People with disabilities have been campaigning for care guarantees to allow them to continue living in their communities. In the past, people with incurable diseases have lobbied for an investigation into the causes of their illnesses and the development of treatments. But there are some people with severe disabilities caused by degenerative diseases such as ALS, who are also patients with an incurable disease who need a mechanical ventilator in order to live.

**The Care Support System**

**The Independent Living Movement**

A movement advocating patients' right to live as part of the community

In Japan, a care support system for people with disabilities was developed after patients, mainly those suffering from cerebral palsy, campaigned for the creation and expansion of such a system beginning in the 1970s.

This is why the Independent Living Center was established and presently operates as an organization that provides care services. In addition, a care agency established and presently operates as an organization that allows them to choose their carer, was also set up.

The movement demanding care support was driven mainly by cerebral palsy sufferers.

The blind acceptance of the social system also implied the rejection of the way we were living. A movement was needed to enable these patients to lead a fuller life.

The movement aimed to bring society's attention to the disability issue through the provision of care.

In addition to the National SMON Association, an incurable disease patient organization was formed for each disease. The SMON patient movement became a model for the movements pertaining to patients with other incurable illnesses.

The movement in support of terminally ill patients demanded treatments and investigation into the causes of their illnesses.

For incurably ill patients, moving toward a "cure" or "healing" through finding the causes of their illnesses and treatments was one way to ensure that society recognized their existence.

The movement aimed to bring society's attention to the disability issue through the provision of medical treatment.

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**The Incurable Disease System**

**Guidelines for Measures against Incurable Diseases**

A campaign for cause investigation and treatment

The SMON issue finally drew the government's attention to the issue of incurable diseases. In September 1970 it was discovered that SMON was caused by the drug "chinoform," The Ministry of Health and Welfare accordingly designated SMON as a harmful side effect of the drug and indicated that they would offer assistance.

The Japanese Association of Families of the Mentally Handicapped aimed to create the Act for the Welfare of the Mentally Handicapped as a separate component of the Mental Health Act. With fixed support already being in place for muscular dystrophy, this condition was not covered under the Measures against Incurable Diseases Guidelines framework; therefore, any other disease for which a patient organization existed were classified as incurable diseases (Eto, 1993).

In Japan, a care support system for people with systemic disorders, which provides care services. In addition, a care agency established and presently operates as an organization that allows them to choose their carer, was also set up.

The movement in support of terminally ill patients demanded treatments and investigation into the causes of their illnesses.

For incurably ill patients, moving toward a "cure" or "healing" through finding the causes of their illnesses and treatments was one way to ensure that society recognized their existence.

The movement aimed to bring society's attention to the disability issue through the provision of medical treatment.

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*Graduate School of Core Ethics and Frontier Sciences Ritsumeikan University.*
Regarding conditions that require various types of medical care, such as helping the person swallow sputum and treating gastric fistula, the role played by family members is crucial. Due to changes in the body, the person's own demands and requests become uncertain, making it impossible to effectively instruct caregivers. Even if the person's needs are understood, in situations where communication is difficult the instructions themselves become a burden.

People with ALS hoped to reduce the burden of family assistance through treatment and recovery. People with cerebral palsy and other disabilities also face challenges, but their needs can be predicted to a certain extent.

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**Reasons that family assistance cannot be denied:**

- Bodily Impairment
  - Communication through speech is difficult.
  - Medical care, such as assisting patients in swallowing sputum, becomes necessary. These people need 24-hour a day assistance.
- Due to changes in the body, the person’s own demands and requests become uncertain, making it impossible to effectively instruct caregivers.
- Even if the person’s needs are understood, in situations where communication is difficult the instructions themselves become a burden.

**Phenomena resulting from the impairment:**

- Some changes in the form of impairment are difficult to identify.

**People with ALS are defined as having bodies that cannot completely reject family assistance (family roles):**

Regarding conditions that require various types of medical care, such as helping the person swallow sputum and treating gastric fistula, the role played by family members is crucial. In many cases, others who are not family members have no choice but to depend on family assistance.

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**References**


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The movement for people with ALS reflected these issues faced in daily life.
Guaranteed Assistance and Intractable Diseases

Self-determination ➔ Independence as a person who is alive.

An important point discussed by people with disabilities in the movement for people with disabilities was the ability to gain an identity as living persons; in other words, they sought independence as a person who is alive. With regard to their relationships with caregivers, in particular, people with disabilities defined their “independence” as being in charge of their own everyday lives by instructing caregivers on what is necessary and what they wish to have done. This issue surfaced as a problem in various situations in daily life when it came to the policy's actual implementation.

With respect to their relationships with medical professionals, due to the gap in specialized skills there are cases where medical professionals gain control over the patient’s daily life. This exemplifies the unique power structure maintained by the medical profession.

**The unique power structure maintained by the medical profession**

This is captured on a social level as a professional group rather than in terms of the characteristics of the individuals who belong to the profession. Control is enabled and sustained through a monopoly over work in the medical field and by securing their position in their relationship with patients rather than seeking it by means of superiority in terms of knowledge and abilities.

**Professional organization**

- Right to decide educational programs
- Right to decide license requirements
- Right to decide the scope of work

**Professional control**

- Patients do not talk back to doctors
- Patients obey doctors

**Personal assistant**

He decides on a caregiver, instructs the caregiver, adjusts their shifts, and manages their pay, among other actions. A caregiver is identified among people other than housemates and family members, such as friends and acquaintances. Recruitment and interviews of caregivers and instruction and education on care and other activities are performed by Mr. Masuda himself. His own daily life is freely and independently organized by selecting a caregiver himself rather than having one dispatched by a caregiver agency.

Current there are 15 personal assistants and most of them are students. Students stop being personal assistants upon graduating. Therefore, personal assistants are constantly being recruited.

**Problems that occur due to the implementation of daily “medical care”**

In terms of their relationships with caregivers, patients can gain independence, and with medical staff being confronted with this independence, there is a possibility of building a relationship that is not based on control or a relationship as a patient and a caregiver.

The issue of relationships with caregivers, which has been raised as part of the movement for people with disabilities, has also served to change the dynamic of this control.

If this is the case, the work done by personal assistants of people with ALS is a realistic means of achieving ongoing change.