

## Preface

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This special issue of *Ars Vivendi Journal* is dedicated to the question of disability. It begins by an article of Professor Colin Barnes that gives an overview of the development of disability studies during the last thirty years, mostly in the U.K. and in the United States. The central claim he makes is that disability studies have been profoundly transformed and developed during that period through the action of disabled people and their advocacy groups. As he says “The challenge to the established view did not come from within universities and colleges but from disabled people themselves.” The driving force behind the development of disability studies has not been the academy as such, but the disabled people. Thus it is the changing relationship between university researchers and disabled people which among other things has become much more militant and politicized that has changed disability studies. This has not always been a simple, or even a peaceful, relationship, there have often been disagreements between the goals and objectives of researchers and those of the self-advocacy groups of disabled persons, however it has always been a productive relationship that helped to better the living conditions of people with disabilities. Over the years disabled people have gained a voice and some political power and it is this voice which is now being heard in disability studies. Much remains to be done but progress lies in continuing this dialogue and collaboration.

Interestingly, integrating disabled persons as researchers and equal participants in the studies that bear on them has, from the beginning, been had the heart of the approaches favored by the Ars Vivendi Research Center. The two other articles in this special issue precisely illustrate the central place of disabled people activism in disability studies. While the article of Professor Barnes is more theoretical, giving an image of recent development in disabilities studies those of Professor Osamu Nagase and of Hiroko Satou are case studies. That of Professor Nagase, as its title clearly says “Promotion of Self-Advocacy of Persons with Intellectual Disabilities: Case of Myanmar” is a report on the creation of the first self-advocacy group for persons with intellectual disabilities in Myanmar. One of its interests is the extent to which it shows the collaboration between disabled person’s advocacy groups and agencies from different countries. Because it is based on the author’s active participation in the meetings that led to the creation of

this group and others, it also shows that if more and more disabled persons are becoming researchers, it is also the case that researchers are becoming central participants in these groups.

The last article, by Hiroko Satou centers on the situation of persons with disabilities who are dependant on electrically powered medical equipment in the aftermath of the 2011 Tohoku earthquake in the Tokyo area. As the author says, there is a sense in which the difficulties experienced by these persons were minor disagreements compared to what was suffered by those who were at the heart of the earthquake and tsunami. However, these difficulties clearly reveal the limits and failure of the existing systems of help and point towards necessary changes in policy and greater disaster preparation. In the Tokyo area, difficulties for persons who are dependant on electrically powered medical equipment stemmed from the “rolling blackouts” that were announced and partially implemented by Tokyo Electrical Power Corporation (TEPCO). Fortunately these blackouts, when and where they did take place, did not have any major consequences for these people. However interviews with the persons concerned indicate the lack of preparation on the part of both the local and central governments, and especially the lack of centralized easily accessible information concerning the number, the location, and the needs of persons who for medical reasons are particularly vulnerable in cases of events like a long term blackout or an earthquake. Like the previous article it illustrates that the best source of relevant information concerning the needs of persons with disabilities comes from the disabled persons themselves who are experts on their own disability.