



PANDÉMIES, ÉTHIQUE, SOCIÉTÉ



Challenging the “Bellagio Statement on Social Justice and Influenza” – and the Perspective of Disabled People

Katrin Gruber, Direktor, Institut Mensch, Ethik Und Wissenschaft (IMEW), Germany

The Institut Mensch, Ethik und Wissenschaft is a non profit public company. It has essentially been funded by the German foundation Deutsche Behindertenhilfe - Aktion Mensch. It belongs to a network with nine partner disability and self-advocacy organisations. Our research activity deals with the problems of disabled and chronically ill people (as seen from their own perspective), as well as the impact of bioscience on society as a whole. Ethics does not only deal with pandemic-related dilemmas. We should keep the perspective of the whole society as the relevant one. My own perspective as a researcher is that of political science. My focus is more on norms than on ethics. We are working on the concept of “disability mainstreaming”. It means that the interests of people with disabilities should be made an integral part of processes in politics, administration, society and scientific research – from the very beginning, not just as an “add-on” once basic decisions have already been made. When things are planned and devised by collectivities, disabled people have to be taken into account. So far, the perspective of disabled people seems to have been neglected when setting up pandemic plans. We only examined the German and Austrian plans so far, as we haven’t been working very long on the matter.

The Bellagio Statement¹

What is the Bellagio Statement’s interest considering disabled people? It has been previously highlighted that the needs of disabled people are diverse. A key distinction exists between disabled and chronically ill people. Impairment does not overlap chronic illness.

These are some quotes of the Statement:

¹ <http://www.hopkinsmedicine.org/bioethics/bellagio>.

-“solidarity and trust”;

-“communications should be tailored to overcome obstacles”;

-“civil society groups (...) should be involved in helping to overcome barriers to effective engagement by disadvantaged groups”;

-“evaluation of the impact of interventions and policies (...) especially with respect to prospects for providing fair benefits and avoiding undue burden on disadvantaged groups”;

-“promotion of equitable access to vaccines etc. (...) for traditionally disadvantaged groups”.

Moreover, in the booklet released by the WHO², it is stated that: “Considerations of equity may lead to giving priority to:

-the worst-off (in terms of severity of illness);

-vulnerable and disabled populations;

-uninfected persons who are at high-risk of developing severe complications and dying from influenza if they become infected.”

It is worth noticing that there is no reference to a homogeneous population of disabled people but that many groups are mentioned. And in the paragraph dealing with the discrimination risk, the disabled are missing.

What do the German and Austrian plans forecast?

We first have to keep in mind that some categories of disabled people live in institutions, for example mentally retarded persons. What will be done in these institutions to cope with a pandemic situation must be made clear now.

Even in non-institutional contexts, some disabled persons rely on others 24 hours a day. Following the German plan, nursing homes should be able to care for their patients as long as possible³. Sometimes, they are not able to communicate. Reaching those who have learning as well as communication difficulties will be highly problematic in a severe pandemic situation. What is planned? In Austria⁴, it is forecast to “*contact the media so that the population is informed as objectively and comprehensively as possible*”. Different texts and leaflets will be printed and targeted to different kinds of readers. In Germany, it recognized that translation of information into many languages will be necessary. This is positive. Nevertheless that is probably not enough as this notion of “translation” should be understood in a very wide way. We must not forget sensory disabilities, learning disabilities, autism...

² Ethical considerations in developing a public health response to pandemic influenza, WHO.

³ Nationaler Pandemieplan, RKI, Germany.

⁴ Influenza Pandemic Plan Federal Ministry of Health, Family and Youth, Austria, English translation of the 3rd Edition.

The Convention on the rights of persons with disabilities puts the stress on the fact that mainstreaming disability issues is “*an integral part of relevant strategies of sustainable development*”. When we debate on the flu pandemic risk, this mainstreaming must now be put forward. We do not have the right to postpone the discussion about the inclusion of disabilities in preparedness plans.

Setting up a consultation with disability organisations would be a very valuable first step. Disabled people should express themselves in committees.

We advocate that both international documents and national pandemic plans must be disability mainstreamed. This means that the different needs of disabled people and people with a chronic disease have to be included.