

## **Functioning and Disability Reference Group (FDRG) Annual report for 2008-09**

FDRG has lead responsibility for a large number of tasks in the WHO-FIC work plan (ID numbers 150-202). These tasks are carried out by 8 task (or project) groups with designated leaders. The task leaders and the FDRG co-chairs comprise the secretariat of the Group, which has had several teleconferences throughout the year.

### **Midyear meeting**

The FDRG held a midyear meeting in July, in Sao Paulo Brazil, in conjunction with the conference of the Latin American and Caribbean ICF Network meeting. In a crossover session FDRG members heard a range of presentations on ICF implementation in the region – including in social policy and administration and clinical use.

### **Bridging Task Group**

The Bridging Task Group work with the Washington Group has progressed and a report will be presented to FDRG, including a recommendation that further specific work continue into 2010, on communication in areas of measurement and ICF guidelines.

### **Work of the eight task groups**

This report provides a very brief overview of the work of each FDRG task group, identifying the area of the WHO-FIC work plan, the key goals for the year, the main activities carried out, and an overview of progress:

1. Principles of Use, Coding Rules and Guidelines.
2. ICF update recommendations
3. ICF implications for ICD
4. ICF measurement and statistical use
5. ICF educational materials (*in collaboration with the WHO-FIC Education Committee*)
6. ICF, ethics and human rights
7. Environmental factors
8. ICF and terminologies

Ros Madden and Gerold Stucki  
Co-chairs, Functioning and Disability Reference Group  
September 2009

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**FDRG Project 1: Principles of Use, Coding Rules and Guidelines.**

**Task leader: Diane Caulfeild**

**Areas of WHO-FIC work plan: ID 150-51 (to result in FDRG 'agreed advice')**

**Key goal for 2008-09:** 'Develop draft guidelines for use with scenarios and worked examples for applications in the case based data stream and sub-populations and circulate to FDRG members for feedback' (from WHO-FIC work plan).

**Background and overview**

This group developed a forward work plan in 2006-07 and has since worked steadily and collaboratively as planned. In 2006-07 they assembled and analysed key reference material. In 2007-08 they expanded their group of experts, developed a matrix of applications for each of which guidelines were to be prepared, and began drafting a prototype of ICF Guidelines for different user groups. In 2008-09 they worked on drafting ICF Coding Guidelines for major user groups (e.g. clinical, administration/policy and statistical) in preparation for publication to gain broad user feedback.

**Key work plan goals for 2008-09**

- Draft a prototype of ICF Guidelines for each of the different user groups – for example; clinical application (e.g. APA guidelines), administrative application (e.g. utilization of the ICF Short version) and census and survey application (McGill/Mayo and Stucki)
- Determine a communication and dissemination of information strategy
- Draft the ICF Coding Guidelines for major user groups (e.g. clinical, administration/policy and statistical) in preparation for publication to gain broad user feedback

**Main activities for 2008-09**

- Face-to-face working meeting first week of June 2009 to write content for the Guidelines document. Significant progress was made.
- Face-to-face working meeting of a sub-group in August 2009 to further develop the content for the Guidelines document.
- Submitted an Abstract for the WHO-FIC meeting in Seoul so the document can be brought forward to the FDRG task group leaders for discussion at the WHO-FIC meeting
- Participated in a teleconference with the Bridging Task Group to talk about the development of the Guidelines document with the Washington City Group

**Progress against work plan**

- Drafted prototype of the Guidelines using a matrix recognizing the major user groups as the primary structural feature

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- Communication has mainly been through email and teleconference every few months. Also there were two face-to-face meetings for the purpose of writing the Guidelines document.

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**FDRG Project 2: ICF update recommendations**

**Task leader: Nenad Kostanjsek**

**Areas of WHO-FIC work plan: ID 153-56 (to result in FDRG 'agreed advice')**

**Key work plan goals for 2008-09**

- Finalise the update platform and related user guide.
- Finalise the management process and resourcing with FDRG and URC.
- Initiate the submission of ICF-CY related update proposals.
- Develop and implement strategy for communication and dissemination including launch of update process

**Main activities for 2008-09**

Work has continued on the update platform and related user guide, with comments being received on the latter and revisions made. Work in FDRG and liaison with URC chairs have resulted in proposals for the update process as well as enhanced terms of reference for the URC.

