

Extended sets – draft proposal

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Margie Schneider (Workgroup coordinator)

Principles

- One or more sets
 - feasible
 - cross country comparability
 - ICF framework – holistic description (ultimate aim)
 - Use of ICF terms
 - Functioning and Disability = Umbrella terms
 - Body structure + function, activity, participation and
 - Context: Environmental barriers and facilitators + Personal factors
 - Review of existing sets
 - Congruency and coherence between short and extended sets
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ICF Framework

- ❑ Disability = outcome of an interaction (Health condition + context)
 - ❑ Three levels of outcomes –
 - body (impairments)
 - Person (activity)
 - Societal (participation)
 - ❑ Starting point = basic activities (consensus)
 - ❑ Extended sets = to include complex activities or not? (no clear consensus)
 - ❑ Activity domains – with and without assistance (technical and personal) (consensus)
 - ❑ Environment = seen as essential but no clear consensus on how to incorporate
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Purpose of extended sets

- Equalisation of opportunities and Prevalence of disability (same as for short set)
 - Other purposes?
 - Data use
 - individual country needs – e.g. policy development, advocacy, monitoring and evaluation of interventions
 - International reporting – e.g. population health and functioning
 - Summary measures or individual impairment types? Or both?
 - Other data uses?
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Identifying population of interest

- ❑ Population at risk vs population with disability – same or different popⁿ?
 - ❑ Are Qs on basic activities sufficient to identify population?
 - ❑ Are Qs on complex activities required to identify population?
 - ❑ What evidence do we have for each?
 - ❑ What are cross cultural comparability issues?
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Proposal 1: 2 types of sets

- Type 1: functioning (within ICF)
 - Type 2: complementary (background?) questions (not ICF)
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Type 1: functioning (within ICF)

- a) Parsimonious set – for summary measure?
(existing work – WHO/ UNESCAP, WHS, ??)
 - b) More detailed set with additional domains including complex ones (e.g. upper body mobility, learning, domestic tasks, interpersonal interactions, work/education, social and community life) + with and without assistance (micro E) + a couple of 'broader' E questions (meso and macro E)
 - c) same as for b) with more detailed meso and macro EFs. e.g. CHIEF questions
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Type 2: Complementary Qs

- ❑ Age of onset and cause of Activity limitations
 - ❑ Duration, frequency and intensity – Activity limitations
 - ❑ Impact of pain on activity limitations/ participation
 - ❑ Level of distress (?)
 - ❑ Other personal factors – age, sex, educational achievement, employment status, health condition(s) (problematic for self report), etc. (already always included? – background Qs)
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Proposal 2: Suggestions for sets

- Short set + some domains = parsimonious set (Which additional domains?)
 - Measure of disability status (Summary measure?) using:
 - Short set
 - Extended sets
 - Individual domain information using:
 - Extended sets
 - More domains? or More questions on same domain? Or both?
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Proposal 2: continued

- Measure disability status (identifying popⁿ) and compare inclusion rates (employment and education as outcomes)
 - Compare 'disabled' in terms of effect of assistive devices (with AD and no difficulty, with AD but still difficulty, and without AD)
 - Add Qs on nature of functioning (onset, frequency, duration, etc.) within domains covered – to explain interaction
 - New (?) purpose = assessment of E (not domain specific)
 - New purpose = fulfillment of societal roles – problem of cross cultural comparability (?) (Still within ICF framework?)
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Proposal 1 and 2 compared

□ Proposal 1

- A = 'within the skin' and includes basic and complex Activities
- P = with effect of E and includes basic and complex Activities
- E measured as a way to differentiate A from P
- Employment, education and leisure etc. as complementary to A and P measures on these domains

□ Proposal 2

- A = basic activities
 - P = complex activities
 - E used as an independent measure
 - Outcome i.t.o education, employment and leisure as separate from P (?)
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Outstanding issues

