Good questions and bad questions

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Strengthening disability measurement in South Asian Countries, Bangkok, 2 – 4 April 2008
Outline

- Factors affecting how people respond
- Framing questions
- Which component to measure?
- Functioning questions
- ‘Other’ questions
Factors affecting responses (surveys and censuses)

- Population – reasonably well understood; relating to the population as an entity
- Individual – poorly understood; experiences that the person brings to bear on his or her responses to questions
- Methodology – reasonably well understood;
Population factors

- Population demographics:
  - ageing population = high prevalence
  - Contribute more in older populations than younger ones
- level of development of the country and access to health care services: what happens in managing injuries and illnesses? (Meltzer, 2003)
- curable health conditions persisting: e.g. untreated middle ear infections leading to permanent hearing loss;
- level of industrialisation and use of cars: more developed have higher rates of injuries
Individual factors

- a person’s overall sense of independence and identity,
- social inclusion or exclusion,
- overall disadvantage experienced (e.g. limited access to education and employment),
- poverty resulting from the impairment,
- access to health care services – having a diagnosis to report,
- age of the person,
- cultural beliefs and notions of health and functioning,
- level of education,
- socio-economic status,
- cultural beliefs,
- racial, ethnic and gender identities, and
- access to knowledge and resources.
Methodology factors (1)

- 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 ‘
  - more response options - grading from ‘no difficulty’ through to ‘extreme difficulty/unable to do’; people with mild difficulties more comfortable saying ‘yes, some difficulty’
- 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’?
Methodology factors (2)

- 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?*
- severity rating used in the analysis (Meltzer, 2003) – using a more ‘severe’ cutoff point counts in less, and vice versa.
- 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?*
- 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?*
Methodology factors (3)

- 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’.
- The duration of the condition, i.e. whether it has lasted more or less than six or twelve months. (Meltzer, 2003).
  - Has this to do with issues of adaptation and how people report before and after adaptation?
- 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.).
Framing questions (1)

- Use of neutral terminology
  - ‘Difficulty’ not ‘disability/disabled’
  - ‘have’ not ‘suffered’
- Use of concrete reference points
  - ‘Walking a kilometre’ vs ‘walking’
  - ‘remembering important things’ vs ‘remembering’
  - ‘Concentrating for 10 minutes’ vs ‘concentrating’
- Time frames: not sure on this – wide variation; respond ‘usually’; need to average out for period
- Introductory phrase: health or not; some variation across surveys; What is understood as being health?
Framing questions (2)

- Response options: use 4 – 5 rather than yes/no. Create binary variable (disabled vs non-disabled in analysis)
Which component to measure? (1)

- Functioning level
  - Health condition or impairment = difficult to measure self report (differences are not real but artefact of access to health services)
  - Basic Activity: good responses on self-report
  - Complex activity: can get good responses on self-report but not sure if measuring with or without influence of environment
- Need to choose one but understand that it gives only part of the picture
- Complement with other Questions to ensure get full picture – e.g. questions on transport, membership of groups, employment, education, and barriers experienced
Which component to measure? (2)

- Environment
  - Micro or immediate environment: Assistive technology and personal assistance; easy to report on as ‘follows the person’; relate to individual domains
  - Meso or ‘community’ level environment: beyond the person (e.g. transport, infrastructure, accessibility, service provision at local level, attitudes of others) – easy to report on; not domain specific (?)
  - Macro or broad environment: whole country policies and legislation, societal attitudes and practices; not domain specific and difficult to report on.
Functioning questions: Census

- Small set of functioning questions
  - WG Short set – 6 domains
  - Australian approach: needing assistance in three domains (mobility, communication, self care)
- Ensure good questions for measuring outcomes
  - Employment status
  - Educational status
  - Transport use
  - Access to services
  - Membership of civil society groups/organisations
- Response options that include aspects such as inaccessible, negative attitudes, etc. (environment)
  - Why do you not use transport? ‘inaccessible’
  - Why are you not working? ‘negative attitudes’, ‘inaccessible buildings’, etc.
Functioning questions: Surveys

- More space
- Cover all domains
- More than one question per domain
- Basic and complex domains (cover all chpts in ICF A/P classification)
- Detailed questions on Environment
  - Micro: Ask about use of assistive devices and personal assistance for each domain
  - Meso: Access to services, local attitudes and inclusion into family and community, transport....
  - Macro: Societal attitudes and practices; facilitating policies and legislation (but maybe not so appropriate in self-report survey)
‘Other’ questions

- Important aspects to measure for full picture, and include:
  - Age of onset: AL/difficulty or health condition/impairment?
  - Cause: as understood by respondent
  - Frequency of occurrence: e.g. ‘time to time/occasionally’, ‘always present/on a regular basis’.
  - Duration: permanent (>6 months or >12 months); how expected to last
Trends in surveys (1)

• Most common domains:
  - Vision
  - Hearing
  - Mobility
  - Self care
  - Emotional functioning

• In the middle:
  - Pain
  - Cognition
  - Learning
  - Communication
  - Interpersonal interactions (sometimes together with emotional functioning)
  - Domestic life

• Least common domains
  - General tasks/demands
  - Community/civic participation
  - Work/employment (more often as outcome)
  - Education (more often as outcome)
  - Life activities
  - Appearance

• Response options
  - 4 or 5 = most common
  - 2, 3 or 6 = least common
Trends in surveys (2)

- Environment
  - Mostly assistive technology and personal assistance (chpts 1 and 3 in ICF). Asked
    - without or with
    - Both with and without
    - Not specified and then with
    - Not specified at all
    - Extensive set of questions for each domain

- Very rarely on other chapters
- Ask about
  - Micro – individual domains
  - Meso and macro – separate from domains
Trends in surveys (3)

- ‘other’ questions
  - Onset (AL/difficulty or unspecified)
  - Cause (open ended or with closed options)
  - Frequency and permanence/duration – not asked frequently
  - Cost of disability: not common but important (direct costs as well as lost income opportunities)
- Time frames: wide variation
  - None
  - 1 week
  - Last 30 days
  - Last 6 months
  - Last 12 months (chronic condition)
Purpose of data collection

- Make sure everyone understands purpose
- Three main data collection purposes for Censuses/surveys:
  - Equalisation of opportunities: identify population at risk and measure outcome i.t.o employment, inclusion, education, etc.
  - Population functioning: type and severity of difficulties in the population (broader measure than equalisation?)
  - Service needs: need detailed set of questions on difficulties and service needs arising from these; country specific (?)
    - but can do in census as per Australian Census using need for assistance as measure to identify population.
Other purposes for data collection

- Measuring impact of interventions
- Eligibility for benefits (e.g. disability related social assistance, road accident fund compensation)
- Administrative records for monitoring service provision and staffing requirements
- Individual intervention plans

- All use the same basic framework for collecting data on disability – different levels of detail, modes of collection (e.g. observation vs self report).
References