



EGYPT DISABILITY SURVEILLANCE

THE FACTS: Population: 83, 171, 000 (CAPMAS, 2010) Income group: Lower-middle

Disability conceptualization has changed since the signing of the UN convention for the rights of the persons with disability (Egypt, 2009). The ICF is the internationally agreed, WHA endorsed standard language that describes human functioning and is the best tool to represent disability in all aspects. Use of ICF in national and international documents and data sets describing disability is a pre-requisite to fulfill the commitments mandated by the UN convention. Egypt is in a special position to review the national perception of disability and the policies and programs addressing it and to do so starting from sound and scientifically based data on which all stakeholders (governmental and non governmental organizations, state offices, health provision systems, advocacy groups) may rely and agree. To this end WHO Egypt, the Egyptian Ministry of Health, with the support of the Research Branch of the Italian WHO-FIC Collaborative Center launched a scaling up plan to test and introduce in Egypt an ICF-based disability surveillance system.

Objectives

-To identify information needs and technical requirements for a disability surveillance system in Egypt

To set the stage for a locally based ICF training dissemination

To draft a plan outline for the development of an ICF based disability surveillance system. This goal is preceded by a pilot implementation test articulated as follows:

Test the coding ability and feasibility at selected test sites

Frame a commonly agreed ICF based form to report functioning and disability data to the MoH

Test the form over a 6-8 months

Define the information load and the analytical methodology to handle the information produced

Report to MoH on the results of the pilot phases for further action $% \left({{{\rm{A}}_{{\rm{B}}}} \right)$

Achievements Phase I

ICF profiles were completed in 6 sites in for 240 cases, mostly children and adolescents with mainly neurodevelopmental and psychiatric disorders. Coding was mainly completed from available medical records. Different methodologies were followed (from free coding to the ICF checklist).

<u>Main problem</u> was identified in the lack of non-medical but functionally relevant information.

<u>Main benefit</u> was seen in the change in perspective brought by the need to describe the person in all his functioning aspects in interaction with the context.

Phase 2: <u>The ICF form</u> displays expandable fields for body functions and structures (up to 5 categories per chapter), a fixed menu of 42 codes for A&P, and free coding of up to 3 environmental factors attached to the function or the A&P category being affected. The final electronic format of the document, which should take into consideration the type of data analysis to be conducted both locally and centrally, will be defined with the Health Information Center of the MoH. The e-form should also allow check for double encounters..

Activities

Phase I: training, pilot testing, November 2011-March 2012

The program started with a training workshop involving 19 professionals of different background and from various Institutions.

Aim: to introduce the ICF and train the participants in its use for describing and reporting functioning and disability information at the clinical level.

<u>Pilot testing</u>, in which each participant tested the ICF in his clinical setting. Aim: test feasibility and provide information needed to frame the definitive common ICF based form to be used in the following phase.

Phase 2: development and testing of the common ICF form; training dissemination. June-September 2012. - Review of the results of phase I pilot and the discussion in order to define a commonly agreed ICF-form;

- Definition of the ICF report form;

- "Lab-test" of the form on real cases to confirm in its validity and applicability. B

- test-training of participants to the workshops in view of their activity as on-site trainers for their Institution and initiators of ICF training dissemination.

All prospective trainers are expected to conduct at least I training course involving all needed participants at the local level by February 2013. Training efficacy will be objectively tested with pre/post test questionnaires.

Partners:

WHO Responsible for overall coordination of the consortium partners; providing technical and partial financial support to elements relating to capacity building for disability surveillance, classification and data system setup, management and recommendations for securing the rights of people with disabilities.

Ministry of Health and Population (MOHP) Responsible for diagnosing, managing and rehabilitation of cases of people with disabilities (PWD's) together with other health provision agencies.

Ministry of Social Affairs (MOSA) Responsible for social support, rehabilitation and employment opportunities.

Ministry of Housing (MOH) Responsible for the provision of adequate housing and facilities according to subject's needs.

The Armed Forces Rehabilitation Center Responsible for the implementation of surveillance systems and providers of data to the collection source.

*All partners will provide technical support to the Government of Egypt throughout the implementation of activities.



Future plans

I- **The** form will be field tested for six months at nine sites in four Provinces

2- ICF training Arabic material tested at different sites

3- Complete ICF record describing functioning and disability for 500 new encounters consecutively seen at the participating sites

4- Fully defined, electronically supported and fieldtested ICF based form for Disability and Functioning description in facilities providing services for the persons with disability

5- Defined paradigms for data entry, transmission, storage, analysis

6- Plan for nationwide extension of the process

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