# Undertaking a Rapid Realist Review in Managing Aggression in Adults with Learning Disability


NIHR | National Institute for Health Research

No conflicts of interest

My research is funded by the NIHR

The views expressed are those of the presenter and not necessarily those of the NIHR.

# Structure of the session

1) Project overview

2) Introduction to realist methodology

3) Search and screening process

4) Summary of records for inclusion

5) Quality appraisal

6) Analysis – developing & refining theory

7) Questions/discussion

# PETAL – Project Overview

**Research aim**

To develop & test in a randomised controlled trial a personalised treatment package for aggressive challenging behaviour for adults with intellectual disability

**Background**

- Aggressive challenging behaviour is common & persistent over time. It has significant impacts on quality of life for the individual, as well as their family & paid carers.
- It is a complex condition with varying aetiologies
- Hence, we propose to develop a personalised multimodal approach to treatment.

## Setting

Community in England, Scotland and Northern Ireland

# Why we chose to carry out a realist review?


How do you think interventions for aggressive challenging behaviour work?

# Workstream 1: Rapid Realist Review

- Interested in complex interventions
- Interested in complex causal pathways
- Provide evidence for process evaluation gaps that would be useful in intervention implementation

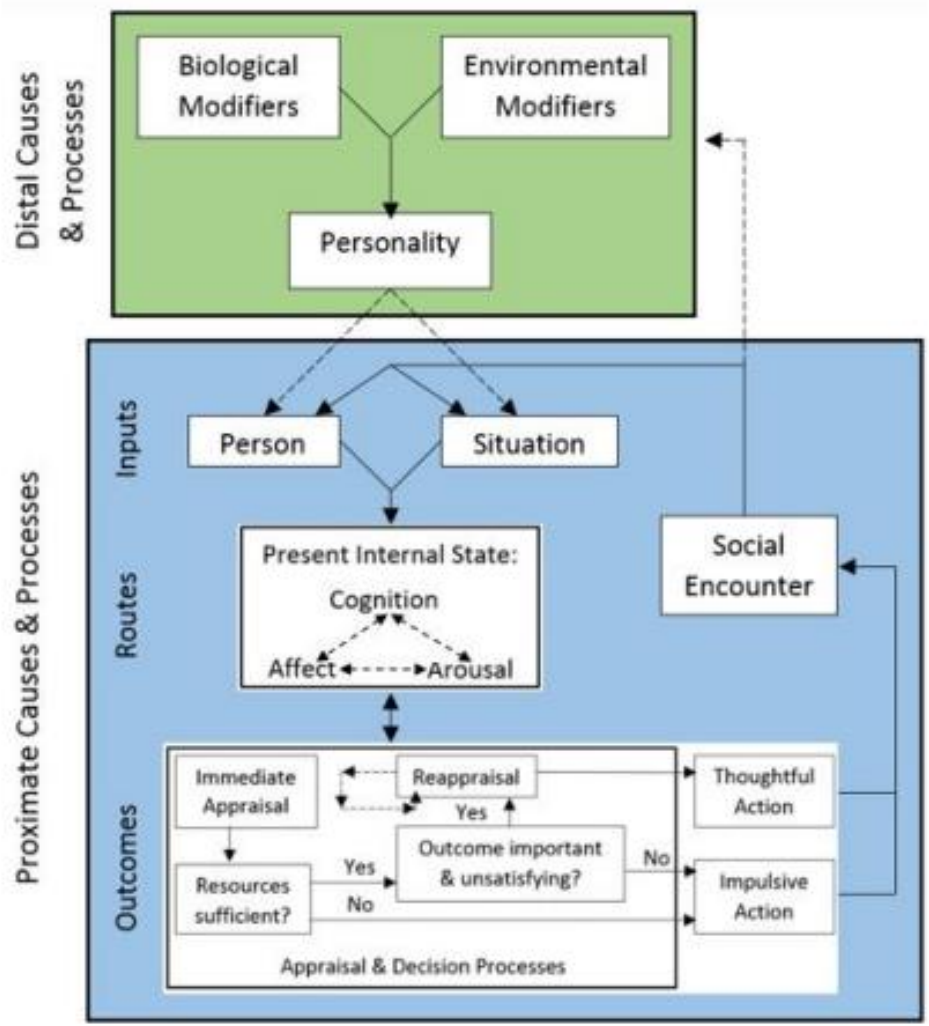



Figure 1 *The General Aggression Model (GAM): Proximate and Distal Causes and Processes*

