

**Material for APCD Training of Managerial Personnel of Independent Living
Centers, 28 February – 7 March, 2006**

Shoji Nakanishi
Human Care Association

Contents:

- I. Philosophy of Independent Living Movement and Independent Living Center**
- II. Activities for Advocacy**
- III. Bodies of Movement and Enterprise Should not Be Separated**
- IV. The Body of Enterprise and Body of Movement**
- V. Support for Empowerment**
- VI. Peer-counseling Strategy**
- VII. Necessary Medical Knowledge for Independent Living in Community**
- VIII. Necessary Management Abilities as President of IL Center**
- IX. Management of Personal Assistant Service**
- X. ILC Management: Budgeting, Planning and Fundraising**
- XI. Problem Solving**
- XII. Recruit and Employment of Staff: Human Resource Acquisition and
Development**
- XIII. In-Office Care**
- XIV. IL Movement in Asia**

I. Philosophy of Independent Living Movement and Independent Living Center

History and Philosophy of Independent Living Movement

In the United States, the 1960s was the era of vigorous civil rights movement by African Americans. As a part of minorities, persons with disabilities (PWDs) were also eager for the implementation of civil rights. Since then, the movements by PWDs have had strong influence from civil rights movement.

In 1972, Ed Roberts was about to graduate University of California in Berkeley. He had disability from polio and used wheelchair equipped with respirator. When he was a university student, he could use on-campus services, such as, assistance, housing, wheelchair repair, or peer-counseling. However, these services would be cut off with his graduation. Hence, he established Independent Living Center (ILC) in community with support from his family and friends. This was the beginning of Independent Living Movement.

In another countries in this period, however, the reality went to opposite from ideal direction. The government of Netherlands implemented policies of colonizing PWDs, and built large-scale living institutions “Head Dorf”. In the United Kingdom, the government promoted the policy of collective living of PWDs, and built group-homes with care. The world trend of policies for the living of PWDs was still headed to living institutions or group-homes except the cases of independent living movements in the USA and “focus house ” in Sweden.

The Center for Independent Living in Berkeley had four principles:

1. A person with disability should live in the “community” instead of “institutions.”
2. A person with disability is neither a patient who should receive medical treatment, nor a child who should be protected or a god who should be worshiped.
3. A person with disability is in a position to control aid.
4. A person with disability is a victim of “social prejudice” rather than his/her “disability.”

Up to this day, PWDs have been imposed life-long goals to become like non-disabled persons under the name of rehabilitation. For example, in the idea of rehabilitation, they have good evaluation if they can change clothes without help from other persons even though it takes two hours. The philosophy of independent living, however, considered that the use of assistance was not shameful nor hurting subjectivity. It declared the significance of choice and decision based on one’s own will.

Rehabilitation was the only medical treatment in the limited period and should not be the base to control the life of PWDs.

Following the beginning in Berkeley, the IL movement was quickly spread around in the United States. In the same year of the Center for Independent Living of Berkeley, PWDs in Huston established their ILC. In 1974, Boston also had ILC. In 1978, the collective effort of PWDs in the United States won the revision of the Rehabilitation Act. Due to the revision, PWDs could have more aid from the federal government. In 1979, Gerben DeJong, up-and-coming sociologist in the United States, published *The Movement for Independent Living*, and theoretically proved effectiveness of ILC in the comparison with rehabilitation. Due to the spread of the IL movement and its theoretical support, the ILCs sprung up all over the United States like wildfire.

In Canada, Henry Enns has aimed “emancipation from rehabilitation” and made steady efforts to organize PWDs at grass-root level since 1980. He began the movement in Kitchener, Ontario, and criticized rehabilitation as enforcement of protection and control. It was this period that the world trend for PWDs began to shift towards “independence”.

In the last 30 years, ILCs gained extra-ordinary achievement. In the United States, through the vigorous movement, ILCs won the article 504 of the Rehabilitation Act and had the federal government recognized their significance. Then, ILCs proposed ADA [Americans with Disabilities Act], the first legislation to eliminate the discrimination of PWDs, and succeeded its enactment in 1990. Currently, many PWD leaders are participating into the core of federal administration and taking initiatives in federal affairs. Also, growing numbers of ILCs take in charge of Medicare assistant services of federal government.

In Canada, its first ILC was opened soon after the establishment of DPI in 1981. In 1989, ILCs 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 ILCs the promotion of Direct Payment at local municipalities.

In Sweden, with support from personal assistance user’s coop, ILCs have taken in charge of self-managed personal assistance services for 14 years. PWDs themselves assess the services.

From September 21 to 25 in 1999, the world conference of independent living movement was held in Washington, DC.. It was the first world IL conference in the history, and gathered more than 100 PWD leaders from 50 countries. The global

coalition of PWDs was established at last.

History of Independent Living Movement in Japan

IL movement in Japan began from the activities of *Aoi-shiba* (“Blue Lawn”) in Kanagawa prefecture in the early 1970s. *Aoi-shiba* had been a service club of persons with cerebral palsy at the time of establishment, but became a radical movement organization. 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. Even though the court turned down the objection from *Aoi-shiba* in the end, this mother’s criminality was widely understood. Such actions of *Aoi-shiba* strongly influenced movements by PWDs.

In November 1970, some residents of Fuchu Medical Center for the Severely Disabled began hunger strike with protesting poor treatments by the center. In September 1972, they set up tents in front of the building of Tokyo metropolitan government, and began sit-in protest. Their protest continued about two years. As a result, the metropolitan government set a policy of reforming rooms of institutions into compartments. The metropolitan government also established and implemented the program to dispatch care workers for persons with severe cerebral palsy in 1974. Along with this progress, the national government also began to apply to persons with severe disabilities “a special criterion for adding welfare benefits for care” in 1975. With the arrangement of these programs, the conditions of persons with severe disabilities for their living in community gradually improved in some regions.

In 1976, Tokyo metropolitan government established a committee for discussing house with care. I also became a committee member. Tokyo chapter of *Aoi-shiba* and the network of cervical spine injury raised the issue of house with care. The committee was the attempt to seek for the realization of the houses in communities by modeling the complex housing with care assistants in the United Kingdom. As a committee member, I recommended the system of dispatching care assistants to each PWD’s house for independent life in community. The committee, however, chose the style of group-home with capacity of 20 residents. Me and other members who insisted independent life in community resigned the committee.

In 1977, the committee was re-organized as the council for the construction of houses with care. The first house was built in 1979 and began operation in 1980. But about the operation of the house, there was conflict between *Aoi-shiba* and other

members of the council. *Aoi-shiba* insisted to operate the house as the space for the disability movement. Other members, however, wanted the house only to be residential space. The conflict was not stopped, and dismissed the construction of another house. If the operation of the house with care were successful, there might not be IL center in Japan.

In 1973, 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 movements for community building. Since then, the national conference has been held in every two years in major cities, such as, Kyoto, Nagoya, and Tokyo. The need to operate the conference also fostered the growth of young PWD leaders and grass-root PWD organizations.

Corresponding to the surge of the movements for community building, Tokyo metropolitan government established a board on community development in 1973. Some PWDs participated as board members. Around this period, the first public housing for wheelchair users was constructed in Kirigaya, Kita-ku, Tokyo. Activities for outing to community led to the improvement of transportation devices. 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.

In 1981, International Year of Disabled Persons, Ed Roberts visited Japan, and promoted IL movement. After his visit, many IL leaders also came and traveled around in Japan for organizing lectures. They discussed philosophy of independent living with great zeal, and moved audience.

However, they did not speak about services of IL centers at all. Because of this, it took some more years for the establishment of IL center in Japan. In June 1986, Human Care Association, the first IL center in Japan, was opened in Hachioji, Tokyo.

Principles of Independent Living Center

Japan Council on Independent Living Centers (JIL) defines principles of independent living center. According to JIL, whilst IL center commits to advocacy and information referral as its basic activities, it should fulfill following principles:

- 1) President and secretary general of independent living center have to be persons with disabilities.
- 2) More than 51% of board members of independent living center have to be persons with disabilities
- 3) Independent living center provides following services:

- a) Peer-counseling
 - b) Independent living program
 - c) Personal assistance service
- 4) Independent living center provides cross disability services.

Human Care Association

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 later, 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.

HCA provides services of peer-counseling, independent living program (ILP), personal assistance (PA), housing information, and lift-van transportation. 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 skills, 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 of 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 2005. 364 persons with disabilities are using our PA service. HCA employs 28 staff (11 PWDs/ 17 non-PWDs) in the office and 460 active full- and part-time personal assistants.

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 demand subsidies for ILCs.

In 1988, Tokyo Metropolitan government set up a foundation. I negotiated with the government to support ILCs by explaining that ILCs would be established widely in the nation and also cover services for elderly persons. As a result, the foundation decided to subsidize 10 million yen to each ILC for ILP and personal assistance services. Since then, 25 ILCs have been established for 10 years in Tokyo.

In 1996, on the basis of activities of ILCs, the Health and Welfare Ministry of Japanese Government at that time started the project to support the living of disabled persons in community and institutionalized the support system through consultation. ILCs collaborated for the establishment of the system in which ILP and peer-counseling were acknowledged as fundamental programs for support. Due to this project, peer-counselors were widely recognized as significant staff working with subsidies from national government. This was the indication of paradigm shift in community support from professional- to disabled person-led support.

In 2003, the national government launched monetary support system for disabled persons. This system finally realized the provision of public supports under the contract on the basis of needs and decision of disabled persons. This was the near completion of the support system, except for the issue of direct-payment, of which ILCs had demanded for 20 years.

In 2005, however, Health, Labor and Welfare Ministry the Ministry (MHLW) attempted to convert monetary support system into so-called Independence Support Act for reason of financial shortage derived from the success of monetary support system. This Act introduced the systems of medical-model assessment and screening panel by

Human Care Association
1F Myojincho 4-14-1, Hachiojishi, Tokyo, Japan

professionals and had disabled persons to face restricted use of support services. Organizations of disabled persons with more than 12,000 members united and protested in order to stop passing the Act in the Diet. Despite of their protest, this Act was enacted and implemented on April 2006. Currently, to prevent further deterioration of support service, ILCs, as the body of social movement, seek for the construction of unified organization under the coalition between disabled and elderly persons.

(Translated by Hiroaki Furihata)

II. Activities for Advocacy

Personal Advocacy

If PWD is abused from staff in institution or from one's parents and other family members, ILC takes actions for advocacy, such as, escape from the site of abuse, consultation, counseling, and improvement of the situation. Actions are often taken with local municipal, related agencies, and lawyer. Sometimes there are PWDs who borrow money from loan sharks. ILC mediates them if necessary.

When PWD meets life threatening situation due to the shortage of welfare services, ILC with he/she arranges the table for negotiation with local municipal and demands for sincere response. When problem shifts from the issue of individual to whole PWDs, activities to change system are necessary. Such activities are called system advocacy.

System Advocacy

Individual activities have limitation in order to improve accessibility to public transportations and promote barrier-free buildings. For these issues, ILCs make appeal to other PWD organizations and take nation-wide movement. However, if public understand our movement as only for filling personal interests, we have huge disadvantage. Thus, it is necessary for us to explain to society that accessible transportations and barrier-free buildings are necessary not only for PWDs but also for parent with baby carriage, pregnant women, and elderly persons.

ILCs necessitate government subsidies, or establishment and improvement of services of personal assistance or pension system. If ILCs stay quiet, however, anything is not realized because no one knows our need. Therefore, we have to appeal our demand. Actions for appeal may not be able to realize all our demand, but at least make a progress for the improvement of situations.

How to move bureaucrats

This could be clarified if one considers in terms of the position of bureaucrats. The best wish of bureaucrats is the promotion of rank in the organization. Thus, those bureaucrats who take in charge of PWD issues could agree to our demand if it is better off to their promotion. When they clearly identify our need and expect that its realization gain better rating to them, they would cooperate with PWDs with consideration that this is good opportunity for the promotion. Having cooperation on

the issue to which mutual benefit is expected is nothing strange. It is important for cooperation to have consultation with bureaucrats for the timing to appeal our demand.

How to use politicians

It is necessary for us to be careful in the use of politicians. The most significant interest for politicians is their reelection in vote. That is, they do whatever necessary for reelection. When they consider the cooperation with us is not useful for reelection, they even turn their back.

When bureaucrats are not cooperative with us, we may use politicians. Bureaucrats, however, so dislike our cooperation with politicians that they make a rift in the relations with us. Thus, we have to consider situations carefully for the use of politicians.

We can promote policies in cooperation with bureaucrats. For its implementation, however, budget is necessary in general. Thus, for the acquisition of budget, we often work upon politicians with bureaucrats.

It is natural to propose policy from the side of ruling party if we expect for its sure establishment. Bureaucrats know well how to work upon ruling party so that we can rely on them in this point. On oppositional parties, we inform them about policy proposal and initiate their interests. Due to this, proposed policy can be significant issue on the diet and expected for establishment with solid vote.

(Translated by Hiroaki Furihata)

III. Bodies of Movement and Enterprise Should not Be Separated

Usually, business entity, such as, profit enterprise, and movement entity, such as, anti-nuclear movement, is mutually excluded.

Movement entity tends not to regard of profitability and eats up its own assets for activities, which are supported by spontaneity of members. On the other hand, business entity has to manage human resource, assets, and money for its profit. Its activities for gaining profit are accompanied with obligation and responsibility. Business entity has to consider the conditions for its sustainability. The entity cannot be sustained if it is burdened with deficit and relies on personal assets and donation.

