Questionnaire Design, Translation and Interviewer Training

Marguerite Schneider

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Questionnaire Design

- Stakeholder involvement
- What purpose?
- What research question?
- What definition of disability?
- What measure of disability?
- What methodology?
- How survey links to other data sources?
- What analysis? (Ken Black)
- How to disseminate and to whom? (Ken Black)

Stakeholder involvement

- Data users
  - Government departments (education, labour, social development, health, etc)
  - Disabled people's organisations (DPOs)
- Involve them from the start to the end
  - What are data needs
  - What are their research questions
  - How the process will pan out
  - Reviewing analysis and results
  - Understanding results and how to use them for policy or advocacy – good use of results!

Purpose

- 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).

Research Question

- Counting number of people with different difficulties (disability) for determining rate of employment, education, social inclusion, etc. or eligibility for services, benefits, etc.
  - Population based / representative sample
  - Large number
- Understanding experience of disability
  - Smaller purposive sample
  - More open questions
  - Not counting

Definition and measure of disability

- Definition
  - Broad or narrow
  - How to identify target population
  - Where to put cutoff points on data in analysis – level of severity
  - All disability types or only some?
- Measure
  - Fits with definition
  - Will identify correct population
  - Is feasible as self-report format

Methodology

- Sampling type – need large number to pick up sufficient numbers of moderate and severely disabled people
- Two stage :
  - Screening Household Questionnaire
  - Detailed questionnaire for those identified as disabled on screen – further assessment or more questions on other aspects
- Single stage:
  - All respondents get all questions (useful for comparing disabled to non-disabled population) – more time consuming than two stage

How survey links to other data sources

- What other data sources are there?
- What do they measure and for what purpose?
- How do the measures to be used in survey match with these other data sources?
- Establish ways to link them.
- Census/Survey data can be motivation for setting up health information systems that collect disability data

Writing questions: 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.).

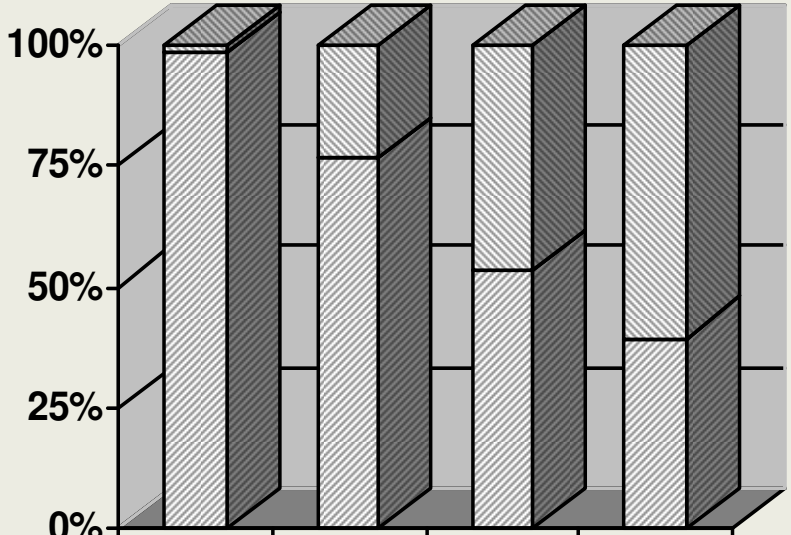
Framing questions (1)

- 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)

- Severity: obtain in response options rather than using severity reference in the question.
- Response options: use 4 – 5 rather than yes/no. Create binary variable (disabled vs non-disabled in analysis)

Un-weighted responses for WG revised set compared to the Census 2001 question (Household Questionnaire responses only)



	No difficulty	Some difficulty	A lot of difficulty	Unable to do
Disabled (census question)	1.52%	23.32%	46.80%	60.63%
Not disabled (census question)	98.48%	76.68%	53.20%	39.37%

