

# It's your decision

## Negotiating consent for research

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Foundation for People  
with Learning Disabilities



# Norah Fry Research Centre

- Research issues affecting disabled children, adults with learning difficulties & their families.
- Policy and practice related
- Making information easier to understand



# The Mental Capacity Act (2005)

- A new law in England and Wales
- A framework for assessing people's capacity to make decisions
- Assume people can make their own decisions
- Guidance for supporting decision making



# The Who decides? project

- How are people with learning disabilities supported to make decisions?
- How is decision-making capacity assessed?
- How are decisions made for people assessed as lacking capacity?



# Research methods

- Ethnographic
  - Getting to know you meetings
- Video recordings
  - Decision making activities
- Conversation analysis



# Including people as participants

- People haven't always been included
- Especially if they have high support needs
- But it's important to do so
- Talking today about my experience in this project

*“It is important that research involving people who lack capacity can be carried out, and that it is carried out properly. Without it we would not improve our knowledge of what causes a person to lack or lose capacity, and the diagnosis, treatment, care and needs of people who lack capacity”*

Mental Capacity Act: Code of Practice (2005: 202)

# Negotiating consent for research

- Voluntary informed consent
- A choice, made by participants, after they've received information
- MCA – requires that you provide 'relevant information' to make the decision
- But what is relevant?



# Researchers responsibilities

## Under the Mental Capacity Act:

- Assess capacity
- Assume capacity
- Support the person to make the decision for themselves

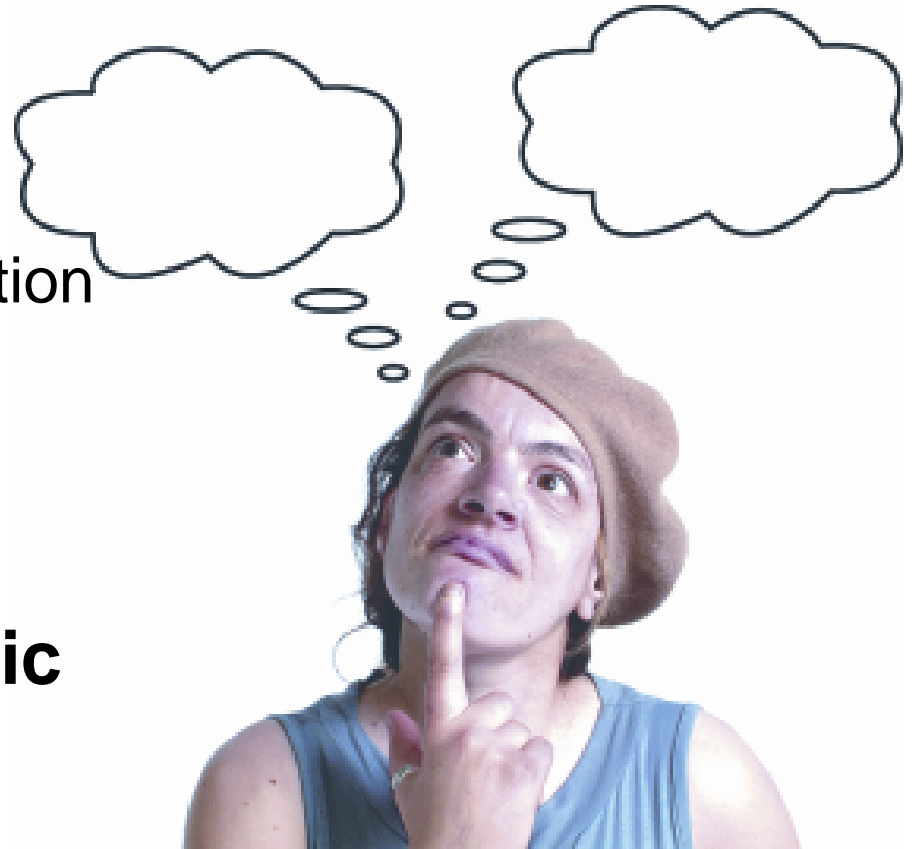


# Assessing capacity

## A functional approach

- Understand relevant information
- Retain
- Use or weigh up
- Communicate

## Time and decision specific



# Negotiating Access

Challenging gatekeeper's assumptions about:

- People's ability

*“Tessa wouldn't be able to make that decision, but Sarah might”*

- Research

*“You might have a wasted visit ... the two who are in wouldn't be very good at answering questions”*

# Assume capacity

## Putting the principles into practice...

- Assuming capacity



# Support the person

## Provide relevant information

- What was relevant to the ethics committee?

