



Department of Health Sciences

Module on
“Disability and Social integration”

Washington Group meeting

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Dublin

Howard Meltzer

Background

- The European Action Plan on Disability 2006/07 calls for information on the situation of disabled people in the enlarged European Union.
- Through the European Statistical System (ESS) and within the Community Statistical Programme consistent statistics are being developed on disability and social integration of disabled people.
- Project launched by and developed in collaboration with Eurostat
- In the framework of the European Health Survey System (which includes the European Health Interview Survey).

Project management

- Principal investigator – UK.
- Advisory Group, experts from:
 - Belgium
 - Denmark
 - Netherlands
 - DPI/EDM
- Partners for fieldwork testing
 - UK, Italy, Lithuania

Content of module (based on ICF)

- Chapter 7 of A/P: Interpersonal interactions and relationships.
- Chapter 8 of A/P: Major life areas – education; work, economic life.
- Chapter 9 of A/P: Community, social and civic life.
- Environmental factors.

Module design challenges (1)

- Designing questions which reflect the interactive nature of the ICF definition of disability
 - No longer ask does your health problem prevent you from doing a particular activity
 - Need a set of questions which takes into account the person, their impairments and the environment
 - Need questions which can be asked of everybody

Module design challenges (2)

- Utilising a classification to design a questionnaire
 - the purpose, structure and language of a classification are different to that of a questionnaire
 - language is too academic, too jargonised
 - achieves comprehensiveness by sacrificing mutual exclusivity
 - thousands of entries (e.g. specific interpersonal relationships)

Module design challenges (3)

- Should environmental factors be covered in their own right or related to particular activities?
 - Personal assistance in general or to perform particular tasks
 - Assistive technology in general or to performing particular tasks
 - Some environmental factors are task- specific others impinge on all aspects of life

Module design challenges (4)

- Getting reliable information on barriers and facilitators
 - People know what they can not do and what prevents them from doing it.
 - When barriers are removed they may not be aware that there was a potential problem in the first place
 - Barriers and facilitators may be societal or cultural as well as physical

Module design challenges (5)

- Participation (in either work or social life) requires a degree of volition.
 - People vary in the desire for social participation
 - Capacity measures what people can do
 - Performance measures what people actually do
 - Participation includes what people can do, allowed to do, actually do and want to do.

Module design challenges (6)

- Getting comparable statistics from performance and participation questions
 - Participation is context-specific (e.g. opportunities for work, availability of services, location of leisure facilities)
 - Family, economic and geographical factors influence social integration
 - There are transnational differences in types of participation.

Module design challenges (7)

- Making the questions compatible with other EHIS modules.
 - Are there any overlaps with questions in the Health Status module?
 - Do the questions have the same format in terms of concepts, time periods, number of response categories etc.?

Module design challenges (8)

- Keeping the module short. Making sure that although the number of questions are limited:
 - Questionnaire design principles are adhered to (simple, unambiguous, short)
 - Questions are not too general or wide in scope to be meaningless.

Content of questionnaire (1)

- Chapter 7 A/P Interpersonal relations
 - Receiving respect and consideration
 - Giving respect and consideration
 - Controlling emotions in respect to relationships with family members
 - Controlling emotions in respect to relationships with non-family members
 - Romantic and intimate relationships.

Content of questionnaire (2)

- Chapter 8 A/P Major life events
 - Limitations in learning opportunities
 - Limitations in work opportunities
 - Working
 - Looking for work
 - Economically inactive
 - Economic life (paying bills on time)

Content of questionnaire (3)

- Chapter 9 A/P Community participation
 - Social participation
 - Sport, leisure and recreational activities
 - Spiritual activities
 - Political participation
 - Autonomy (control over ones life)

Content of questionnaire (4)

- Environmental factors
 - Internet use
 - Mobility
 - Getting out and about
 - Use of car
 - Use of transport
 - Attitudes (discrimination)
 - Accessibility to buildings

Details of field testing

- Carry out 30 cognitive interviews in UK
 - Disabled and Non-disabled samples
- Carry out 70 pilot interviews in the UK.
- Produce translation protocol
- Carry out 30 cognitive interviews in Italy and in Lithuania
- Finalise module
- Suggestions for placement in EHIS

Cognitive testing protocol (1)

General probes

- Did you have any problems with that question?
- Did you feel you understood what the question was asking?
- What do you think the question designers really want to know?
- Can you use your own words to tell me what you think the question is asking?
- Was there anything that you were not sure about?
- What went through your head when you were thinking about what answer to give (think aloud)?
- What problems or difficulties - if any - did you have with giving an answer?
- How confident did you feel about the answer you gave?
- How strongly did you feel about the answer you gave?

Cognitive testing protocol (2)

Specific terms and phrases

- Probe for understanding/interpretation of highlighted terms/phrases
- What did you take this word/phrase to mean?
- Did you have any doubts or feel the meaning was unclear or ambiguous in any way?
- Can you think of a better word or phrase that could have been used instead?

Complete section probing

- Can you think of a better way of expressing/asking that question or do you think it does the job well enough?
- Having had time to think about the question would you like to change the answer that you gave?

Wrap up

- Have you any last comments that you would like to make about this question?

Cognitive testing results

- General issues
 - People modify their behaviour, their desires and their expectations to take account of their limitations
 - Asking why people do not participate worked well: range of barriers emerged
 - Specific questions work better than general questions.

Cognitive testing preliminary results

- Specific issues
 - Accessibility questions – the issue was not getting into the building but using the facilities in the building
 - People answer mobility questions with their facilitators
 - Questions on interpersonal relationships were most difficult, how to operationalise inappropriate behaviour

Outputs

- Rationale behind module sections.
- The questions
- Interviewing instructions
- Show cards
- Coding rules/jumps/signposting.
- Translation protocol

Timetable

January 2007 to March 2007	Decide on topics, prepare first version of module.
April 2007 to June 2007	Cognitive test in UK. Send version to Italy and Lithuania
July 2007 to September 2007	Pilot test in UK
October 2007 to December 2007	Revise all survey docs and prepare translations.

Timetable (continued)

<p>January 2008 to March 2008</p>	<p>Cognitive Testing of the translated modules and prepare analysis</p>
<p>April 2008 to June 2008</p>	<p>Finalise English version of the module, with interviewer instructions. Finalise linguistic versions of module. Preparation of final report.</p>

Scrutiny of progress

- Regular input from Eurostat and Advisory committee.
- Information/consultation of DG EMPL and DG SANCO
- Core group HIS – March 2007
- Technical group HIS – June 2007
- Eurostat meeting on disability statistics – September 2007.
- Washington Group meeting – September 2007.