



# Extended sets

## Another year on.....

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# Agenda for 8<sup>th</sup> WG meeting

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- Review work done
- Consider proposed extended sets
- Discuss issues of concern
- Finalise Questions for cognitive and field tests
- Revisions after testing

Nothing is fixed in stone – the cement is still wet but needs to dry.....



# Structure of session 2

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1. Background and guiding principles
2. Matrix : structure for moving forward
3. Present sets + issues of concern
4. Present individual questions + issues of concern



## Potential sources of disability data

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- ✓ National censuses
- Specialized surveys
  - Health or disability surveys
  - Other population surveys
- Modules on surveys
- Administrative data
  - Registries
  - Medical and/or insurance records

# Disability statistics: What information do we need?

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- Determine
  - Purpose – Equalisation of opportunities
  - Data users
- Identify the population at risk for 'disability'
- Describe the experience : indicators of disadvantage and discrimination
- Undertake relevant analyses

# Identifying the population at risk for 'disability'

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- Decide who the 'true' population is: What component to measure
  - Health condition?
  - Impairment?
  - Activity limitations?
  - Participation restrictions?
  - Something else?
- Develop questions to identify this population based on component selected for measurement
- Create a demographic variable from measures

# Considerations in deciding what to measure

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- Health condition and impairments: not reliable as self-report
- Basic Activity:
  - self report is possible
  - Can measure with and without assistance
- Complex Activity:
  - Self report is possible
  - Difficult to measure with and without effect of environmental factors
- Environmental factors:
  - Self report on barriers but not facilitators
  - Immediate/micro and community/meso = possible
  - Macro/distant = not easy in surveys

# Full picture of disability in country requires .....

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- Measure of HC and impairment: Health examination surveys
- Activity and participation: observation + self report
- Environmental factors: self report + observation
- Measure of disadvantage and discrimination (through analysis)

# Developing the measure

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- Activity: basic only or also complex activity?
  - Basic:
    - domain specific;
    - can measure with and without E (Assistance);
    - ? Miss people who have no AL but have HC + participation restrictions (e.g. disfigurement)
  - Complex:
    - with or without E?
    - Health-related or not?
    - If have complex AL then will have basic AL?
  - Who is missed?
    - no Basic AL but have HC + experience discrimination/disadvantage (e.g. disfigurement)
- Extended sets: try to cover as much as possible



# Methodology factors (1)

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- Not much published but increasing cognitive testing
- WG cognitive and field testing for Short Set
- Some issues:
  - Type of surveys – health, general, etc.
  - Structure of survey:
    - Screening + follow up
    - Everyone gets all Qs
  - Question placement
  - Question wording
  - Response options
- For discussion in later WG meeting
- Tried to take some of these principles into consideration

# Methodology factors (2)

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- question wording (Bajekal et al, 2004; Meltzer, 2003; Altman and Gulley, forthcoming; Schneider, 2008).
  - 'have' vs 'suffered' (Meltzer, 2003)
  - 'Disabled/disability' vs 'difficulty' (Schneider, 2008)
- response options provided (Bajekal et al, 2004; Meltzer, 2003; Schneider, 2008)
  - 'yes/no' response options – all or nothing; fewer people indicate 'yes'
  - more response options - grading from 'no difficulty' through to 'extreme difficulty/unable to do'; people with mild difficulties more comfortable saying 'yes, some difficulty'

# Methodology factors (3)

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- Including a notion of severity within the question wording (e.g. 'do you have a serious disability....?'). (Schneider, 2008).
  - 'serious disability' – 'yes' by people with mild, moderate and severe difficulties; Can mean quite different levels of difficulty and therefore not very useful.
  - *Not sure what would happen if asked about 'serious difficulty'?*
- number of questions asked (Bajekal et al, 2004; Meltzer, 2003; Altman and Gulley, forthcoming) – the more questions asked the more likely one is to count in more people.
  - *How many is enough and when have we counted in all who should be counted in?*

# Methodology factors (4)

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- question order and context (e.g. survey or Census) (Bajekal, 2004; Meltzer, 2003) –
  - *if the survey is entirely about disability does this sensitise respondents?*
  - *If the questions are placed together with health questions does this affect the responses?*
- Types of questions: The least variation for questions about basic activities such as sensory, physical, mental and self-care disability and the most variation between 'going outside' and 'employment disability' (Stern, n.d.).