# How Are They different from Systematic Reviews?

| Systematic reviews | Rapid realist reviews |
|---|---|
| Focused on covering every single relevant study on a particular topic | Can reach a point of data saturation if researchers conclude there is sufficient evidence from included studies to build a programme theory |
| Often recommend excluding low quality studies which may generate noise | Records are not excluded based on quality ratings & grey literature may also be included |
| Tend to take a longer time to complete | Can be conducted in significantly shorter timeframes |

# Heyvert et al (2010) conclusions

- The meta-analysis shows that there is evidence for the effectiveness of pharmacological, psychotherapeutic and contextual interventions, used alone or in combination.
- No indication for the superiority of one of the treatment approaches or combination types.

# Non-pharmacological interventions for challenging behaviours of adults with intellectual disabilities: A metaanalysis (Bruisma et al, 2020)

- Significant moderate overall effect of non-pharmacological interventions on challenging behaviours (d = 0.573, 95% CI [0.352–0.795]),
- This effect appears to be longlasting.
- Interventions combining mindfulness and behavioural techniques showed to be more effective than other interventions

# Training direct care staff working with persons with intellectual disabilities and challenging behaviour: A meta-analytic review study (Knotter et al 2018)

- Aggressive challenging behaviour
- Training effectiveness of direct care staff when they experience challenging incidents in their work
- Change in clients with ID showing challenging behaviour problems

# Knotter et al findings

- Staff behaviour: training goal (skills, knowledge, attitude) and training content (to prevent/manage/cope with the impact of CB) did not moderate the effect of a training program
- Intervention characteristics (training hours, time intervention, attrition, format and training techniques) did not moderate the effect of staff training
- High percentage of male staff workers in the experimental group led to higher effect size of training
- No significant overall effect for staff training programs on the behaviour of clients with ID (d=0.305)

**Q**

- Can staff change client behaviour
- Topologies of aggression
- Training may require both individual and on the job coaching
- Team and organisational characteristics
- Client perspectives

# Theory driven evaluation

- Alternative methodological approach for social sciences
- First emerged in the 80s (Chen and Rossi, 1980, 1983, 1987)

for any intervention, a programme theory can be described that explains how the planners expect the intervention to reach its objective.

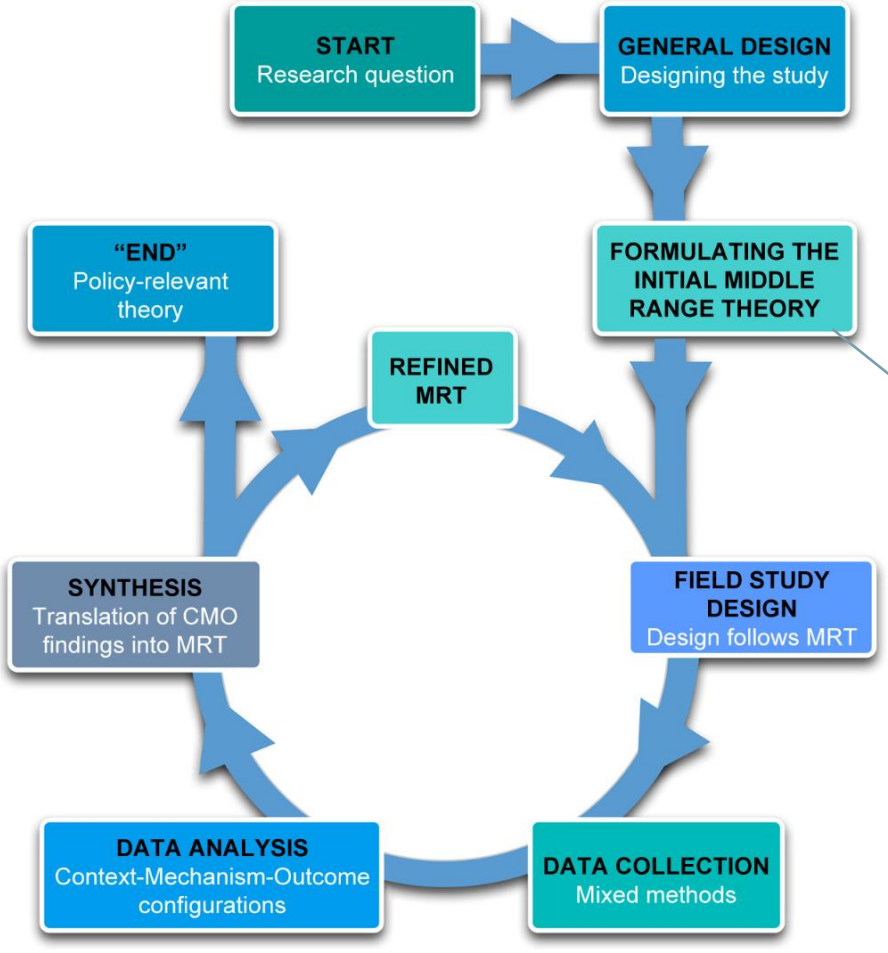
- It has “an eye” on implementation
- Two schools of research approaches

