Disability, Destitution, and Disaster: Surviving the 1995 Great Hanshin Earthquake in Japan

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On the morning of January 17, 1995, a magnitude 7.3 earthquake struck the port city of Kobe, Japan. 6,400 people died and over $80 billion in property damage occurred. Among those rendered homeless was a small group of people with severe disabilities. Over the next decade, this group leveraged discourses surrounding civil society, disability, poverty, and the role of government in natural disasters, to become one of the most powerful and vocal proponents of disability rights in Japan. What lessons can we learn to make disability advocacy a leading, rather than trailing, element of social policy?

Key words: advocacy, disability, civil society, social welfare, government

Introduction

A tremendous natural disaster strikes a major metropolitan area. Thousands are thought to have immediately perished and hundreds of thousands are rendered homeless. The local government is overwhelmed as provision of basic services such as medical care, electricity, telephone, water, and food supplies are all disrupted. The elderly, disabled, and poor are hit the worst. The national government dallies for days while people are dying in the streets and the eventual response is too little, too late. Citizens all across the country are enraged at this state of affairs and demand change.

This was not New Orleans 2005. This was Kobe City, Japan in 1995.

In the early morning hours of January 17, 1995, a Richter magnitude 7.3 major earthquake struck 16 km below the surface in the Hanshin-Awaji area near the port city of Kobe, located west of Osaka, Japan. Although many Japanese had thought that their country had some of the highest earthquake resistant construction standards in the world, these beliefs were shattered when the earthquake hit. Simply put, this major metropolitan region of 3.5 million residents was devastated. Overhead highway trusses split in two, the Shinkansen Super Express train derailed, ferroconcrete buildings were pitched onto their sides, and wooden residential homes burned for days. This was not supposed to happen.

Over 6,400 people died, over a million were rendered homeless, and over $80 billion in property damage occurred. People across Japan were horrified at a scale of destruction that had not been seen since the Pacific War and were enraged at the national government’s subsequent mishandling of the rescue and recovery effort. National self-defense forces were not sent in for several days, as local and national bureaucrats clashed over jurisdiction and accusations of political scheming. In one famous incident, specially trained survivor rescue dogs and their human teams from Switzerland were held back at Narita airport for several days over quarantine requirements, thus rendered useless (Grubel 2000:121).

Just as with New Orleans 2005, Japanese citizens in the 1995 Kobe earthquake were outraged that news media were able to get helicopters in for live coverage of the ongoing tragedy while the national government was seemingly still in denial. The result of the bungling of the rescue effort was a massive outpouring of financial and physical assistance by the citizens of Japan and the creation of a new era of active civil society in Japan. Three years later, the government passed the first Non-Profit Organization Law (NPO Law of 1998), allowing small non-profit organizations to incorporate for the first time.

Located near the epicenter of the earthquake in the suburb of Nishinomiya was a small organization of people with severe physical disabilities called the Mainstream Association. Their office building was destroyed and most of the members were rendered homeless. Ten years after the earthquake, Mainstream Association had become one of the strongest and most militant organizations of people with physical disabilities in Japan. This paper discusses the ways that Mainstream leveraged discourses surrounding civil society, disability, poverty, private and public giving, and the government’s role in natural disasters.

Disproportionate Impact

Although the quake struck the entire Kobe metropolitan region including the downtown business area and shipping
port facilities, it disproportionately affected parts of the city where there were more elderly, people with disabilities, and low-income earners. This is because of an unfortunate confluence of factors. Low-income housing in Kobe tended to be closer to the shoreline or rivers, built on silt, or in reclaimed areas. Building foundations in these places were set in weak soil or landfill that liquefied during the quake, toppling entire structures. Furthermore, low-income residences tended to be older, built close together, and made of wood. Roads were twisted and unimproved, and access was very difficult for firefighting equipment and rescue vehicles. In contrast, the upper class areas of Kobe were located in the mountains facing the bay. There, houses had solid foundations in the bedrock, there were more natural firebreaks, and the houses were of newer construction with contemporary building materials and more earthquake and fire resistant designs. Roads were wider, too, aiding evacuation and allowing support vehicles such as ambulances and fire trucks to move in quickly.

