

The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury

Alarcos Cieza, PhD, MSc, MPH

It is a pleasure for me to write this editorial on the Learning Health System for Spinal Cord Injury Initiative, and in particular the International Spinal Cord Injury Survey (InSCI) that is the essential data platform for this initiative.

The LHS-InSCI initiative is important to the World Health Organization (WHO) for 3 reasons. First, the initiative, and especially InSCI, is built on the understanding of functioning and disability contained within WHO's *International Classification of Functioning, Disability and Health (ICF)*¹; second, the initiative follows directly from the extensive work done at WHO and the World Bank in the development of the *World Report on Disability (2011)*² and the joint production of WHO with the International Spinal Cord Society of the report *International Perspectives on Spinal Cord Injury (2013)*³; third, the development of the InSCI has been based very closely on the *Model Disability Survey*, a major initiative of my unit.⁴

The current work of WHO on disability since 2014 has been guided by the WHO *Global Disability Action Plan 2014–2021 Better Health for All People With Disability*.⁵ The Action Plan has 3 objectives:

1. To remove barriers and improve access to health services and programs;
2. To strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation; and
3. To strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.

The initiative, even though it is focused on a single health condition, namely, spinal cord injury (SCI), is linked to each of these 3 objectives. First, the information collected from InSCI and the anticipated analyses of the participating countries societal responses to SCI needs will identify—in terms that are far more detailed and concrete than is possible with standard population data collection exercises—information about the nature of barriers that limit access by persons experiencing disability to health services and programs. The initiative will also be able to expand our knowledge about global needs to strengthen rehabilitation services, within health systems, and the best strategies for doing so. One of the primary lessons learned from the IPSCI report is that SCI, although of low prevalence, can serve as a kind of “canary in the mine” to highlight barriers to accessing rehabilitation services: SCI calls up the full range of rehabilitation services, from acute all the way to community-based services. Finally, the urgent need to reform how we collect data about disability, and in particular the important role that the *ICF* can play as an information reference system for internationally comparable functioning and disability data, will be thoroughly tested and confirmed by the multicountry implementation of the *ICF*-based InSCI survey. Because InSCI is linked to the *Model Disability Survey*, it will be possible to compare the small SCI population with the general population of a country in order, for example, to assess whether in the implementation of the *Sustainable Development Goals*⁶ persons with SCI are not left behind.

I am very optimistic about the success of the initiative and the value of the InSCI survey. I would like to wish all participating countries continuing success.

REFERENCES

1. World Health Organization: *The International Classification of Functioning, Disability and Health*. Geneva, Switzerland, WHO, 2001
2. World Health Organization: *World Report on Disability*. Geneva, Switzerland, WHO Press, 2011
3. Bickenbach JE, Officer A, Shakespeare T, et al (eds.): *International Perspectives on Spinal Cord Injury*. Geneva, Switzerland, WHO, 2013
4. World Health Organization: *The Model Disability Survey*. Available at: <http://www.who.int/disabilities/data/mds/en/>. Accessed October 31, 2016
5. World Health Organization: *Global Disability Action Plan 2014–2021*. Available at: <http://www.who.int/disabilities/data/mds/en/>. Accessed October 31, 2016
6. United Nations: *Sustainable Development Goals*. Available at: <https://sustainabledevelopment.un.org/?menu=1300>. Accessed October 31, 2016

From the Blindness and Deafness Prevention, Disability and Rehabilitation, World Health Organization, Geneva, Switzerland.

All correspondence and requests for reprints should be addressed to: Alarcos Cieza, PhD, MSc, MPH, World Health Organization, Avenue Appia 20, CH-1211 Geneva 27, Switzerland. Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article. Copyright © 2017 Wolters Kluwer Health, Inc. All rights reserved.

ISSN: 0894-9115

DOI: 10.1097/PHM.0000000000000683