# Count me in: challenges of conducting a cognitive interview study with adults with an intellectual and developmental disability

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**Collaborating Center for Questionnaire Design and Evaluation Research**

# Acknowledgements

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- NCHS CCQDER Staff

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  - Amanda Titus
  - Lauren Creamer
  - Stephanie Willson

- All our research participants

# Outline

- Project background
- Methodology
- Project lifecycle
  - Set up
  - Data collection
  - Analysis and write up
- Lessons learned

# Purpose

- Share strategies to facilitate effective interviews
  - Supported by experience

- Cognitive evaluation study

- People with ID/DD are rarely interviewed in cognitive interview studies

  *"I've had problems throughout my life when I've tried to voice my opinion, people just shut me out. They don't want to listen to nothing I have to say."*

# Project background

# What are intellectual and developmental disabilities?

- Diverse group of conditions due to an impairment in physical, learning, language, behavior areas

- Begin during development, before age 22

- Affect a person's day-to-day life

- Intellectual disability is a type of developmental disability

# Background of the study

- People with ID/DD can participate in cognitive interviewing studies

- "Nothing about us without us"

- Challenges to our typical project model emerge
  - With responsiveness and respondent-centered approach it is not only possible but also beneficial
  - Challenges are not excuses for exclusion

# Methodology

# Cognitive interviewing methodology

- Purpose of question evaluation
  - Detect flaws
  - Understand the question constructs

- Interpretivist cognitive interviewing style
  - Focus on respondent's personal experiences
  - Data: the narrative of how the respondent came to their answer
  - Emergent, unscripted probing
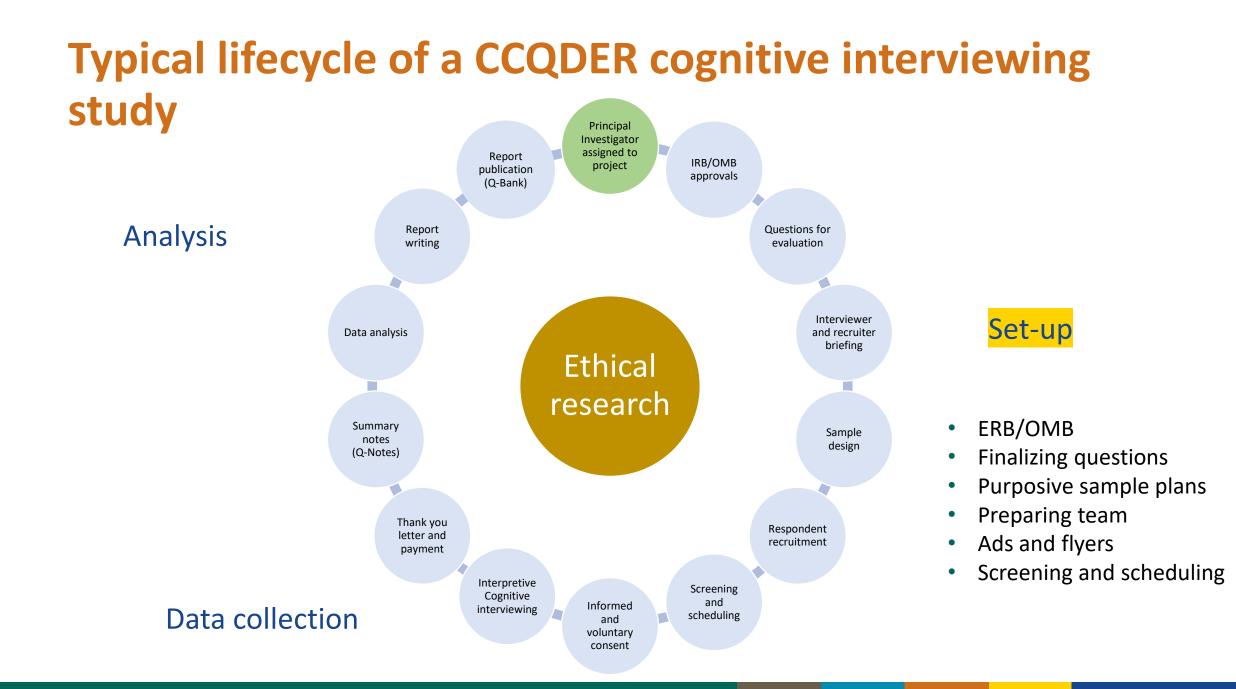  - Elicit respondent narratives and life experiences

