Assessing the utility of future research in Psychotropic medication in conjunction with Positive Behaviour Support

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&
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Background to the study:

- Research shows people with intellectual disabilities across the lifespan receive high rates of antipsychotic and other psychotropic medications for challenging behaviour despite the absence of an identifiable mental disorder.

- Research also shows 25% have a record of challenging behaviour vs 21% of mental illness vs 49% receiving psychotropic medication.

- Literature into the clinical effectiveness of this intervention is limited but it is now a research recommendation in the NICE guideline 11.
The Nice guideline asks the question:

Are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?

The rationale behind this question is that the most common reason people with intellectual disabilities require placements or hospitalization is due to the presentation of behaviour that challenges. It is reported in the guidelines that little is known about which people respond best to which interventions (e.g. positive behaviour or medication) or about the duration of the interventions.

NICE recommends that the above question should be addressed by a programme of research evaluating these interventions that includes:

“Assessing the feasibility of the formal evaluation of the interventions in a randomised controlled trial (in particular, recruitment). “ This is essentially our aim in this project.
The Research Team

Core research team:
• Professor Angela Hassiotis (Principal Investigator)
• Kate Kimona (Research Assistant)

Advisory Group:
• Joanna Moncrieff
• Professor Shoumitro Deb

Funding:
This project is awarded NOCLOR Capability Research Funding
What are we currently trying to achieve?

Before planning the future research, we are interested in looking at the opinions of stakeholders about the idea of carrying out work specifically in the area of antipsychotic medication for behaviours that challenge.

Stage 1: Stakeholders opinions
We want to gather strong evidence for the usefulness of this type of research via stakeholder opinions (i.e. parents, carers, people with mild ID who are able to verbally communicate, professionals working in community intellectual disability services, known experts in the field and policy makers)

Stage 2: Estimates of potential eligible participants
We will be asking professionals that work with people with intellectual disabilities to estimate numbers of potential participants who could take part in the study
Who are we interested in for this research?

- A diagnosed intellectual disability and registered with intellectual disability services
- Those who have exhibited challenging behaviour in the last 12 months
- The individual is 18 years and over
- The individual, his family and the professionals looking after them would consider a change in medication or starting medication
- Receiving positive behaviour support or other psychosocial interventions
Recruitment

We will be recruiting family, carers and professionals via different routes.

**Route 1:** We will be contacting local and national support group services (e.g. *Camden advocacy service, the challenging behaviour foundation, People first*) to help us facilitate focus groups and semi-structured interviews in order to gather as much information as possible in relation to the study and also gathering data on ethical implications and recruitment issues.

**Route 2:** We will use our networks of ID community services within London to communicate with consultant psychiatrists and team managers in the first instance about their views on future research and then also with the wider team.

**Route 3:** We will aim to conduct ‘high level’ interviews with policy makers and known experts in the field to also get their opinion and insight into the utility of this work.
What do we need from you?

• We would like to facilitate an informal discussion with your team about your views in carrying out research into the use of psychotropic medication for people with intellectual disabilities who present with behaviours that challenge

• We would appreciate for you to let us know of any factors that we should consider in regards to recruitment and any other ethical issues you foresee

• We hope to use up to an hour of your time to gather as many opinions as possible. This can be held at your place of work for your convenience.

• We will ask for your team manager to help us get an estimate of potential numbers of participants that might be eligible for a future research project
Post analysis of data

- From stakeholders opinions we will be looking to develop a project including a recruitment strategy.

- Dissemination of these key findings will also be at national conferences, peer reviewed publications as well as summaries of the data collected will be sent to all participants who volunteer.
Any Questions?
Expert Group Consultation: Psychiatrists

• For the consultation part of the session, we would like you to be split into smaller groups and share as well as write down your ideas of the following questions.
• This way we can capture as much as your opinions as possible
• Please use the flip chart paper and pens provided
• You will be given a couple of minutes to write down your views per question

• Total time for exercise: 40 minutes (approximately)
Question 1:

What do you think generally about the state of knowledge and evidence regarding the use of psychotropic medication given to people with intellectual disabilities and challenging behaviour?
Question 2:

Do they think we need to know more about these interventions?
Question 3:

What do you think about the NICE guideline research recommendation?

NICE Research recommendation (11):

Are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?

It is reported in the guidelines that little is known about which people respond best to which interventions (e.g. positive behaviour or medication) or about the duration of the interventions.

NICE recommends that the above question should be addressed by a programme of research evaluating these interventions that includes:

“Assessing the feasibility of the formal evaluation of the interventions in a randomised controlled trial (in particular, recruitment). “
Question 4:

What type of question would you want to be answered, if you do not agree with what NICE has proposed?
Question 5:

Would you refer participants in the case that a related research project was developed?
Question 6:

Are there any ethical issues you can think of that may impact this type of research?
Question 7:

Can you think of any potential risks in carrying out this type of research?
Question 8:

Do you have any other views?