FACE it – on lived health, illness or disability

Bodil Jönsson
Rehabilitation Engineering, Lund University, Sweden
Bodil.Jonsson@certec.lth.se

The concepts of empowerment, learning and enabling have all undergone basic changes during the information age. This has in turn yielded substantial operational changes in the sectors of healthcare, disability and medication – better information, second opinions, e-prescriptions, new forms for distribution, etc. However, there are other levels than the operational ones to consider. The lived health and illness of a person will increasingly influence the course that health as well as illness takes. Although sometimes labelled “subjective” by the professionals, it could be reconsidered and given due status as the experienced health and illness. The acronym “FACE” might be used as a reminder: Functioning is not the same as Enabling but is strongly influenced by Attitudes as well as by the sense of being in Control, i.e. F = F(ACE).

Mutual respect for and coexistence of personal experiences and professional knowledge does not arise on its own, especially not since it must at times rely on overlap, at times on pure complementarity. On the experiential side, the lived side, there is a need for new concepts, new personal measuring methods, new formulations of demands based on recommendations and medication that is subordinated to the life you want to live. The patient Community of Practice requires tools and opportunities to develop its knowledge as has been the case for centuries for the professional community of practice. Meanwhile, old phenomena such as the “placebo effect” (the “meaning effect” for the patient) and side effects of different kinds of medication might acquire another flavour. Of special interest is how the path from lived illness to lived health in ESS, Environmental Somatization Syndromes, can be influenced by a change in concepts and methods for measuring and treatment.