Disproportionate impact was also caused by social and demographic factors. While younger, richer, or able-bodied residents could relocate to relatives in other parts of Japan, those who were poor and who required attendant care, day services, or barrier-free housing were not as mobile. Japanese houses tend to be small with little room to spare and not designed for barrier-free access. The genkan (raised entrance to Japanese homes) is symbolic of the problems that people had relocating.

On the positive side, there was an outpouring of support from all across Japan for the earthquake victims. Contrary to the common stereotype that Japanese civil society and volunteerism is weak, neighborhoods, clubs, and other organizations quickly rallied to provide food, clothing, and other services for the newly homeless. For example, members of the Osaka Lesbian Project made hot coffee and bicycled thermoses of coffee into the area. Even the Japanese yakuzza (mafia) were famous for providing food through their network of (usually underground) distribution services well before municipal and national governmental supplies were sent in.

This is where my ethnography begins.

**Mainstream Association**

This article explores an independent living center near Kobe called the Meensutoriimu Kyousai (Mainstream Association). I conducted fieldwork at Mainstream in 2005-2006 as part of a larger project on disability politics in Japan, funded by a grant from the Abe Fellowship and Social Science Research Council. The choice turned out to be fortuitous as Mainstream's history was deeply marked by the Kobe earthquake of 1995 and my research period coincided with the 10th anniversary of the Kobe earthquake.

Mainstream Association was founded in 1989 by local disability activists who had organized a national conference for wheelchair users in the area. After the conference ended, there were leftover funds, and the organizers decided to put the money into establishing a center for people with disabilities, drawing on the newly introduced independent living model. The independent living (IL) movement had started in 1986 in Japan after some men and women with disabilities who had visited and interned at IL programs in the United States came back and established the first center in Tokyo, the Human Care Association. Independent living centers are based on the premise that people with disabilities are in the best situation to help other people with disabilities to live independently. They do this by providing attendant care services, independent living training and transitioning services, peer counseling, running of sheltered workshops, and so forth.

The first several years were difficult, as Mainstream tried to find a sense of direction in the absence of strong social and political support for disability awareness. Apart from organizing sports events and conferences, much early energy was spent on combating the stigma of being in a wheelchair and in making public facilities such as train stations accessible. Although it was registered as an independent living center, very few of its members were living independently in the early 1990s. When the earthquake struck in January 1995, residences of key members who had been living independently were destroyed, as was the main office.

**Shimoji-san's Tale**

When the earthquake struck in 1995, Tsutomu Shimoji had already been living independently in his own apartment for about four years. Before that, he had been in a nursing home for over a decade, following a teenage gymnasium prank gone wrong that had left him with a spinal injury and wheelchair dependent, with only limited mobility in his arms. The nursing home was a "total institution" (Goffman 1961) where all personal activity was controlled by the staff: waking up, sleeping, dressing, eating, defecating, watching television, or going outside.

With help from the Mainstream Association, Shimoji-san was able to leave the nursing home and live on his own. The personal care attendants that Mainstream provided were under his control, not the other way around. He could tell them when he wanted to wake up, what he wanted to wear for the day, what type of breakfast he wanted to eat, where he wanted to go, and so forth. For living expenses, he received a stipend from the government through the disability welfare pension and social welfare systems. As he recalls, his life at the time was finally a "seiatsu rashii seiatsu" (life worth a life) after years of institutional living. The earthquake changed all that.

After the disaster destroyed his home, he could not find a place to rent. All of the affordable housing had been damaged by the earthquake. Because he needed attendant care, Shimoji-san had to live near a train station and in a building with a working elevator, but these were now premium properties. Even if he could afford a place by spending some of his own savings toward rent, the social welfare system capped the maximum amount of housing expenses he was allowed
Figure 1. Shimoji Tsutomu in 2005

them found housing with friends, relatives, or in the public housing system, but two of them, Shimoji-san and Tamaki-san, were still homeless. It was decided at the meeting that these two men should go to Nagoya where a neighboring independent living center could assist them.