Recent flourish of NPOs, however, gives us expectations for new relations between business and movement entities. Some of NPOs have both aspects of business and movement entities in a same time. They indicate that business and movement entities can be compatible each other.

Organizations that have both aspects of business and movement entities are rare even in the history of PWD movement. IL center, however, is very example of such organization.

Even though the basics of actions of movement entities are the realization of their vision, the issue of management is not ignorable for them.

Movement entities for advocacy, including PWD movements, tend to neglect efforts for management. Nonetheless, any movement activity necessitates managing human resources. In addition, development of activities may require handling money, assets, and services. In such situation, only vision and motivation are not enough.

Under nursing-care insurance and financial assistance systems, private companies have entered into the provision of care services or personal assistance services. In this situation, business entities run by citizen lose their significance if they cannot provide better services than private companies. In addition, these entities have to make effort in order to be chosen by service users. Otherwise, they cannot remain in competition.

Mere setting of IL philosophy in their management concept does not mean they can provide quality services to PWD users. For quality services, they always have to be conscious about users' needs in terms of the user-first principle of which it is users who choose services. The strength of entities that concern with PWD movements is that they are very close to PWDs' needs and have accumulation of experience in relationship.

IL centers are the pioneers of 24-hour personal assistance services in Japan.

They have set up fulltime shift of personal assistants and responded to users' needs any time day or night. Even holidays do not suspend the provision of services. IL centers also arrange the system of staff coordinators substituting personal assistance in case of emergent needs. Their devotion towards service provision, of course, is not profitable at all. Even sometimes they have to fill expense from their savings. Such devotion is the attribution of PWDs running IL centers. Because these PWDs, as actual service users, know needs and significance of services, they can provide services despite of low profitability.

More than 100 IL centers were established in Japan within the last couple of decades. We can mention one strategy that rapid increase of the number of IL centers became possible. As the first step, a staff of IL center takes a role of personal assistant and supports independent living of a PWD. Through the practice of independent living, they clarify the needs in assistance. Based on clarified needs, IL center demands to local public administration for enlarging support to fulfill the needs of PWD for independent living. With enlarged support from local administration, IL center looks for PWDs who need assistance in community, while arranging its organizational form. Due to the increase of service users, IL center can have more earnings as a business entity. With increased earnings, IL center can hire extra staffs and provide better services. Based on this strategy, IL centers could increase their numbers.

There is a principle that "there is no welfare service without demand". There was no example of public administration, which willingly provides services based on PWDs' voice. Assembly members are rarely elected from their efforts to improve local welfare services. In general in Japan, public administrations reluctantly make effort to improve welfare responding to the demands from PWDs. IL centers skillfully used such tendency of public administration for their development.

Some other movement organizations also provide services to PWDs. Some of them, however, strictly stick to their movement principles and exclude those PWDs who do not assent to the principles. IL centers, however, understand that service users are customers and consumers as if private companies do, and take a stance of non-exclusiveness. They provide same services regardless of any differences, such as, creed, religion, ethnicity, type of disabilities, or gender.

IL centers are run by PWDs, have philosophy to provide services based on the PWDs' needs, and do not set limitations upon service contents and conditions in general. In this sense, IL centers are business entities which provide service goods of which PWDs guarantee quality.

In reality, organizations which began as movement entities have serious

difficulty in doubling with the characteristics of business entity. This is because the aspect of business entity on management and responsibility tends to take primacy over the characteristics of movement.

We can see example of separation between movement and business entities in co-op organizations. Co-op began as movement entity with lofty vision towards environmental conservation and food safety. Nonetheless, the separation between management side of co-op shops as business entity and co-op members as driving force of co-op movement developed gradually. In the separation, small number of full time staffs at business entity gained power to control over organizations, and put movement entity under their management. As the result, some members of movement entity disappointed and left the movement.

This kind of separation often occurs whoever takes the role of management if movement philosophy cannot be buttoned well to the management side. It is not rare that the movement entity becomes mere business one which is no different from private profit organizations.

IL Centers have been conscious to the possible separation between movement and business entities, and, thus, taken necessary measures the prevention. For example, Human Care Association gives one week training program for new staffs about the philosophy of IL, the history of IL centers, and the principles and reasons of user-centered management and services. Since any matured movement has different staffs from its beginning, there might appear gaps between original and new staffs in understanding about movement philosophy. Thus, giving training program to new staffs is indispensable for the succession of philosophy.

For the establishment of Human Care Association, we used a space of *Daiichi-wakakoma-no-ie*, which was a rehabilitation institution for physically disabled. *Wakakoma-no-ie* was the first organization of being operated by PWDs with grants from Tokyo Metropolitan Government and Hachioji-city. PWDs used this institution as the space for their autonomous activities based on their proposals. They could choose, decide and operate what they want to do in this institution. For example, those who wanted to learn computer skills could propose their plan at management board of the institution, hire instructors after approval, and organize workshop for computer.

Wakakoma-no-ie also had the aspect of movement organization. PWDs in this institution committed the movements, such as, the improvement of accessibility to railway station. They also planed and organized events, such as, bazaar frequently. For the movement activities, various kinds of volunteers dropped into the institution irregularly. Even some of them came to the institution office in the evening and stayed

until midnight. PWD members of the institution were influenced from irregular visits of volunteers, and tended to lose punctuality of the management.

Human Care Association was launched as the body of enterprise by PWDs using a corner of *Wakakoma-no-ie*. Nevertheless, HCA staffs needed certain effort to have recognition to HCA as the body of enterprise because they also tended to be influenced by irregularity in the movement aspect of *Wakakoma-no-ie*. Thus, to have firm recognition as the body of enterprise, HCA set its business hour from 9 AM to 7 PM and demanded staffs to come at work with business suits from the opening day.

We believed that the body of enterprise had responsibility to its service users. If HCA had neglected responsibility, users would have soon loose their trust to us. Thus, we needed to construct the system to be responsible to our users. For example, we established the system of sharing necessary information among all staffs and being responsible to users' inquiries even though the person in charge was temporary absent.

Since its establishment, HCA, as the body of enterprise, has been occupied with the daily work for dispatching personal assistants. Our users also indicated new needs frequently.

Certain services of HCA, such as, independent living program and peer-counseling, are the mid or long-term projects with the involvement of service providers. These are recognized as the projects which are not the mere response to the needs of service users but emerged in the field of movements. Those who take in charge of these projects necessitate attentions to situations and decisions to careful strategic planning.

The body of enterprise requires more human and financial resources. It tends to eat these resources more than the body of movement. Thus, we need the management skill to take the balance between enterprise and movement in the allocation of resources.

Any body of enterprise which is sprung up from citizen movement experiences problems coming from the tendency of its separation from and primacy over the body of movement. We believe, however, that IL centers can provide interesting information to address the problems from separation. This is because IL centers always have to consider integration of bodies of enterprise and movement in order to maintain its management.

Tendency of Supremacy of Income Generating over Non-generating Sections

Activities of IL centers are sustained with income from management fees for the arrangement of personal assistants, funds from publications, and subsidies from

municipality. Total income of IL centers does not increase in proportion to the amount of work. Some kinds of work are not income generative and operated in limited amount of resources.

On the other hand, consigned personal assistance services are usually operated by sections with corporate veil as NPO. These sections can generate income in proportion with the amount of work. With the increase of income generation, voice from these sections becomes louder than other sections and makes balanced management of IL centers difficult.

Thus, IL centers put PWD representatives on both income-generating and non-generating sections, and make effort not income generating section to have preponderance of power over other sections. IL centers also contrive ways to promote understanding between income-generating and non-income generating sections by sharing office space. These sections can see activities and grasp situations each other. I believe such effort contributes to the prevention of preponderance of power of income generating to non-income generating section.

(Translated by Hiroaki Furihata)

IV. The Body of Enterprise and Body of Movement

IL Center as the Body of Enterprise

A specific characteristic of IL Center is that it is not only the body of movement but also the body of enterprise. There was not any example of this kind of organization before. This type of organization is our product as the method to realize the philosophy of IL in capitalist society. PWD organizations had tendency to be organized upon the different types of disability and regions. They did not have imagination to build organization for their operation by recruiting necessary personnel regardless of types of disability or regions.

The body of enterprise for services

For the establishment of IL center, its staffs should be neutral from any organizations, such as, disability, regional, voluntary, any social movement, or work place ones. IL center as the body of enterprise should not be established for the pursuit of profit of single organization. Rather, it is the body to provide services for each citizen as customer. If IL center tilted to give favor to specific organizations, it could not have gained trust. Local municipality could not trust, and, thus, not consign project to IL center. Above all, citizens do not want to use such IL center.

To be the body of enterprise, IL center necessitates filling following points. IL center should be operated in regular timetable (such as, from 9 AM to 5 PM). Requests from users should be dealt certainly. What informed from users should be transmitted to persons in charge correctly. Office space should be arranged neatly. Staffs should wear appropriate clothes and handle customers politely. Document materials should be organized well. Project report should be submitted on time. Regular meeting should be held for coordination.

For those PWD organizations and workplaces that have managed their operations without rigid manners, being the body of enterprise necessitates them to have so much preparation.

Requirement of rigid manners for the operation, however, does not purpose to establish profit making corporation. IL centers do not intend to earn profit and commit many activities for advocacy, such as the demand to public administration for increasing the amount of support for PA services. Rather than being profitable corporation, IL centers intend to be the body of enterprise for supporting independent living of every person with severe disability in community. With this intension, IL

centers provide various services, such as 24 hour PA services or IL program.

Manufacturing and service industries are making great effort to fill the needs of consumers. In this situation, it is strange that the field of welfare service neglects the needs of its consumers and continues to construct unwanted living institutions. Due to the shortage of services to fill the needs of PWD as consumers, many PWDs, especially those who live in regional area, are unwillingly to use living institutions even in 21st century. Such service provider-oriented condition in the welfare filed should be stopped.

Significance of IL centers is their introduction of the pay system in PA services, which were believed as voluntary work based on charity. As the result of the introduction of pay system, PWDs became from objects of pity to employers of personal assistants, and changed the relation with personal assistants into that of equality. Contract for PA service is arranged among PWD as service user, personal assistant, and IL center. In the contract paper, PWDs are clearly defined as responsible subject for the contract.

Many PWDs have been treated as if they were not responsible to their own life and constrained their activities under the name of the prevention of accident. In the history of welfare in Japan, IL center is the pioneer who defined PWDs as responsible subjects.

IL centers and other NPOs as the bodies of enterprise differ from existing voluntary organizations in recognition towards payment for services. Existing voluntary organizations tend to believe that every activity should be voluntary and unpaid. IL centers, however, consider that payment to staffs is necessary, and that their unpaid work is not suitable to the purpose of IL centers to improve the quality of services with responsibility and continuity. It is ideal that if staffs can sustain their household through the payment from their organization even though they cannot enjoy fat salary.

Social responsibility of service providers

PWD movements have tended to be divided into various organizations along with types of disabilities, such as cerebral palsy or spinal cord injury, and each organization had negotiation with public administration and took demonstration only for itself. Some other PWDs have made friendship clubs in community and worked for their own interests. Certain characteristic of these organizations and clubs is that organization members gather occasionally when they want or feel necessity, and work together on some projects and activities.

The movement organizations sustain their existence as long as needing to insist their demand. They, however, would be dissolved when they achieve or give up their objectives. They tend not to have clear administrative system and thus weak in taking responsibility. They also tend not to have rigid proposals for activities and budget. Their staff members are often changed each time of their activities. Even if their projects and movements end up failure, no one is asked for responsibility. Their credit in society might be lowered from failure, but they still can continue their activities.

On the other hand, the body of enterprise must recruit staffs who fill it objectives, pay for them, and operate office from 9 AM to 5 PM everyday without interruption. All staffs must share necessary information and can respond to inquiries. These are indispensable conditions for the body of enterprise in order to have trust. Thus, the body of enterprise cannot interrupt its operation despite of some difficulties. It bears social responsibility.

A body of enterprise has to set its necessary budget for management. For the budget, it has to set clear objectives for three years and make plan for its projects every year. For example, when a body of enterprise intends to launch new three-year project, it uses first year for the research of model projects. Based on the common understanding towards the project, the body of enterprise selects and researches model projects. In second year of the project, it begins pilot project for preparation and arrangement of necessary internal system and documents for full-scale operation of the project. This year is also used for the proof of its ability for the project to public administrations. Then, it also demands for the budget to run its operation to public administrations and other organizations. It also uses this year for recruiting its staffs. Third year is for full-scale operation of the project. The body of enterprise officially employs its staffs and operates its project. These steps are minimum requirements for the project of the body of enterprise.

Sheltered Workshop and the Body of Enterprise

There are organizations that want to transform themselves from sheltered workshops into IL centers. Some of them have had to take the form of sheltered workshops for the financial necessity even though they wanted to be IL centers. For fulfilling financial necessity from subsidies, these workshops anyhow acquire certain numbers of PWDs in their registration. The less the number of registered PWDs, the less the amount of subsidies they obtain. Thus, they have incentive to register any PWDs to their membership in order to assure subsidies.

Due to institutional regulations, registered PWD members cannot be hired as paid staffs when sheltered workshops transform themselves into IL centers. Thus, these organizations have to make a decision whether hiring PWDs with cutback of subsidies or asking them stay as users of workshops.