# Project methodology

- Two rounds of one-on-one cognitive interviews
- Interviews with adults with ID/DD and, for some, a proxy respondent
  - Round 1: 27 interviews, Fall 2019 (in-person)
  - Round 2: 29 interviews, Spring 2023 (virtual)

- About one hour each
- $40 renumeration
- 16 questions evaluated on functional difficulties

# Project Lifecycle

# Typical lifecycle of a CCQDER cognitive interviewing study

# Working with respondents with ID/DD

# Typical lifecycle of a CCQDER cognitive interviewing study

Analysis

Set-up



Principal Investigator assigned to project

IRB/OMB approvals

Report publication (Q-Bank)

Questions for evaluation

Report writing

Interviewer and recruiter briefing

Data analysis

Ethical research

Sample design

Summary notes (Q-Notes)

Respondent recruitment

Thank you letter and payment

Screening and scheduling

Interpretive Cognitive interviewing

Informed and voluntary consent

Data collection

- ERB/OMB
- Finalizing questions
- Purposive sample plans
- Preparing team
- Ads and flyers
- Screening and scheduling

# Setting up the project: challenges

- **Challenges**
  - <u>Recruitment</u>
  - Gate-keeping in the ID/DD community
  - Typical methods to recruit hard-to-reach populations did not work
  - Initial lack of rapport and trust

  - <u>Screening and scheduling</u>
  - Schedule management
  - Increased time

# Setting up the project: solutions

- **'State to local' approach**
  - Sponsor brokered introductions to organizations at the high level
  - Foundation formed for local-level relationships
  - Consistent person to interface with organizations

- **Embracing longer processes**
  - Repeated explanation of the study
  - Multiple calls, as needed
  - Relationship building for each respondent and their loved ones

# Typical lifecycle of a CCQDER cognitive interviewing study

Analysis

Set-up

Data collection

- Continual informed consent
- Interpretive cognitive interview
- Closing interview
- Thank you letter and payment

Principal Investigator assigned to project

IRB/OMB approvals

Questions for evaluation

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Report writing

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Ethical research

# Data collection: challenges

- **Challenges**
  - Informed consent
  - Is consent capacity impaired for those with ID?

  - Communication
  - Diverse language and communications abilities
  - Use of non-verbal cues
  - Varied depth of description

  *"I have a lot of difficulty remembering a lot of things. If you tell me too much information at once, it won't register as quick in my brain as you'd think it would [...] if you break it down and tell me little by little, then I can repeat it back to you."*