# Methodology factors (5)

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- Reference group used to elicit the response (e.g. 'Compare yourself to others of the same age' vs reporting 'any difficulty') (Meltzer, 2003)
  - Comparing self to others of the same age = lower than asking about being limited 'in any way'.
- severity rating used in the analysis (Meltzer, 2003) – using a more 'severe' cutoff point counts in less, and vice versa.
- Mode of administration, i.e. face-to-face interview vs telephone interview vs self completion, and so on. (Meltzer, 2003; Stern, n.d.)
  - *what effect arises from these different modes of administration?*



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Now, let's look at the Matrix

# Structure of proposed Extended sets (1)

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- Identifying population at risk
  - Short Set (Censuses)
    - Single questions per domain
    - Limits on space
  - 'Expanded Short Set' (surveys)
    - Single questions per domain
    - Additional domains: upper body mobility and learning
    - Limitation in space
  - Extended set (surveys)
    - Multiple Qs per domain
    - More domains
    - Micro and meso Environment
    - No space limitations

# Structure of proposed Extended sets (2)

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- Describing experience of disability:
  - Develop indicators of discrimination/  
disadvantage:
    - Education and Skills training
    - Employment
    - Social inclusion
  - +
  - Built environment, services, natural environment
    - Social protection and access to services
    - Transport
    - Accessibility of built and natural environment
    - ??

# Indicators for discrimination and disadvantage (not developed)

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- Use current Qs asked by countries in all surveys
- Add some questions on accessibility of built environment, natural E, social inclusion, etc.
- Ensure that response options include disability related ones, e.g.
  - why do you not use public transport?
    - Attitudes of bus driver's
    - Inaccessible buses and trains
    - Etc.

# Short Set Expanded: Upper body mobility

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- Do you have difficulty raising a 2 litre jug of water from waist to eye level?
- Is this a common enough activity?
- Ask with and without assistance?
- Cognitive testing:
  - 'do you have....' vs how much difficulty...'
  - If use assistance, ask what type

# Short Set expanded:

## Learning adults and children

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- Children: 'Does [name] have difficulty learning new things?'
  - Proxy or not?
  - Learning of new knowledge
  - No good ways of measuring in more detail
- Adults: 'Do you have difficulty understanding and using information such as following directions to get to a new place?'
  - Use/application of new knowledge
  - What about acquiring, applying and processing info, problem solving, executive functioning, etc.?
  - Cross cultural comparison
  - Overlap with concentrating and remembering
- WHODAS II: 'How much difficulty did you have in learning a new task for example learning how to get to a new place?' (last 30 days)

# Extended Set: Vision

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- Do you wear glasses or contact lenses? Y/N
- Do you have difficulty clearly seeing someone's face across a room [even if wearing glasses or contact lenses]?
- WHO DASII: 'How much difficulty did you have in seeing and recognising a person you know across the road taking into account eye glasses if you wear them?'
- Do you have difficulty clearly seeing the picture on a coin [even if wearing glasses or contact lenses]? [Add 'at arm's length?']
- WHODASII: 'How much difficulty did you have in seeing and recognising an object at arm's length or in reading?'
- Is use of coin example appropriate?
- Cognitive testing: compare newspaper print to coin to object?

# Extended set: Hearing

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- Do you use a hearing aid? Y/N
- Do you have difficulty hearing what is said in a conversation with one other person in a noisy room [even if hearing your hearing aid]? (if 'no difficulty skip next Q)
- WHODAS II: How much difficulty did you have in hearing someone talking on the other side of the room in a normal voice (take into account hearing aids if using them)?
- Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even if hearing your hearing aid]?
- WHODASII: Same except for 'How much difficulty....?'
- Distance aspect (hear near or far) or noise aspect (hear in noise or quiet)?

