

Society for East Asian Anthropology

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Severe Disabilities, Liberalism and Social Welfare Policy in Japan and the US

By Karen Nakamura (Yale U)

I spent the past year in Japan exploring social welfare politics in the context of people with severe physical disabilities. I define “people with severe physical disabilities” here as people with major physical impairments such as cerebral palsy, muscular dystrophy or spinal injury so severe that they cannot cook, bathe, eat, defecate, go to a movie theatre or other activities of daily living without the use of a full-time personal attendant. Methodologically, my work blends political anthropology and visual anthropology in a comparative study of the US and Japan.

People with severe disabilities challenge the American liberal notion of equality under the law, which is the basis of much disability rights legislation. In the US, the Americans with Disabilities Act (ADA) of 1990 prohibits employment discrimination on the basis of disability and calls for “reasonable accommodation” of persons with disabilities. While this benefits those with mild disabilities who require little in the way of accommodation (the median expenditure is a measly \$420 per person), people with severe (and even moderate) disabilities fall entirely out of the scope of the ADA due to “undue hardship” on employers. What remains of the ADA has successfully been whittled away by Supreme Court challenges over states rights, sovereignty and a rapidly shrinking definition of disability. Further complicating the situation for people with severe disabilities are the current cut-backs on social security (SSDI/SSI), Medicaid and other public assistance programs.

Japanese disability policies can be as paternalistic in the best and worst sense of the word. Article 25 of the Japanese Constitution guarantees the “right to maintain the minimum standards of wholesome and cultured living,” which underlies both disability legislation and welfare policy. People with physical, developmental or psychiatric disabilities are required to register for and carry a *shōgaishatechō* (disability ID card), which gives them a broad array of benefits including a disability welfare pension, public assistance from local governments, free travel on municipal transportation and discounted travel on JR railways.

Since 2003, people with severe physical disabilities are also eligible for part-time or full-time personal assistance coverage if they wish to leave their families and nursing homes and live independently. They are facilitated by Centers for Independent Living (CILs) that coordinate personal attendant care. People with disabilities manage the CILs and receive administrative overhead reimbursement from the government for the personal attendant



Photos of the May 5, 2005, demonstration of disability advocates were not published by many media sources. Photo courtesy of Karen Nakamura

care services they provide to themselves. Activists in Japan reject a negative moral reading of their reliance on welfare funds by arguing that what they do is *work*. That is, running the CILs and advocating for disability rights is 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 Japanese government has tried to limit the explosive growth of personal care attendants and in late 2004, declared that they were ending the program. This created a massive response by the CILs who staged a series of large protests in Tokyo, in front of the Ministry of Health, Labor and Welfare building in Kasumigaseki. In confronting the government, Japanese disability advocates have tried to play into the insecurities of the politicians and bureaucrats by showing how far behind Northern European countries Japan is in its disability welfare policies. In response to the protests, the MHLW successfully staged a media blackout by pressuring news and television corporations to withhold coverage of the events. Through this process, I was actively documenting, photographing and blogging the disability protests on my home page (photoethnography.com/blog) and was one of the few (non-mainstream) media sources reporting on the issue. The photograph accompanying this article is from their May 5, 2005, demonstration.

Documentary photography has long been associated with exploitation of subjects. Through my photoethnography, I work collaboratively with my informants to produce visual material that accurately reflects their worldview as active

agents of social and political change. Since my photography and reportage has subsequently been used in activist magazines and billboards, I am trying to determine the appropriate balance of participant and observer in my fieldwork. When anthropologists blog on breaking events, do we leave the cozy confines of academia and become news reporters? This is an issue that I struggle with on a daily basis when in the field.

[Karen Nakamura is assistant professor of anthropology and East Asian studies at Yale University. This research was conducted on an Abe Fellowship granted by the Center for Global Partnership and Social Science Research Council.]

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Society for Latin American Anthropology

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Lynn Stephen on Rethinking “Latin America”

For nearly a decade, SLAA discussions have grappled with how to define our field in more inclu-



Lynn Stephen

sive ways in dialogue with Latin American anthropologists and social movements. In the April 1997 *AN*, then-president Michael Kearney wrote that until recently, the society’s membership had been “centered in North America while its objects of study were primarily to the South ... ‘we’ used to ‘go down to’ Latin America to study the ‘Latin Americans,’ and then publish most of our work in English.” Kearney advocated rethinking Latin America to encompass all Latino/a communities. When Joanne Rappaport became president, she called for “an effort to view Latin America, not as a geopolitical reality upon which we as North Americans have an ‘impact,’ but as a place from which to speak, write and to theorize” (www.indiana.edu/~wanthro/matt1.htm).

Over the years, SLAA has prioritized networking to broaden its membership and conversations with Latin American and Caribbean anthropologists and activists, and develop linkages with ALLA and research with Latino diaspora communities. At this month’s AAA meeting, the SLAA business meeting considered the proposal to change the section’s name to Society for Latin American and Caribbean Anthropology (SLACA) (discussed by President Gabriela Vargas-Cetina in last month’s column).

The issues go far beyond geographic scope. At the AAA meeting this was explored in the