In transformation to IL centers, there might be problem about willingness of non-disabled staffs for their work. It is not certain whether non-disabled staffs who have been treated as instructors to PWDs can work under the instructions from PWD who are representative and senior staffs of IL centers. There also might be problem between PWDs in IL centers. Some PWDs become paid staffs to operate ILCs. Others remain registered members of workshop. There might emerge rupture between PWDs.

Suppose IL centers are successfully launched with the solution of these problems. Other issues would emerge after the establishment of ILCs. One expected issue is the creation of atmosphere to work at ILCs. At the time of sheltered workshops, punctuality might not be strictly required: Some members appear to workshops around 9 AM, and others at 10 or 11 AM. Workshops might blur responsibility to their late or absent.

For IL centers, however, operations and staffs are required clear responsibility. Staffs are required to work with concentration during their work hours. Late or absent without rational reason is not accepted. To be paid staffs, PWDs necessitate certain skills, such as, proper telephone manners, or dealing with requests from service users. For necessary skills, PWD staffs might take training programs. They might also need psychological preparation for their work. For psychological preparation, change of clothes from casual wears to business suits might be interesting attempt.

Figure: Comparison between bodies of movement and enterprise

Body of Movement	Body of Enterprise
Not necessarily be a solid organization	Must be a solid organization
Gather people temporary when necessary	Recruit staffs for everyday work
Not strict to late or absence	Staff cannot take absence without acceptable reason. Office organization should be well arranged.

Only work upon specific issues, such as, accessibility or negotiation with public administrations.	Must provide services responsible to, such as, users' fees, commissions, or subsidies.
Members can act based upon idea and will of each of them.	Teamwork and role sharing between accountant, negotiations, consultations, and peer-counseling.
Staff and members do not necessarily share all principles and information.	Necessity of share principles and information among staff (significance of meetings) Respond not as individual but as organization (All staff should be able to give certain response to contacts from users and other persons even if the absent of person in charge.)
Movement body does not necessarily need continuity (if it achieves objectives, it can stop activities or dissolve itself.)	Necessity of continuity (it cannot quit its provision of services.)
Activities are irregular. Limited range of activities	Significance of regularity of activities, such as, work from 9 AM to 5 PM Social responsibility - Attitude and behavior that can gain trust from society. Wear business suit and tie. (Staff must be careful their social responsibility, especially at the period of transition from body of movement to enterprise.)
Unpaid (not much responsibility and obligation)	Paid (responsibility and obligation)
Blur distinction between activities and private life	Clear distinction between work and private life. Break should be taken evenly by using shift. Necessity to make job contract.

<p>It is possible to run movement body without project schedule.</p>	<p>May & June: Project plan to ask budget to public administration Aug & Sep: Ask budget to public administration Feb & Mar: Making project plan for next year. Necessity of future project plan 1st year - preparation and simulation of project 2nd year - negotiation with public administration, budget negotiation 3rd year - implementation of project</p>
<p>Movement can be organized without budget planning</p>	<p>Budget planning is indispensable (This is also necessary for continuity of activities.) Budget planning in each section of project → wrap-up and coordinate project Arrange project of next year from summer season. Recruit of new staff, preparation for enlargement of organization and new projects.</p>

How does conserve the priority of the body of movement upon that of enterprise?

Establishment of IL center tends to end up failure if founders just want to have organization to provide services. Even though management of the body of enterprise is much easier to understand because there are many concrete examples. Nonetheless, too much incline to the side of the body of enterprise often leads to the dysfunction of IL center.

Organization like IL center which contains both aspect of the body of movement and enterprise is rare historically. Usually, companies and public administrations are the bodies of enterprise and do not commit to movements. On the other hand, anti-nuclear movement is the body of movement and does not work for the provision of services. Different from these organizations, IL center should take balance between the movement and provision of service. Too much inclination to the activities for the provision of services often sacrifices significant movement activities.

Thus, taking balance between the body of movement and enterprise is significant in the management of IL center.

IL centers are the organizations, which are established upon the intentions to realize independent living. PWDs have been despised and put lower status in the society. In order to build equal relationship with non-disabled persons, it is important for PWDs to be employers who pay salaries and service fees. If they are hired in the organization to provide services by non-disabled persons, they cannot have equal relationship. IL centers are the organizations in which representative should be PWD. Reliance upon volunteers for the operation of organizations often puts volunteers above PWDs. In order not to put them above PWDs, IL centers should not depend upon volunteers in their operations, and provide all services as paid.

PWD organizations tend to be established by differences of areas and disabilities. IL centers, however, do not select staffs by disabilities. Rather, PWD staffs are gathered based upon capacities to operate organization for the provision of services. Without this consideration, IL centers are ended up as mere organizations for the movement.

It is indispensable for IL centers to put persons with the most severe physical disabilities upon their significant positions. This necessity is derived from consideration of the general tendency of organization. Generally, organizations for the provision of services need to pay for staffs for their operation. This means that if they cannot pay salaries, they will be dissolved. These organizations, thus, tend to provide services that are highly profitable for them. In the light of profitability, they prefer those who have mild disabilities to severely disabled persons.

IL centers, however, put the priority upon the provision of services for every disabled persons rather than profitability and protection of organizations. They have the most severely disabled persons take significant positions in order not to neglect the services for severely disabled.

Generally, we cannot expect good will of organizations to choose and provide less profitable services. Thus, IL centers also allocate more than 51% of their board members to PWDs as well as putting severely disabled to significant positions, and systematically protect services for severely disabled persons. If IL centers cannot protect life of severely disabled persons, they have better to be dissolved. But, if they recognize the significance of services for severely disabled, they can sustain organizations towards necessary direction.

Generally, organizations have natural tendency of self-multiplication to expand their size when they have surplus. If there are mishandle of surplus for expansion,

they tend to be corrupted. Thus, having clear purpose to use surplus is necessary. On the basis of consideration about this tendency, IL centers use surplus for enriching supports for PWDs rather than increase their own payroll. For example, with surplus, IL centers can increase the number of PWDs whom they support, or expand their services to other type of disabilities.

Organizations have tendency to try to preserve them permanently. For example, residential institutions are busy to gather PWDs because maintaining their existences become the purpose of activities. If these institutions had the will to promote independent living of PWDs, they would have had no resident and, thus, disappeared. This is the same for welfare system. Welfare system exists for those who are put under special conditions. If special conditions were disappeared, welfare system would have lost its necessity. Unfortunately, it seemed difficult for me to expect the realization of the society which does not need welfare system during my life. So, I considered that we must establish IL centers.

IL centers are the system of self-dissolution. This means that IL centers will be unnecessary organizations when all the people have comfortable life in the society as the result of social change. Disabilities are the social production. Our necessity of peer-counseling is derived from social discrimination. Thus, if we have ample life experience without discrimination, we do not need peer-counseling anymore. This is same to PA services. If the ample provision of PA services becomes natural in the society, we do not need to organize movements to demand for supports. If every citizen understands the sovereignty of PA service users, other service providers can also handle PA services. If such society is realized, IL centers will be dissolved in the future. I believe this the best for us.

(Translated by Hiroaki Furihata)

V. Support for Empowerment

Mere support for PWDs does not lead to their empowerment. The key is their subjective participation into the support process.

Those who lived in residential institutions or parents' home for a long time tend not to know how much they can do by themselves because they have depended upon staffs of institutions or family members in many aspects of their life. The lack of experience leads to their anxiety, which reduces their will for independent living. For psychological empowerment, they need to have peer-counseling, and have experience of independent living by taking distance from residential institutions or parents' home temporarily.

1. Support for psychological empowerment

Support for the recovery of self-reliance through peer-counseling is part of the method of psychological empowerment. Psychological establishment of self and acceptance one's own disabilities are tough part of the process as well as acquisition of skills for independent living. Human beings tend to believe themselves as incompetent and valueless if they are continuously told as "don't do this because you are disabled," "you cannot be married," or "you will bother other persons if you go out." Support by peer-counseling is a useful method for PWDs who have suffered from such situations. They regain self-reliance through peer-counseling so that they can have vivid life with self-confidence. That is, they can take the first step for independent living through peer-counseling by opening their closed mind and releasing themselves from trauma.

Peer-counselors inform that having disabilities is a part of "individuality," which is nothing wrong itself. Disabilities, however, have been negatively treated as if they give wrong effect upon personality and dignity. Thus, it is very difficult for PWDs to accept and affirm themselves as they are. Nonetheless, for subjective concerning to social life and pursuit of life with freedom and happiness, realization of self-reliance is indispensable. Self-reliance, hereby, means that PWDs become to like themselves as they are with disabilities.

2. Support for experiential empowerment

There are two types of support for experiential empowerment. One is the utilization of experience room for independent living, and the other is the implementation of independent living programs. Those PWDs who only know the life

at residential institutions or hospital, or that of parents' house, have difficulty in imaging independent living in community. Even if they can, they often have unrealistic images of life. Some of them become too unnecessarily worried to begin independent living. Thus, the use of experience room helps them having concrete and realistic images of independent living in community and recognizing their needs.

Independent living program (ILP) is implemented with the use of experience room, or sometimes independently. For example, in ILP organized by IL center, PWDs learn necessary knowledge and skills for life based on disabilities through practical methods, such as, fieldtrip or role-play. In sum, users recognize their own needs clearly, and learn skills to fulfill their needs through the support for experimental empowerment.

3. Method of experiential empowerment

Utilization of experience room for independent living

The concept of experience of independent living is different from livings in parents' home or residential institutions, and significant process to realize independent living in community. Generally, there are three types of utilization of experience room for independent living:

- (1) Overnight: Purpose of this type of utilization of the room is that user recognizes possibilities of having life outside a residential institution (or parents' house), and has a good opportunity to know oneself. By having overnight stay several times and accumulating experience, user can have self-confidence for challenging to the next step.
- (2) Three days and two nights: This is the plan to experience the assistance for toilet from PA other than family members. If user gets to this stage, he/she has motivation to leave residential institution or parents' house. Utilization of the room in three days and two nights also has purpose for user knowing one's own body and mind and getting used to other persons. That is, this is the process to learn maintaining good human relations.
- (3) One week: Utilization of the room in this length has the purpose for user actually taking a step to begin independent living. Through the life in the room, he/she actually learns how to use PA, such as, the way to give instruction for self-management, the way of communication, or the way to give instruction for cooking. Usually, user takes this process with ILP and peer-counseling.

Experience of independent living in plan (1) and (2) has significance in staying outside of residential institution or parents' house. Experience in plan (3), on the other hand, has significance in users checking their own needs in actual independent living

through one-week experience in the room. Users may have difficulty in finding their needs in everyday life from experience of overnight, or two-night stay in the room despite they can feel the possibility of their independent life. From one week or more use of the room, however, they can recognize their needs because they have to anyhow experience various matters in daily life, such as, meals, bathing, toilet, shopping, or relationships with personal assistants. By using the experience room, they can simulate independent life in community and grasp their want in lifestyles, their needs, and necessary social resources. Peer-counselors support users for grasping and organizing their needs.

4. Independent Living Program (ILP)

IL centers commit to following ILPs. One is the program which is regularly held 2 to 3 hours per week, and continued 10 to 12 times. The other is 3 days intensive course program which is held in the style of study camp. These regular ILPs are usually carried out in a group of 3 to 6 persons. In regular ILPs, participants can stimulate each other. Other than these programs, there is individual ILP that is based upon concrete case of each individual. This is literary the program for a specific individual. Use of IL experimental room is also set in this individual ILP. Users of individual ILP can set the content of program based upon their own pace. Thus, ILP can concern with individual issues and consultations in detail.

ILP has practical contents and is very effective for realization of their independent living. For example, users can learn human relationships, communication with community residents, and trouble shooting through the program. Users also can learn the way of outing through actual field trip practice, and trouble shooting through role-playing. They also visit homes of severely disabled persons who already achieve IL in community, and actually see and hear about realization of dreams.

5. Dispatching personal assistant (PA)

PA service is indispensable for severely disabled persons who live in communities.

We conducted nation-wide survey to severely disabled persons who are leading independent living with PA services. Survey shows 90% of respondents necessitating PAs, contents of assistance, self-choice of service time, and self-decision. It also indicates preference in asking of requests: 60% of respondents are willing to ask to organizations dispatching emergent PA and searching substitute PAs in case of

cancellation.

Personal assistance differs from ordinary commodities. It cannot be generalized by classification and degree of disabilities because needs for assist are highly personal. Even having same degree of disability, persons can have different life styles. For example, one PWD stays in one's own house for the use of computers. There is also PWD who needs more than 8-hour assistance per day due to activities at PWD organization. Some of those who have just achieved transition from residential institution to living in community might consider PAs not to be with them as much as possible, and ask assists only 3 times a day for toileting. In fact, through experiences of failures in toileting in the midnight, or through experiences of using PAs for cooking dinners and for assists three nights per week, they have finally got used to the use of PAs. No one want to use unnecessary number of PAs because over use of PAs often leads to the leak of privacy. As these, personal assistance cannot be generalized as ordinary commodities.

For the realization of need-centered PA service, support for user empowerment is sometimes necessary. For example, when user has troubles about PAs, such as, frequent leave of PAs, it is necessary to inform users about know-how for the establishment of relationship with PAs, the solution of troubles, and the training of PAs. Support methods are referred in independent living programs and *Handbook for Self-managed Care*, published by Human Care Association.

Home help service in activities for house support under monetary support system allows users having less-expensive PA services for daily life support and outing beyond the ordinary framework of helper system. Thus, negotiation with local municipals for shift items in PA service is one method to fill scarcity of necessary time for PA.

