

The role of carers of institutionalised people with learning disabilities, autism and long-term mental health co-morbidities in reducing restrictive practices

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LEARN SWAP

Background

- 1.5 million individuals with a learning disability in the UK
- 40% of adults with learning disabilities or autism also experience mental health problems- more than double the rate compared to the general population
- In England a patient with learning disabilities is restrained, on average, every 15 mins

What is LEARN SWAP?

- SWAP (Study Within A Project)
- Compliment LEARN realist review funded by the NIHR, entitled: approaches used to prevent and reduce the use of restrictive practices on adults with learning disabilities
- Used as the foundation of a much larger research funding bid
- Co-investigators: Joy Duxbury (PI), Alina Haines-Delmont, Beth Morrison, Alexis Quinn, Rohan Morris

LEARN SWAP Overview

Aims

- To better understand communication needs and the behaviour labelled as ‘challenging’;
- To identify acceptable ways to meet these needs/respond and prevent distress;
- To identify appropriate ways to improve communication between staff and patients;
- To explore ways in which carers could play a significant part in the decision making regarding the care pathway and treatment of their loved ones.

Objectives

- To partner with PABSS, Pennine Care NHS Trust and The Restraint Reduction Network to conduct focus groups to explore the carers role in preventing restrictive practices on people with LD, Autism and mental health comorbidities
- Findings will be analysed twice:
 - (1) thematically
 - (2) Interpretative phenomenological analysis (IPA)



Focus Groups

Focus Group Details

- Group 1&2 | Beth Morrison from PABSS Scotland | Online (N=6 & N=8)
- Group 3&4 | Alexis Quinn from the RRN | Online (N=3 & N= 5)
- Group 5&6 | Rohan Morris from Pennine Care NHS Trust | In person at Pennine Care site (TBC)

Exclusion & Inclusion Criteria

- Must be a carer of a person with learning disabilities/autism and long-term mental health co-morbidities
- Loved one has been an inpatient in a mental health setting
- Carer must be over 18
- Carer is not an inpatient staff member

Topic Guide

1. Can you give any examples of the type of behaviour your loved one might use to try and communicate a need, that has been misinterpreted as 'challenging behaviour'?
How did the service/staff respond?
2. Were you debriefed after that event so the service/staff could try and learn from it? [Prompt] If so, how, and what happened? Did the service/staff change their response? [Prompt] If not, what is it you would want the service/staff to know about your loved one through that incident?
3. Can you give any examples of how can carers help services/staff understand their loved one's communication needs/style better?
4. Have you ever been included in the decision-making process about service/staff responses to your loved ones? [Prompt] If so, how? [Prompt] If not, how would you want to be?
5. How can carers involvement lead to reduction/prevention of restrictive practices used on their loved ones?

Findings

'Challenging behaviour'

- E.g., self-injurious behaviour- cutting, head banging, refusing medication
- Misinterpreted by staff as attention seeking -> adds distress as need not met
- Sometimes this 'behaviour' is learnt (as not happening at the home)
- Perceive risk as constant
- Systemic problem

- The whole approach/culture is wrong, e.g., labelling people with 'challenging behaviour'
- The terminology, the tools used, the response to unmet need (via the use of restrictive practices)
- It is a reflection of the fact that 'people that's done to are not seen as equal to them/us
- Staff in MH settings – ignorant about autism
- There is no 2-way communication, no respect for carers
- Through the trauma experienced by the individual, the families get traumatised too

With Beth, one of the things that was really misinterpreted was her stimming...when she gets incredibly anxious, she will rock. ..this was seen and interpreted as her being full of rage. The staff response at that time was instead of trying to work out what was wrong...to go in and strip the room out because they were frightened that she was going to kick off.

[Participant #1, Focus Group #1]

Findings

Debrief

- It almost never happens – only told when people ‘do not behave/when there is a difficult day’,
- It feels like ‘ticking a box’
- ‘Challenging parents’ are completely excluded
- Family members are made to feel guilty
- It is never the staff’s fault
- Debrief only make sense in the context of an organised, therapeutic care plan which is in place and followed
- ‘best interest meeting’ on request but takes time to organise
- Has led to some changes e.g. bringing down medication dose

There was never any kind of constructive debrief. It was all very much you’re made to feel he’s challenging, he’s trouble, he’s hurt people and none of it is the staff’s fault.

[Participant #5, Focus Group #1]

Findings

How to improve understanding of communication needs

- Need to really listen, pay attention, make note of patterns, believe what people are saying
- The involvement of families is tokenistic if not non-existent;
- The environment/care can only be therapeutic if there is true partnership
- Staff come and go but carers are there for the long term
- Staff training on its own does not work
- Using strategies to help people feel safe, to trust again
- Using communication passports

Findings

How can families/carers help reduce RP?

- Staff can be trained in 'autism' for example, but they do not really know the individual
- Families can support staff understand the person better to alleviate distress, for example (i) have a meaningful contribution in the MDT meetings; (ii) spend time on the ward, to show staff how they can deal with situations and de-escalate; (iii) be involved in developing a care plan that works for their person, as blanket restrictions enforced on everybody in the same way all the time will not work, will only make things worse.
- Certain medications aggravate physical conditions
- Carers need to feel like their children won't be punished if they try to speak up
- They would be able to offer more information if they weren't blamed/shamed



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