# Extended Set: Mobility (1)

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- Do you use any aids or equipment or receive help for walking or moving around? **Change to walking and climbing stairs?**
- Which of the following types of aids or equipment do you use?
  - Cane or walking stick
  - Walker
  - Crutches
  - Wheelchair
  - Someone's assistance
  - Other
  - **Add stair lift?**
- If uses aid, refer to it in next Qs

# Extended Set: Mobility (2)

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- Ask without assistance and then with assistance: **What if person uses a wheelchair – ask without assistance?**
- Do you have difficulty walking 500 metres on level ground, that would be about *[country-specific example]* [without using your *[insert aid]*]? (if no difficulty, skip next Q)
- Do you have difficulty walking 100 metres on level ground, that would be about....?
- Do you have difficulty walking up and down a flight of stairs? **(or climbing and going down steps?)**
- If does not use an aid skip 'with assistance' Qs
- WHODASII: How much difficulty did you have in walking a long distance such as a kilometre?
- **Add something about maintaining body position? (NB for people with an amputation of one or two arms or paralysis; issue of balance)**

# Extended set: Mobility (3)

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## WHODASII:

- How much difficulty did you have in standing for long periods such as 30 minutes?
- How much difficulty did you have in standing up from sitting down?
- How much difficulty did you have in moving around inside your home?
- How much difficulty did you have in getting out of your home?
- How much difficulty did you have in walking a long distance such as a kilometre [or equivalent]?

# Extended set: Communication (1)

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- Do you have difficulty speaking clearly (i.e., using spoken language)? **'Speaking' and 'spoken language' are 2 different concepts.**
- Do you have difficulty making yourself understood when speaking?
- Are you able to communicate any easier when using one of these non-spoken-forms of communication?
- Or **Do you use any of the following to assist communication?**
  - Sign language
  - Hand writing
  - Typed or text messages
  - Communication or picture board or cards
  - An interpreter
  - Other

# Extended set: Communication (2)

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- Focus is only on 'expressive' communication and not on 'receptive' communication (understanding):
  - hearing impaired – picked up anyway and also on hearing Q
  - If cannot understand unlikely to be answering Qs – need a Q for proxy questionnaire.
  - Equipment Q is last – cannot ask 'with assistance'. Should we ask Equipment Q first?
- Cognitive testing:
  - ask if understand that Qs are about spoken language
  - See how Deaf person answers
  - Develop Q about receptive language to test
- WHODASII:
  - How much difficulty did you have in generally understanding what people say?
  - How much difficulty did you have in starting and maintaining a conversation?

# Extended Set: Cognition (1)

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- On how many days during the last week have you had difficulty remembering important things? (no. of days)
- SET A: Thinking about the last time you had difficulty remembering (incl. important things or anything?), how much difficulty did you have?
- SET B: Do you have difficulty remembering a few things, a lot of things, or something in between?
- WHODASII:
  - How much difficulty did you have in concentrating on doing something for ten minutes?
  - How much difficulty did you have in remembering to do important things?
  - How much difficulty did you have in analysing and finding solutions to problems in day to day life?
  - How much difficulty did you have in learning a new task, for example, learning how to get to a new place?

# Extended set: Cognition (2)

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- Which set?
- Response options:
  - no difficulty, a little difficulty, a lot of difficulty, unable to do this
  - no difficulty, a little difficulty, a lot of difficulty, or something in between a little and a lot of difficulty
- Use of assistive devices?
- Aspects considered in Q: frequency, severity, and/or duration
- Other aspects to consider: concentrating, decision making, making judgements, personal safety, executive function and reasoning.
- Include Q on whether difficulty is of concern
- Does 'important' work? To avoid common, innocuous instances of forgetting
- Use of proxy respondents if report more than mild difficulties? Switching mid-interview?

# Extended Set: Upper body (1)

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- Do you have difficulty raising a 2 litre jug of water from waist to eye level? (without assistance)
- Do you have difficulty using your hands and fingers, such as picking up small objects or opening and closing containers? (without assistance)
- Do you use any special equipment or receive help with lifting, carrying or using your hands or fingers?
- WHODASII: How much difficulty did you have in using your hands and fingers, such as picking up small objects or opening or closing containers?