(Translated by Hiroaki Furihata)

VI. Peer-counseling Strategy

How peer-counseling is used at IL center in daily basis: Relations with PA service and independent living

It is often heard that even peer-counseling programs for those who hesitate of independent living are recognized, it is not clear what kind of activities peer-counselors do as individual in daily life. It is often asked about the difference between independent living and living alone. Some of those who live alone, however, depend upon other persons or families. IL movement does not say all persons should live in complete independence from other persons. Society is organized because all persons depend each other in certain degree. Life is also enjoyable when one depends on someone in certain degree. Nonetheless, if one too much depends on other persons, that person tends to have feelings of unable to live without dependence to other persons. Such feelings make not only that person unstable, but also PAs felt that they cannot be responsible to such dependence. Then, PAs often quit so that that person runs often into difficulty to maintain independent living.

When PWDs have such troubles in their independent living, peer-counselors will be necessitated. If PWDs have lived at residential institutions or with families for a long period, they are often accustomed with a habit to be sensitive to other persons' moods whenever they ask for something to these persons. They are always discontent as well as servile to other persons. They do not recognize their own problems. In a sense, such habit is the part of art of which PWDs have acquired for going through the life in institutions or protection of families. There is no opportunity to break such habit unless they have will for change the situation.

Thus, troubles, such as, having complains from PAs or ceasing of PAs, are good opportunities, in a sense, for PWDs realizing their habits and recognizing the necessity of change. Peer-counselor can support for change through counseling. If peer-counselor can talk own experiences of similar troubles, counseling could lead to the chance for PWDs to change the habit and improve relations with PAs.

There are many PWDs who can decide to start independent living with the support from peer-counselors. When PWDs are put into closed environment, it is often happened that they fall in love with staffs of institutions or volunteers who are working closely to them. In such case, peer-counselor also can be reliable senior who had similar experiences, which are useful to be listened.

As to making plan of PA services, peer-counselor is reliable colleague who can consult based on own experiences about early stage of independent living. As to troubles with

PAs, peer-counselor can discuss problems with users as same PWDs even if coordinator has difficulty in solving problems. Through participation into peer-counseling and IL program, users are getting to solve problems in relationship with PAs. Even when there are difficulties of coordination between disabled staffs or between disabled and non-disabled staffs, peer-counselors might promote solutions of problems by using peer-counseling method. Thus, at job sites, peer-counseling is often used even without mentioning this term.

Relations between peer-counseling and PA services

IL centers provide PA services based on the situations of users. Some users need PA service for their established independent living in communities. Some want to have service for transition of living from residential institutions or house of families into communities. Others ask for PA service for their practice to establish independent living in the future.

PA services are provided based on the plans for establishing independent living, which are prepared by IL centers based on the situation of each PWD. The plans are always improved in response to new information and conditions. Thus, the plans are changeable even in weekly basis, and difficult for being filed as written documents. Peer-counselors and coordinators only orally confirm directions of the plans. These plans are highly confidential.

Broad framework of the plans towards independent living is decided through meetings. Following persons concern with the decision: Director of IL center, PWD staffs who take in charge of IL, and coordinator (non-PWD) of PA services. It is preferable that the director is also the user of PA services for long hours a day. As to PWD staffs, it is recommended that more than one of them are those who are single and need 24 hour support in daily basis.

PA service and individual IL program are provided to each user as a set. Provision is responsible to the plans, and does not separate PA service and IL program. It is implemented by same staffs in charge under the guideline of organizations based upon the will of service users.

In addition to IL program and PA service, IL center offers various services, which include individual peer-counseling, negotiation with public administration, consultation, advice and provision of information under the guideline of organization. All services are offered based upon perspective of user empowerment. IL center also utilizes IL program and peer-counseling, and supports subjective social participation of users with their use of PAs. It is appreciated if supports to various PWD users lead to

their subjective commitment to the issues, such as, transportation, medical, advocacy, labor, or PWDs at developing countries, for social change and improvement.

Expertise of Peer-counselor

Even though PWDs intend to begin independent living, they often feel anxiety of difficulty in having life in community. Through peer-counseling, peer-counselors can support them to deal with such anxiety by informing their own experiences that tell each PWD has capacity to live independently. Since peer-counselors are PWDs who also experienced similar situations, their words for supports have special significance, which cannot be had from the support by rehabilitation specialists. Peer support from peer-counselors who have same disability and are committing life in community can be incomparable anchorage, while supports from non-disabled PAs and specialists give anxiety of which they might leave with their personal reasons. It is more important than anything else that PWDs take in charge of provision of PA services because they have learned what services users necessitate through their own experiences.

There are attempts to integrate peer-counseling into official qualification system. We, IL centers, are opposing such attempts. Opposing to such attempt does not mean that we are meaninglessly intending to abolish any qualification system. We recognize the necessity of qualification for the guarantee of minimum services and provision to users the guideline of their choice. What we are criticizing is that the official qualification system might wear new authoritarianism as deputy agent of state and paternalistic expertise, which leave PWDs behind.

Japan Council on Independent Living Centers (JIL) has certified peer-counselors with following qualification: Those PWDs who have more than one year experience of independent living and finished 80 hour JIL-organized training program are certified as peer-counselors by the committee at JIL. By preparing our own certification system, we have protected unique operation of peer-counseling without having restriction from public administration.

For not having restriction from public administration, of course, it is prerequisite that civic organizations by PWDs, including IL centers, have solid accomplishments and good social reputation. It is our opinion that qualification of peer-counselors should be certified by PWDs in civic sector, not by agents from public sector.

(Translated by Hiroaki Furihata)

VII. Necessary Medical Knowledge for Independent Living in Community

Necessary medical knowledge

1. Pressure sore

Prevention and skin-check

Don't sit on wheelchair without cushion! If person does not have sensation, only two hour seating may cause pressure sore. Even though that person has sensation, continuous seating on wheelchair without cushion causes sensory paralysis and also lead to pressure sore. Once person has minor pressure sore, it takes about one month to be healed. If that person has serious pressure sore, it takes from 6 months to one year to be cured. If once pressure sore breaks deep layer of skin, it sometimes reaches to bone and kills that person. Pressure sore also sometimes turn to be cancer. So, everybody has to be cautious about pressure sore.

Cushion is useful to prevent having pressure sore. Even cotton or sponge cushion can be useful. But, for those who do not have sensation, ROHO cushion is recommended. ROHO cushion disperses body pressure and stop concentration of pressure upon, such as, ischial bones. You can recognize the effect of ROHO cushion by observing distribution chart of body pressure. Distribution chart of usual sponge cushion indicates that pressure concentrates around ischial bones. It is apparently dangerous if person does not make hole on sponge cushion and disperse pressure. But, distribution chart of ROHO cushion shows that body pressure does not concentrate on.

While dispersing body pressure, you also have to be careful about dampness of cushion. When you sit whole day, cushion absorbs moisture and gets to be damped. Dampness, however, is harmful because it worsens pressure sore. So, it is important to change cushion once in a day. If feces, urine or water is spilled over when you sit on wheelchair, you have to change cushion and clothes immediately. Even small wound on skin might turn into serious pressure sore if you sit wheelchair without changing cushion and clothes.

Every night, especially on the day you feel your hip had hit, you check your hip by mirror or by other persons. Red spot on the skin is the site that was pressed on that day. Most of cases, same site on skin has been always pressed, and is getting to be black. If so, such site might soon become pressure sore when it is damped or soaked because skin of the site is already deteriorated. I have had such site with red spot at ischium for 40 years, and sometimes made scratch on the site when I hit my hips. But I found out scratch soon, and cured by lying myself down for 2 to 3 days. Early

detection and rapid cure are very important.

If you have pressure sore

First-degree: scratch on skin

If you have scratch and see inner skin but no percolation liquid, you stay away from wheelchair and dry and heal scratch in 1 or 2 days. When you have to use wheelchair anyway, you put gauze without vulnerary and stay being careful to dry scratch. If gauze sticks to your skin, you leave it 2 to 3 days until it is naturally removed while taking a bath.

Second-degree: percolation liquid seeping out from wound

You have to cure wound by going to a clinic. You need treatment according to the type of wound. For example, if wound is deep, you put gauze with anti-biotic on it. If wound is better to be dried, you apply ointment. Orthopedists who have ample experiences of treating pressure sore of PWDs are highly recommended. Information about such orthopedists might be obtained from PDWs who also experienced pressure sore.

Third-degree: Lip of wound is small, but its inside becomes like cave.

You need to be hospitalized for a certain period, and have operation. If you left wound intact, it would have reached to your bones and might have been fatal. If wound is detected in relatively earlier stage, it might be cured in a month. For ease of your mind about pressure sore, having certain kinds of operations, such as, flattening the bulge of ischium, or cover ischium by muscle of thigh might be recommended.

2. Urinal Care

Along with treatment of pressure sore, management of urinary system is indispensable for PWDs with spinal cord injury. If you neglect this management, you might have infections of urinary system, such as, inflammations of the bladder or renal pelvis. If infections are not treated well, these often lead to decrease of kidney function, and even fatal situation. Once kidneys are damaged, recovery of functions is difficult. All one can do is to maintain present conditions. Thus, careful management of urinary system is indispensable.

For managing the condition of urinary system, it is necessary to have ample water. It is often said that one should have 2000cc of water per day. Having ample water facilitates urination, and maintain conditions of kidney.

However, some PWDs, especially who have spinal cord injury, reluctant to have much water because they have difficulty in controlling urination. Thus, for urination control, use of certain gadgets might be helpful. For men, portable gadget to collect urination has already been available. For women, since such portable gadget has not yet invented, diaper or urinary catheter for urine collection is available method for urination control.

Another method to prepare for urination is having operations for catheterization. For men who have difficulty in urination by overreaction of bladder sphincter, it is a method to having operation to remove sphincter muscle and insert catheter. This kind of catheterization requires bladder irrigation once or twice in a week. Replacement of catheter is necessary once in a month. One can replace catheter by oneself, but it is better to ask to doctors for replacement for safety. For women, insertion of catheter is sometimes made by surgical incision of abdomen above bladder. If catheter is inserted through abdomen, one cannot replace it by oneself. In this case, replacement of catheter has to be made by doctors once in a month.

Those who are using catheter for urination need to have urine test once or twice a year for examining propagation of germs. Along with urine test, medical check of kidney is also necessary once or twice a year at well-equipped clinic or hospital. Despite of careful attention to health conditions, however, it sometimes happens that germs intrude into body through catheter and cause of infection with high fever. In such a case, immediate medication of antibiotics is necessary to hold in the fever from infection. For this, periodic communication with doctors and preparation of stock of some amount of antibiotics are indispensable.

Continuous use of antibiotics, however, makes resistance in germs and weakens drug efficacy. Thus, it is necessary to check resistance to medications constantly, and to know which antibiotic has efficacy to infections. Such knowledge about antibiotics might save the life in case of urgent hospitalization.

3. Maintenance of correct posture

Maintenance of correct posture is necessary in order to manage health conditions. If one uses unsuitable wheelchair, one sometimes has to bend one's body like a shrimp. Taking posture like shrimp presses viscera and causes difficulty in breathing and blood circulation. In order to maintain correct posture on wheelchair, one modify angle of cushion or height of steps.

Posture on the bed also affects one's health. If one lies face up for a long time, pressure sore often appears at, such as, hips or ankles. Thus, change of body posture

on the bed is necessary once in three to four hours. For those who often have pressure sore, use of mat that disperse body pressure by concavo-convex surface or air-mat that modifies air pressure by electric motor helps taking correct posture and preventing pressure sore. Since wetting mat worsens pressure sore, mat has to be dried all the time.

4. Muscular dystrophy and ventilator

Those who have muscular dystrophy need the support from ventilator when the progress of disability weakens breathing. There are two types of ventilator: positive pressure and negative pressure. Positive pressure ventilator is popularly used currently. This type of ventilator directory pump air into lung. Even those who have weakened breath can sustain 1200cc breathing-capacity. This improves circulation and health condition. Thus, social activities also become possible.

One of ventilators with positive pressure is called “Bipap.” Since it provides air regularly, user needs to be used to the rhythm of breathing. For this, arrangement of Bipap and some training at hospital are necessary. Recently, one model of Bipap is equipped with censer that monitor the rhythm of breathing, and adjust the timing of pumping air. Advantage of this model is that it does not cause of skin problem because it does not use mask but small vinyl tubes that are free from skin irritation.

(Translated by Hiroaki Furihata)

VIII. Necessary Management Abilities as President of IL Center

As the pillar of organization and representative figure to society, president of IL center is required certain qualities for management. To consider necessary qualities, significant roles of the president should be considered at first. Some significant roles of the president of IL center are following:

1. The president makes final decision about activities of IL center

The president has to make decision by him/herself, and be able to explain the reason why he/she makes that decision. The president also owes all responsibility to a result of decision.

2. The president explains to society about significance of IL center

The president has to stress contribution of IL center to society by using any opportunity in order to gain understanding from the society about IL center as PWD-centered organization. He/she has to explain how provision of welfare services by PWDs themselves is efficient and effective. He/she also has to appeal that IL center is the work place where PWDs can utilize their abilities and achieve their empowerment.

3. The president has to converge the views of board members

Management board is the site where board members decide the direction of IL center's activities. In order to converge the views of board members, the president has to be able to explain to board members about certain points of activities in detail with confidence. These points are, for example, concrete procedures of activities to achieve objectives of IL center; expected outcomes within a certain period of time; possible achievement from outcomes; and contribution of IL center's activities to the life of users and other citizens.