Nagoya: The AJU Center for Independent Living

Shimoji-san and Tamaki-san decided to head to the AJU Center for Independent Living in Nagoya, about an hour by train east of Kobe. Established in 1975 as an association of and for wheelchair users, AJU is one of the oldest and largest organizations of people with disabilities in Japan. The AJU acronym stands for Ai no Jikko Undoukai (the Movement to Promulgate Love). AJU owns an acronym living center and a residential facility and runs several businesses (including attendant care provision, mobility services, computer data entry, etc.).

In Japan, all social welfare services and benefits—from disability care to nursing facilities—are provisioned by local governments. Just as Medicare/Medicaid users in New Orleans after Hurricane Katrina found it difficult to reestablish their welfare services in other states such as Texas or Mississippi, many people on welfare in Kobe were not able to move to other cities because they were afraid of losing their benefits. Soon after the earthquake, AJU successfully petitioned the Nagoya City Government to offer victims of the Kobe earthquake access to Nagoya City facilities and eligibility for social welfare services. This was quickly approved, and so Shimoji-san and Tamaki-san traveled from Kobe to Nagoya to live in a municipal residence for people with disabilities near the AJU facility. Personal care attendants from the area were dispatched to help them in their daily needs.

Even though their personal needs were being taken care of, Shimoji-san and Tamaki-san soon became bored and felt guilty that they were not able to do anything for their friends back in Kobe. They decided that while they were stuck in Nagoya, they should raise funds to help Mainstream get back on its feet. And so it was decided that they would both stand (or sit) in front of Nagoya Central Train Station and ask for donations for earthquake relief for people with disabilities in Kobe. The fundraising was phenomenally successful. While he commented that people in the Osaka/Kobe area were renowned skinflints, Shimoji-san noted that it was common for Nagoya residents to drop $100 bills in their box while they were outside the station.

Shimoji-san really loved the fundraiser. When he was living in Kobe, he rarely went outside and did not get to meet many new people. Sitting in his wheelchair in front of Nagoya station with a box asking for money, he encountered a wide variety of people and struck up conversations with them. He remembered one person who rushed up to the box and dropped a large envelope in it and tried to scurry away. Shimoji-san chased after him so that he could at least get a name and address to write a thank you note. The fundraiser went on for two weeks. Sometimes, it was just Shimoji-san and Tamaki-san standing

to pay. Furthermore, many landlords were unwilling to rent to a wheelchair user: they were worried that the walls would get damaged or that the tatami (folded or piled) flooring would be ruined by the wheelchair wheels. Or, in the aftermath of the earthquake, they said, they could not have any disabled people because they would not be able to evacuate in an emergency, and the landlords did not want to have that liability on their hands.

Shimoji-san visited over 250 apartments but he could not find a single one that he could rent, except for some flophouses built three decades ago. He applied for emergency public housing but he lost the lottery (not surprising since people with disabilities were not prioritized in any way and space was short). In retrospect, he says he was glad because the emergency shelters were not barrier free and were located in what he thought were bad areas of town.

About a week after the earthquake, there was a meeting at Mainstream. Shimoji-san and the other members all went. There was a lot of enthusiasm but also a lot of concern. At the time, several people had been living independently. Some of
outside the station. At other times, local boy scouts or AJU staff would come by and help. The best time was on weekends, and at the peak they had 100 volunteers helping them. A regional television news program covered them—and included their bank deposit information in their broadcast. Deposits flooded in from across the area.

They raised $250,000 in two weeks, all from private donations. The largest single donation was over $80,000 from a doctor. Shimoji-san recalled that he had never seen a check with that many zeroes and had to count them individually. When the president of Mainstream Association called the doctor to thank him, the doctor apologized for not giving more. Corporations were less forthcoming and very little was obtained from them or from the Kobe City Government. This was really an expression of grass roots support from regular Japanese.

The $250,000 raised by Shimoji-san and Tamaki-san transformed Mainstream. It allowed them to purchase their own building, an open design created specifically around the needs of people with disabilities. They were able to expand services considerably to include people who were deaf as well as people with serious physical impairments. But more profoundly, it affected them psychologically. Shimoji-san became one of the leaders in Mainstream and played a more dominant role, while Tamaki-san became a strong advocate for disability services, visiting residential care facilities and evangelizing about the independent living program. In the wake of the Kobe earthquake as well as recent cutbacks in disability services, they see their social role and political voice as more important than ever.

