



## EUROPEAN ACADEMY OF REHABILITATION MEDICINE: COMMENTARY ON “TWO PERSPECTIVES ON THE SOCIAL RESPONSE TO DISABILITY”

The European Academy of Rehabilitation Medicine (EARM) meeting, held during the 21<sup>st</sup> European Society of Physical and Rehabilitation Medicine (ES-PRM) congress in Vilnius, Lithuania, on 1–6 May 2018, included a debate in the session “Rehabilitation for all”, based on the paper “Two perspectives on the social response to disability” (1). The commentaries presented offered many insights, not only into the nature of disability, but also into the social role of the rehabilitation professional.

The original paper argued that, within the context of rehabilitation as a social response to the needs of persons with disabilities, the notion of “disability” points to two different concepts. On the one hand, disability is understood as a mark of a minority group that has historically been socially disadvantaged and, more recently, has been organized into a political movement seeking full inclusion and human rights. On the other hand, disability is seen as the result of the impact of health conditions and impairments on people’s lives, in interaction with their physical and social world. According to this second view, far from being a mark of a minority group, disability is a universal human phenomenon. The paper concluded that rehabilitation and rehabilitation professionals may be uniquely positioned to reconcile these apparently conflicting perspectives of disability.

During the session, Angela McNamara and Brigitte Perrouin-Verbe provided commentaries on the paper that illuminated their unique perspectives, and sought not only to expand and enhance the apparent dilemma of “two disabilities”, but to ground the discussion in personal experience. Both emphasized the fact that leadership in physical and rehabilitation medicine is a key factor in patient recovery and outcome, as well as a determinant of disability as it is actually experienced. In addition, both speakers were keenly aware of the importance of viewing experiences, such as quadriplegia, not only holistically, but also “from the inside”.

Angela McNamara (2), as both a rehabilitation medicine specialist and a patient, described her experience with acute-phase quadriplegia due to Guillain-Barre syndrome. Her commentary outlined her treatment in the intensive care unit (ICU), in acute rehabilitation in the Mater University & National Rehabilitation Hospitals, and through to multidisciplinary rehabilitation in the spinal injury rehabilitation hospital, where she was the consultant-in-charge before her illness. In the ICU, while unable to communicate, she was aware of the medical risks and observed the absence of rehabilitation medicine team leadership. Physiotherapy in ICU,

she observed, focused mainly on respiratory function with demonstrated little interest in complications due to immobility. This experience highlighted for her a lack of insight into the disease and the patient’s needs in the acute early stage of recovery and led her to see the need for holistic multidisciplinary treatment, led by a physician in rehabilitation medicine, from the acute illness through to the community.

Like all health professionals, there is a strong and understandable tendency among rehabilitation professionals to want the patient to “dance to our tune”. However, this must be resisted if catch-phrases, such as “shared decision-making”, “continuity of care” and “patient-centred treatment” are to become realities and not empty slogans. Rehabilitation professionals need to appreciate the process that patients go through for them to come to terms with their own disabilities.

In her commentary, Brigitte Perrouin-Verbe, as both rehabilitation professional and a person who has lived with a spinal cord injury (SCI) for 4 decades, could directly address the dilemma of “two disabilities”. She made the point that, especially for SCI, the impact of rehabilitation on the experience of disability can be profound. We know that rehabilitation in SCI decreases the risk of mortality during the acute phases and decreases the incidence of SCI-related complications and optimizes functioning, leading to better inclusion and participation in the community. In this sense, rehabilitation is committed to the broader understanding of disability as a universal human issue that requires a sustained social commitment. In recent years, primarily as a response to economic problems, the benefits of rehabilitation are increasingly being threatened, which should raise an alarm.

Yet, underscoring the need to view disability “from the inside”, Perrouin-Verbe also warned against the “banalization of rehabilitation”, the tendency to focus on optimizing a person’s functioning and independence while downplaying the reality of the often negative impact that social conditions have on life with disabilities. Living with SCI, being independent in activities of daily living, carrying out a full-time job, while at the same time coping with a non-adapted and unaccommodating environment, are exhausting and lead to medical complications, psychological problems or both. The realities of living with SCI, in other words, resonate with the other sense of disability as a form of social disadvantage, a problem that impacts more directly on the lives of a minority of people.

In the end, both McNamara and Perrouin-Verbe reminded the audience that it is important always to think

of disability as an outcome of an interaction between health conditions and impairments that are part of the universal human condition, and the physical, attitudinal and social environment that disadvantages some individuals far more than others. In this way, rehabilitation professionals can be part of the social response to the needs of individuals whose physical lives are fragile and in need of protection, while at the same time recognizing that the ultimate goal of person-centred care should be to enhance the opportunities of persons with disabilities to experience autonomy and full social inclusion and participation in all areas of life.

Summary: the medical rehabilitation profession potentially embodies the resolution of the two disabilities: a recognition of universal human frailty as well as the need to optimize functioning, but also to contribute to the social task of removing physical, attitudinal and social barriers that, in the real lives of persons with disabilities, threaten to limit their participation in society.

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