4. The president has to organize staff of IL center

Comfortable working environment is indispensable in order for staff working together with satisfaction. For comfortable working environment, the president has to explain to staff about philosophy and significance of IL center clearly and arrange IL center in which staff can work at suitable occupational fields. As to consultation from staff, it is important for the president to listen carefully to what they speak including private issues. As to work, the president should not try to deal with entire works by him/herself, but share works with staff without afraid of their failures. Even though staff make failures, the president should evaluate failures as good experiences for them and cover their works. The president should

also evaluate staff not from their abilities but from their effort to realize their potential.

In order to execute these roles, the president of IL center is required following qualities.

1. The president him/herself should be a role-model who leads independent living
Unless the president manages independent living, he/she cannot explain to staff nor society about significance and activities of IL center persuasively.
2. The president should be able to analyze current conditions and make proper decision based upon future vision
Conditions from state and local municipalities change are ever-changing. Hence, the president is required ability of analysis and decision-making with forethought.
3. The president should be able to grasp conditions of staff constantly and have flexibility to respond to problems without missing opportunities
The president have to be able to work to solve problems flexibly when staff have problems.
4. The president should be able to abandon personal greed and think to change the society for severely disabled persons
If the president had personal greed in management, IL center would have begun to cut off support to severely disabled persons as not profitable. Such person cannot manage IL center.
5. The president should have ability to collect financial resources for management
The president has to be able to know about available systems and foundations, and gain subsidies or grants from them. He/she also has to be able to raise necessary funds from private sector for management of IL center.
6. The president should be able to think hard times and crisis as opportunities, to learn from failures, to be modest about success, to be optimistic, and to commit to management with positive attitude
Troubles in management of IL center often happen. In the same time, however, troubles are opportunities to improve management because these clarify problems of IL center. To turn troubles into opportunities, the president has to be able to think positively as troubles can be overcome definitely when he/she faces them.
7. The president should always be able to set objectives of IL center to improve the quality of users' life rather than to expand the center
If the president are only interested into management, he/she loses interests to users when organization of IL center is expanding.

Human Care Association
1F Myojincho 4-14-1, Hachiojishi, Tokyo, Japan

8. The president should have ability to manage IL center from broader perspective to change society by cooperating with other organizations as social movement body rather than from narrow view point to operate the body of service provision only.

(Translated by Hiroaki Furihata)

IX. Management of Personal Assistant Service

Independent living program (ILP) and peer-counseling course in IL center inform users methods of independent living as knowledge. Personal assistant (PA) service should be provided together with these services for severely disabled persons. PA service plays a role to support life of PWDs when each PWD decides their objectives in life through ILP and peer-counseling. Since PA service is necessary to maintain independent living, any problem in PA service has to be solved through methods of rebuilding human relationship by peer-counseling and problem solution by ILP.

Philosophy of personal assistant service

Major difference between general care service and PA service by IL center is that while general care service targets elderly persons, PA service is provided especially to PWDs. Care service for elderly persons evaluates good credit to care givers if they give service with consideration of preference ahead of request from users. On the contrary, personal assistants in PA service by IL center listen to requests from users and support what users want to do. In general care service, care givers are the center of activities. On the other hand, PWD users are the center in PA service.

In PA service, one of the purposes of assistance is to accompany with young PWDs for that they can accumulate experiences in society and grow up through failures and successes. Since assistance can lead to PWDs' acquisition of new knowledge and enhancement of the sense of self-reliance for managing their own life, PA is very meaningful work. This job, however, may sometimes stressful. This is because PA service is user-centered. Some personal assistants already know the result of behaviors that PWDs have not experienced yet. However, personal assistants have to reserve their intervention even they know better ways of behaviors, and leave behaviors to PWDs' subjectivity. Hence, PA service is sometimes stressful to personal assistants.

In comparison with care service to elderly persons, PA service need to spend longer hours for observation or escort of users. Sometimes personal assistants have to commit to long-hour assistance and night shift.

Personal assistants also sometimes play a role to bridge communication for those who have difficulty in communication due to language or intellectual disabilities. Personal assistants support to inform users' will to other persons with understandable manner. This kind of support, however, requires certain amount of experiences in order to inform other persons not from the standpoint of personal assistants but as

users' own words. Hence, personal assistants have to brush up their skills constantly.

It is better that same organization provides both PA service and ILP/peer-counseling. This is because PA service section can share problems with peer-counselors and PWD staff for ILP, and work for solution together. Some organizations, however, provide only PA service that is coordinated by non-disabled staff. From these organizations, one can see many examples of which their PA services became authoritative and protective that interfere PWDs' empowerment.

System of PA Service

When IL center received a request of personal assistants, coordinator of PA service and peer-counselor make a team and visit to PWD's house at first. There, they interview to gather necessary information, such as, what types of PA service is necessary in which hours in a day, or what are necessary PA service in monthly unit. They also ask questions, for example, usage of welfare equipments, available assistants from family, housing renovation that was already made, or degree of utilization of public welfare services. Presence of peer-counselor in interview is important because it becomes possible for PWD to inform and ask about some sensitive issues such as, bathing or toileting, with relaxed atmosphere. Consultation with peer-counselor also lead to recognition of hidden needs.

After the interview, they return to IL center and hold a meeting with other coordinators and peer-counselors. In the meeting, they discuss whether completion of PA service is possible within current registered personal assistants and other resources. If difficulties are found, the meeting also make decisions, such as, calling for help from other organizations, or recruiting new personal assistants, for realization of service.

After the meeting, coordinator chooses the most suitable personal assistant with consideration of some elements, such as, user's needs, personal characteristics, and distance of houses between user and personal assistant. Then, coordinator brings personal assistant to user's house and teaches how to assist. If personal assistant cannot learn at a time, trainings should be held twice or three times. At the time of personal assistant reaches to satisfactory level for user, IL center offer continuous commitment to assistance.

If personal assistant has health or other problem and finds out difficulty in continuing assistant job during contract term, IL center has to dispatch a person for substitute. In case of emergency, coordinator goes to user's place as substitute. In case of long-term contract, IL center has to find other personal assistant for replacement.

Sometimes user and personal assistant cannot communicate well. Or claims are raised from either side. In such cases, problems are discussed and scrutinized at the weekly meeting by coordinators and peer-counselors. The meeting indicates solutions. Then, peer-counselor consults with PA user, and coordinator to personal assistant, respectively. Through consultations, they accommodate problems. Please remember that the purpose of consultation is to seek for better solutions for both side in order to maintain provision of PA service. If trying to punish either side, coordination may end up with failure.

At the end of month, user of PA service has to submit the monthly usage report about amount of PA service to IL center. Based upon the report, IL center makes out invoice and collects service fee from user. Sometime in the early part of next month, salary is paid to personal assistant at the office of IL center. At that time, coordinator asks personal assistant to inform about any problems in PA service and requests to IL center. Feedback from personal assistant is significant opportunity for IL center to grasp any change and problem in PA service in a month.

Volunteer- and Paid-systems

Equal relationship between user and personal assistant is ideal for IL center. For a long time, PWDs have had to rely upon volunteer assistants. Since they have to rely upon good will of volunteers, many PWDs have felt hesitation or even the sense of guilty when they ask some assistance. It is true that many of them have also felt that they had better not to do anything if they bothered other persons and spent inactive life.

Despite of such problem, however, IL center at initial stage may have to use volunteer-based PA service by necessity when public support for PA system is not established yet. In such situation, IL center have to be really careful to establish and maintain equal relationship between users and personal assistants. For this purpose, staff of IL center constantly have to discuss how to train personal assistants and their mental attitudes. IL center may also need to care for certain issues about assistants, such as, fees for transportation and meals. It is also necessary for IL center to be careful about sexuality of user and assistant. It is often reported that some provision of PA service, especially in rural area, use assistance in different sex due to difficulty in finding male personal assistants. Assistance in different sex, however, often cause of troubles. Hence, IL center should cling to assistance in same sex as general rule.

When PWD receives assistance, he/she owes certain sense of debts to personal assistant. In volunteer-system, PWDs have paid debts by saying “thank you” or “I am sorry for bothering you.” For PWDs, however, asking volunteers for a long period, such

as, asking to wake him/her up 7 o'clock every morning for a year, is surely heavy psychological burden. In such situation, paid-system of PA service is the most effective method to reduce psychological burden because PWDs can pay back debts by cash. There are some other merits in paid-system. For example, IL center can establish equal relationship between users and personal assistants by users having rights to dismiss bad personal assistants and maintaining employment of good assistants. Paid-system also has merits in recruiting personal assistants for difficult or severe assistance as paid work. Some PWDs may have difficulty in recruiting personal assistants in volunteer system. In paid-system, however, such difficulty is also resolved.

Due to above reasons, PA service with paid-system is ideal for IL center. For realization of paid-system, IL center(s) have to negotiate with public administration for establishment of institutionalized public support for PA service. This negotiation is necessary because there is difficulty for IL center sustaining this system only by its own resources.

Fee for PA service are used for labor cost. Hourly wage of personal assistant is set within payable amount in society. Both developed and developing countries have their own standards of payable amount. Hence, it is misunderstanding that only society of developed country can establish paid-system of PA service.

Unlike the establishment of residential institutions, PA service does not need huge amount of financial resources for operation. Any IL center can begin PA service immediately if service is provided as a model case.

The role of IL center is to launch a model case of PA service. It is better for you to consider that the establishment of institutionalized PA service system is the role of state or local administrations. For the establishment of the system, however, IL center as social movement organization has high responsibility to negotiate with state or local administrations. Without activities as social movement organization, PA service is remained as model case and cannot save many ordinary PWDs.

Recruitment of Personal Assistants

PWDs tend to prefer personal assistants from young part-time workers or students rather than senior persons. Such preference may cause from that many PWDs feel assistance from senior persons as if they are put under custody or control of parents. On the other hand, PWDs feel easier to manage and give instructions to younger personal assistants. It is also easier for them to say opinions and complaints. Active PWDs may also prefer young personal assistants because they can go out

together for activities, such as, sports, hiking, walking town, or watching movies.

Recruitment of personal assistants mainly targets students and young part-time workers. For recruitment, we ask to universities to put up posters on bulletin boards, and hand out leaflets on a street or in front of a station. We also ask to university instructors for letting us speak during lecture hours about necessity of personal assistants, or ask some other persons to notice their friends about recruitment. Putting up posters in town, or use of media, such as, community magazines, newspapers, journals, or radio-television is also effective method for recruitment. (*See a sample*)

After receiving a phone-call for application, IL center organizes a briefing session within a week. In the session, we explain philosophy of PA service by IL center, wage and transportation fee, and very basics of assistance such as how to push a wheelchair. Those applicants who understand and agree with the contents of PA service register to IL center as members of PA service.

If a PWD personally wants to recruit assistants, IL center can also assist that person. In such case, that person pays fee to IL center for advertising. IL center can be a site for contact and interview of applicants, and assists training of personal assistants.

Role of Coordinator

Coordinators stay at the office of IL center and coordinate PA service based upon requests. They also take in charge of following works: organization of interview with new users; introduction of new personal assistants to users; substitute of personal assistants in case of emergent requests of PA service for night or weekend. Coordinators have to memorize every location of user's house and grasp all the contents of assistance. Coordination between users and personal assistants is especially significant work of coordinators. They spend considerable amount of energy for coordination in order to respect wills of both users and assistants as well as not damaging anyone in PA service.

Coordinators also have to take in charge of various office works, such as, preparation of PA training meeting, management of office documents, organizing assistance records, arrangement of monthly PA schedule of each user, collection of service fee from users and payment to personal assistant.

Generally, more than three male and three female coordinators work as a team. In order that all coordinators can respond to any problem, they have to share information. For example, responsible coordinators in certain work period inform to next coordinators in charge about requests of assistance and troubles that they received.

Both male and female coordinators are necessary for IL center because there are various issues which are preferable for users to speak to coordinator with same sex.

Role of Peer-counselor

Peer-counselors with other staff with disabilities participate into coordination meeting that is held once in a week at IL center. They lead the meeting in terms of PWDs for the provision of PA service based upon user's will. The meeting sometime reports certain problems, which are derived from the user's lack of social experience or excessive preference to specific personal assistant and difficult to be solved only with the effort of personal assistants. Along with coordinators, peer-counselors seek for solutions of such problems.

Peer-counselors also work with users who have difficulty in using personal assistants. Generally, IL center asks users to take peer-counseling and independent living programs before they begin independent living with PA service. However, sometimes there are users who have already began independent living without taking these programs. Since some of them still have not been able to accept their disabilities or cannot consider of situations of personal assistants, they often have difficulty in using assistants. Some of them spent more than 20 years in residential institutions or family home and also have difficulty in using peer-counseling. Peer-counselors and staff of IL center consider that their difficulties are not attributed to themselves but derived as social problems, and work with such users by taking plenty of time.

Coordination Meeting of PA Service

Coordination meeting is held once in a week. In the meeting, coordinators report problems, which were happened in previous week and necessary to be shared with all staff members. Through the solutions of these problems, certain rules can be composed in order to respond to specific needs of users, even though IL center is not willing to decide rules that is applied to whole PA service. Examples of specific rules discussed at coordination meetings are following: Those who serve to night shift can take half-day off: If assistance to bathing is burden to a single personal assistant, his/her burden should be reduced by increasing the number of assistants to two: Different wage should be applied when personal assistants accompany to one week trip of users. Coordination meetings have also discussed following points: Who would pay meals of personal assistant if shift of assistance covers meal time: Who would pay transportation and entrance fees: How to deal with absence of student personal assistants during long school holidays and at the end of school years. Employment

about new staff of IL center is also discussed at coordination meetings.