Mainstream Association itself became a key actor in disability politics. Today, in national protests, with their bright yellow hachimaki (headband bandanas), its members are often the largest, loudest, and most visible group of demonstrators.

**Growth of the Centers for Independent Living**

Inspired by American activists such as Judy Heumann and Ed Roberts, the independent living movement had been active in Japan since the 1980s but it had struggled with lack of funding and purpose. During the inception of the movement, social welfare organizations tended to be closely affiliated with and monitored by the Ministry of Health, Labor, and Welfare or its prefectural counterparts. It was very difficult to incorporate in Japan as a non-profit organization without substantial assets and a close working relationship with the government (Estévez-Abe 2003; Nakamura 2002). As a result, many Centers for Independent Living were unincorporated and, thus, ineligible for any type of government funding, grants, or contracts.

This changed in 1998, when spurred by the government’s embarrassingly slow response to the 1995 Hanshin Great Earthquake, the national legislature passed a new NPO Law which made it easier for socially-minded non-profit organizations to incorporate (Pekkanen 2000, 2003). The NPO law of 1998 and the changes brought about by the Support Payment Plan system in 2003 transformed the independent living movement. The NPO Law reduced the financial threshold for the incorporation of Centers for Independent Living (CIL). The Support Payment Plan provided the mechanism by which a CIL could fund itself. As it turned out, it would only take four people with severe physical disabilities to serve as both the core staff as well as clientele for a CIL to operate, which entirely shifted the political economy of disability services.

For example, if four people with severe physical disabilities who required full-time attendant care and were living in a nursing home incorporated a CIL, they could deinstitutionalize and live independently. Their CIL would be the licensed provider of their personal attendant care. Each of them might require 720 hours of attendant care a month or 2880 hours a month combined. The government would pay the attendants about $19 an hour and the CIL would receive approximately $2 an hour in administrative overhead. This would yield a monthly revenue for the CIL of about $5,000—enough to rent a small office and to pay a small salary to each of the CIL officers (in addition to their disability pension and social welfare income). Furthermore, the Support Payment Plan allowed clients to negotiate with their care providers as to the degree and type of services provided. The government only had a minimal degree of oversight into the program. If the care provider was a forceful advocate for their clients (as many of the self-run CILs were), local government officials were often very reluctant to impose artificial ceilings on the amount of care provided.

The idea of CILs funded by the Support Payment Plan caught like wildfire. Designed for people with mild to moderate needs, the Support Payment Plan quickly became a mechanism for people with severe disabilities to move out of institutions or their parents’ homes and live independently, often for the first time in their lives. The CIL members with whom I talked rejected a negative moral reading of their reliance on welfare funds by arguing that what they were doing was work. That is, running the CILs and advocating for disability rights was an important part of Japanese civil society, thus they should treat their disability pensions (and the administrative money for the personal care attendants) as their salary, not as a public benefit. “We are not just laying around,” they explained to me, “we are building a new society,” a new Japan.

The CILs represent a totally new form of disability organization in Japan. The immediate post-war period saw the creation of three national, top-down organizations of the blind, deaf, or physically disabled (Japanese Federation of the Deaf, Japanese Federation of the Blind, and the Japanese Federation of Organizations of the Disabled Persons). The groups are single-disability and each have memberships running in the several thousands with local offices in each prefecture and town. The colossal size of the groups and their emphasis on a single disability category has given them particular clout in working with the national government on disability issues (Nakamura 2002).

In contrast, the CILs are small-scale (often less than 10 members) and locally based. The groups are not usually hierarchically organized and leadership roles are typically
shared among the members in the spirit of self-determination and self-autonomy. Their size and local base also broke down disability categories and separations. Previously it was inconceivable that someone with cerebral palsy might be in the same group as someone with a spinal injury and someone who was deaf, as each would have belonged to a different national association.