**Progress against work plan**

The first two tasks are complete, pending finalisation and approval at the annual WHO-FIC meeting of 2009. The latter two tasks have been developed and will be discussed in Seoul at the annual meeting

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**FDRG Project 3: ICF implications for ICD**

**Task leader: Catherine Sykes**

**Areas of WHO-FIC work plan: ID 157-59 (to result in FDRG 'agreed advice')**

<b>Work plan ID</b>	<b>Key work plan goals for 2008-09</b>	<b>Main activities 2008-09</b>	<b>Progress</b>
157	Communicate the key ICF terms to ICD Revision Steering Committee and develop, with RSG, a strategy to guide TAGs on appropriate use of functional terms in ICD	Communication with RSG chair in 2008, and RSG chair and WHO-FIC members of RSG following FDRG mid-year meeting, including request to forward to ICD drafters	Completed
158	Make and review proposals on the ICD revision platform to ensure appropriate use of functional terms in ICD	Scan of ICD update platform. Discussion of terms: 'Functional' (used as an adjective with diseases e.g. functional dyspepsia) 'Sequelae'	To be discussed at 2009 meeting a process for reviewing the proposals that is sustainable for FDRG. Terms at left for discussion with WHO-FIC reps on RSG
159	Explore further work on content overlap in selected areas of the ICD to advise the RSG, for example advise in relation to between the risk factors component of ICD and the Environmental factors component of ICF	Signs and symptoms in ICD-10 mapped to equivalent ICF terms. Analysis of ICF categories relevant to factors affecting health status, beginning with E factors component (with FDC)	Completed for S&S chapter, to be provided to RSG for comment after review by FDRG. Ongoing
198	Study the linkages with ICD-11 and its information model (With Task Group 8)	Exploration of the literature describing two diseases; Parkinson's disease and spinal cord injury to find which ICF categories are used as a means of establishing a diagnosis.	Discussion about meaning of functional impact in the ICD information model relayed to RSG.

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**FDRG Project 4: ICF measurement and statistical use**

**Task leaders: Gerold Stucki and Judith Hollenweger**

**Areas of WHO-FIC work plan: ID 160-165, 202 (FDRG as a 'development forum')**

<b>Work plan ID</b>	<b>Key work plan goals for 2008-09</b>	<b>Main activities 2008-09</b>	<b>Progress</b>
160	<p>1) <u>Parsimonious ICF Sets</u></p> <p>1a) Finalize the definition of the process to define parsimonious sets of ICF categories representing functioning from a generic perspective, i.e. across conditions, across health care situations and in the general population.</p> <p>1b) Propose the parsimonious set of ICF categories representing functioning from a generic perspective based on existing tools, approaches and data sets</p>	<p>1) <u>Parsimonious ICF Sets</u></p> <p>1a) Statistical steps to come up with a parsimonious set of ICF categories to assess and define functioning from a generic perspective have been defined.</p> <p>1b) Based on analyses of data from a large sample of clinical populations, data from the German National Health Survey 1998 (GHS98) and the National Health and Nutrition Examination Survey 2005/2006 (NHANES05/06) a parsimonious set of ICF categories representing functioning from the generic perspective have been proposed. A scientific paper has been prepared and will be submitted to a scientific journal after The WHO-FIC meeting 2009.</p> <p>The Institute Carlos III in Madrid, which is the research institution belonging to the Ministry of Health in Spain, has finalized a health survey for the general population in Spain using the ICF Checklist and the</p>	<p>1) <u>Parsimonious ICF Sets</u></p> <p>1a) Completed. The process will be presented and discussed at the FDRG meeting during the WHO-FIC meeting 2009.</p> <p>2b) Completed. The results will be presented and discussed at the FDRG meeting during the WHO-FIC meeting 2009.</p>