Training of Personal Assistants

IL center organize training meeting of personal assistants once in a month. In the morning section of the meeting, philosophy of personal assistance, necessary attitude of personal assistant, way of assisting persons with cerebral palsy, muscular dystrophy, and cervical cord injury. During lunch hour, participants assist taking meals each other and have experience as users. In the afternoon section of the meeting, participants push wheelchair one after the other and have training of assistance of outing even sometime by boarding on a train.

In case of difficult assistance based upon personal needs of users, specific trainings are organized at user's house. For example, for assistance of users who use ventilators, training of how to operate ventilators and how to vacuum up sputum is held with instructions from doctor or family members. Assistance for bathing needs user by user training because ways of bathing differ greatly in users.

Program of Basic PA Training at the Time of Registration

• Morning section

What is Independent Living Center?

History of independent living movement and IL center

User-centered service

Philosophy of PA service

Ethics of Personal Assistant

Basic attitude as personal assistant

Points of attention and agreements for assistance

Explanations about Disabilities

Explanations about three major physical disabilities (cerebral palsy, cervical cord injury, and muscular dystrophy)

Points of attention for assistance

• Afternoon section

Practice of Basic Assistance

Outing by wheelchair

Transfer to wheelchair, change of positions, change of clothes

Registration to IL Center

Sample of Recruitment Advertising

電 京王八王子駅歩3分
八王子 介助スタッフ
時給800円~1,400円
未経験 歓迎
フリー 時・曜 応相談

在宅障害者の生活をお手伝いする
お仕事です!! 未経験の方も大歓迎!!



仕事内容 ▶ 障害者の身辺、及び生活介助です。
※未経験の方でもしっかりとした研修がある
ので安心です。
勤務地 ▶ 八王子市
時間 ▶ 8:00~17:00(16:00)
16:00~22:00, 19:30~22:00
22:00~翌8:00(多少の変動あり)
※週1日からOK / 他時間帯あり
資格 ▶ 18~40才位
※未経験者歓迎!
※ホームヘルパー2級取得者は
尚、歓迎します!!
待遇 ▶ 交通費1日1,000円迄支給
業種 ▶ 障害者の在宅介助サービス及び障害者の
自立生活サポート
応募 ▶ 1枚の上、履歴書(写真貼付)ご持参下さい。
P R ▶ 在宅障害者介助のバイオニア的団体です。

八王子市明神町4-14-1
リーベンスハイム八王子PART1-1F
☎0426-46-4877 採用担当

ヒューマンケア協会・ケア八王子

(Translated by Hiroaki Furihata)

X. ILC Management: Budgeting, Planning and Fundraising

When we establish IL center, we have to find financial resources. Nevertheless, no one is willing to provide financial support if there is not project plan about IL center. Therefore, it is very important for us to make project plan. Let's think about one year project of IL center. What are necessary activities of IL center? Independent living program (ILP), peer-counseling and personal assistant service are indispensable activities of IL center. For organizing peer-counseling course, we need peer-counselors. If our IL center does not have peer-counselors, we have to invite from other IL centers. But, we have to pay some costs to invite them. In order to launch personal assistant service on volunteer basis, we have to put up posters and hand in leaflets. For this activity, we hire part-time staff. However, we also need some costs for staff. Without office and telephone, we cannot receive contacts from those who want to be personal assistants. Hence, we need a rent of office, office equipment and facilities, such as, telephones. Office is also equipped with accessible toilet, which needs cost for renovation. To open office permanently, we also have to employ at least one non-disabled staff. While putting aside the issue whether you carry out these activities at once, these information make you possible to consider a project plan about first year activities of IL center. If you once make the plan, the total amount of necessary fund become clear as the target of fund raising. Based upon this, you will prepare a plan for fund raising.

Fund-raising plan must include following contents:

1. Background of necessity of the project: The plan must explain background of why IL center needs to provide services, such as, personal assistance or peer-counseling. Explanation should be easily understood by officials and staff of foundations.
2. Project plan: Fund-raising plan must be attached with one-year project plan.
3. Budget for the project: When you prepare the budget, you have to write details of each item. Details may include, such as, the number of persons, unit price, or process of calculation.
4. Expected result of the project: Fund-raising plan must explain expected results, such as, possible achievement in terms of the purposes of IL center and its spillover effects. Please remember that foundations for grant tend not to be persuaded if the plan only refers to achievement within single IL center. Since the

foundations attach importance to spillover effects of the project, explanation about possible spillover effects may be decisive for acquisition of grant. Possible spillover effects include, such as, nation-wide establishment of other centers, cultivation of PWD leaders, or establishment of personal assistant system in the country.

After you make the fund-raising plan, you need to research which foundation is willing to accept the plan. It is the best if you can visit foundation and present the plan. When you send the plan by mail, it is effective if you attach materials that are not necessarily required in application form. Such materials include newsletters, articles about your organization, related documents and photos. Recommendation letters by persons who concern with foundation are highly supportive for acquisition of grant.

(Translated by Hiroaki Furihata)

XI. Problem Solving

When a trouble has taken place between a PWD and his/her attendant, it is a principle that both a disabled staff in charge of ILP (ILP staff) and a non-disabled coordinator will intervene them for mediation. Sometimes a meeting will be arranged where these four persons assemble for discussion in one place. Such a way of problem solving based on a principle as it were "a two-way support principle" is superior to the other methods because it promotes constructive talks between the parties, also makes it possible for ILC to be on neutral ground.

Troubles that often arise

It rarely happens that the cause of a trouble can be attributed to either party. Mostly both parties are required to make some reflection and improvement. Why it has happened and how it can be settled depend on the kind of relationship between the PWD and the attendant. So any action for problem solving should be based on this recognition. Here are examples of troubles that frequently occur:

Case 1: Unpunctuality

Claim by A (PWD): "Attendant B often comes late behind schedule. 2 or 3 minutes delays are taken for granted. When he/she was nearly one hour late, he/she made a phone-call to me, but in other cases never made contact with me beforehand. I warned him/her not to come late, but couldn't improve his/her attitude."

Case 2: Abuse of confidentiality

Claim by C (PWD): "When I had tea with a friend of mine D, a PWD, D said "I heard you had gone to see that movie. Was it exciting?" I did remember not telling D of the movie before, so asked D from whom D had heard of it. D answered he/she had known from the attendant E who is working for both of us. I think it's not a serious issue, but I feel very ill at ease because E might tell anyone even those things about myself I don't want to be known to others."

Case 3: Complaint of a personal assistant (PA)

1) PA F complaints: "I was told by the employer G to go and buy long onion for supper. Although the price seemed relatively too high, I bought some and brought it home. However, I was scolded by G, "Too much expensive. I didn't tell you to buy it at

such a high price."

2) PA H complaints: "I always feel at sea because there is little dialogue between me and the employer J. I have no plan how I could break this uncomfortable situation. One day J told me of the other attendant very amusing. Hearing it, I felt more discouraged."

These are just a few examples. It's not too much to say if there are 20 kinds of attendant-employer relationships, the same or more number of different troubles may occur.

Now let's examine how to deal with various daily happenings:

How the matter has come to be known is important

As is often the case, a third person has come to know a trouble between an attendant and its employer, and informs ILC of it. In this case, the following manner is recommended: You (an ILC staff) should thank the informer saying, "We appreciate your help. We are going to have a talk with the person concerned."

But don't forget to say in addition, "If you are consulted with that person again, would you advise him/her to go to ILC." Strictly speaking this case shows a confidentiality problem, because the third person must have heard of the trouble from either party concerned. But the important thing is not to find fault with him/her, but to use this as a chance to build a close relationship between ILC and those clients. Usually an attendant goes to the employer's house directly and back home without dropping into ILC. This easily leads to distant relations between them. So when such a trouble takes place, it is recommended you should take this as a rare chance to let the attendant and the employer realize once again that ILC could serve as a mediator, also they have the duty of confidentiality.

Fact-finding

In principle, claims from a PWD should be dealt with by a disabled staff in charge of ILP, also those from attendants should be by a non-disabled coordinator. The important thing to be noticed here is that a trouble which seems to have arisen from some temporary cause might be a more serious problem that shows the building-up of stress between the two parties. If so, all the persons concerned have to realize this. You should make a lot of time for interviews to find out more about the matter.

Talking the matter out

When requested for consultation, a staff in charge of ILP (ILP staff) and a coordinator should try to find out the fact. Also they have to decide whether any discussion between the parties are necessary or not, and how it should be done if necessary.

If the problem is not so severe, it would be better for the persons concerned to have a face-to-face talk and decide among them. When such method is impracticable, or ILC considers its intervention needed, it is recommended to arrange a meeting where the two parties and ILC staffs talk together over the matter. ILC's intervention has its merit in offering an opportunity for a heart-to-heart talk between the parties. However the most important thing is to encourage them to correctly recognize the point of the matter and manage to find out any solution for themselves. Even in the quadripartite meeting, the participants should keep this in mind.

Dealing with the aftermath

If direct talks were made among the persons concerned, ILC should ask them of the result and consider whether it should arrange a quadripartite meeting when requested by either party. Whichever way of solution ILC has chosen, dealing with the aftermath is important.

When some trouble has taken place between an attendant and his/her employer, their relationship becomes somewhat worse. If even in this case the same person-to-person care still continues as before, it must be intolerable to those concerned. ILC has to try to set matters right, keeping an eye on whether the cause of the trouble has vanished or not.

Concretely speaking, two weeks or one month after the meeting, the ILP staff should have a talk with the concerned PWD and the coordinator with the attendant over how the case has developed thereafter. This smoothing over must be done periodically.

With all these abovementioned in mind, we can say it is impossible to know what has happened at the actual spot without visiting the PWD's house or talking directly with him/her or his/her attendant. So we have to keep in mind that the obligation of ILC as an attendant-placement agency cannot be fulfilled by making such actions only after the trouble, but by striving for it on a day-to-day basis based on the understanding of its importance.

(Translated by Tsukasa Abe)

XII. Recruit and Employment of Staff: Human Resource Acquisition and Development

Discovering and training a competent PWD

I often hear people say there are only few disabled persons, or no self-group of them or no potential leader with disability around here. In such a case how should we call in IL service users and develop an independent living center (ILC)?

Any region has no such a center at first. So you must find a disabled person who could be a leader or a central figure for building-up of an ILC as a first step. However, every potential leader with some disability cannot shoulder the burden of management of an ILC. The ILC provides various types of care services, so one cannot give an adequate advice on its services or attendants if he/she isn't in need of such services as well as a regular user of them. Even if he/she has been acting as a community leader for a certain group with years tradition, it doesn't of itself prove his/her competence as a peer counselor. Rather, a disabled person having experienced an independent living can be a suitable counselor for those who want to carry such a life. As he/she has lived so for a long time, he /she must have much information about community care services and met so many troubles as to come to know fully how to solve them. He /she can be a reliable person for those to consult with.

On the other hand, such a predecessor might be felt by the followers as if a goal beyond their reach. In this case, a disabled person with only one-year experience of independence can be a more suitable counselor than those with 10 years' career, because the challengers feel the former closer to themselves than the latter. Also he/she can talk about his/her independent life in a more lively way and offer a mental support. "Role model" means such a person who can set an actual example by him/herself. It is necessary to gain co-operation from those whenever needed.

When there is no self-support group in a region, it's one of the ILC's role to build up such but not so easy a task. First, you should find a disabled person leading an independent life. Go to sheltered workshops or nursing care facilities, or visit disability groups to collect such information.

However, in most cities and towns or villages there must be neither disabled person who has carried an independent life in the community even for two years, nor disability group that provides such services as to enable an independent living. No such services are borne without any user of them, and vice versa. In those cities, towns and villages where severely disabled people are forced to stay within their houses or

institutions, you should transform the existing community care services into those enriched in such services as to enable an independent life, taking whoever really wants to live independently as a role model.

When a self-support group is borne with the severely disabled person as its core, the environment surrounding those will surely begin to change.

For newly employed staff, we organize training program with following contents:

Training Program at Human Care Association for Newly Employed Staff

- Mental Attitude as Staff of IL Center
- The Concept of Independent Living, and the Role of IL Center
- Mental Attitude as a Member of Society
- Philosophy of Personal Assistance Service, and Task of Coordinator
- What Is Independent Living Program?
- What Is Peer-counseling?
- History of Independent Living Movement and Human Care Association
- Welfare Systems for PWDs in General

Recruit, interview and training

Careful consideration is needed before hiring staff. Once you have accepted somebody as a staff into your ICL, you cannot dismiss him/her too easily whether he/she is a PWD or not.

