Disability data and statistics, monitoring and evaluation: the way forward, a disability inclusive development agenda towards 2015 and beyond

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Information infrastructure for disability statistics

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Introduction

To inform policy on disability a range of data from a range of sources are required to describe the population, whatever levels of human functioning, and the services they receive. Where data on causes of death and diseases have been around for a long time statistics on functioning and disability are relatively new. Where the former are coded by physicians or trained coders, information on functioning may be provided by self-report or by carers or service providers too.

Disability may be viewed in different ways depending on environment, personal circumstances and professional education. There is no one definition of disability. Over recent years there have been efforts to improve comparability of census and survey question sets, but less effort to improve data from individual and administrative sources. There has been emphasis on what to collect but less on how to build the capacity to collect data, particularly at individual and service level. The International Classification of Functioning, Disability and Health (ICF) [1] is recommended as the ‘universal framework for disability data collection related to policy goals…’ [2]. In operationalising the ICF there is a need for a workforce who understands disability data development and the information infrastructure to support their efforts. This paper will outline some of the information infrastructure that may underpin the collection of functional status information.

Frameworks and models

Framework or models offer a common understanding of systems of health, functioning, disability and services across the range of collectors and users of data; statistical agencies, government agencies, international, non-governmental, and disabled people’s organisations. The model below (figure1) expresses the information needed for a comprehensive health information system [3]. The model has been informed by s several countries.

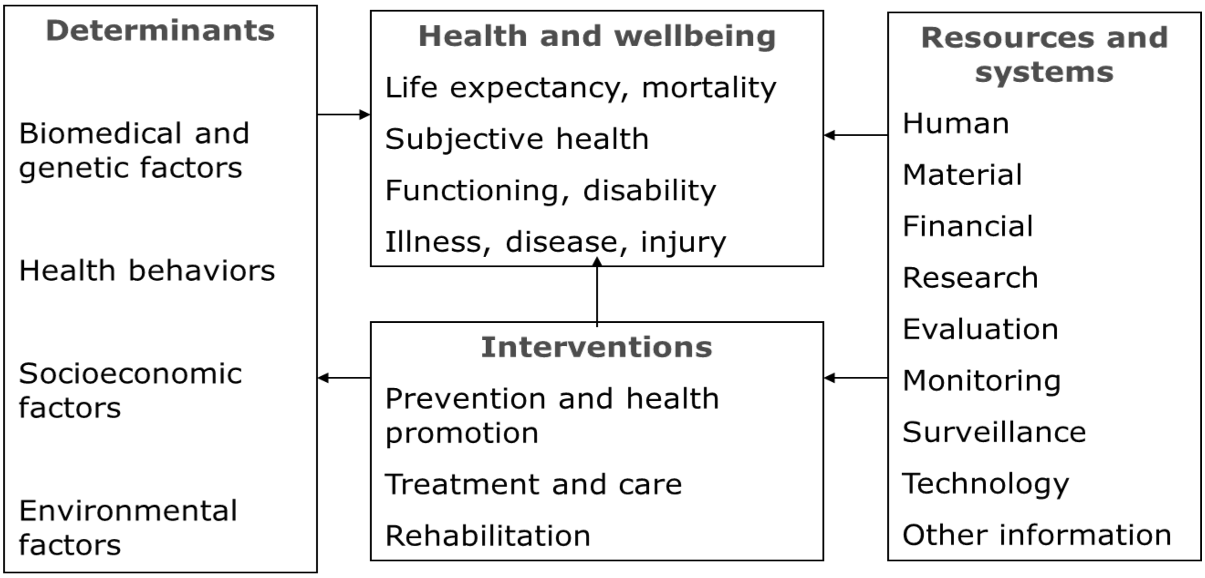
Within the ICF [1] is the framework relating components of functioning with diseases/health problems and environmental and personal factors. The components of ICF can inform elements of the broader model of health systems.

Classifications

The WHO Family of International Classifications (WHO-FIC) is a suite of classification products that may be used in an integrated fashion to compare information internationally [3]. To get a full picture of the situation of people and populations, whatever the level of functioning, requires not only disease and functional status information but information on the services needed. Classifications relevant to service delivery in the WHO-FIC include the Anatomic Therapeutic Chemicals classification [4] and a classification of technical assistive devices [5]. The development of the International Classification of Health Interventions (ICHI) is well underway and due for completion by 2017 [6].

Resources may be covered by classifications with in the United Nations family of classifications, for example, industries and occupations. The Organisation for Economic Co-operation and Development's (OECD) system of health accounts is broadly used for expenditure reporting [7].

Figure 1 Conceptual framework for health



Classification development and maintenance.

Classifications, to reflect current knowledge, must be updated and from time to time undergo revision, For the WHO-FIC classifications there are evidence based, peer review update processes. Users of classifications can make proposals to correct errors, provide further information or examples and to add, move or remove codes.

