

# 2015 QUEST Workshop

## Challenges in using cognitive interviewing with people with intellectual disabilities.

Elena De Palma

depalma@istat.it

Helsinki, 29 April 2015

# Background

## **UNCRPD (2006)**

Persons with disabilities include those who have long-term physical, mental, **intellectual** or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

## **The World Disability Report (2011)**

To collect data also on sub-group of persons with disabilities

*The importance of obtaining information is increasingly stressed by researchers, PwD and advocacy group as well as policy-makers*

## **Istat- Ministry of Welfare**

New project: To propose survey measures in order to estimate persons with mental and / or **intellectual disabilities**

# Background

People with disabilities want to participate in researches and help researchers to learn about their experiences, needs, and opinions so that policy makers may use these knowledge to improve the lives of persons with disabilities

Participation in research provide also psychosocial benefits such as increased self-esteem, an opportunity to demonstrate their worth and value as well as to challenge themselves, a sense of equality, confidence and belonging, meet new people, do something and learn...

Researchers consider people with disabilities as reliable informants as they have unique insight of their disability and their situation

Nevertheless, some types of disabilities - such as intellectual disability- may represent a challenge for researchers in developing survey questionnaires and conducting interviews.

## Intellectual disability (AAIDD)

*ID* is a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behaviour**. It originates before the age of 18.

***Intellectual functioning*** refers to general mental capacity, such as learning, reasoning, problem solving, and so on.

***Adaptive behaviour*** is a collection of skills that are learned and performed by people in their everyday lives:

- *Conceptual skills*
- *Social skills*
- *Practical skills*

# Question-response model

To answer to a question a person needs to:

- determine what the question is asking
- recall or retrieve the necessary information
- make a judgment about its relevance and accuracy as an answer to the question
- map the answer into the response categories/communicate the answer

*Are persons with intellectual disability able to participate in surveys and cognitive tests?*

*People with intellectual disability are seen as potential reliable informants who have the right to be heard*

## Ethical issues/risks for Persons with I.D.

Among others:

- Are they able to make free informed choices about participating in research?
- Can they weigh the risks and benefits of participating in research?
- Do they run the risk of disclosing sensitive information to researchers without appreciating the consequences of doing so?
- Are they likely to incur in psychological harm because of the unfulfilled expectation that the relationship with the researchers will continue?

## What people with intellectual disability want/need (a)

### Researcher should:

- show respect and genuinely cares about them → feel more comfortable/safe
- be friendly, nice, positive, direct, relaxed, welcoming, patience
- make eye contact and be professional
- take time, even before the interview, talk with them/get to know them
- explain everything, repeat information when asked to, ask them if they have any questions
- talk slowly and allow plenty of time to answer questions

## What people with intellectual disability want/need (b)

### Researcher should:

- do not pressure them to answer a particular question
- provide help if they feel sad (e.g., by listening to experiences and opinions)
- stop the interview if they feel badly
- be aware of other individual possible needs
- value their time/contributions (→ compensation)
- private and familiar accommodation
- provide snacks or drinks to boost participants' comfort

## Intellectual disability and research

Difficulties in conducting interviews and using self-report questionnaires with this population are widely reported.

The use of questionnaires developed for the general population is generally inappropriate for these people as they have problem with several aspects such as:

- Question content
- Question phrasing
- Response format

# Problematic questions for people with intellectual disability

- questions concern quantitative judgments (frequency/degree), direct comparisons, abstract concepts, inferences about the attitudes of others to the self, generalizations, and unfamiliar or sensitive content.
- questions with complex sentence structures, negatively worded, with passive tense, with modifiers, with examples
- answer categories: Yes-No (acquiescence), Multiple-Choice Formats, Open-Ended Questions



- ✓ To avoid them in questionnaire, using alternative proposed by literature
- ✓ To focus attention of these type of questions (when used) during the CT
- ✓ To formulate the probe considering these limitations