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		<p>WHODAS as tools for collecting data. This survey was performed in collaboration with the ICF Research Branch CC FIC (DIMDI). The data of over 3000 persons is available and will be used to validate the results of the proposed parsimonious set of ICF categories from the generic perspective.</p>	
161	<p>2) <u>Metric equivalence (Qualifier)</u></p> <p>2a) Operationalize as many ICF categories of the Parsimonious ICF Sets as possible based on items of other questionnaires and instruments, so that the ICF qualifier can be used as a reference for other instruments.</p> <p>2b) Identify instruments with interval-scale properties for as many ICF categories of the Parsimonious ICF Sets as possible to permit a calibration of the instrument into the ICF qualifier.</p>	<p>A collaboration between the Guttman Institute in Barcelona and the ICF Research Branch CC FIC (DIMDI) has been initiated. The Guttman Institute has large databases of longitudinal data that will enable us to proceed with this work.</p>	<p>Preparation work has been done. This preparation work will be presented and discussed at the FDRG meeting during the WHOFIC meeting 2009.</p>
162	<p>3) <u>ICF derived measures</u></p> <p>Continue the stream of work to develop ICF derived measures. Identify the ICF categories whose qualifier values can be aggregated and the principles of aggregation.</p>	<p>Two PhD students from ICF Research Branch CC FIC (DIMDI) Germany started to work in this field in May 2009. During the last 5 months they have familiarized themselves with the corresponding statistical analyses and the data that will be analysed.</p>	<p>Initiated</p>
163	<p>Create and update the methodological approaches to map the content of existing instruments to the</p>	<p>The methodological approaches to map the content of existing instruments to ICF categories</p>	<p>Almost completed. The results will be presented and discussed at the FDRG meeting during the WHOFIC meeting 2009.</p>

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	ICF categories	have been updated. A scientific paper is in preparation. The submission is planned for the end of 2009.	
164	Implement ICF in the management of children's education	A MHADIE deliverable has been finalised: 'A protocol to develop a model for the integration of clinical, administrative and educational data and the overall application of the ICF model in educational setting'.	In Switzerland, the ICF is used in education as a model and classification to establish eligibility (see <a href="http://www.sav-pes.ch">www.sav-pes.ch</a> ) and to organize school-based support (Hollenweger, Lienhard 2007).
165	Report the results of FDRG task group 4 both in form of scientific publications and/or reports that will be provided to the FDRG members before the meetings.	We have not implemented yet the reporting of the results of the task group 4 in form of FDRG reports.	We will set a plan how to proceed with this goal of the work plan at the FDRG meeting during the WHOFIC meeting 2009.
202	Report back in 2009 on Bridging Task Group work with Washington Group, particularly on communication in areas of measurement and ICF guidelines.		Reporting will take place during the FDRG meeting at the WHOFIC meeting 2009.

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**FDRG Project 5: ICF educational materials**

**Task leader: Cassia Maria Buchalla**

**Areas of WHO-FIC work plan: ID 167-71 (to result in FDRG 'agreed advice')**

ID Item: 167

Key work plan goals for 2008-09: Engage new contributors, working closely with other FDRG task groups and new collaborating centres.

Main activities for 2008-09: During this year the FDRG met the Latin American and Caribbean ICF Network. A joint session was held between the two groups meetings.

Progress against work plan: Done

ID Item: 168

Key work plan goals for 2008-09: Finish and test the first training tool (ICF basic course), based on ICF curriculum modules V1, and make it available on WHO website.

Main activities for 2008-09: The introduction Module was drafted and was evaluated twice during the year. At this stage the focus of the work is on finishing the Introduction module. The group in charge of this development Alarcos Cieza, Alicia Garza Ramos De Gündogdu with the collaboration of Catherine Sykes and Nenad Kostanjsek are considering the suggestions made by the members of the FDRG and the Education Committee after the first revision.