- What do we mean by
 - cross country comparability?
 - Equalisation of opportunities and how do we ensure this purpose is met?
 - Wording of Qs: 'Do you have....' vs 'How much do you have.....?' Does it make a difference?
 - Response options: 4 or 5? Does it make a difference?
 - Measuring Environment – different levels
 - Choice and desire – an issue or not?
 - What makes up the 'identified' population?
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Cross country comparability

- ❑ Basic activities – same measure but different frame for responding – **is this comparable?** (e.g. walking in rural area with no transport compared to urban area with transport)
 - ❑ Interpersonal interactions, working, attending school, etc.: Generic vs specific
 - ❑ What are we comparing?
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Equalisation of opportunities

- ❑ What is the measure?
 - ❑ How do we ensure that the correct Qs are asked to allow for analysis?
 - ❑ How do prevalence of disability and equalisation of opportunities differ (if they differ) in terms of measurement requirements?
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Wording of Qs and number of response options

- ❑ Does the wording make a difference?
 - ❑ What is the effect of 4 vs 5 response options?
 - 'does not make a difference and there are techniques to link the two'
 - 'Makes a difference in summary measure and continuum - get bunching of responses between two anchor points with reduced options
 - What is easiest in terms of self-report and translations?
 - What does the evidence say?
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Measuring Environment

- Basic activities: With and without = micro E ('goes with the person')
 - Complex activities: meso and macro E and not clear link for each domain
 - Community and national levels
 - Affects all – not just an individual
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Choice and desire

- Is this an issue?
 - How are these dealt with?
 - Add a phrase indicating
'difficulties doing activities that want and/or
need to do'
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Way forward

- ❑ Deciding on proposed sets: Purpose, Nature/structure and number of sets
- ❑ Compiling the sets
- ❑ **Building an evidence base**
 - Cognitive testing
 - Statistical analysis of existing data (e.g. IRT and factor analysis of existing data sets to evaluate extended sets) to determine
 - ❑ What domains – including only basic or also complex?
 - ❑ Cross cultural comparability
 - How different sets work i.r.t intended purpose?

Analysis and reporting

- Summary measure(s)?
 - Composite of responses on extended set (or short set) or weighted score (based on IRT or similar)?
 - Individual question responses?
 - How is prevalence estimated (once data has been collected)?
 - How do we decide on cut off point?
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Strengths of WG

- ❑ Country involvement
- ❑ Link to statistical offices and Censuses
- ❑ Initial cognitive and field testing
- ❑ Strong proposal for Censuses – Short set

But need to work on:

- ❑ Further statistical analysis on existing data and with other groups (e.g. UNESCAP) to build evidence
 - ❑ Clarification of concepts
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Possible assistance

- ICF Research Branch of WHO Collaborating Center for the Family of International Classifications, Germany (G Stucki, A Cieza)
 - UNESCAP new project and existing data and analyses
 - Other collaborations? – Eurostat, Budapest Initiative
 - Use of existing data – set out analysis required to determine what domains are important/work for identifying the population
 - WG field and cognitive tests (e.g. Vietnam and Latin America)
 - South Africa
 - Tanzania (?)
 - Kenya (?)
 - Others
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Next steps – how do we achieve them?

- Analysis plan
 - Putting evidence into coherent framework
 - Compile sets from existing and/or new Qs
 - Tasks for Workgroup and reporting for Phillipines meeting
 - Funding
 - ??
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Discussion

- Purpose of extended sets
 - Is there agreement on 2 purposes: Equalisation of Opportunities and Prevalence?
 - Are there additional purposes of expansion of the two?
 - Number and nature/content of sets
 - 'relaxing' short set into longer set – basic activities
 - More complex activities
 - Participation
 - Environment at different levels
 - Comprehensiveness in terms of ICF chapters and components
 - Any 'no go' domains? If yes, why?
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Discussion (Contd)

- Coherence and congruence of extended sets –
 - Between themselves
 - With WG short set
 - With other international initiatives
 - Implementation issues
 - Screening Qs
 - Post censal surveys
 - Modules in surveys
 - Links with other information systems (?)
 - Sets for children
 - Next steps
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