The 122 CILs loosely coordinated by the Japan Council on Independent Living Centers are united in the goal of achieving independent living, but each CIL is very much its own entity. The CILs disparagingly called the three national disability organizations (deaf/blind/physically disabled) the “three amigos” because of their close collusion with the government and their top-down hierarchical structure. In contrast, they saw their grassroots, acausal networking as the source of their power. While the “three amigos” could claim memberships in the tens of thousands, the Japan Council of Independent Living Centers could counter this with their claim of 122 independent living groups across Japan.

The Government’s Response: A Grand Design

Unfortunately, the new Support Payment Plan program was financially untenable. A severely disabled person required over $10,000 a month for full-time attendant care services ($19/hr x 720 hours). Even a small CIL could consume half a million dollars a year in government funds, and these types of CILs were flourishing. The increase in social awareness and political and economic investment in disability services led “disability” as a social category to expand rapidly.

As a result, the Ministry of Health, Labor, and Social Welfare proposed in 2004 a “Grand Design” that would substantially cut back on attendant care services for people with disabilities. The ultimate goal of the Grand Design was to integrate disability care into the Long Term Care Insurance Program (LTCI or Kaigo Hoken). The political scientist John Campbell has written about the motivation behind the creation of LTCI (Campbell and Iegami 1999, 2003). Implemented in the year 2000, the LTCI Program is an insurance program for frail elderly Japanese to provide for them in the case of decreasing physical or mental ability due to old age. All citizens start paying premiums into the system starting at age 40. The LTCI Program pays for home health care, attendant services, day care, nursing care, and so forth—but a 10 percent co-payment is nominally required for all services. The types of services that are provided through the program are determined by local administrative boards on the basis of results from a computer-administered evaluation of the ability to conduct Activities of Daily Living (ADL). The Japanese government considers the LTCI Program to have been a success in providing quality care for elderly citizens while at the same time controlling spiraling costs. It was not surprising that confronted with increasing disability care costs, officials within the Ministry of Health, Labor, and Welfare would consider modeling disability care into the same type of insurance program as LTCI.

CIL Reaction to the Grand Design

The Grand Design proposal bewildered the disability community who considered the Support Payment Plan to be successful in that many people with moderate to severe disabilities who had been institutionalized for decades were living independently for the first time. Furthermore, many Centers for Independent Living had a solid funding basis for the first time in their history.

Beginning in June 2004 and over the next year, a coalition of various disability organizations staged a series of protests in Tokyo in front of the Ministry of Health, Labor, and Welfare building. The protests involved up to 2,000 people with disabilities and their supporters. In confronting the government, Japanese disability advocates tried to play into the insecurities of the politicians and bureaucrats by showing how far behind Northern European countries Japan was in its disability welfare policies. In response to the protests, the Ministry stonewalled the protesters and staged a media blackout by pressuring news and television corporations to withhold coverage of the events.

CILs formed a large part of the protest movement. This included not only CILs that were under the Japan Council on Independent Living Centers, but also groups affiliated with People First Japan (an organization of people with developmental disabilities, affiliated with the international NGO People First) as well as a smattering of groups affiliated with people with psychiatric disabilities. Only very loosely coordinated, the demonstrations were large, rowdy, and disorganized—but visually spectacular in their myriad diversity.

The protests were initially successful. The Ministry had not foreseen the degree to which the Grand Design would be criticized and withdrew the proposal from consideration. Unfortunately, it was resurrected under a new name: Jiritsu Shien Ho (the Independence Support Law), which maintained much of the same contours as the original Grand Design.

From the perspective of the activists, the key problem with both the Grand Design and the Independence Support Law was that the ministry sought to change the basis for disability care fundamentally from an entitlement program (i.e., funded from the government’s general coffers) to an insurance program (funded in part by co-payments by beneficiaries). Demonstrators argued that it made no sense for disability care to operate as an insurance program. First, it was constitutionally improper—Article 25 of the constitution mandated that all citizens be eligible for a minimum quality of life, and support for full-time attendant care and independent living was seen by the activists to be part of the contractual obligation on the government. Second, the language of insurance programs was unsuitable for people with disabilities—why were the essential services that they needed to live being classified as “benefits” subject to co-payment? For people with congenital disabilities, would it make sense to view them as people who were insured, even though they were this way at birth?
Other issues arose. The Independence Support Law proposed to use ADL criteria to objectively evaluate the needs of people with disabilities. However, the disability community in Japan argued that ADL criteria were entirely inappropriate for many people as it used the non-disabled body as its standard and focused on specific tasks (such as putting on socks) rather than goals (such as being able to work or being able to go to a restaurant). Furthermore, the review boards established by the Independence Support Law did not require any representation by people with disabilities. In fact, the requirement that members of the boards be “neutral and objective” meant that members of a CIL or other disability organization might be disqualified.

