

November 7, 2008

**Policies for Persons with Disabilities in Japan
from the Viewpoint of a Person with a Disability**

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1. Self introduction - From a special school/institution for children with disabilities to an ordinary school

- Born prematurely in a state of suspended animation. Diagnosed as having cerebral palsy at the age of one. Affected lower extremities are of spastic type?
- Spent my elementary school days in a special school/institution for children with disabilities. My experiences in the institution:
 - Entering the institution was decided by a Child Guidance Center and my parents. I was informed one week before entering.
 - Wanted to bring many books with me, but it was not allowed because of property restriction rules.
 - Found name tags with "No. 51 Koji Onoue" written with a felt-tipped pen, sewed on everything from the jacket to the undergarments.
 - Dreadful experiences of a surgical operation and exercises before going to bed (Refer to Material 1.)
 - The special school was on the second floor of the institution. We spent 24 hours each day just being in the institution: "What does a traffic light look like?" "A shopping day"
 - It was always emphasized to us that "a person with a disability must have endearing qualities so as to be cared for by others."
 - Some staff in the institution and teachers of the special school who provided moral support when transferring to an ordinary junior high school

November 7, 2008

- Attending an ordinary junior high school
 - Upon enrollment – “Now that you are in an ordinary school, we shall not be giving you any special treatment. Do not depend on the help of facilities, teachers, or other students.”
 - “Is doing nothing for me equal to ‘no special treatment’?”
 - Surprised at a students’ general meeting – “Are there this many people?”
 - Being carried on the back of my classmate – moving to the music room, etc.

2. Development of the independent living movement and postwar policies for persons with disabilities

After the war ~ 1960s: “Generalization of countermeasures for wounded veterans” →isolated institutionalization/rehabilitation

1949	Enactment of the Law for the Welfare of Physically Disabled Persons
1960	Enactment of the Mental Hygiene Law (the present Mental Health and Welfare Law) Enactment of the Law for the Welfare of Mentally Retarded Persons (the present Law for the Welfare of Intellectually Disabled Persons) Physically Handicapped Persons’ Employment Promotion Law (the present Law for Employment Promotion, etc. of the Disabled Persons)

※Policies for persons with disabilities were implemented based on the above-mentioned three laws, but the focus was placed on economic regeneration, and those who were not capable of doing that were left in social isolation.

★After the war, various organizations for persons with disabilities were established and the Law for the Welfare of Physically Disabled Persons was enacted (1949).

= The background of the enactment of the law includes the fact that Countermeasures for Wounded Veterans ceased to exist due to the abolition of the Military Protection Agency in the course of GHQ’s policy of the “democratization and abolition of militarism of Japan.” In that sense, it can be said that a big aspect of the enactment of this law has to do with the

November 7, 2008

“Generalization of countermeasures for wounded veterans.”

- ★1960s– High economic growth and “socialization of issues of persons with disabilities”:

“Law for the Welfare of Mentally Retarded Persons” and “Physically Handicapped Persons’ Employment Promotion Law” (1960) – The isolated institutionalization /rehabilitation policy as seen in the concept of Zenkoku (nationwide) Colony network (1965) evolved into the establishment of Nishikomago Colony in Nagano Prefecture, Funagata Colony in Miyagi Prefecture (1968), Kongo Colony in Osaka Prefecture (1970), National Colony Nozomi-no-sono (1971), etc. In the time of high economic growth, along with the shifting of labor forces creating thinly populated and overpopulated areas, the number of nuclear families became larger. Thus, the issues of persons with disabilities, which used to be hidden behind the support of bigger families, came to the fore. At the same time, since there occurred many incidents of killing children with disabilities and double suicides, the movement calling for the establishment of institutions by parents’ associations and others became rampant.

1970's: Emergence of persons with disabilities as subjects of social movements

(Refer to Material 2)

- ★ The incident of the killing of a child with a disability that occurred in Kanagawa Prefecture in 1970 led to parents' associations demanding leniency in the commutation of consequent punishment. Relative to this, the Kanagawa Aoishiba-no-Kai (The “Green Grass Association”) raised the issue and denounced the move, saying, “Please realize the gravity of the fact that a person was killed.” Through this process, accusations and raising the issue were carried out from the standpoint of persons with disabilities who were deemed to be “a life that should not exist,” and this ideological stance was established.
- ★ Since then, protest campaigns against the Eugenic Protection Law (renamed as the Maternal Protection Law in 1995), which helped encourage abortion of babies with disabilities, were carried out. Also, moves to acquire the right to

November 7, 2008

transport, to struggle against public administrations in various places were done. Moreover, through this process, “independent persons with disabilities” emerged, meaning that persons with severe disabilities who need full attendance became independent by renting apartment houses in their communities with the help of 24-hour personal assistance (1975). And the movements for enrollment of children with disabilities in nursery schools and ordinary schools also became more active.