The International Classification of Diseases (ICD) currently in its 10 edition has been regularly updated since 2001. It is undergoing a major redevelopment towards an ICD 11. Pilot testing is anticipated in the forthcoming months and finalisation in 2017. The ICF update process started in 2011 and is ongoing. To place proposals on the ICF update platform classification users need to request registration from WHO by entering the platform at https://extranet.who.int/icfrevision/.

ICHI currently at the Alpha 2 stage of development is expected to be finalised by 2017. To express interest in pilot testing ICHI contact Megan Cumerlato, secretary to the ICHI development group at megan.cumerlato@hotmail.com

If any of the WHO reference classifications are not meeting the needs of users there is an established process for updating and revising them. Users are encouraged to register on the update platforms.

Online browsers

Online browsers assist users to become familiar with the classifications and look up codes and definitions. For anyone coding these resources are invaluable. There are browsers for:

ICF http://apps.who.int/classifications/icd10/browse/2010/en
ICD http://apps.who.int/classifications/icfbrowser/; and to download ICHI
Alpha2: http://sydney.edu.au/health-sciences/ncch/resources.shtml

Metadata

To produce high-quality, consistent data that meets the needs of all users of the data, and attracts the necessary level of agreement on content and authority behind the data specifications requires sound data development practices. Data development requires a considerable investment of time, staff and other resources so it needs doing well. The use of electronic health records is increasing throughout the health and community services systems and the feasibility of electronic continuous patient/client records is becoming a reality. The advent of electronic data capture and communication systems provides a unique opportunity to improve the quality and coverage of information and the potential to re-use and share data becomes even more relevant [8].

In the disability sector the developers and users of data are diverse. Key stakeholders include the public, policy makers and service planners, service providers, funding bodies, information managers, educators and researchers, and reporting agencies for example statistical and programme offices. So a broad understanding of data development common across these stakeholders is important. Underpinning all data development is metadata, or 'data that defines and describes data' [9]. The purpose of metadata is to describe and represent data that helps users understand the meaning and content of data. It is well accepted that metadata leads to better data. This is because metadata standards enable all people collecting, using and exchanging data to share the same understanding of its meaning and representation.

Metadata registries.

Metadata registries are the repositories of metadata standards. They provide agreed data definitions and tools for creating new definitions based on already agreed components. Using the standards improves comparability across many different data collections and avoids wasting resources creating similar standards. Online registries such as METeOR are open access. A functioning and disability data set specification based on ICF has been included in national data dictionaries since 2006 [10].

An example of metadata that can be used to identify people with long term health conditions or disabilities is a 'disability flag' for inclusion in generic information systems and collections, such as housing, education, transport and community services. The 'standardised disability flag' is designed to provide consistent and comparable information across services, over time and across data collections [11].

User guides and online education

The ICF Australian User guide [12] and more recently the UNESCAP Training manual on disability statistics [13] and ICF Practical Manual [14] are intended to complement the ICF, to assist users to understand to the classification, to inform about actual and potential uses and to provide advice and direction to further sources of information. For disease classification volume 2 of the ICD is an instruction manual [15].

Online education tools for users and potential users of classifications are available. The education goal is for consistent and reliable collection of data. The content includes overviews of the classifications, examples of use, guidance for use and quizzes. The ICD training tool is available on the WHO website [16], whilst the ICF e-learning tool is being finalised a draft is available [17]. In future these tools will be available in languages other than English.

The Monitoring manual and menu for Community Based Rehabilitation (CBR) and other community based disability inclusive development programmes [18] is an example of an evidence based tool which allows for community participatory approaches to data development. The tool encourages CBR workers to use the ICF and other data standards and guides on the selection of items appropriate to the local situation.

Data capture tools

ICF based electronic tools facilitate the capture of data on functioning and associated environmental factors, thus enabling the complexity of disability to be examined in ways not previously possible. ICF based data capture tools enable clinically relevant data to be aggregated for administrative and statistical purposes. To date the tools have been country specific.

A mobile application is currently being developed, facilitated by the WHO Functioning and Disability Reference Group [19]. The aim is for a tool to assist service providers to identify a service user's (e.g. patients, client, child) issues in terms of functioning, as well as personal and environmental factors that are influencing health. This information can then be used to assist service providers with person-centred decision-making. Depending on local legislation, the amalgamation of this data could be used centrally for analysis. To date: a project plan has been developed, a survey of ICF users and potential users is underway and meetings to review the results of the survey and confirm design specifications are scheduled for October 2014. Parties interested in taking part in the development and pilot testing of the mICF should contact the FDRG co-chairs; Catherine Sykes csykes@wcpt.org and Andrea Martinuzzi andrea.martinuzzi@lanostrafamiglia.it

Summary

While surveys and censuses attract government funding and professional data development there are a range of other sources of data to inform the functioning status of the population and the services they receive that are less well resourced; data collected in the course of service delivery for example. To facilitate the capture of quality data that can be related to the census and survey data requires a workforce that is disability data aware and supported by a range of information infrastructure. A range of tools and resources have been outlined and opportunities for engagement in developing and maintaining these resources identified.

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