Progress against work plan: The E-learning Tool Introduction Module has been prepared and had a preliminary evaluation. Protocols for wider testing will be discussed in Seoul, as will correspondence with the Guidelines work (TG1). The group will continue to collect case examples from many cultures.

ID Item: 169

Key work plan goals for 2008-09: Start working on the advanced and master ICF courses

Main activities for 2008-09: The Introduction Module allows aggregating a number of potential collaborators for these activities.

Progress against work plan: Not progressed. The strategy to continue the following modules has to be discussed.

ID Item: 170

Key work plan goals for 2008-09: Agree on a basic introduction to ICF for the general public, relying on resources for a plain English writer and editor.

Main activities for 2008-09: The ICF Overview is being evaluated by the members of the FDRG and the Education Committee.

Progress against work plan: Version 8 will be presented at the 2010 meeting for finalisation plans.

ID Item: 171

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Key work plan goals for 2008-09: Review how each of the four A&P options in the ICF are being operationalized in practice so as to develop examples for educational materials

Key activities for 2008-09: A questionnaire was developed, discussed and revised.

Progress against work plan: The project and materials developed have been referred to the Implementation Committee to inform the design of the implementation database

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**FDRG Project 6: ICF, ethics and human rights**

**Task leaders: Jerome Bickenbach and Matilde Leonardi**

**Areas of WHO-FIC work plan: ID 172-76 (FDRG as a 'development forum')**

**Key work plan goals for 2008-09**

- Publish and disseminate paper 'Relating ICF to UN Convention for Monitoring'.
- Organize and hold the International Conference on Disability, justice and long term care, Milan 2009
- Formulate advice on using ICF in disability eligibility policies (for ICF guidelines) (to 2010).
- Review ICF annex 6 (to 2010)
- Formulate advice concerning the representation of ethical aspects in the ICF web training and curriculum modules (to 2010).

**Progress against work plan**

The first two tasks were completed in 2009. The remaining tasks (planned to continue into 2010) have been commenced.

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## FDRG Project 7: Environmental Factors

Task leader: Janice Miller

Areas of WHO-FIC work plan: ID 177-8, 190-91 (to result in FDRG 'agreed advice')

### Key work plan goals for 2008-09

- 177 – Draft Paper on 'Operationalizing Environmental Factors'  
Draft and circulate paper on 'Operationalizing Environmental Factors'  
Final draft to FDRG for input 2008  
Submit to target journal early 2009  
Identify gaps in priority areas for environment scan
- 178 – Harmonization of ICF EF & ISO 9999 (Assistive Devices)  
Harmonization of ICF EF & ISO 9999 (Assistive Devices)  
Coordinate inputs from ISO and FDRG working groups (Feb 09)  
Compile inputs and recommend process by mid-year FDRG meeting
- 190 – Risk Factors in ICD  
Advise on FDC work on Risk Factors in ICD, with FDRG task group 3
- 191 – Input on updates related to EF for ICF-CY  
Comment on EF aspects of ICF-CY round of updates

### Main activities for 2008-09

- 177 – Draft Paper on 'Operationalizing Environmental Factors'  
Since 2007 work led by Jan Reinhardt (Swiss Paraplegic Research, Nottwil Switzerland) has included drafting of an initial paper, "*Operationalizing Environmental Factors*". The scope of the draft was diverse and included conceptual aspects of measurement of environmental factors as well as technical aspects (e.g. psychometrics of existing measures and ICF linking to those measures).  
The current plan proposed for publication(s):
- submit a conceptual paper for Soc Sci Med including some sections on the definition of environment and one on ecological validity (Bronfenbrenner 1979)
  - submit a paper to Disability and Rehabilitation focused on psychometrics of existing measures of the environment and linking to ICF
  - finalize the larger foundation paper as a reference document for FDRG / TG 7 work. One option being considered is to submit the paper and a poster for the annual WHO-FIC meeting, October 2009.
- 178 – Harmonization of ICF EF & ISO 9999 (Assistive Devices)  
There has been ongoing interest and input from this ISO committee (ISO/TC 173/SC 2/WG 11) focused on 'Classification and terminology for the revision of ISO 9999'. Contributors to TG 7 are also on this ISO committee (Y. Heerkens, M. de Kleijn-de Vrankrijker, T. Bougie, P. Winkelmann).  
A meeting of the ISO WG11 committee took place in April 2009. It was not possible to have a representative from TG7 or WHO at this meeting but an invitation will be sent to WHO in advance of their next meeting, November 18-19, 2009 in Metz France.  
Following their April meeting the WG11 requested some clarification from WHO on certain terms which may be understood or interpreted differently in ISO 9999 and ICF. These included:
- disability vs disabilities
  - mobility (use of the term for walking/transportation vs manipulating objects or maintaining body position)
  - different uses of the terms 'training', 'learning' and 'education'