-Theory of change (Connell et al, 1995; Fulbright-Anderson et al, 1998)

-Realist evaluation (Pawson and Tilley, 1997)

# Terminology

| Term | Definition |
|---|---|
| Context | The backdrop of an intervention. |
| Mechanism | That which leads to the outcomes. Mechanisms can be thought of as the reasoning/response of participants to the resources offered by the intervention. |
| Outcome | What ‘happens’ - the consequences of an intervention. |
| CMO Configuration | A means of refining theory. They are based on the theory that mechanisms operate in certain contexts to generate outcomes: C + M = O. |
| Programme Theory | The theory explaining how interventions may work. |
| Middle Range Theory | The account of the processes that explain how an intervention leads to a particular outcome |




Aka: Initial programme Theory

**Figure 1.** The realist evaluation cycle (adapted from Pawson and Tilley, 1997).

**What realist evaluation can do is to help the researcher to find out in which specific conditions the intervention works (or not) and how, and to refine the findings in a process of specification.**

**This in turn leads to an accumulation of insights that help decision makers to assess whether interventions that proved successful in one setting may be so (or not) in another setting and how (Pawson and Tilley, 1997).**

# How to develop theory (RAMESES project)

| Realist assumption | Focus Questions | Realist programme theory |
|---|---|---|
| 1. Programmes intend to cause a change. | What change (outcome) does it intend to create? | Identifies *intended* outcomes. |
| 2. The programme intends someone to do something different, or differently, to cause the change. | *Who* does it intend to do *what* differently? (May be several groups). | Identifies whose decision-making should be examined. |
| 3. Programmes provide resources or opportunities, or change environments, to enable the different choice/ behaviour. | What does it provide to enable that choice or behaviour? | Identifies the 'resource' (in 'reasoning and resources'). Most programmes provide multiple resources each of which can trigger different reasoning. |
| 4. Programme staff and participants make active choices and respond differently to resources. | How might different sub-groups of staff and participants respond to the resource? | Identifies various sets of 'reasoning' (in 'reasoning and resources'). Contributes to identifying 'for whom' programs may / may not work. |

# Stages of a realist review

- Definition of review scope (identify question, purpose, articulate theories)
- Search for and appraise the literature
- Extract and synthesise findings
- Draw conclusions and make recommendations

## You also need by your side

- Local Reference Group (Terms of reference, membership)

PETAL- 7 professionals incl OT, Nursing, commissioning, 3 family carers and 1 representative of people with ID and lived experience of aggressive challenging behaviour

- Expert Advisory Group/Panel (Terms of Reference, membership)

PETAL-5 coapplicants plus CI and RA

## Some issues to be aware of

- MRTs can be too abstract especially where little is known about an intervention or population on which it is implemented
- Programme Theories can be inserted between MRTs and CMOs to create links
- Mechanisms can be considered at individual, group, organisational and societal levels