Q. What are the potential risks and burdens for research participants?

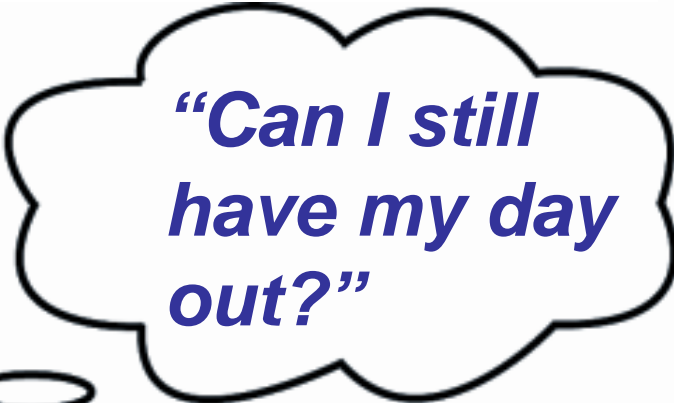
Q. Who is organising and funding the research?

Q. Who has reviewed the study?

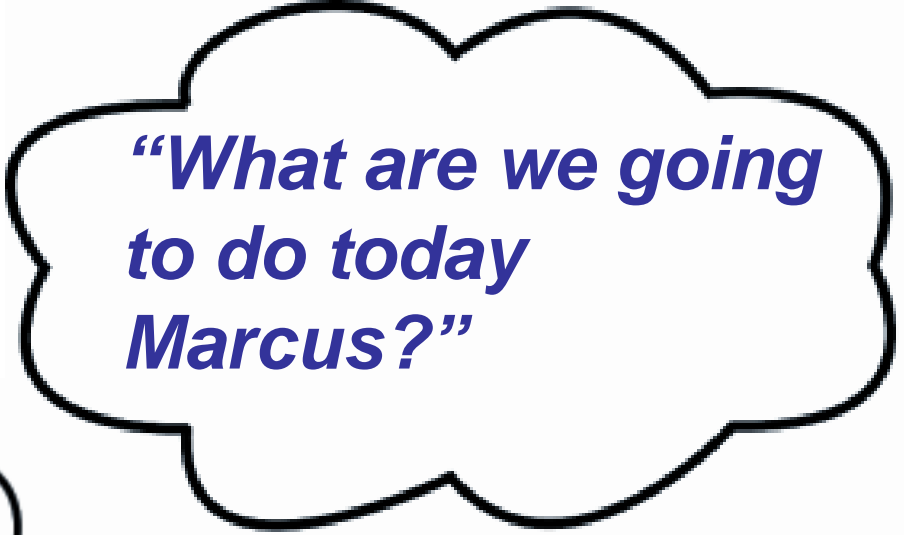
Q. How do you intend to disseminate the results?

# Support the person

- What was relevant to the participants?



*“Can I still have my day out?”*



*“What are we going to do today Marcus?”*

# Support the person

- Communication
- Sharing information
- What is important to them
- Could anyone help with the decision?
- Information in chunks
- Picture information



I am Marcus

# Making it real

An extract from the information sheet:



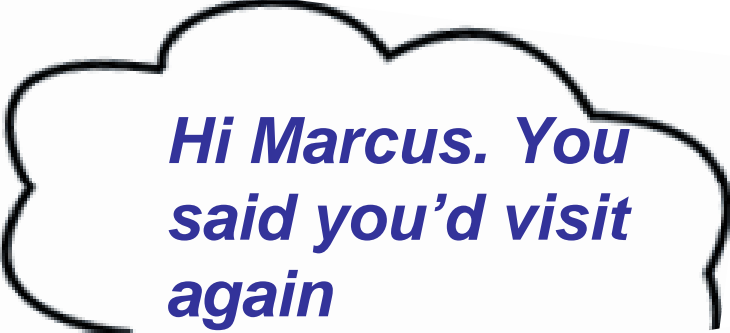
I will use a video camera to record when decisions are being made.

**In practice:**


***“Here’s the camera, would you like to have a go?”***

# Practicalities

- When does the person need to have capacity?
- Ongoing **process consent**



*Hi Marcus. You said you'd visit again*



*That's right, and do you remember what we talked about before?*



*No!*

# Consultees

- Consult if you assess that a person lacks capacity
- They **advise** on consent
- Additional safeguards
  - alert to person's behaviour
- Form of 'assent'



# Discussion

## The Mental Capacity Act:

- Researcher assesses capacity
- A framework to support the decision
- People can still be involved if they can't consent



# Discussion

## Who decides project

- A flexible approach
- Challenging barriers
- Consent – when and how
- Interactional decision making
- Building a relationship (ethics of care)



# For further information

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