
Exclusion from the family and the community: the challenges of deinstitutionalization in Japan

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Résumé

Recently, inclusion of people with disabilities into the local community and the guarantee of their autonomy has become a global standard in disability policy. Two major policies of deinstitutionalization (shrinkage or closing of large-scaled facilities and transition to community-based living arrangements) and socialization of care work have various impacts on the lives of people with disabilities and their families in different countries and regions. Although people with disabilities are in the mainstream, their families are regarded as spokespersons, and they do not have autonomy as caregivers with needs, in contrast to people with disabilities. Furthermore, there is political pressure to have family members remain as informal caregivers to reduce the welfare budget.

In this paper, in light of the social trend of depending on the families for the care of people with disabilities, I will examine briefly the disability policy and discuss issues such as deinstitutionalization, challenges in the community, and caregiving and the social position of families of people with disabilities in Japan. The latter will be examined through particular cases of conflict between people with disabilities and their families with regard to institution-oriented care.

In Japan, deinstitutionalization sometimes causes high anxiety and opposition on the part of the families of people with disabilities, particularly the parents, because they have to bear the burden of taking care of people with disabilities on a daily basis. If the families of people with disabilities are not provided with adequate support in the form of group home use or personal assistance, and they suffer from the heavy burden that is placed on them, (care is only provided by their family and) the disabled are institutionalized and excluded from their families and community when the families cannot take care of them anymore. Although the discourse of "Institutionalization is requested by the families of the people with disabilities" seems to respect the families of people with disabilities as caregivers, this disguises the truth that families have no rights and are forced to bear an excessive responsibility for caregiving. Moreover, the families of people with disabilities are excluded from the community as informal caregivers together with the disabled people they care for. There is no "human rights approach to caregiving" consisting of "a right to give care", "a right to receive care", "a right not to be forced to give care" and "a right not to be forced to receive care" (Ueno 2011: 60).

Based on the Japanese experience, the government will not make efforts to provide services that allow people with disabilities to live independently in the community according to the policy that care will be provided by their families. Then, institutions and hospitals will become the solution when families cannot take care of them and a system that does

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not guarantee the rights of the disabled to decide where, with whom, and how to live would be created. I will suggest that one of the conditions for successful deinstitutionalization is guaranteeing caregivers' rights such as "a right to give care" and "a right not to be forced to give care", and clarifying responsibility of the government to provide adequate services.

References: Ueno, Chizuko (2011) *Care no Shakai-gaku. (Sociology of Care.)* Ohta Shuppan, Japan (in Japanese)