End of 1960's~	Moves to accuse and denounce discrimination of persons with disabilities progressed. • Battle against Fuchu Rehabilitation Center for Persons with Severe Disabilities, Araki class action, etc.
1970	Kanagawa Aoishiba-no-Kai criticized the move towards leniency in the commutation of punishment in the killing of a child with a disability Awareness of being persons with disabilities who were deemed to be “a life that should not exist” came to the fore, and so their voices started to be heard.
1973	Formation of Zenkoku (nationwide) Aoishiba-no-Kai – Start of the “Go-out-to-town-like-a-breeze movement” (Movement of going outside the home)
1974	Start of the Tokyo Metropolitan Attendant Dispatch Service for Persons with Cerebral Palsy (later referred to as the Attendant Dispatch Service for Persons with Systemic Disabilities)
1976	Formation of Zenshoren (National Liaison Conference of the Liberation Movement for Persons with Disabilities)
1979	Special school for children with disabilities became part of compulsory education – Protest campaigns against this move spread on a nationwide scale in 1978

November 7, 2008

※ As we look at the above-mentioned movements in the 1970's, please note that the concepts of "normalization" and "independent living" which we hear about every now and then did not come about suddenly, but they emerged out of the struggles of persons with disabilities against isolation and discrimination. Please note also the opposing factors that brought about these concepts.

* Transition from the medical model to the independent living model

In the past, the dominant ideas were that "to be able to perform daily necessary activities independently" meant "independence in ADL" and that "to earn money by acquiring skills" meant "vocational independence." These ideas are common in lacking a perspective of considering disabilities in a relationship with the environment and aiming to adapt persons with disabilities to the current society.

Such a "social adaptation theory" led to creation of institutions and schools only for persons with disabilities and isolating them from the society. Also, persons with disabilities have been forced to play a passive role as "subject of treatment / training" or "subject of protection," and not considered as beings with subjective intention. Initiative role is played by so-called specialists, such as doctors. Therefore, the above-mentioned views of independence are also referred to as a "medical model" or "rehabilitation model."

On the other hand, new views of independence, such as "independent living" and "independence in the community" have been advocated in the movement by persons with disabilities themselves and efforts have been made toward their realization since the 1970s.

- (1) "Self-determination" – Persons with disabilities themselves decide where they live, what kind of life they want to have, etc., on their own will, and take control over their life.
- (2) Establishment of "life in the community" instead of protection / isolation -- Persons with disabilities being protected / isolated from the society is not a normal situation. Furthermore, it is very difficult to realize self-determination by persons with disabilities in such a situation. The goal is to establish life in the community, shifting from such protection / isolation.
- (3) Reform of society, such as establishment of systems, social resources, etc., in order to realize "independent living" and "independence in the community," and elimination of discriminative consciousness and attitude toward persons with disabilities (Normalization means to reform a society that excludes persons with disabilities into a normal form -- society that includes them.)

November 7, 2008

Such a view of independence, which originated from review of the “medical model” and the “rehabilitation model,” as a concept that opposes the models, is called the “independent living model.” This view of independence has become dominant internationally mainly in Western countries. Also in Japan, the view has steadily been established among citizens, as the idea of normalization has spread since the International Year of Disabled Persons and the independent living movement has progressed.

“Rehabilitation Paradigm and Independent Living Paradigm”

	Rehabilitation Paradigm	Independent Living Paradigm
Definition of problem	Physical impairment / lack of vocational skill	Dependence upon professionals, family members and others
Focus of problem	In the individual	In the environment; in the rehabilitation process
Solution to the problem	Professional intervention by doctors, physical therapists, vocational rehabilitation counselors, etc.	Peer counseling, consumer self-control with self-help, barrier removal
Social role	Patient / client	Individual with a disability
Who controls	Professional	Individual with a disability
Desired outcomes	Maximum ADL	Independent living

(Gerben DeJong: Independent Living, From Social Movement to Analytic Paradigm, Dec. 1979)

1980's: International Year of Disabled Persons, regional movements, and enhancement of grass-roots international exchanges

1981	International Year of Disabled Persons
1982	The Independent Living Movement in the United States was introduced. There came an increasing number of community workshops and small-scale workshops, where persons with disabilities can exist. Kyoudouren (Liaison of Joint Community Workshop) was formed.