For hiring a non-disabled staff, you must make sure that a candidate really wants to work for the ILC. If he/she has only a vague idea of working for the welfare of disabled people, he/she is considered disqualified for an ILC staff. Particularly such a person as have a long-year experience of working in institutions, though well acquainted with PWDs, is not suitable because he/she wears a bad habit of "protection and control". However, if one has come to dislike working in institutions after three-months and visited us, he/she can be a candidate for our staff. We could welcome those having no working experience in this field. An interview to a non-disabled candidate will begin with the question whether he/she can do bathing or toilet assistance without reluctance. If the candidate hates to do such assistance, it proves that he/she does not think a PWD to be a human being. It's impossible to build an

equal relationship between such a person and a disabled one. You had better not try it from the first. Some candidates might show willingness to do any kind of assistance because one usually makes utmost efforts to get a job in such a situation. So you should make a full explanation about what it is to work in an ILC as follows. ILC's fundamental concept is that disabled people should form the core of its staff, so non-disabled employees cannot be promoted to the top however tenacious they may be in their work. You have to ask the candidate if he/she is willing to work on week-ends or until late at night, and if he/she can get an approval on it from his/her family. A non-disabled staff is sometimes called on to go to a client's house in a short time when needed, so he/she is required to live close to them. Also he/she must have some means of moving, such as cars or automobiles, for going out at midnight. Finally it must be ascertained whether the candidate has no lower-back pain and is not sensitive to colds.

When the interview is finished, two or three of 10 applicants are left as candidates. As the next step, pick up one of these left who looks the least suited for our work and make him/her try to work as an attendant for one week or so. Of course, a senior coordinator will go with him/her to the client's house at first. During this, you have to pay attention to the client's response and ask your coordinator whether the candidate has a good sense for the job. There are some who might change their attitude toward the client when only two of them are left, even though he/she showed a polite way of speaking to the client while the coordinator stayed with them. To bring him/her deliberately into a quiet client is a good way to expose the candidate's true colors.

Coordinator is a stressful job. So ask the candidate if he/she has a stress relief method of his/her own or what type of hobby he/she has. If the candidate gives you a clear answer, such as playing sports or talking with friends, it is OK. One who has worked in hospitality industry can easily become an expert at attending a PWD. So work experience is one of important points in judging the suitability of a candidate.

Finally we choose only one of these candidates. After three months trial, this person will become a regular employee if both ICL and he/she agree to it. Some person may quit after the trial period even if he/she has passed the initial training of a few weeks. It depends on his/her true nature, that is, whether he/she really likes to take care of others. If working in ICL doesn't suit the candidate's personality, it must be happier for him/her not to do such work and the same for the ILC not to accept him/her as a staff.

Employment of staff with disability

For a disabled person to be hired as an ILC staff, he/she must have carried an independent life at least for one or two years and gone through such experiences as receiving an attendant care, renting a room, remodeling his/her house and using governmental services. Briefly speaking, taking pains to undergo such experiences is needed. I have worked in an ILC for a long time, to find that disabled people without any exception want to work stylishly. Of course they want money. Some cannot understand why he/she has not been hired while another disabled one employed. The important thing in hiring disabled persons is not that they have a working capability in its general sense, but that they are competent for the tasks needed in an ICL. So we don't hurry in coming into an employment relationship. For example, when some disabled person comes to our ICL and wants to work with us, we ask if he/she is willing to take one-or-two-year training. If he/she says yes, we first give a lecture on the concept of the ICL and tell him/her to take notes and submit a report on it within one week. At the next step, we begin to teach about services and projects we offer one by one, so the trainee is forced to write a report on each topic. One who cannot write letters because of disability in hands or illiteracy may make his/her own attendant to write down what the trainee says. Such a person as highly motivated will read voluntarily those books related to the topics and add what he/she has learned to his/her report. If the trainee doesn't submit a report, he/she will fail. As this initial training will last for seven to ten days, it must be fairly hard to continue making reports. Trainees sometimes give questions or express their opinions and we give answers.

Then the trainee is required to take a course for training peer counselors and participate in an independent living program (ILP). It doesn't matter whether these are offered by us or the other organizations. We provide the trainee with such entry fees as needed, but pay no money as a salary. Some might show eagerness to join these courses and programs. To such a really motivated person, we offer a chance to attend our internal meetings at least twice a week, which enables him/her to know the situation inside. Then we ask him/her to do some work, such as an assistant to the ILP, of course on a paid basis. It takes about two or three years for a trainee to enter this stage. The trainee is now expected to develop him/her self to become a peer counselor in the near future.

When he/she has got accustomed to coming to the office twice a week and become able to do some paperwork related to peer counseling courses and ILPs, we enter into an employment relationship with him/her.

It seems too deliberate and waste of time to make a disabled person to follow such

many steps, but is really a good thing for him/her because he/she can learn how to do the work gradually. Now both disabled probationers and non-disabled ones are required to take a joint training for new comers. One or two hour lecture is delivered as to each of the following topics such as rules for work, difference from the other business offices, non-disabled staff's obligation to serve as a supporter for disabled counterparts, the concept of an independent living and the role of an ILC. You had better make a paper where the topics are described so that any staff could give a same lecture. As many of these would-be employees have just graduated from schools or colleges, we urge them to have self-awareness as working adults. We even teach such fundamental skills as manners on the phone. Particularly in case of a disabled person who has been unaccustomed to answering the phone, we tell him/her to inquire the person on the other end of the name, phone number and things to be done, also put down the time when he/she received the call. It's the role of the office president or managing director to speak about the ideology behind the attendant care services and the details of rules and responsibilities of a coordinator. The purpose of this lecture is to strongly impress the newcomers of the face of the person who employs them and represents the whole organization. So the president must make such a speech for him/herself, never leave it to another.

For peer counseling services and ILPs, those staff in charge of them will speak. For the independent living movement and the history of the ILC, any staff should be prepared to speak. Newcomers are told to form a habit of taking notes on all these lectures. It takes one hour and a half to give a lecture on any of these topics. So the joint training spends four days, with three lectures per day. It means every staff should be able to make a speech of such length.

Fostering the sense of togetherness

Sense of togetherness

Each staff, whether disabled or not, is different from another in competence, or in strengths and weaknesses. If all work in the same condition, those blessed with physical strength or ability in its general sense will surely overwhelm the others. ILC has the principle as its basis that disabled persons who are inferior to non-disabled ones in working efficiency should take the lead in its management. So it is not enough to follow the examples of business enterprises or public corporations.

In an ILC, the meaning of the word "work" is redefined as in the follows:

1. Anyone is never requested to work beyond the limit of his/her ability and physical strength, and should be offered a place where he/she can work to show most

- efficiently his/her ability acquired in his/her own life, such as living skills, educational know-how, etc, while necessary support is given by non-disabled staff.
2. As a precondition for working in an ILC, a disabled person should be independent both in public and private, also have surplus power and emotional stability much enough to help others.
 3. Non-disabled staff should help those disabled to work if necessary when something irregular has taken place. If a disabled staff wants a regular care on the job site, an assistant for his/her use only should be offered by the ILC as far as possible.
 4. Whether a severely disabled person totally dependent will become able to live independently with the help of an ILC is a living proof of the quality and the level of the services it provides. So it becomes one of the goals for an ILC to enable the most severely disabled person to work in the ILC and clear the hurdles mentioned here (1, 2 and 3).

We can say easily that disabled persons take the leadership in management of an ILC, but nothing can be done if both disabled staff and non-disabled ones don't work as if in one body. So a full discussion among them at the time of the formers' entry is an evitable so as to bear an agreement about the above-mentioned point 3. Without such consent by non-disabled staff, the sense of togetherness will never arise. Disabled newcomers should be urged to understand fully what the point 2 means. Particularly for those who cannot be sure of their capability to work, it's necessary to tell that the kind of disabled persons needed in the ILC is not those of much working ability in its general sense, but those who have cleared the hurdle 1 and 2. Be sure to urge them to work together with enthusiasm.

(Translated by Tsukasa Abe)

XIII. In-office Care

If a disabled staff needs an assistant care when at work in the ILC, how should we deal with this?

When I set up an ILC in Japan, I had neither such experience nor any know-how about it. So I did a great deal of trial and error.

While at work in the ILC, I need somebody to assist me in dialing the phone, taking notes, bringing documents down from the shelf, etc. It must be burdensome for anyone of the non-disabled staff to do such attendant care works other than his/her duties. So I once employed a secretary as my personal assistant (PA) on the job site. But it didn't go well because, as I am the president (head chief) of the ILC, this part-time PA came to have an easy access to such secret data and information only for insiders. It might cause some secrecy to come out anyway. At last I decided in consultation with the rest of the staff to divide the care works for myself among all of them.

It's considerably easy for the president (head chief) to ask any staff to help him/her, but not so for an ordinary employee who is disabled. In a very important meeting full of secrets, we tell the disabled staff to make his/her PA to leave the room. We also urge him/her to ask another non-disabled staff to take notes or make a report on his/her behalf. In this way the disabled staff is expected to learn how to get somebody's help wherever and whenever he/she needs assistance while at work. So in the Monday meeting of our ILC, disabled staff shows when and where they need such an in-house assistance this week and non-disabled staff not busy for the week will respond to the requests. Providing such a care is an extra work for non-disabled staff, so they might feel displeased with it if it increases too much. In order for this not to happen, non-disabled newcomers are told that assisting those disabled staff is an essential element of their work at ILC. Disabled staff cannot continue his/her work if he/she has fallen a pen or been unable to take out some file, and no other staff has helped him/her to pick it up or take it out. In this case, helping this disabled staff has a high priority, so any non-disabled staff should go for it even at the cost of his/her own work. Be sure to tell non-disabled newcomers emphatically about this at the time of entry into the ICL. It's important to make them realize they need to work at ICL in a different manner from that in any other place.

When a non-disabled newcomer comes to work with us, for example, we always tell him/her why he/she cannot be promoted to the top of our ICL. I say, "If ever you

are the president (head chief) of the ILC, can you give priority to helping disabled people at the cost of your life? I'm sure to do it because I am disabled." To become the top of the ILC exactly means this. The duties of the president of an ILC cannot be fulfilled without a firm resolution to protect the lives of disabled users at the cost of one's own life. In contrast with ordinary business corporations and NPOs, an ILC is mainly composed of disabled persons.

So non-disabled ones cannot work together with disabled counterparts unless they share the same dreams and hopes with them. That is, they must have a vision of realizing a community where the most severely disabled people can live independently, in other words a social reform for the welfare of the disabled.

Working conditions differ between the two. Some of disabled staff work three or four days a week, while non-disabled ones are requested to work for five days in principle. If a disabled person has continued working overtime, his/her strength won't last for long. So disabled staff always go home at 5:00, with the rest of work left to non-disabled staff. I mean, every disabled staff should be aware of the limit of his/her strength and try not to go beyond it. But all of the staff don't go home at 5:00. I stay in the office until 6:00 p.m., and those in excellent health will sometimes stay until 7:00. Each person's working pattern is decided on his/her declaration as to how many hours a day he/she wants to work.

This is the way of the ILC. Of course, non-disabled staffs declare their pattern as they like it. For example, when one has worked overnight, he/she will take a day off for the next day. Disabled staff should realize that the burden is relatively heavy for non-disabled ones and be careful not to give too much burden on them. All this is what I mean by division of roles between the disabled staff and the non-disabled ones.

Disabled staff and Coordinator

There is no rule about it whether a coordinator should be a disabled person or not. In a certain ILC I know, coordinators are categorized into several groups and the leaders of each group are all disabled persons. There are both male and female ones. Both disabled coordinators and non-disabled ones have merits as well as demerits. When there are non-disabled coordinators only, they do all of the needed works such as answering the phone, giving advice to personal assistants and users, etc. This may cause a deep rift between coordinators and disabled users. In contrast, disabled coordinators are likely to be too partial to users because they have no experience of working as personal assistants. So a good coordinator is, I think, one who understands well both demerits. In our ILC, to remedy such a defect, a disabled staff participates in

the weekly meeting of non-disabled coordinators. Also he/she regularly reads the daily report and give an advice if requested by a non-disabled one.

Non-disabled coordinators sometimes face an issue very hard to make a decision on it by themselves, but it will become easier to solve when a disabled staff joins in the discussion. For example, a certain user with some problem in mental health has requested a PA to stay with him/her all day long. Non-disabled coordinators have been at the mercy of this user and unable to say no. They cannot come to a clear conclusion that helping the user (client) is one thing, but responding to such a selfish demand is another. In this case, only a disabled staff could take a realistic attitude and make a decision to separate the former from the latter.

Coordinators are responsible for several support services to users, and they act jointly with GM in any service provision. No coordinators are allowed to decide on their own initiative. For example, if a user has caused an accident to expose somebody to serious harm, the coordinator taking care of this user will surely consult with GM about it whether it's necessary to give any support to the user or how and to what extent he/she should provide such support. All the other arrangements such as matching of PAs, rotation, etc. are made on the final say of GM.

Of course the way of management differs from one ILC to another. I do not mean our way of doing things is the one and only.

Sometimes a disabled staff gives a hard advice to a user. He/she may be disliked by that user. However, we are sure the fundamentally important thing must be understood by this user. We are committed to protecting the lives of users and providing services to support their living. It's because they realize this why no user would fly away from us. The most difficult thing is to build up such a relationship of trust. It is often the case with ILCs that because of a problem user and PA will quit one after another. There are some users who have caused similar problems repeatedly for ten years and been unable to alter their attitude. I don't think the users are only to blame for this. The fundamental reason why this happens is that people with severe disability tend to lack in life experience as a member of society. We should rather put the blame on the society that has kept those disabled in institutions or within houses.