## Extended set: Upper Body (2)

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- Jug Q: not common as an activity?
- Captures functioning and not whether person has missing limb or not
- Assistive devices: too many and too varied; so ask single Q at end
- Cognitive testing: ask for examples of assistive devices used.

# Extended set: Affect (1) - Set A

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## ○ Anxiety:

- How long in past year did you feel anxious? (Not at all, daily, weekly, monthly) If 'not at all' » Depression
- Do you take any medication for anxiety?
- Thinking about last time you felt anxious, how would you describe your level of anxiety [even when taking your medication]? None, a little, a lot, in between {Rephrase: ....how anxious were you?}

## ○ Depression:

- As for anxiety – same Qs

## Extended set: Affect (2) - Set B

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- Do you take any medication for anxiety or depression? Y/N {need for routing to skip if No?}
- On how many weeks in the past year did you feel anxious/depressed? No. of weeks + add 'never'
- During those times you felt anxious/depressed, how would you describe your level of anxiety/depression?
- WHODASII:
  - How much of a problem did you have with worry or anxiety? (last 30 days)
  - How much of a problem did you have with feeling sad, low or depressed?

## Extended Set: Affect (3)

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- Reference period too long? – usually 7 days – 1 year used for seasonal, infrequent but significant occurrences
- Need to choose between Set A or B or another
- Whether 'anxiety' and 'depression' are understood and translatable in other languages, or measurable in same way across cultures
- 'Thinking about last time....' try to avoid person having to average out
- Use of standardised and tested scales? Against sets proposed?

# Extended set: Cognition (4)

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- Cognitive testing:
  - Translatability of terms
  - How medication Qs work: intermittent use captures? Prescribed or over-the-counter, or both?
  - 'Do you take medication?' vs 'Are you taking medication?'
  - Better to use existing scales or not?
  - Capture issues relating to seasonality

# Extended Set: Pain (1) – Set A

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- Do you use medication for pain? - *or* - Are you taking medication for pain? Y/N
- On how many days during the past week did you have pain? (none, 1–2 days, 3-4 days, 5 + days) (none = skip Q 3 and 4)
- Thinking about the last time you had pain, how long did the pain last [even when taking your medication]? (< 1 hour, 1-2 hours, or > 2 hrs)
- Thinking about the last time you had pain, how would you describe the level of pain [even when taking your medication]? (none, a little, a lot, or somewhere in between a little and a lot?)
- Thinking about the last time you had pain, was your experience of pain usual, worse than usual, or better than usual [even when taking your medication]?

# Extended Set: Pain (2) – Set B

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- Do you have chronic or frequent pain? Y/N
- Do you use medication for pain? - *or* – Are you taking medication for pain? Y/N ('No' = skip Q3)
- Thinking about the last you had pain, how would you describe the level of pain [even when taking your medication]? (none, a little, a lot, or somewhere in between a little and a lot?)
- WHODASII:
  - How much of bodily aches or pains did you have?
  - How much bodily discomfort did you have?

# Extended set: Pain (3)

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- Capture frequency, duration and intensity
- Experience of pain varies – do we ask for average or worst or least pain experience?
- Cognitive testing:
  - Translation of pain
  - How medication Q works
  - Seasonality of pain

# Extended Set: Fatigue (1)

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- Do you have chronic or frequent feelings of being tired? Y/N
- How often during the past year did you have chronic or frequent feelings of being tired? (daily, weekly, monthly, less than monthly, or not at all?)
- *If "not at all" skip Q3*
- Thinking about the last time you felt tired, how would you describe the level of tiredness? (none, a little, a lot, or somewhere in between a little and a lot?)

# Extended Set: Fatigue (2)

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- Capture duration, frequency and intensity
- Use of assistive technology is not appropriate (e.g. medication)
- Experience of fatigue varies – wording 'last time' used to avoid having to average
- Cognitive testing:
  - Translation
  - Seasonality
  - Response categories



# Cognitive testing: General aspects

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- 'How much difficulty.....?' vs 'Do you have difficulty.....?'
- Response options: 'something in between a little and a lot'