## What can go wrong

- Not understanding why the need for a RR
- Not buying into the methodology
- Questions can be too broad
- Role of Programme theory
- Multiple methodologies can be resource and skill intensive
- Finding enough data

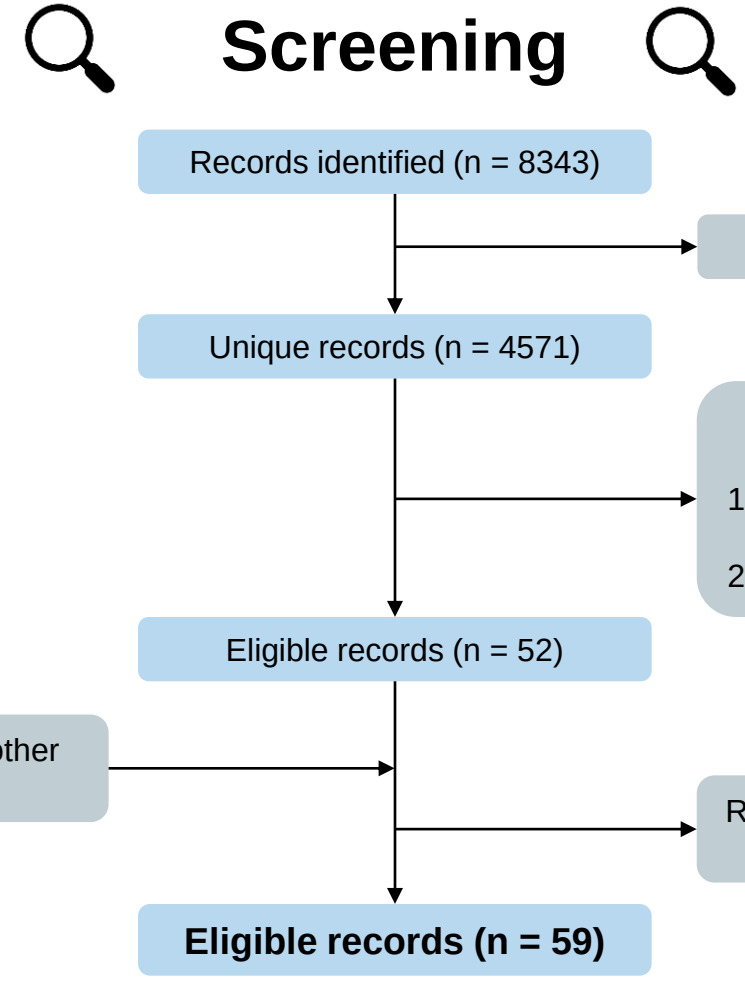
# Search

- We developed search terms & iteratively refined them through discussions with our expert knowledge user groups.

- We searched six databases for records consisting of quantitative and qualitative research, as well as grey literature.

- Due to the multiple comorbidities & age range of individuals with intellectual disability, findings from other population groups (dementia, autism spectrum disorders…) in other settings (inpatient and forensic) were also included.

# Screening


Records identified (n = 8343)
Duplicates removed (n = 3772)
Unique records (n = 4571)
Records excluded from screening (n = 4519):
1. Titles and abstracts (n = 4087)
2. Full text (n = 432)
Eligible records (n = 52)
Identifying records from other sources (n = 12)
Records removed in place of full NIHR reports (n = 5)
Eligible records (n = 59)

# Records for Inclusion – Condition & Age

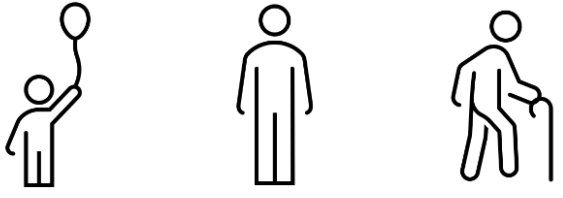
**Condition**

- Intellectual disability / developmental & behavioural disorders or difficulties (n = 38)
- Autism spectrum disorder (n = 2)
- Dementia (n = 8)
- Personality disorder / personality disorder traits (n= 6)