Response to question of WG revised set

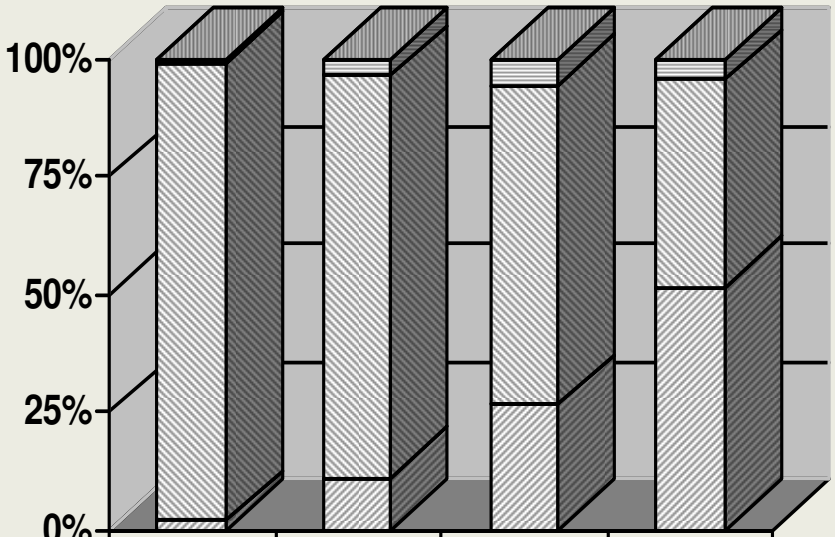
Disabled (census question)

Not disabled (census question)

‘Difficulties’ Qs vs Census 2001 question (Stats SA survey, 2006)

- More severe difficulties on proposed Qs = more likely to ‘yes’ on Census 2001
- ‘Unable to do’ one or more activities on WG:
  - 61% said ‘yes’ to Census 2001
  - 39% said ‘no’ to Census 2001(missed on Census)
- ‘A lot of difficulty’ on one or more activities on WG
  - 47% = ‘yes’ to Census 2001
  - 53% = ‘no’ to Census 2001 (missed on Census)
- ‘Some difficulty on one or more activities on WG
  - 23% = ‘yes’ to Census 2001
  - 77% = ‘no’ to Census 2001 (missed on Census)

Un-weighted responses to the WG Short Set compared to 'Are you disabled? (Adult questionnaire)



	No difficulty	Some difficulty	A lot of difficulty	Unable to do
Missing	0.29%	0.12%	0.35%	0.00%
Sometimes	0.45%	3.51%	5.38%	4.49%
No	97.27%	85.30%	67.70%	43.82%
Yes	1.99%	11.07%	26.57%	51.69%

Responses to WG Short Set questions

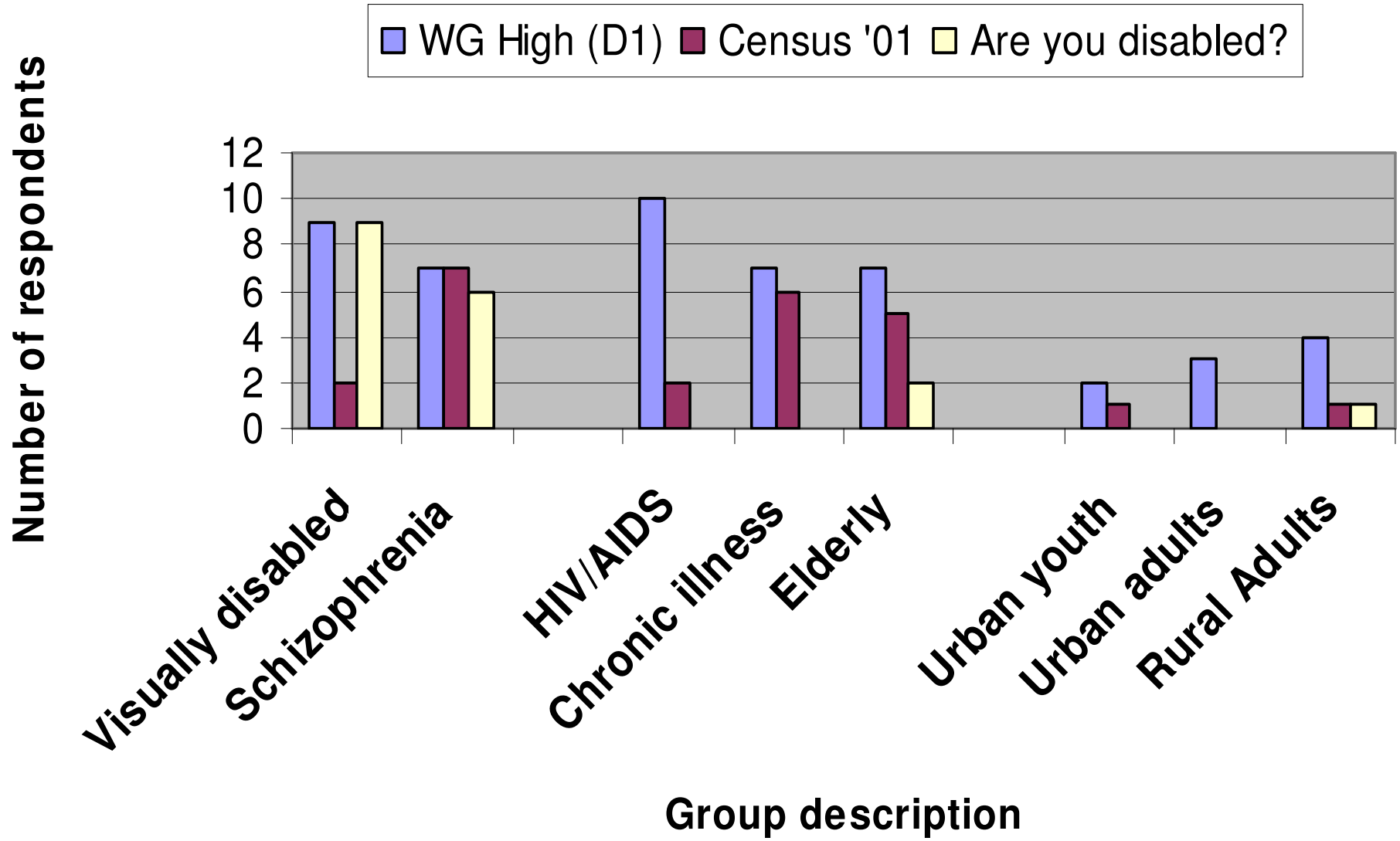
'Difficulties' Qs vs 'Are you disabled?' (Stats SA survey, 2006)

