assistance Service of IL center:

- (1) Unlimited targets (whoever in need),
- (2) no restrictions on purposes (whatever in need)
- (3) unlimited time to dispatch (whenever in need)
- Independent Living Program (ILP) and Peer-counseling.

Assistance for Persons with Disabilities
Wait and see what person with disabilities think and say
" To spend a life independently

Annex 3-List of Resource Persons

List of Resource Persons

No.	Name	Disability	Position	Organization
Japan				
1.	Mr. Shoji Nakanishi	Wheelchair	Regional Chairperson of DPIAP President, Human Care Association	Disabled Peoples' International Asia-Pacific (DPI/AP) an Human Care Association
2.	Mr. Atsuo Takagi	-	Personal Assistant	Human Care Association
3.	Ms. Hiroko Akiyama	Wheelchair	Director	Hino IL Centre
4.	Ms. Mami Ogino	-	Personal Assistant	Hino IL Centre
5.	Ms. Eonjeong Kim	-	Personal Assistant	Hino IL Centre
6.	Ms. Tamaki Sugiura	-	Personal Assistant	Hino IL Centre
7.	Mr. Yoshihiro Mitsuoka	Wheelchair	Human Care staff	Human Care Association
8.	Mr. Hiroaki Furihata	Physical	Human Care staff	Human Care Association
Thailand				
9.	Ms. Saowalak Thongkuay	Wheelchair	Regional Development Officer	Disabled Peoples' International Asia-Pacific (DPI/AP)
10.	Ms. Worapan Buranasilpin	-	Independent Living Project Coordinator	Disabled Peoples' International Asia-Pacific (DPI/AP)
11.	Ms. Supattraporn Tanatikom	Wheelchair	Independent Living Project Manager	Disabled Peoples' International Asia-Pacific (DPI/AP)
12.	Ms. Wilailak Chanphuangsen	-	Personal Assistant	Disabled Peoples' International Asia-Pacific (DPI/AP)
13.	Ms. Sirinrat Meesomboon	-	Personal Assistant	Disabled Peoples' International Asia-Pacific (DPI/AP)
14.	Mr. Satidphong Athipiromsri	Wheelchair	National Project Advisor on Independent Living	Disabled Peoples' International Asia-Pacific (DPI/AP)
15.	Mr. Anurak Suasum	-	Personal Assistant	Disabled Peoples' International Asia-Pacific (DPI/AP)
Hanoi, Vietnam				
16.	Ms. Nguyen Hong Ha	Wheelchair	Project Manager	Hanoi Independent Living Center
17.	Ms. Ha Thi Hoan Xuan	-	Personal Assistant	Hanoi Independent Living Center
18.	Ms. Nguyen Bich Thuy	Wheelchair	Executive Director	Hanoi Independent Living Center
19.	Ms. Le Phuong Hanh	-	Personal Assistant Coordinator	Hanoi Independent Living Center