November 7, 2008

1983	Start of the United Nations Decade of Disabled Persons
1986	Establishment of Disability Basic Pension System <u>Japan National Assembly of Disabled Peoples' International (DPI-Japan)</u> <u>was organized. Human Care Association (Hachioji, Tokyo), the first</u> <u>full-fledged Independent Living center in Japan, was established.</u>
1986	Protest campaign against taxing institutions for persons with disabilities became strong. Around this time the movement toward group homes started at the local government level. In Osaka the Attendant Care Security System (=Attendant Dispatch Service for Persons with Systemic Disabilities) based on the right of persons with disabilities to make choices began (following Tokyo, then the system spread around major cities designated by government ordinance).
1987	Mid-year review of the United Nations Decade of Disabled Persons
1988	At the RI (Rehabilitation International) conference held at Shinjuku, Tokyo in 1988, we appealed to "get out of the control of specialists." Then, we assembled for the international solidarity movement of persons with disabilities and a rally calling for accessible transportation. (Hereafter, activities for accessible transportation became an annual event which became large-scale with the participation of 3,000 people nationwide.)
1989	Group Home System for Persons with Intellectual Disabilities (national government); Osaka City Group Home System for Persons with Severe Disabilities • Ministry of Health and Welfare established the "Gold Plan" which stipulates policy objectives for the next ten years concerning the elderly.

November 7, 2008

1990's: Impact of ADA; further development of the movement towards the foundation of comfortable living environments for persons with disabilities, People First movement, etc.

1990	<p>The ADA (Americans with Disabilities Act) was passed. It was the result of a movement by a network of tens of thousands of people who participated from all over the U.S.</p> <p><u>Revision of eight laws related to social welfare – the Home Attendant Service became a legal service.</u></p>
1991	<p>The members of People First, a movement by persons with intellectual disabilities, visited Japan from the United States.</p> <p>Osaka City and other bus companies introduced passenger buses with lifts.</p> <p>Formation of the Japan Council on Independent Living Centers (JIL), which is a national organization of independent living centers.</p>
1992	<p>Final year of the “United Nations Decade of Disabled Persons”; international symposia at nearly 20 places in Japan</p> <p>In Osaka Prefecture an “Ordinance for the foundation of comfortable living environments for persons with disabilities” was enacted for the first time in Japan (followed by all the other prefectures)</p> <p>A Guide Helper System for Persons with Intellectual Disabilities was begun in Osaka City.</p>
1993	<p>Enactment of the Basic Law for Persons with Disabilities. “Persons with mental disabilities” is included in the definition of the term “disabilities”. “Independence and social participation” are also mentioned.</p> <p>Osaka Psychiatric Human Rights Center, an NPO, accused and investigated Yamatogawa Hospital (leading to the hospital’s closure in 1997).</p> <p>In Tachikawa city in Tokyo and other areas, 24-hour personal assistant service began to be offered.</p>
1995	<p>The National Government formulated the Plan for Persons with Disabilities (a 7-year strategy to promote normalization).</p>

November 7, 2008

1996	Municipality living support service (counseling service) began. In some regions, outsourcing to private independent living centers started – Material 3
1997	<u>Osaka City Support Plan for Persons with Disabilities</u> The description of independent living centers is clearly indicated in the plan. Violation of human rights such as the Shirakawa Ikusei-en Incident occurred one after another. → Discussion on basic social welfare structural reform
2000	Enactment of the Barrier-Free Transportation Law. <u>Revision of the eight laws including the Social Welfare Law.</u> Enactment and enforcement of the Long-term Care Insurance Law.
2002	The DPI World Assembly was held in Sapporo with the participation of more than 3,000 people from 110 countries and regions.
2003	There were protest activities for two weeks regarding the transfer of revenues for counseling services to a general account, and the issue of capping for home care service. The Assistance Benefit Supply System began. Japan Disability Forum (JDF) promoted the UN Convention on the Rights of Persons with Disabilities. Mr. Higashi, an attorney with a disability himself, became an advisor of the Japanese Governmental Delegation to the human rights convention.

2004 ~ present – Establishment of the Law concerning Self-reliance Support for Persons with Disabilities and enhanced morale of the movement of persons with disabilities

2004	
January	“Inauguration of the attendant care system reform headquarters” June Moved toward the direction of revising Long-term Care Insurance to center on “prevention benefit.” Disabled People’s International (DPI), Japan Council of