# Data collection: solutions part 1

- **Continual, affirmative consent**
  - Repeated explanation of the study before interview started
  - Reminders during and after interview
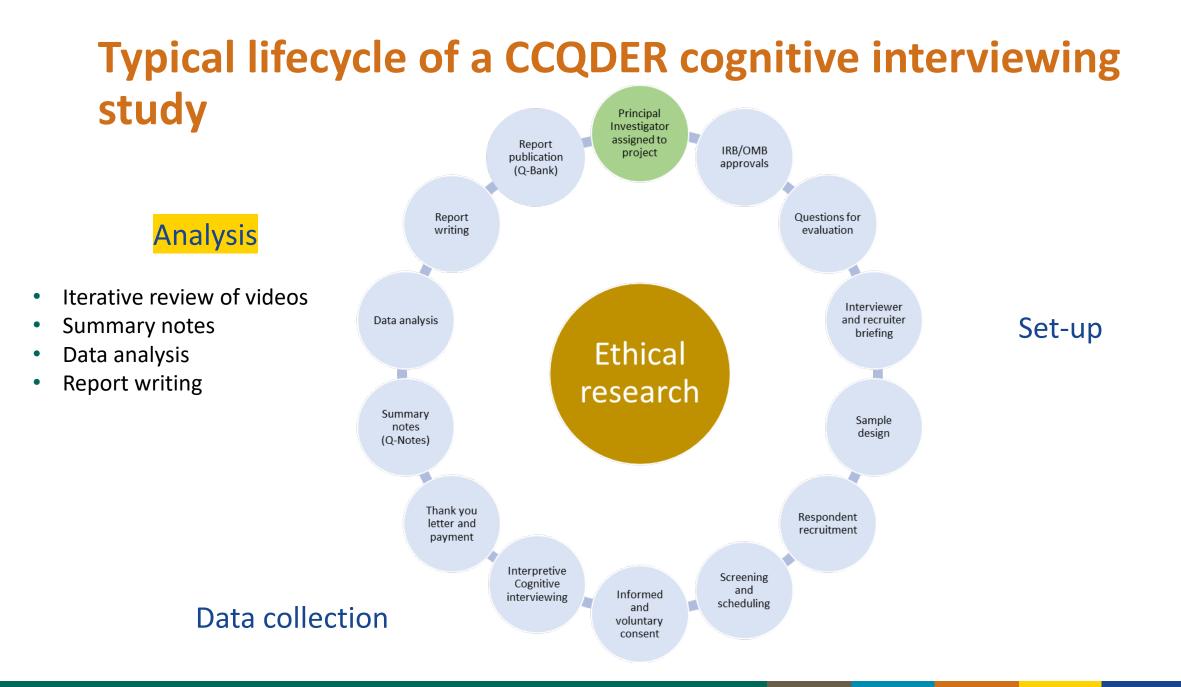  - Additional safeguards in place as needed

# Consent capacity

1. Please tell me, in your own words, what you will be asked to do if you take part in this study?

2. When I say your taking part is completely voluntary, what does that mean to you?

3. Do you have to answer all of the questions in this study?

4. What will you tell me if you don't want to answer a question?

5. What can you do if you start the study but don't want to finish it?

6. If your [aide/caregiver/LAR] wants you to take part, but you do not want to, are you still allowed to refuse?

# Data collection: solutions part 2

- **Rapport building through consistency**
  - One recruiter: same person to screen, schedule, and set up interview
  - Returning at the end of virtual interviews to say goodbye

- **Interpretive interview style as a strength**
  - Flexibility of approaches, probe styles, and pace

  *"You have to explain things to me in a different way. So that I can understand."*
  - Utilizing experienced, adaptable interviewers
  - Understanding emerges more slowly, or even post-interview

# Typical lifecycle of a CCQDER cognitive interviewing study

Analysis

- Iterative review of videos
- Summary notes
- Data analysis
- Report writing

Set-up

Data collection



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Report writing

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# Analysis: challenges

- **Challenges**
  - <u>Complexity of analysis</u>
  - Diversity within the sample itself
  - Non-linear structure of the conversation
  - Cognitive delay and order effects
  - Non-verbal cues

# Analysis: solutions

- **Embracing longer processes**
  - Expecting to learn additional information through iterative review
  - Organization as well as analytic summary
  - Video recording was vital

- **Debriefing notes for all interviews**
  - Systematic way to highlight and preserve certain aspects of the interview
    - Respondent self-perception
    - Interviewer adjustments

- **Two principal investigators**
  - Tracking complex patterns
  - Limit potential biases

# **Summary**

ONE-SIZE-DOES-NOT-FIT-ALL.jpg (640×300) (people-equation.com)

# Lessons learned

- **Cognitive interviews with adults with ID/DD are rewarding**
  - Motivated community with strong self-advocacy
  - Sample should be constructed carefully to account for heterogeneity within group
  - Experienced, adaptable interviewers should be used to make the most of each interview
  - Expectation of greater time and effort for all stages of project
  - Understanding that both informed consent and good rapport are vital to cultivate throughout all stages
- **It is the responsibility of the research team to include people with IDD directly in any research about them.**

# Selected references

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# Thank you!

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