- General mental health unit – mix of conditions (n = 3)
- Inpatient forensic / forensic – mix of conditions (n = 2)

**Age**

- Child/adolescent (n = 7)
- Adolescent + adult (n = 3)
- Adult (n = 41)
- Older adult (n = 6)
- Not specified (n = 2)



# Records for Inclusion – Intervention Categories

- **CBT / CBT-based:**
  - CBT
  - CBT Anger Management
  - Transformers
  - The Research Units in Behavioral Intervention
  - Responsive Aggression Regulation Therapy
  - Reasoning and Rehabilitation

- **Third Wave Psychological Therapies:**
  - DBT

- **Mindfulness / Mindfulness-based:**
  - Soles of the Feet / UMAA-LD
  - Mindfulness training for staff
  - Mindful Parenting
  - Mindfulness-based PBS
  - Ward-based mindfulness programme

- **Positive Behaviour Support**

- **Other Complex Inpatient Interventions:**
  - Triple C
  - Agitation Management Model
  - Safewards

- **Other Complex Community Interventions:**
  - Unnamed phone-based parenting programme
  - Active Support
  - Multisensory room
  - Grip on Neuropsychiatric Symptoms (NPS)
  - Brief Psychosocial Therapy
  - Staff Training in Assisted Living Residences Veterans Affairs (STAR-VA)
  - Dementia Care Mapping (DCM)
  - Improving Wellbeing and Health for People with Dementia (WHELD)
  - Democratic Therapeutic Community Treatment

# Types of studies

- 6 qualitative
- 48 quantitative - 19 randomised control trials, 29 non-randomised quantitative studies
- 5 mixed methods studies

# ★★★ Quality Appraisal ★★★

- Quality ratings will be based on:

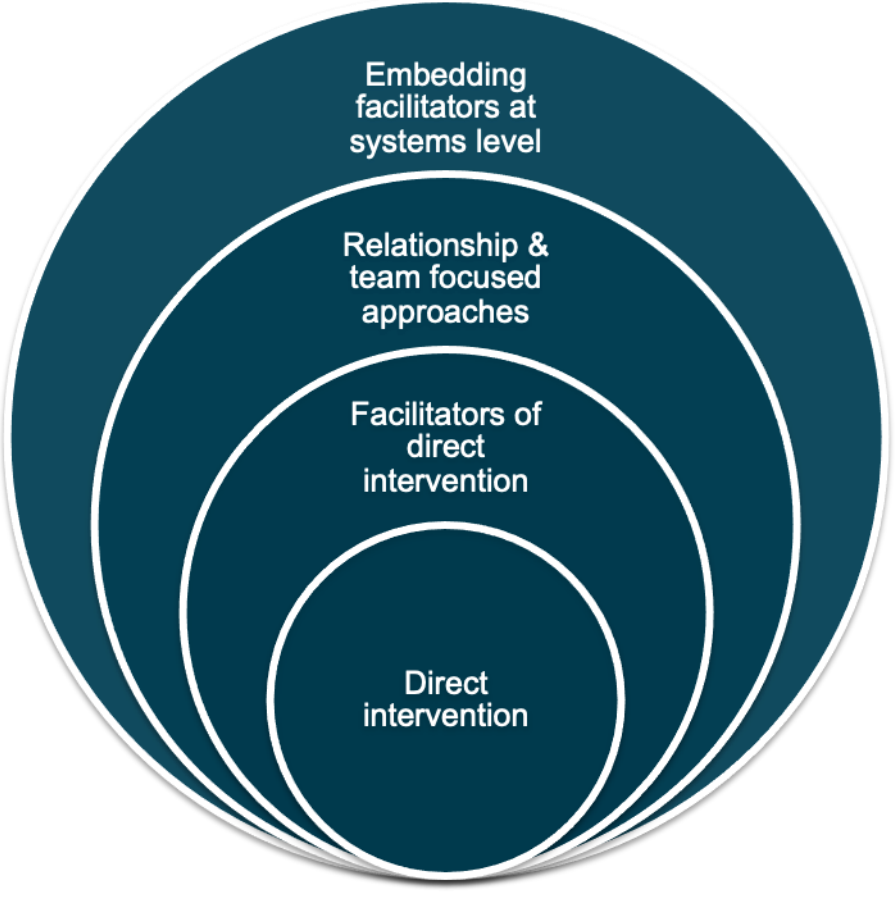
1) **Relevance** – whether data can contribute to theory building.
2) **Rigour** – whether the methods used to generate the relevant data are credible (using tools such as the Risk of Bias 2 [ROB2] tool for RCTs and the Critical Appraisal Skills Programme UK [CASP] tool for qualitative studies).