November 7, 2008

	Independent Living Centers (JIL), and other organization of persons with disabilities, became a promoter, and formed a “national large-scale event to seek realization of establishment of disabled persons’ community life.” National event opposing to “fast and sloppy integration into Long-term Care Insurance = merger” (1,200 persons)
October	The Ministry of Health, Labor and Welfare announced the “future direction of health and welfare measures for persons with disabilities (Grand Design of Reform).”
2005	
February 14	The bill of the “Law concerning Self-reliance Support for Persons with Disabilities” based on the Grand Design was presented to the Diet. Action protesting against “presentation of the bill of the Law concerning Self-reliance Support, without involvement by persons with disabilities themselves” and demonstration for petition to the Diet (2,000 persons)
May 11	Demonstration for petition to the Diet and rally (almost 9,000 persons in total), in response to start of deliberation on the bill of the Law concerning Self-reliance Support for Persons with Disabilities
July 5	Demonstration for petition to the Diet (11,000 persons), asserting that “the current bill of the Law concerning Self-reliance Support for Persons with Disabilities will not lead to disabled persons’ independence!”
August 8	“The bill of the Law concerning Self-reliance Support for Persons with Disabilities” was withdrawn along with dismissal of the Lower House.
September	In the Lower House election, the Democratic Liberal Party had a clear victory. “The bill of the Law concerning Self-reliance Support for Persons with Disabilities” was presented again

November 7, 2008

	(September 30). Despite the actions for an appeal, sit-in protest, etc., near the Diet for consecutive days, the Upper House voted for the bill on October 14, and the Lower House voted for the bill on October 31 – the Law was established.
2006	
April	“The Law concerning Self-reliance Support for Persons with Disabilities” was enforced. The rate of co-payment by disabled persons for the cost of their welfare service / medical care became 10% in principle.
October	Changed to the method of benefit being decided according to disability degree classification by the municipality examination panel. With the slogan of “Start all over again! The Law concerning Self-reliance Support,” 15,000 persons rallied and a demonstration march occurred.
December	Government party announced “special measures” as pressed by 15,000 persons’ actions.
2007	
April	“Special measures” were implemented. For example, the upper limit of co-payment was reduced to a quarter of the initial limit.
October	6,500 persons rallied, seeking a drastic revision of “the Law concerning Self-reliance Support.” All political parties attended.
December	Government party announced “urgent measures.” Changed the range of co-payment from a household to a person with a disability himself. The upper limit of co-payment was reduced from one eighth at the start of the system to one tenth.

* Outline and aim of the Law concerning Self-reliance Support

(1) Outline of the Law concerning Self-reliance Support

- Significance presented by the government is (1) to establish a system common among

November 7, 2008

three disability categories: physical, intellectual and mental; and (2) to consider the expense for home care service as obligatory expenditure and clarify the government's financial responsibility.

- This law changes many things, but the major points are the following three.
 - 1) The method of service supply being decided by the examination panel, according to disability degree classification based on the standards according to Long-term Care Insurance
 - 2) To make the co-payment rate 10% in principle regardless of income, in proportion to welfare service and medical care received.
 - 3) To reorganize the service system into three types: attendant care, training supply, and community life support.
- “Independence” theory presented in “the Law concerning Self-reliance Support” – “Independent living / social life according to abilities and aptitude of persons with disabilities.” Contradiction with normalization that has been presented in the past though not in a perfect way.

(2) Aims of “the Law concerning Self-reliance Support”

1) Reasons for fast and sloppy discussion / bill preparation

Discussion proceeded hastily and the bill was prepared in only four months from the announcement of Grand Design in October 2004, which was unusually speedy and reckless even among Japanese legal system discussions. The reason was to be in time for discussion on review of Long-term Care Insurance, in addition to handling the immediate revenue shortage.

2) Two aims of “the Law concerning Self-reliance Support”

A. To make the system controllable by the government (examination panel method), and to restrict service supply (co-payment according to benefit received), as the immediate goals

B. System design anticipating future “integration with Long-term Care Insurance”

- Standards according to certification of long-term care need and the examination panel
- Introduction of co-payment in proportion to benefit received (according to Long-term Care Insurance)

November 7, 2008

- Exclusion of assistance in transportation (that is not included in the services of Long-term Care Insurance), in principle, from individual benefits
 - ※ As mentioned earlier, in Japan persons with disabilities emerged as the subjects of social movements in the 1970's. The International Year of Disabled Persons in the 1980's helped disseminate the idea of normalization. However, please note that it was only in the 1990's when the support of community life/independent living in the actual systems and services started, and the gap between concept and reality is still very large and solutions are still being called for.

[Profile : Koji ONOUE]

I was born in Osaka in 1960. After spending elementary school years in a special school/institution for children with disabilities, I attended ordinary junior and senior high schools. Upon entering Osaka City University in 1978, I joined afterschool activity, which discussed about the issues of persons with disabilities (PWDs). And it prompted me to begin work on the independent living movement for persons with disabilities.