At present, ILC has no option but to take the responsibility of training those to be mature adults. In our ILC, we sometimes change PAs when a trouble has occurred between a user and an attendant, for leaving the situation as it is will worsen their relationship. However, it doesn't lead to a fundamental solution. We consider it important to continue providing a support even to such a problem user, and wait for a long time for the user to alter his/her personality. If there is no PA to replace the one

Human Care Association
1F Myojincho 4-14-1, Hachiojishi, Tokyo, Japan

who has left from that user, we take it as a good chance to have a talk and urge him/her to change his/her attitude. Sometimes we succeed, but sometimes fail. It's always a challenging issue for every ILC. Also it depends on what kind of education disabled people have received from their childhood days. If the education undergoes a change for the better, the situation will improve a lot and there will be no need for IL programs or peer counseling.

You are doing one of the most difficult tasks, so be sure to be proud of it and enjoy yourself

(Translated by Tsukasa Abe)

XIV. IL Movement in Asia

Independent Living Movement in Developing Countries

It has been many years since experts of rehabilitation recommended training and educations to people with disabilities to enable them to get jobs as non disabled people do. The experts believe that independence means only economical independence. As a result, parents think it impossible for their disabled children to live independently in their communities. Parents tend to put these children into a residential institution for them to live permanently. Following these ideas, the government is promoting to build more institutions and to train more experts for people with disabilities.

The Independent living movement by severely disabled people in America denied institutions that lead to isolation and discrimination. In 1972 The First IL center was established in Berkeley, the second one in Houston, in 1974 the third in Boston. A lot of IL centers have come into the world in a very short time. All disabled people in the whole country were united, and then won the amendment of rehabilitation law in 1978. As a result, IL centers got great opportunities to get subsidies from the federal government. "Independent Living: From Social Movement to Analytic Paradigm", An academic paper written by Gerben DeJong, published in 1978, drastically changed the way of thinking toward disabilities, from rehabilitation to independent living. With this paper, the philosophy of independent living was accepted as a social movement on a academic basis. These two events rapidly promoted the establishment of IL centers nationwide.

Independent Living Movement In Developed countries

The IL movement, which gave dreams and wishes to disabled persons, has grown to service provision systems by disabled peoples themselves and advocacy activities by IL centers in these 30 years in all developed countries, except the Oceania region.

Ed Roberts, the founder of the Center for Independent Living in Berkeley and other activists with disabilities said, "People with disabilities should live in communities." "People with disabilities are neither patients to be cared for, children to be protected, nor Gods to be worshipped." "People with disabilities themselves can identify their necessary assistance and manage it." "People with disabilities are the

victims of social prejudice rather than victims of disabilities." This philosophy was soon accepted in many parts of the world. On the grounds of this philosophy, IL centers are providing these services below:

1. Dispatch of Personal Assistants.

There are two ways of dispatching personal assistants: one is the way of direct dispatching like in Japan, another in the way of introducing through IL centers like in the U.S.

2. Peer Counseling

Counseling, talking or sessions among peers who have the same or similar experiences of disabilities.

3. Independent Living Skill Training

4. Advocacy Activities

5. Providing information

Housing and social welfare referral are included.

Now the organizations of IL centers are established in each country and region, such as NCIL in America, CAILC in Canada, JIL in Japan, and ENIL in Europe. In 1999 The first summit of World independent Living was held in Washington D.C, U.S.A. Since then, three summits have taken place in different areas where a great number of disabled leaders, including leaders from developing countries became involved.

Conditions concerning Independent Living in developing countries

The Idea of independent living, which insists on self-decision and self-management, also fascinated people with disabilities in developing countries. But because of lack of social resources, it is thought to be difficult in developing countries to achieve environments where there are enough services and accessibilities. Moreover, quite a few people thought by mistake that independence means only economical independence, so that they believed that nobody can live an independent life except for a lightly disabled person. It is nearly impossible for people with disabilities to get jobs in Asia, where only 5 or 10 percent of disabled children can have school education.

As a result, almost all developing countries tried to get disabled people to be independent through CBR (Community based rehabilitation) produced by experts, in the same period of the IL movement. Services based on institutions could be only beneficial for disabled people living in urban areas. The main target of CBR is for

disabled people who live in rural areas, occupying 7 or 8 percent of the total population. Non-disabled people in their communities were volunteers trained as CBR workers, and then they did some simple rehabilitation work and help the daily lives for disabled people. Indeed, the quality of life for disabled persons might get improved to some extent, through basic physical training, walking training, sign language education, inclusion by CBR workers, and financial aids of private companies like Micro Credit. But CBR did not necessarily bring independent living for disabled persons though disabled persons had joined as official members since the beginning of providing services. That is because CBR was firstly positioned as extensions of institutions, so that disabled persons were kept under control or management of experts without disabilities.

It is often the case that disabled people who have loved the idea of IL also name their activities IL in some developing countries. For example, a certain disability organization in Mexico established a new organization named "International Organization of Independent Living for People With Disabilities", arranging the curriculum for disabled people which included lessons about fitness, physiology, swimming, manipulation of wheelchair, driving of remodeled cars, sexuality and family life, urology, training of daily living activities etc. In Thailand, one of the staff with disabilities working at Sirindorn National Medical Rehabilitation Center suggested the Independent Living Unit, providing much the same program as Mexico's organization did. Even though these trials may not always share the same meaning of original independent living, it indicates that there are also many disabled people having a try at independent living by themselves, in developing countries.

Scheme for spreading IL in developing countries

In 1980, American disabled people who had got involved in the IL movement began to act in other countries to spread the philosophy abroad. Nowadays, Japan is taking charge of propagation of IL in the Asian region, while in America, IL centers or other organizations like Mobility International are inviting other countries' disabled leaders to their training seminars.

One of 4 activities is often adopted as a way of spreading the IL philosophy in developing countries; first is promoting theoretical framework of IL, second, advocacy, third, participation of severely disabled persons in self-help organizations, and the last, showing a role model as an example of IL.

1. Activity to promote the theoretical framework of IL

Firstly it is necessary to correct the mistake about IL that independence means doing everything alone without any help. In spite of someone's help, it is regarded as IL, if only self-decision and self-management can be done. This idea welcomes people with disabilities as "very good news". But, in most cases, this acceptance does not immediately bring grassroot activities. For instance, a lot of disabled people were excited to meet American activists who came to Japan for an IL promotion tour in 1982, but the IL movement in Japan did not start until the first IL center was established in 1986. It is very important to follow up on their experiences.

The first IL seminar in Asia was held in Bacolod, the Philippines in 1994, mainly promoted by STIL, Sweden and the Human Care Association, Japan. Three Asian persons with quadriplegia joined this seminar. After the seminar, Motab from Bangladesh tried to expand his job at the Center for the Rehabilitation of the Paralyzed to the activity of independent living but in vain because of his death 3 years ago. Male participants from the Philippines, all of whom had already married, got quite interested in the IL movement, but they found it difficult to make a movement in their own country, because they had to prepare for their family before they join the movement. On the other hand, Topong from Thailand, on the grounds of the ideals of the IL movement, held a demonstration for better access of Sky Train, and educated other organizations in local areas. The Human Care Association supported his activities, and then offered him to come to Japan for training

Famous disabled activists participated in the 1999's seminar in Malaysia held by the Asia Disability Institute. One of them was Christine Lee, who had staged a demonstration for access of the mono railway at the risk of being arrested. All participants were wildly enthusiastic on the last day of the seminar, and promised each other to promote the IL movement more actively from now on. But actually, few of them were able to increase their activities in the IL movement. There may be two reasons. One is most of the participants have their own jobs and have no time for the IL movement; the other is that severely disabled persons who really need IL have not joined the movement yet.

Promoting activities are very essential to support and spread the IL movement.

2. Advocacy

The IL movement in Brazil was based on advocacy. Rosangela Berman Bieler, a Brazilian woman with quadriplegia who happened to visit an IL center in America was so impressed with its philosophy that she joined the IL movement. In 1988 CVIRJ, the first IL center in Brazil, was established by her in Rio de Janeiro. CVIRJ began to

start a movement for easy access to the city, such as getting rid of steps on side walks. The problem of accessibility is very meaningful not only because it is a problem that applies to all kinds of disabled people, but also because it will bring visible outcomes as advocacy. The IL center in Brazil made the movement more powerful by keeping contact with IL centers in America. Now in Brazil, there are 25 IL centers established, and the national union of IL centers has been united.

In South Korea, the IL movement has made rapid progress in a short time, because the Korean people getting involved with the IL movement have already created activities of advocacy on a large scale. Chon Manfu, a severely disabled person who applied for the role model of IL in 2000, was empowered through the experiences of joining big demonstration in 2001 and a long-term hunger strike in May 2002, triggered by the death of a wheelchair user at a subway station. These events were arranged by Pack Gyoung Souk, the principal of a night school for the disabled people. A lot of his students, who have studied IL, are taking part in the IL movement, which is one of the reasons why the Korean IL movement has such power. Now, the main issue in Korea is to train disabled people as peer counselors. The physical and mental conditions for developing IL in Korea are being prepared; 3 IL centers in Japan, Human Care Association, CIL Tachikawa, and HANDS Setagaya, collaborated with each other to establish a new project team that dispatches peer counselors to Korea several times a year and provides long-term training in Japan for Korean disabled leaders. As a result, some of them have reached the high standard of peer counselors that JIL is setting. There are 5 IL centers in Korea.

3. Participation of severely disabled persons in self-help groups

In Thailand, many disabled people used to sell lottery as a job, which made enough money to prepare for their own family. But because of this job, the disability movement did not grow among people with disabilities in Thailand. Under these circumstances, Topong, as I said before, thought it was only the IL movement that would change the environment of disabled people in Thailand. He tried to promote the IL movement in collaboration with 3 organizations of disabled people, Nontabri, Chonbri, Nakhonpatom, three of which were very conscious about the rights of people with disabilities. To support his activities, the Human Care Association invited him to come to Japan for an IL seminar.

Each of these three organizations were democratic self-help groups, which provided home visiting services for disabled persons. Leaders of these organizations were willing to accept the idea of IL. The first step of a three year project is to open a

seminar by Japanese disabled leaders, ten participants from three organizations were all studying hard, but none of them were severely disabled. So, the project team gave a task for them that they should find at least five severely disabled persons and take them outside their homes until the next years' seminar was held.

After this, three organizations began to train students to be a voluntary staff, and ask them to take severely disabled persons outside. Some of disabled persons went outside for the first time in their lives; some of them were strongly opposed by their families, so that they were forced to refuse staff visits; some of them gave up to go outside because of their bad health; some of them had lifters fixed in their bathroom by staff who saw families lift the disabled person with great difficulty. As a result, many of them attended the peer counseling workshop held in 2002 empowered physically and mentally. As they are finished learning skills of managing an IL center in 2003-2004 year, the real activities are ready to start.

4. Showing role model of IL

Young disabled persons who belongs to the Mile Stone Society in Pakistan came to Japan for the Duskin Training Program, including the 9 month IL seminar at several IL centers, such as Human Care Association and Main Stream Association. It is almost a year since they have gone back to Pakistan and begun to start the IL movement. They looked around Lahore to discover severely disabled persons confined in their homes, and persuade them to attend training workshops held at an office. They asked some promising participants to experience IL in a room in the corner of the office.

In the end, a young girl with muscular dystrophy made a decision to live independently. She learned various IL skills such as how to take proper care from others and how to tell personal assistants what she wanted her PA to do by actually living in a special room arranged in a corner of her house. In the day time, now she works as a member of the Life IL Center the renamed office, riding in a power wheel chair taken from Japan. It is very meaningful that she began to live independently for the first time in Pakistan, moreover in such an Islamic society, where women are likely to be conservative. After her independence, two male disabled persons, who have been encouraged by her, want and even practice now to live independently.

Spreading the correct philosophy of IL

It is true that more and more people have heard about IL, and especially in developing countries, where their expectation toward IL is getting bigger and bigger. Nevertheless, most of them have given up their dreams, making excuses like these: "We

have no resources to use in our country." "Prejudices against disabled people are still deeply rooted." "Government does not still prepare sufficient welfare systems."

One of the strategies to achieve the targets of the Biwako Millennium Framework for Action is "Strengthened community-based approaches for the prevention of causes of disability, rehabilitation and empowerment of persons with disabilities." It says that "Many developing countries in the region are now beginning to augment and replace traditional institutional and centralized rehabilitation programmes and projects with approaches better suited to their social and economic environments of poverty, high unemployment and limited resources for social services. Community-based rehabilitation programmes form the hub of such strategies. The community-based approach is particularly appropriate for the prevention of causes of disability, early identification and intervention of children with disabilities, reaching out to persons with disabilities in rural areas, raising awareness and advocacy for the inclusion of persons with disabilities in all activities in the community, including social, cultural and religious activities. Education, training and employment needs could also be met by this approach. It is essential that persons with disabilities exercise choice and control over initiatives for community-based rehabilitation.." It even recommends in Strategy 10 that "Governments, in collaboration with organizations of persons with disabilities and civil society organizations, should immediately develop national policies, if that has not yet been done, to promote community-based approaches for the prevention of causes of disability, for rehabilitation and for the empowerment of persons with disabilities. Community based rehabilitation (CBR) perspectives should reflect a human rights approach and be modeled on the independent living concept, which includes peer counseling."

Many people tend to think it nearly impossible to introduce IL to their countries. Naturally the idea of IL can apply to all disabled people in all countries by all ages. The problem is whether you can have the courage of doing what you have not done yet, and whether you have many peers and friends who will support your activity. Pioneers have a lot of difficulties, but have a great impact on other people. Nowadays a variety of IL programs and seminars are prepared for such people. People in developed countries including US are ready to assist you to be a leader of IL movement. We are showing the achievements and good news of IL at all times.