- Whilst the relevance & rigour of records included for review will serve to inform us of their quality, we will not exclude any based on these ratings, as is the norm in realist research.

# Analysis – Developing & Refining Theories

- **Step 1:** Determine the context, mechanisms & outcomes at play for each record.
- **Step 2:** Formulate initial programme theories to determine what works, for whom & in what circumstances using “if/then statements.”
- **Step 3:** Refine the programme theories through regular discussion with various stakeholder groups consisting of experts & experts by experience (PPI service user & family carer groups).

# Categorisation of Programme Theories



# Categorisation of Theories

**1. Direct intervention**

a) Emotion recognition, regulation & skill development for people with mild-moderate ID

b) Sensory stimulation & meaningful activities for people with mild-severe ID

c) Building family carer skills & efficacy

d) Building paid carer skills & efficacy

**2. Facilitators of direct intervention:**

a) Personalising intervention content, session order, pace/duration & format

b) Support self-efficacy / target individuals regularly practicing skills

c) Feeling valued, listened to & supported in therapy

**3. Relationship & team focused approaches:**

a) Improving communication & relational responses with family caregivers

b) Improving communication & relational responses with paid caregivers

**4. Sustaining / embedding change at team and systems level:**

a) Engagement, mentorship & support for deliverers

b) Deliverers learning & regularly practicing skills at convenient / during protected times

c) Collaborative working – within teams

d) Collaborative working – between carers / professionals & families

# 1. Direct Intervention

**a) Emotion recognition, regulation & skill development for people with mild-moderate ID**

b) Sensory stimulation & meaningful activities for people with mild-severe learning disability

**c) Building family carer skills & efficacy**

d) Building paid carer skills & efficacy

## Example: Emotion Recognition, Regulation & Skill Development

If individuals with conditions including ID (mild-moderate impairments) present with difficulties in emotional regulation, they can be taught:

1. To identify anger provoking situations/triggers.
2. To distinguish between ‘appropriate’ & ‘inappropriate’ expression of anger.
3. To develop new positive & functional skills/behaviours to replace less helpful ones.

This can reduce the display of aggressive behaviour, as individuals learn to better identify emotions, self-regulate & learn to respond to feelings of anger in more adaptive ways using functional skills.

# OR

- In care homes where acquiescing or “not causing trouble” is expected (C), young people or adults with (mild) intellectual disabilities may feel both ashamed (M1) and afraid (M2) expressing anger.
- This can lead the service users to hide their difficulties from themselves and to try to avoid getting help in order to avoid being blamed

## Example: Building Family Carer Skills & Self-efficacy

If families are trained to deliver interventions, it can increase their knowledge of aggressive challenging behaviour and their compassion. It can also increase their skills and self-efficacy:

- e.g. mindfulness skills can reduce their stress, free up time/energy while allowing families to interact more positively and better respond to aggressive challenging behaviour.

Families can also sustain behaviour change through changes in care practices and changes in the home environment, while helping those they support to understand the benefits of the intervention.

This can lead to greater engagement with sustained reductions in aggressive challenging behaviour.

# 2. Facilitators of Direct Intervention

a) **Personalising intervention (content, session order, pace/duration)**

b) Support self-efficacy/target individuals regularly practicing skills

c) Feeling valued, listened to and supported in therapy

# Example: Personalising Intervention Content, Session Order, Pace/Duration

Trained therapists (C) can tailor

Intervention content, Session order, Pace/duration, Delivery format

This can help achieve a better fit between therapist and patient as they address individuals' particular experiences, wishes, complex needs and abilities. This can then lead to greater engagement and treatment satisfaction (M), which can then reduce the display of aggressive challenging behaviour (O).