I was actively involved in the introduction of buses with lifts which started to be operated in Osaka City for the first time in Japan in 1991. I was also active in the movement towards the enactment of an “Ordinance for the foundation of comfortable living environments for persons with disabilities” in Osaka Prefecture, which was enacted in autumn of 1992. In the RI (Rehabilitation International) conference I participated in the demonstration for accessible transportation and worked as staff of the assembly for international solidarity. I took part in DPI's actions towards accessible transportation as staff. After the earthquake in 1995, I worked on the rescue operation with the help of PWDs themselves as a member of the PWD rescue headquarters. I voiced my opinion as an unsworn witness in the Diet when the Barrier-Free Transportation Law was enacted in April 2000. I went all over Japan to attend regional assemblies to prepare for the DPI World Assembly which was held in Sapporo City in 2002. I voiced my opinion as an unsworn witness for Law concerning Self-reliance Support for Persons with Disabilities in an ordinary Diet in 2005 and an extraordinary session of the Diet in 2006.

Currently, I hold positions as a navigation committee member of the Independent

November 7, 2008

Living Center, a permanent committee member of Peer Osaka, and the Secretary-General of DPI (Disabled People's International) Japan.

[Material 1: Looking back on the experience of living in an institution (excerpt from a newsletter of an organization of persons with disabilities)]

I attended a special school for children with disabilities for four elementary school years. Then, I moved to an institution for children with orthopedic disabilities. It was more than 30 years ago, but there is something I cannot forget even now.

It was a “doctor’s rounds day” that happened every Wednesday afternoon. I was always scared on this day. A group of head nurses and therapists led by director of the institution marched into our room. They walked around, measuring our knees and lower back with a protractor-like tool. When declared, “Let’s operate on the back of your knee,” you were expected to go to the operation room the next week. I felt scared and uneasy, wondering if it would be my turn this week.

Because of cerebral palsy, parts of my lower extremities connected by joints such as the lower back, knees, and the heels had not been fully straightened. The reason why I wrote “had not been” is that they came to be straightened after an operation. However, this time I was not able to bend the straightened parts of my body. Especially, the worst for me was that I was not able to bend my knees as a result of an operation on the back of my knees (both legs). In daily life it is far more inconvenient to have knees that cannot bend than to have ones that cannot stretch fully. Those who experienced wearing a plaster cast because of a fracture or something can relate to this, I think.

My mother, who observed that my disability became severer every time I came home from the institution for a visit, got scared and decided to send me to an ordinary school from junior high school.

When I was in the institution, every Thursday was operation day. (Although I was a child, I knew the jargon “op day.”) As there were two operating tables, two children were meant to be operated on each week. In fact each of us had operations 4 to 5 times on average. And, no matter how many times we underwent operations, we did not receive any explanation about how effective the operation would be and what possible bad effect should be considered. (You may think the explanation was not given to me because I was a kid, but my parents did not seem to have received a sufficient

November 7, 2008

explanation, either.) And, even when the “expected good effect” did not appear but rather the operation made the disability even worse, I do not remember any case when the doctor's responsibility was questioned. Now, since we have no way of knowing how the doctor is thinking now – whether he reflects upon what he did or he avoids any thought of responsibility – we still feel that we are left hanging and unsettled about this issue.

As illustrated by the above-mentioned medical cases, a doctor had tremendous power in that particular institution. He not only had the authority to decide about surgical operations, but also to determine the details of our lives in the institution – for example, even about our posture whenever we slept.

About three months after I entered the institution, an exercise called “Positioning” suddenly started. In my case I was made to lie prone on a board (like a conference room table top) which was placed on the bed. Then, my lower back was bound by a cloth that looked like bleached cotton. I was forced to stay in that fixed position and I had to sleep for about 12 hours from 6:30 p.m. until 6:00 a.m. of the next day.

To forcibly straighten my body which was not naturally straight, I was bound by considerable force. I used to get up in the morning to find my lower body in dark color, past the stage of being reddish, because of poor blood circulation.

The most painful part of this exercise as a child was toileting.

Because the lower back was tied, naturally, the urinary bladder was pressed. When I was no longer able to endure nature's call, I had to call a nurse by a nurse-call apparatus. Bringing a urinal, the nurse ordered me, “Do it quickly.” But, due to my disability of cerebral palsy, the harder I tried to urinate quickly, the more difficult it became. Then, I was bound again. And again, the pressure made me feel like urinating. Thus, I had to call a nurse again. After repeating this process, the nurse who could not understand what was happening finally scolded me bitterly, saying, “You are telling a lie because you don't want to undergo this exercise.” “It's not a lie,” I muttered in my mind, but the words did not come out of my mouth.

This medical experience in the institution has become a memory I could never forget all my life, a memory which I would even call a “grudge.” It would not be an exaggeration to say that the aforementioned experiences made me leap into the movements of persons with disabilities.

November 7, 2008

[Material 2: All the support is for the realization of community life – “Support” April 2005 issue]

- Two sets of ideas on independence about policy changes for persons with disabilities
Policies for persons with disabilities are at a significant turning point.

