

Implementation plan for an ICF based disability surveillance system in Egypt

Oct – 6 Oct 2012
Brasilia, Brazil

Andrea Martinuzzi*, Hala El Hennawy°, Naeema Hassan Al-Gasseer°,
and the Egypt ICF working group

Please insert
the document
ID here: D0xxp

*E. Medea Scientific Institute, Research Branch of the Italian WHO-FIC CC, Italy
°WHO Egypt

Abstract A shift in attention from acute communicable diseases to consequences of chronic conditions is seen as important both in high and low resource countries. The use of the ICF to provide a reliable standardized picture of the functional profile of persons with disability would provide the solid basis to build any Nationwide disability surveillance system from which to move towards meaningful epidemiological data and on which to base any action aimed at responding and minimizing disability. Egypt has taken the first steps towards this goal by launching with the leadership of WHO-Egypt and the assistance of the Italian WHO-FIC CC an ambitious plan to build a Nationwide Disability surveillance system presently undergoing the first extensive field testing

Introduction

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 of the plan are:

- 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:

O test the coding ability and feasibility at selected test sites

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

O test the form over a 6-8 months

O 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

Methods & Materials

Phase 1: *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.

Pilot testing, 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 1 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 held at least 1 training course involving all needed participants at the local level by February 2013. Training efficacy will be objectively tested with pre/post test questionnaires.

Egypt ICF working Group

AH Abdo Hassan, AA Mohammed Nofal; E Abd Elmonem Gaber, TT Zaghloul, MN Ahmed Kassem; KM El Den Al Weshahy, NA Mahmoud Elghareeb, HA Rahman Sharif El Din, MZ Abdel Modaber, N Fathy Mahmoud, EA Abdelgawad Aboulhussin, AA Aleem Hefny, MH Mahmoud Elnaka, SAF Ahmed Hussein Dina Adel Ghazy,, HR Said Tantawi, NE Sayd Hassan Diab, MT Mostafa Kamal, MA El Dessouki.

Sites

Genetic Center Faculty of Medicine Ain Shams
Qena and Naghamadee Gen Hosp,
GENETIC Counselling Centre Qane
MCH Shubrakhit, Bahire
Army Rehabilitation Centre, Cairo
Health Insurance Organization, Cairo
Hearing and Speech Institute, Giza
El Ramil Children Hospital
Mental Health Secretariat. Abbassia, Child
Psychiatry Unit

Results

Phase 1

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).

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

Main benefit 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: *The ICF form* 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.

The form will be field tested for 6 months at 9 sites in 4 Provinces.

Conclusions

Deliverables (March 2013):

- 1) Fully defined, electronically supported and field-tested ICF based form for Disability and Functioning description in facilities providing services for the persons with disability;
- 2) Complete ICF record describing functioning and disability for 500 new encounters consecutively seen at the participating sites;
- 3) ICF Training material in Arabic tested at different sites
- 4) Defined paradigms for data entry, transmission, storage, analysis
- 5) Plan for nationwide extension of the process.