Herman Van Oyen Editorial | Editorial

Disability surveillance

Dr. Van Oyen is an associated editor of this journal

Disability remains one of the most complex entity among all health related outcomes. In some languages such as Dutch there is not even an acceptable term for "disability". The field of disability is broad and is touched upon by many disciplines o.a. demography, sociology, anthropology, medicine, public health, etc... . Each has developed different models to understand the human functioning, the causes and dynamics of dysfunction and the impact of it on the individual and on society. The World Health Organisation (WHO) has proposed as part of the WHO-family of international classifications the, International classification of Functioning, Disability and Health (ICF) (WHO 2001). The ICF integrates the medical and social models and provides a classification incorporating the biological, individual and social perspective of health. The ICF provides a tool to describe and to create models to study different aspects of the functioning and disability process.

The ICF also contains an excellent set of cornerstones to develop disability surveillance because it incorporates activity limitations, participation restriction and contextual personal and environmental factors. Ageing of populations is a major reason for disability surveillance. The postponement of the disability onset has major policy implications for the labour organisation and the care sector. 2003 was within the European Union (EU), the "Year of people with disability". The main policy goal was oriented towards inclusion and participation of people with disability. The ICF-model enabled redefining the policies. However compared to the United States, a disability surveillance system within the EU still needs to be structured. Almost all EU-member states have health interview surveys containing questions on disability by nature and severity¹ (Aromaa et al. 2003). The disability questions in these surveys are similar, but not identical. Only one third of the member states have organised a typical disability survey which gives in-depth information on the nature, severity, cause, duration and other aspects of disability in the last eight years. In the European Community Household Panel, co-ordinated by Eurostat, a global question on disability was included in all waves and the data have been used to estimate the social participation of persons reporting disability, as compared to persons not reporting disability. In 2002 the European Labour Force Survey contained an ad hoc module on the employment of disabled people. The module produced a comprehensive and comparable dataset on the labour market situation of people with disabilities in the EU Member States. The 1998–2003 Health Monitoring Programme, developed by the EU to establish a Community health monitoring system, has been very positive toward the further development of disability surveillance. A first project worked on post-harmonisation methodologies using disability instruments (Van Buuren et al. 2003). A second project, Euro-REVES, created a coherent set of indicators including instruments covering functional limitation indicator, activity restrictions and global activity limitation (Robine et al. 2003). The global activity limitations indicator is now part of the Minimum European Health Model (MEHM) containing three global level instruments (perceived health, chronic conditions, and activity restrictions) to be used in different EU-wide surveys.

Disability is not only a problem of developed countries, it is also the cause of health related burden in developing countries. External causes, such as accidents, violence (especially wars), are next to infectious diseases and chronic conditions major contributors to their disability burden. The United Nations initiated in 2002 a working group on disability surveillance (the Washington City Group on Disability Statistics). The main objective is to obtain information on disability throughout the world using global measures of disability in a census format. The ICF is again the reference and modular components should be conceptualised that in combination to

¹ see: https://www.iph.fgov.be/hishes/.

encompass the body/structure, activity/participation and environmental components of disability where possible. Surveillance data only is insufficient. More comprehensive and creative research questions need to be formulated to enlarge the understanding of disability. For this issue of Social and Preventive Medicine a set of four papers are selected presenting different disability related issues: 1) evaluation of concepts on disability using empirical data (Verbrugge et al.

2004); 2) differential trends in disability between subpopulations (Arbeev et al. 2004); 3) disability onset and workplace factors (Crimmins & Hayward 2004) and 4) health behaviour and health promotions in young disabled people (Steele et al. 2004). All four papers are based on both surveillance data and just questions.

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