With regard to the “Law concerning Self-reliance Support for Persons with Disabilities” that had been put on the agenda of the Diet on February 10, some 2,000 persons with disabilities and their supporters gathered around the Ministry of Health, Labour and Welfare and the National Diet building, with the slogan, “Please do not decide on matters concerning us without us,” “We will not tolerate a setback from community life.”

The point of criticism is that the “Law concerning Self-reliance Support for Persons with Disabilities,” contrary to how it sounds, poses certain problems causing setbacks and the prevention of independence of persons with disabilities. Some Diet members began to say, “This is an independence inhibition law.”

Is it an “independence support law” or an “independence inhibition law?” We can say that in the undercurrents of various opinions on the matter, there emerged two different theories on independence.

Since the 1970's persons with disabilities have developed the independent living movement seeking “independence in the community,” meaning “No matter how severe the disability is, we shall live in the community, not in an institution or in a hospital.” Later, the International Year of Disabled Persons in 1981 caused the concept of normalization to spread widely– the concept which aims to have persons with disabilities and those without disabilities live equally in the same communities. In the 1990's the Basic Law for Persons with Disabilities (1993), the Heart Building Law (Building Access Law) (1994), and the Plan for Persons with Disabilities (1995) were enacted, and the Barrier-Free Transportation Law was revised (2000). At the same time, the establishment of independent living centers, the improvement of the attendant care system, and the development of group homes as a means of community life have taken place in various places. In the course of these developments, the Assistance Benefit Supply System began in fiscal 2003, with the intention to “respect the self-decision of persons with disabilities based on the idea of normalization.”

While we have such an independence theory with “self-determination” as the core,

November 7, 2008

another theory advocated for a long time is independence in ADL (activities of daily living) and in one's occupation. This theory has it that "to become capable of doing the basics of taking care of oneself, like changing clothes and eating meals" or "to acquire skills to earn a living" (alone) is independence. Various medical treatments and trainings have been conducted to achieve these goals. However, such an independence theory can be taken negatively that a disability is something that should be conquered and be treated, and, after all, the theory has brought about the isolation of persons with severe disabilities, resulting in difficulties to lead a normal life in communities.

It is the independent living movement for persons with disabilities that has criticized such a conventional independence theory. It was also the idea of normalization that regards the issues of disability in relation to society, not as an individual issue.

It is important to know the differences in theories of independence as a background of the "Law concerning Self-reliance Support for Persons with Disabilities."

■ Community life support created by persons with disabilities and by communities

The reason why I stated above the two independence theories comparatively is that it is closely related to the evaluation of the attainment stage of the present policies for persons with disabilities. Furthermore, when we say, "Amend the health and welfare policies of persons with disabilities," the question is "what and how do we amend?"

Endeavors towards independent living in communities have progressed since the 1970's. In those days, however, it was taken as natural, both from the perspective of the government systems and social awareness, that persons with severe disabilities be taken care of by their families, and in case it became impossible, they be institutionalized (in an institution after the parents pass away).

Even in those days, some persons with disabilities got out of the institutions and hospitals, and continued to live in their communities by renting an apartment house and creating an attendant care system with the help of volunteers.

The idea of normalization was widely introduced starting with the International Year of Disabled Persons in 1981. With this, from the latter half of the 1980's to the 1990's, some local governments institutionalized attendant dispatch services for persons with systemic disabilities and guide helper services for people with intellectual disabilities. Also, independent living centers grew as persons with disabilities gave one another

November 7, 2008

support through peer counseling. The number of joint community workshops rapidly increased since the 1980's. Furthermore, group homes as a means of community life also started to grow in various places.

All these were created based on local communities (local governments) with the persistent endeavors of persons with disabilities and their supporters. Until the revision of the eight laws related to social welfare, the Basic Law for Persons with Disabilities and the Plan for Persons with Disabilities came about in the 1990's, there was not any notable system or mechanism to support community life on the national level. Therefore, we can say that the activities and mechanisms that supported community life for persons with disabilities were created by themselves and by the communities on the local level. Moreover, as a person who was involved in the movement to create a guide helper service for persons with intellectual disabilities in Osaka City for the first time in Japan, I would say that the services created according to the needs of persons with disabilities are the ones that are easy to use and that are highly evaluated.

The "guide-help", incorporated in the Assistance Benefit Supply System as mobile attendance, spread all over the country. Only the negative side of this system tends to be talked about from a financial point of view, but we should not forget that the community life support developed by persons with disabilities and by their communities has been elevated as a system to the national level.

■ System design and service reorganization based on community life

What is being called for when amending the health and welfare policies for persons with disabilities is the mainstreaming of support/services aimed at independent living in the community developed by persons with disabilities and their communities. Furthermore, all the support regarding persons with disabilities should be reformed to aim at the actualization of community life.