Another stated goal of the law was to reduce the geographic disparities in care coverage as well as the disparities between the three disability groups (physical, psychiatric, and developmental). However, many activists felt that this would lead to the reigniting of areas that provided too much disability care (such as the Kansai area) rather than raising the bar for areas with few resources (such as the northern Honshu area). It would also weaken the social and political role of CILs in providing services for people with disabilities, limiting their power at a time when grassroots networks were starting to gain voice.

Success and Then Failure

As mentioned above, the protests were initially successful in that the Ministry withdrew its proposal for the Grand Design when it saw that it would be politically difficult to pass the bill in the legislature. However, in October of 2005, then-Prime Minister Koizumi called for a snap reelection in order to push through his postal reform policies. His leading Liberal Democratic Party (LDP) won in a surprise landslide election. As a result, the LDP was able to push through a number of bills that had been successfully tabled by opposition parties, including the newly renamed Independence Support Law. This happened so quickly that the disability community was unable to stop the bill from passing. Furthermore, the protests engendered so much ill-will with the Ministry of Labor, Health, and Welfare that they were not able to participate as much in the implementation details as they might have, had they operated more cooperatively with the Ministry.

When I revisited many of the activists in June 2006, the Independence Support Law was scheduled to be implemented in two stages starting in April with full implementation by October 2006. The impact of the law was still not yet felt and many details had still been undecided. On the ground, service provisioning seemed to be going on as before. Even though the Independence Support Law made changes in the provision of care, the reality is that most people with severe disabilities will not have to pay co-payments as they are on public support and fall under the minimum income requirements. None of my informants reported drastic changes to the level or degree of care provided—although the government has begun the computer-based analysis of their ADL needs in preparation for full implementation in October.

What was most tangible was the sense of disappointment within the community. An enormous amount of psychological and physical energy—as well as money—had been spent the previous year fighting the ISL. The bill had passed anyway, and many members felt that they had nothing to show for all of their efforts. Although the protests had brought together activists from the three main disability categories (physical, intellectual, and psychiatric) into a unified coalition for the first time, it also revealed significant differences of opinion and direction.

Conclusions

Much of the attention on civil society in Japan (for example, in Schwartz and Pharr’s (2003) influential edited volume) has focused on larger and more traditional organizations such as national-level non-profit or international non-government organizations. However, questions of the degree of transparency and democratic participation in large NGOs can be legitimately raised (Hirata 2002). To what degree, for example, can the Japanese Federation of the Deaf be said to represent the entire will of all 20,000 of its members? With organizations this large, the board of directors tends to be relatively distant from the local membership and decisions are made top-down.

Centers for Independent Living present a very different type of associational life in Japan that is smaller, much less tightly coordinated, and locally based. The structure and communication patterns of the CILs made them dissimilar to many of the standard large organizations than those that political scientists usually classify as civil society (non-profit and non-government organizations).

Although the CIL-based disability movement is currently struggling after political losses in recent years, it is clear that there has been a slow shift of power away from the larger national organizations of people with singular disabilities to smaller, more locally based ones that are cross-disability and more horizontally structured. These have proven to be more responsive on the ground level, as the example of Mainstream Association shows, especially in reaction to natural disasters. As the Japanese government itself decentralizes and pushes more responsibility to local governments and peripheral regions, these types of locally based organizations may be exactly what are needed in the next chapter of the disability movement in Japan.

Notes

1In Japan, independent living programs must be run by people with disabilities (the board of directors must be majority disabled) in order to qualify for membership in the Japan Council on Independent Living Centers.

2For example, the main floor is not subdivided into separate rooms but has flexible seating and tables and a handicap-accessible bathroom. The three-story building has a built-in elevator, which is rare in small buildings in Japan.
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