# 3. Relationships and Team Focused Approaches

a) Improving communication and relationships with family caregivers

b) Improving communication and relationships with paid caregivers

## **Example:** Improving communication and relationships with family caregivers

If family members (C) are taught to:

1. Take care of themselves by using mindful techniques (M1)
2. Better understand the specific triggers for the aggressive behaviour (M2)
3. Respond to incidents of aggression with greater empathy and acceptance (M3)

it can lead to decrease in aggressive challenging behaviour and reduce the family carer's own stress levels (O).

## Example: Improving communication and relationships with paid caregivers

If paid caregivers are trained in the delivery of a personalized intervention (C) they can be taught:

1) To better understand the reasons for aggressive challenging behaviour (M1)
2) To use de-escalation when necessary (M2)
3) To reduce conflict through more adaptive behaviours (M3)

This can help to build trusting relationships with service users as staff are able to create a culture of compassion where vulnerability is accepted (O1). The staff learn to better anticipate expressions of aggression, and respond appropriately leading to a more open conversation about how to manage anger (O2)

# 4. Sustaining/Embedding Change at Systems Level

a) Engagement, mentorship & support for deliverers

**b) Learning and making time to practice new skills**

c) Collaborative working – within teams

**d) Collaborative working – between carers / professionals and families**

## Example: Learning and making time to practice new skills

If paid caregivers are facilitating intervention delivery (C), time should be allocated for them to learn and to practice new skills at convenient times.

This can lead to a culture of staff feeling supported by their managers (M1) and to feel that they are being valued (M2). This can lead to increased confidence and competence in applying and generalising new skills (M2), ensuring changes in behaviour are sustained (O).

# Example: Collaborative Working - Between Professionals & Families

If professionals are to collaborate effectively with families (C)

1. They need to reflect on how to foster common values and treatment goals (M1)
2. They must consider that love underpins a family's motivation for wanting good support as well as potential frustration when support services do not meet expectations (rather than prejudging families, which limits collaboration) (M2).

This can help families to feel listened to and valued, while allowing them to build trust in the professionals. This can facilitate positive collaborative relationships, helping interventions to achieve their stated outcomes (O).


TIME FOR A
BREAK

# Next Steps

- We are continuing to refine these theories by engaging in ongoing discussions with our expert knowledge user groups.

- We have tested the theories in 5 case studies of a professional and family/paid carer dyad.

- The findings of this review will inform the content thr PETAL treatment package for adults who display aggressive challenging behaviour.

# Some insights from the case studies

- 4 healthcare professionals (psychologists) with inpatient forensic and community clinical experience
- 1 service manager
- 1 family carer

Because an environment that is calming, that has greenery, that has colours on the walls, where there's not paint flaking off, where the echo is reduced, it's not over stimulating all the time.

So that anybody around that person, any staff member or adult who had a relationship with that young person, knew about the treatment they were doing, knew about the progress that they we were making, knew about the skills that they were practising, and was encouraged to actually support them with that

He felt frightened. He felt shamed by some of the work that we were doing, and he had this, sort of, explosion and problematic behaviour.

And if they're not supported by the wider service, that makes it even harder to do systemic interventions because then you just get resentful staff and are less able to reflect on what they're bringing in to something if themselves are under threat or feeling threatened.

# Discussion


How do you think interventions for aggressive challenging behaviour work?

# Questions

# Thank you

a.hassiotis@ucl.ac.uk
@PETALProgramme
@likahassiotis
@EPICC_ID

# Thank you!

Email: a.hassiotis@ucl.ac.uk
Twitter: @PETALProgramme

UCL Division of Psychiatry

uclan

University of Glasgow

NHS Camden and Islington NHS Foundation Trust

Priment Clinical Trials Unit

The Mental Elf

Ulster University

Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities

CDA Camden Disability Action

Institute of Psychiatry, Psychology & Neuroscience