It has been more than 20 years since the idea of normalization was widely introduced in Japan. We are now in the stage of implementing this idea. In such endeavors we may encounter temporary confusion or setbacks. However, it is certain that the trend is the shifting of the paradigm from "protection/rehabilitation" to "independence/right". The trend from "institution" to "community life" is also based on necessity, and this trend can never be reversed.

November 7, 2008

In addition, from the international perspective, the discussion on the Convention on the Rights of Persons with Disabilities is going on. For instance, the draft has an item “Independent living and inclusion in community.” The system and design based on “independent living in community” will be the demand of the times. Let me write down the key points:

- Realization of self-determination by persons with disabilities and the promotion of social participation to be a basic target (to enable persons with disabilities to lead independent lives in the community no matter how severe the disability is)
- Systems and design supporting the individual needs of each person ~ actualization of personal assistant service which is now practiced in other countries
- Systems and policies that proactively adopt activities, ideas, and services of persons with disabilities themselves (Indispensable if you advocate for mechanisms based on universal design)
- Enhancement of social resources in the community (so as not to reverse the flow “from institution to community,” which is now available thanks to the assistance benefit)
- Systems focusing on individual services rather than structures (to be able to get individual support which a person with disability needs, rather than general services or housing)
- Mechanisms of support focusing on recipients, not on service projects (support-givers)
- Systems of support that make independent living possible even while parents are alive (by accessing social services), not “an institution after parents pass away”

Too often attention is paid to financial issues, but I hope that discussions and studies focus more on our historical issues and concepts.

[Material 3. “Disabled Persons’ Needs are the Power for Social Resources Development,” included in the June 2002 issue of “Gekkan Fukushi (Monthly Magazine Welfare)”

Koji Onoue, representative of Center for Independent Living – Navi

- Establishment of CIL Navi based on the movement by persons with disabilities

November 7, 2008

We, Center for Independent Living – Navi (hereinafter referred to as CIL Navi, Osaka city), “conduct various activities for persons with disabilities to realize independent living in the community based on their own will. We aim to promote implementation of independence support activities, development of social resources, and rights advocacy activities, from the standpoint of persons with disabilities themselves” (cited from the Center’s regulations.)

We promote building self-confidence and establishing a specific image of independence through peer counseling, independent living programs, etc., and also provide information and develop social resources. Four out of five staff members are peer counselors with severe disabilities.

CIL Navi was established in 1998, but the history of the disabled persons’ organization that was the parent body of CIL Navi dates back to events 30 years ago, such as the “Go-out-to-town movement.” Also, we have been involved with the enrichment of care service and barrier-free transportation in Osaka city.

Partly due to our background, we are often asked for advice from severely disabled persons with systemic disabilities, such as cerebral paralysis and muscular dystrophy, which is one of our specialties. Furthermore, we began to be entrusted by Osaka city with municipality living support services in fiscal 1999, and the content of counseling has become more diversified due to referrals, etc., from ward offices and other agencies. Centered on peer counselors, we handle 40 to 50 cases of counseling a month.

Both the representative and director of secretariat have disabilities, and more than half of the working committee members also have disabilities.

■ Peer counseling is the core of an independent living center

As is already known, an independent living center has two major characteristics: operation through initiative by persons with disabilities and supply of service toward independent living. An independent living center’s basic services include peer counseling, independent living programs, information supply, and advocacy of rights.

Peer counseling helps persons with disabilities be freed from self-abnegation - ideas such as “I cannot do anything” and “I am no good because I was born with a disability,” which have been developed through past suppression - and it helps them regain self-confidence and establish assertiveness. Regarding independent living programs,

November 7, 2008

there are programs for groups consisting of four to eight people each, as well as individual programs specifically implemented toward independent living according to each individual's situation. In addition, we conduct field trips for actual experience in going out and role play to perform an assumed role. Also, we implement an independence program in which an actually independent life is simulated by using an independence experience room, etc., and a schedule and attendant care system are arranged, to be checked through actual experiences. Of course, the person with a disability himself becomes a leader in implementing such a program.

Peer counseling and an independence living program are the major pillars of support, and through the process, we provide information as needed. On such occasions, we not only provide administrative information but also introduce various social resources necessary for daily living (for example, introduction of a beauty salon where a disabled person can receive service in a wheel chair).

In the above-mentioned counseling process, we go to related agencies with the persons concerned for coordination, according to needs, and also work to establish a new system and service as advocacy of rights. Furthermore, we introduce disabled persons' activity groups, as needed.

In this way, independent living centers' services are conducted based on equality from the perspective of a peer (another person with a disability), aiming to realize disabled persons' independent living based on their self-confidence, by empowering them through various experiences and information supply.

Peer counseling, which plays a core role with these series of processes, is a service that symbolizes the uniqueness of an independent living center.

