Development a National Minimum Data Set for Disability in Iran: A Prerequisite for Development and Implementation of Electronic Disability Records

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Dear Editor,

Disability is a common unavoidable human condition such that it can affect the health and life of every person whether provisionally or perpetually. Nearly 15% of people around the world are affected by disability, three percent of which are severe. Indigent, jobless women and elder people are determinants factors of disability (1). A study by Soltani et al. found that disability in Iran has been reduced from about 4% in 1997 to 1.3% in 2011. However, because of population aging, modification in disability definition, increasing of long-term illnesses and consequences of accidents, floods, earthquakes, drugs and medicaments addiction, disability rate is increasing in Iran and globally. Soltani et al. argued that the decreasing trend of disability in Iran was due to a variation in the description of disability and the diverseness of the data gathering method (2).

Providing health care services to people with disabilities and vulnerable groups is considered one of the main responsibilities of health industry managers in countries (3). High-quality data play a key role in planning, policymaking, and providing health care services (2). In addition, providing quality data to people with disabilities and empowering them with new technologies are essential (4). However, little information is available on people with disabilities in undeveloped and developing countries (1). Moreover, much less information is usually collected about people with a lower level of disabilities compared to people with more severe disabilities. The standardization of data and their comparability at both national and international levels are essential for benchmarking and monitoring disability policies (2).

Minimum data set (MDS) facilitates the collection of accurate, complete and consistent data in a specific field and enables the comparability of data at different national and international levels. On the other hand, MDS is a standard tool for the collection of data and can feed health information systems. Developing and applying MDS is a prerequisite for effective disease management in the healthcare industry and is considered an approach to improve the quality of care. The MDS provides an organized approach to data management that enhances the effectiveness of the care plan. This tool provides reliable definitions for common terms and data elements by identifying necessary data in each field and enables the collection of high-quality data. Therefore, the main purpose of MDS is to make data comparability and conformity at different national and international levels possible via data standardization (5). The development of MDS should be done nationally according to domestic experts’ perspective in accordance with national regulations and requirements (6).

The design of the MDS will be done in two stages, including reviewing existing literature and resources used in the field of disability and implementing the Decision Delphi technique based on experts’ agreement.

Current health information technologies in health care facilities such as hospital information systems (HISs), electronic health records (EHR), and other applications that help in requesting and collecting medical documentation mainly focus on diagnosis, treatment, and payment and less cover the disability status and benefits (7). We believe that development of a national MDS for disability, as well as the development and implementation of electronic disability records (EDRs) based on disability MDS data elements, not only are of benefit to reduce costs by simplifying medical data collection processes and increasing complete, accurate and timely data, and effective responses to...
medical evidence requests but also are very essential to improve disability data.

The EDRs, by providing high-quality data and information, can facilitate decision-making about the level of disabilities of people, allocation associated benefits, and reduces delays causing societal costs (7). Therefore, disability minimum data set for Iran will be forefront of development and implementation of EDRs for Iran, because complete, accurate, and standard data elements are prerequisites for development and implementation of each health information system including EDRs (5).

Footnotes

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