- More severe difficulties on 'Difficulties' Qs = more likely to say 'yes' to 'Are you disabled?'
- 'Unable to do' one or more activities on WG:
  - 52% said 'yes' to 'Are you disabled?'
  - 44% said 'no' to 'Are you disabled?'
  - 4% said 'sometimes' to 'Are you disabled?
- 'A lot of difficulty' on one or more activities on WG
  - 27% = 'yes' to 'Are you disabled?'
  - 68% = 'no' to 'Are you disabled?'
  - 5% = 'sometimes' to 'Are you disabled?'
- 'Some difficulty on one or more activities on WG
  - 11% = 'yes' to 'Are you disabled?' (!!)
  - 85% = 'no' to 'Are you disabled?'
  - 4% = 'sometimes' to 'Are you disabled?'

Population counted in or out for 3 sets of questions

- Counted in with WG Short set:
  - Elderly people
  - People with HIV/AIDS or other chronic conditions
  - People self-identifying as having a difficulty but not as being disabled
- Census 2001 and 'Are you disabled?':
  - Exclude most of above
  - 'Yes' on Census 2001 = mild (23%), Moderate (47%), unable (60%) on WG – mixed severity indication on 'serious disability'.
- WG counts in a broader population and does not exclude anyone.

Number of respondents identified as disabled by 3 Q sets (focus groups)



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

	Basic activity domains						Complex activity domains			
Question topic/type	Vision	Hearing	Mobility	Commu nication	Cognition	New domains	ADL	Getting along with people	Life activities	Participation in society
Short set										
Extended set						Upper body, Learning, Affect, Pain, Fatigue				
Micro-Environment	Technical & personal assistance that follows the person: wheel chair, eye glasses, personal attendant									
Functioning with Assistance										
Experience of Pain or Fatigue										
Age at onset										
Cause										
Duration										
Impact										
Meso-Environment	Environment beyond the person: transportation, service provision, attitudes of others									
Macro-Environment	Affects the entire country: policies & legislation, societal attitudes and practices									

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)