■ From Osaka city's disabled persons care management model project

In training conducted by the government, the following factors have been presented as characteristics of care management of persons with disabilities: (1) priority on a disabled person's needs; (2) development of social resources; (3) care management of Long-term Care Insurance is based on "care service at home," but for persons with disabilities, a guide helper, communication support, securing of housing, and employment support are also included from the viewpoints of independence and social participation; (4) the final goal of care management of persons with disabilities is in

November 7, 2008

self-management; and (5) emphasis on empowerment of persons with disabilities through all the processes.

In order to spread disabled persons' care management based on such ideas, Osaka city has been implementing system establishment promotion projects for two years. As part of the projects, CIL Navi was also entrusted with a model project.

We studied cases of requests for cooperation in a model project from the viewpoints of "having (not singular but) complex needs," "having severe / multiple disabilities," "requiring development of social resources, as existing services cannot meet needs," and "request for shift to / continuation of community life." The reason is that we believed that the method of care management of persons with disabilities should be used especially for such cases.

This model project has clarified the importance of the following: living based on disabled persons' needs, and development of services and social resources to realize such living, as well as the realization of their empowerment in the process. From the model project, we would like to introduce several cases here.

Mr. A, who has ALS and uses an artificial respirator, initially complained of anxiety and frustration as his disability progressed, and a peer counselor repeatedly visited him and listened to him. At one point, (because his family member who mainly took care of him became sick), he was about to be socially hospitalized for a long time, but nursing service could be enriched based on the report through care management, which enabled him to continue community life.

In addition, a routine nursing system was secured, which led to development and clarification of his needs. In order to realize his desire to see the professional baseball manager who he had known since his school days, his needs gradually expanded to include securing a system to help him go out, related practice, and adjustment of transportation service. This indicates that solution of immediate needs does not mean completion, but it develops into following needs.

We prepared a report on the situation that became clear through care management of persons with disabilities and on enrichment of nursing services based on needs. This has realized a certain level of enrichment of the care system, dispatch of a helper for longer hours of care than certified through cooperation of a help center concerned, and practically 24-hour care. In addition, we worked to realize similar services also for Mr.

November 7, 2008

B, who has multiple disabilities of hearing disorder and cerebral paralysis. These two cases required not only full nursing care but also communication support (sign language, expression of intention by blinking, reading / hearing of speech with severe difficulty) and irregular-hour nursing care that requires experience.

Also, Mr. C, who has cerebral paralysis, wants to end an institutional life that lasted over 15 years since school and start community life. Towards this end, he participated in an independent living program and visited a person with a disability who is already living independently. He has also begun to regularly go to a local workshop for persons with disabilities to enrich daytime activities. Furthermore, he experienced a trial move-in, working toward independence. Because of the bureaucratic vertical structure of institutional and home services, the care costs, etc., for going to the workshop or moving in for experience cannot be covered by the existing system. These programs could be implemented by participating in a model project for shifting from institutional life to community life, that Osaka city started as its original project.

■ Can the ideas of care management of persons with disabilities be used in the Assistance Benefit Supply System?

Starting in 2003, many welfare services for persons with disabilities shifted to the Assistance Benefit Supply System. Related to the shift, I would like to discuss the issues I have noticed through implementation of the model project, as the closing words of this report.

Firstly, it is important to grasp disabled persons' needs with focus on social participation and communication support, instead of limiting to service in a living room.

The second point is to work to switch from the conventional idea of "independence in activities of daily living." An idea of the independent living movement is that "it is more independent as a way of living for a person with a disability to do daily necessary procedures in 15 minutes with the help of a care giver and spend the remaining 45 minutes for the activity he likes and for social participation, rather than taking one hour to do the procedures on his own." It is important to search how the life a person with a disability desires can be realized, instead of considering if it is possible or not.

The third point is the relationship between care management of persons with disabilities and development of social resources. In this recent model project, we

November 7, 2008

could realize 24-hour nursing care service through understanding and cooperation by the local government concerned and the help center. We need a system to expand services based on disabled persons' needs.

The fourth point is related to the third – we need a system for care management (including self-management) of persons with disabilities to positively affect decision-making on assistance benefits and budget (in the next fiscal year and thereafter if budget is short in the fiscal year concerned) and enrichment of services.

The fifth point is the importance of support for the shift in promoting “leaving an institution and living in the community.” For a person who has stayed in an institution for a long period to shift to a community life, programs and services focused on preparations, such as daytime activities, and life experiences including going out and independence experience, are essential. It is necessary to establish systems / services that can be used during such transition phases.

We hope that principles on care management of persons with disabilities such as “priority on a disabled person's needs,” “development of social resources,” “self-management,” and “empowerment” will be used in operation of the Assistance Benefit Supply System.