## Main challenges on interviewing people with I.D. (a)

- poor **memory** performance
- scan information being held in working memory more slowly
- low receptive and/or expressive **communication abilities**
- limited time of **concentration** / attention span / tiredness
- get easily bored to a long interview
- get easily **confused** if they have to respond repeatedly to similar questions
- more suggestible to **leading questions**

## Main challenges on interviewing people with I.D. (b)

- **emotional distress** and general psychological discomfort
- performance anxiety and **poor skills in managing stress performance**
- relationship with the researcher: may have **hard time to trust others**
- feel uncomfortable in **unfamiliar location** for the interview)
- may want to be accompanied by another person/support person
- may have **other type of impairment** (visual, hearing, challenging behaviour...)

## Conducting an interviews (a)

### Researcher should avoid:

- correcting or completing sentences for the interviewee
- restating what they have understood asking if the information is correct, because they may not feel comfortable correcting the interviewer.
- keeping reading all answer categories when an answer has been already provided, may be confusing as they think the answer is not correct
- delay in accepting the response because it may be interpreted as an indication that the initial response is unacceptable or incorrect

If similar questions should be asked, it is important to clarify why

## Conducting an interviews (b)

- look and speak directly to the person being interviewed (eye contact)
- use his/her usual tone, rate and volume of voice, unless asked to slow down or speak up
- keep the language simple and clear (e.g. plain and concrete), however, it is important to treat each person in an age-appropriate manner
- be attentive to the respondent's non-verbal signals such as body orientation and movements, gestures and facial expression (question problem/signal of tiredness/lose interest)

## More time is needed for... (a)

- ✓ Preparing specific / appropriate documentation for presenting the survey/CT (consultation with experts on I.D.; visual materials; feedback from previous participants....)
- ✓ Recruitment
  - find candidates
  - obtain informed consent
  - .....
- ✓ Find interview location: safe and familiar locations → different locations
- ✓ Organize transportation, if needed

## More time is needed for... (b)

- ✓ Interview:
    - build a trustful relationship
    - obtain informed consent
    - understand the level of language and communicate at that level
    - explain the interview procedure/process and practice before start with the real survey questions
    - carry out the interview
    - ....
- 
- to establish reasonable goals for CT interview

# Main topics for discussion

- *How to find people with intellectual disabilities?*

Internet /advertisements/ local advocacy groups/ services?

Recruitment may be hampered by a range of gatekeepers who may feel that participation in research is not a good idea for this people.

- *How to be sure that the person is able to conduct a cognitive test?*

Gatekeeper (primary caregivers/members of the family) as informant?

Direct from the potential interviewed? When? How?

- *What type of cognitive test could be used?*

Think aloud method: concurrent vs retrospective?

Probe: pre-scripted vs spontaneous

- Other methods?
- What training for the interviewers?

## Some bibliography

- Coons K. D., Watson S. L. (2013), Conducting research with individuals who have intellectual disabilities: ethical and practical implications for qualitative research, *Journal on Development Disabilities* 19(2)
- D'Eath M. (2005), Guidelines for researchers when interviewing people with an Intellectual disability, NFR
- Finaly W. M.L. & Lyons E. (2001), "Methodological issues in Interviewing and using self-report questionnaires with people with mental retardation", in *Psychological Assessment*, Vol 13 n. 3
- McDonald K.E. et al. (2015), "You can't be cold and scientific": Community views on Ethical Issues in Intellectual Disability Research, in *Journal of Empirical Research on Human Research Ethics*, 1-13
- McDonald K.E. et al. (2009), "Including adult with intellectual disabilities research: scientists' perception of risks and protections", in *Journal of Policy and Practice in Intellectual Disability* vol.6 n.4
- McDonald K.E. & Colleen K.A. (2012), "What is right? Ethics in Intellectual Disabilities research", in *Journal of Policy and Practice in Intellectual Disability* vol. 9, n. 1
- Nind M. (2008), Conducting qualitative researcher with people with learning, communication and other disabilities: methodological challenges, ESRC NCRM