References

- Altman, B, and Gulley, S P. (forthcoming). *Unraveling Disability Measurement: An Examination of Methodological and Conceptual Differences in Disability Estimates of Using Four Varieties of Disability Questions*.
- Bajekal, M, Harries, T, Breman, R and Woodfield, K. (2004). *Review of Disability Estimates and Definitions*. In-House report 128, Department for Work and Pensions. UK. Accessed on 15 February 2008 at www.dwp.gov.uk/mediacentre/pressreleases/2004/march/iad3103-rded.asp
- Meltzer, H (2003). General measures of health for use in Health Interview surveys and Censuses: The UK Experience. Presentation to Washington City Group meeting, Ottawa, 8-10 January 2003. Accessed on 8 February 2008 at www.cdc.gov.pugwash.lib.warwick.ac.uk/nchs/about/otheract/citygroup/products/meltzer.ppt
- Miller, K and DeMaio, T J. (2006) *Report of Cognitive Research on Proposed American Community Survey Disability Questions*. Study Series (Survey Methodology #2006-6), National Center for Health Statistics and U.S.Census Bureau,
- Schneider, M. (2008) Disability measurement and statistics – The state of the notion. Paper prepared for the Conference on the UN Convention on the Rights of Persons with Disabilities: a Call for Action on Poverty, Lack of Access and Discrimination, Addis Ababa, Ethiopia, 19 – 21 May 2008.
- Stern, S M. (n.d.) *Counting people with disabilities: How survey methodology influences estimates in Census 2000 and the Census 2000 Supplementary survey*. Poverty and Health Statistics Branch, U.S. Census Bureau, HHES Division, Washington DC 20233-8500. Accessed on 15 February 2008 at www.census.gov/hhes/www/disability/finalstern.pdf.

Cognitive testing

- Aim of Cognitive testing protocol – to determine
  - Administration ease
  - Interpretations
  - Factors considered
  - Degree of consistency with physical abilities

- Some Techniques
  - Respondent to repeat questions – note errors
  - What were you thinking about when answering?
  - What do different words in question mean?
  - Ask additional questions and look at consistency of responses

Translation

- Two approaches:
  1. Translation and back translation of whole questionnaire or key words
  2. Team of language speakers and content experts – discuss content and decide on translation; independent check on translation
- Specific issues in disability
  - Find neutral or positive term for disability
  - Differentiate ‘disability’ and ‘difficulty’
- Test reactions to translation

Interviewer training: outline

- Who to select and using disabled interviewers
- Training interviewers
- Interviewing disabled respondents

Who to select?

- Do you use disabled interviewers?
  If yes,
  - What accommodations are required? (e.g. accessible transport, tape recorder, brailled questionnaire, sign language interpreter)
  - What effect does this have on responses?
  - What effect does having non-disabled interviewers have?
  - How do you select these interviewers?

Training interviewers

- Understanding of disability – who is disabled?
- Sensitisation (use local disabled people's organisations to assist)
- Issues of confidentiality when using interpreters (e.g. sign language users or for spokesperson for intellectually or communication disabled person)
- Role of personal assistant/attendants
- Importance of question wording – not using term 'disabled'
- How to accommodate different impairment needs

Interviewing disabled people

- Show respect and treat like anyone else
- Don’t use first names unless permitted
- Address the person directly (not their attendant)
- Ask how you can adapt your presentation to make it easier (no need to ask what is wrong with person)

Hearing difficulties

- Lip reading
- Lighting
- Face person
- Get attention before speaking
- Reduce background noise
- Set context – especially when changing topics
- Use written communication (literate)

Physical difficulties

- Accessibility of building where conducting interviews
- Presence of attendant and confidentiality issues
- Get to same level (e.g. sitting for person using wheelchair)
- Person to be seated comfortably
- Address person directly
- Pointing may be difficult

Visual difficulties

- Large print and small print for cue cards
- Braille versions of cue cards
- Good contrast printing for pictures and print (black on white or yellow)
- Identify yourself and others in the room verbally

Communication difficulties

- Clarify preferred mode of communication
- Repeat what you think was said to clarify unclear speech
- Limit to yes / no questions

Specific learning difficulties

- Manage problems in spatial orientation, hand-eye coordination
- Limit auditory, visual and tactile distractions
- Avoid written text
- Explain carefully (if verbal language skills are affected)

Intellectual difficulties

- Be careful with informed consent
- Explain terms simply
- Listen carefully
- Have familiar person (friend or relative) close by
- Use pictures or role play with little human or animal figures

Emotional of mental health difficulties

- Side effects of medication
- Break up interview if too fatigued
- Give encouragement and support
- Manage expressions of frustration
- Manage stress

Hidden difficulties

- Might not come forward with information because of fear of stigma
- Effect of medication
- Need to break up interview