### Progress against work plan

- 177 – Draft Paper on 'Operationalizing Environmental Factors'  
Draft reference document circulated to FDRG TG leaders, input incorporated; draft to TG 7 members & collaborators; final draft prepared for review at Seoul meeting  
Publication plan for 2 papers - Soc Sci Med & Disability & Rehabilitation – to be confirmed
- 178 – Harmonization of ICF EF & ISO 9999 (Assistive Devices)

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ISO WG 11 representative attending FDRG meetings in Seoul (see paper, M de Kleijn); FDRG/WHO attendance at ISO meeting November 2009 planned;

190 – Risk Factors in ICD – review of papers from FDC & TG3

191 – Environmental Factors & ICF-CY – work plan pending initiation of ICF-CY update process

Other – review of TG 1 Guidelines Draft – circulated to TG7 members & collaborators for input – September 09

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**FDRG Project 8: ICF and terminologies**

**Task leaders: Nenad Kostanjsek and Matti Ojala**

**Areas of WHO-FIC work plan: ID 192-99 (FDRG as a 'development forum')**

<b>Work plan ID</b>	<b>Key work plan goals for 2008-09</b>	<b>Main activities 2008-09</b>	<b>Progress</b>
192	Review semantic modelling use cases and terminology and standards which are of interest for ICF	Presentations and initial discussion in ICF ontology and Protégé workshop 1-5-12.2008	At the early phase. Semantic modelling use cases review papers needed in 2010
193	Model selected ICF concept fields in Protégé	WHO has done the primary modelling in 2007	The model is to be circulated and commented for finalizing in 2010
194	Start to collect the ontological ICF term repertoire in Protégé as a collaborative activity of interested parties	In 2009 ICF has been mapped to e.g. ICD-10 Ch XVIII concepts and some surveys. This material in Excel form the first stage term repository to be developed further for an ICF term repository in Protégé.	At the early phase. For the ontological term repository in Protégé the results of WP 193 and 195 should be available.
195	Create the information model with first draft in 2009	Presentations and initial discussion in ICF ontology and Protégé workshop 1-5-12.2008. The Protégé model according to ISO TS 22789:2007, Health informatics – Conceptual framework for patient findings and problems in terminologies is available	The information model of ICF is under discussion. Result expected in 2010
196	Pilot ontological ICF concept definitions in digital environment. e.g. web portal	No activities in 2009	Pending on WP 193 and 195
197	Identify use cases in EHR context e.g. anamnesis and status documentation	No common activities in TG 8	A Finnish TOIMIA- expert group is starting starting a pilot

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			project in October 2009
198	Study the linkages with ICD-11 and its information model	No common activities with ICD and ICF	A project is needed to start in 2010
199	Study the linkages with other concept sources e.g. classifications such as, ICNP and ICPC, terminologies such as SNOMED CT, ontologies such as FMA, assessment instruments such as RAI-HC and specific term sets such as UN Convention on the Rights of Persons with Disabilities	Presentations and initial discussion in ICF ontology and Protégé workshop 1-5-12.2008. The experiences on mapping ICD 10 Ch XVIII and ICF will be presented in Seoul.	Project and systematic approach with the various topics needed in 2010. The term repository of the mapped terms will be established.