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Extended Research Article

Approaches used to prevent and reduce the use of restrictive practices on adults with learning disabilities: a realist review

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Scientific summary

Approaches used to prevent and reduce the use of restrictive practices on adults with learning disabilities: a realist review

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Scientific summary

Background

The human and societal burden linked to the use of restrictive practices (RP), for example, restraint, seclusion and long-term segregation on people with a learning disability (LD), autism and mental health comorbidities is an issue which can no longer be silenced and needs urgent attention.

While there is a major drive in mental health settings to consider these practices a treatment failure, the same is not true of settings more broadly where those with LDs are being cared for. Furthermore, while some evidence supports the use of various approaches to reduce RP, there is a knowledge gap in how and why such approaches might work in varied environments.

In this report, the term 'people with learning disabilities' is used to refer to people in healthcare settings, that is NHS and independent sector, who have a primary diagnosis of a LD and may also have a diagnosis of autism and/or mental health problems.

Objectives

- To conduct a realist review to understand what works, for whom, under what circumstances to prevent and reduce the use of RP on adults with a LD, autism and mental health comorbidities in NHS and independent sector settings; and
- To coproduce pragmatic recommendations with people with lived experience and their carers, policy-makers, practitioners and experts in the field to improve evidence and inform policy and practice.

Methods

Design

The study followed a realist approach to evidence synthesis, including four main steps: (1) locating existing theories, (2) searching for evidence and selecting papers, (3) extracting and organising data and (4) synthesising the evidence and drawing conclusions, including coproducing recommendations. The views of stakeholders (academics, practitioners, people with lived experiences, carers) were captured to supplement systematic searches of the literature, develop theories, support the interpretation of results and co-develop recommendations. The review adhered to current Realist And MEta-narrative Evidence Syntheses: Evolving Standards (RAMESES) quality and publication standards (Wong G, Westhorp G, Pawson R, Greenhalgh T. Realist synthesis. RAMESES training materials. *BMC Med* 2013:61–14).

Data sources

1. Secondary data from existing literature (scoping review, evidence synthesis including 53 articles and supplementary searches).
2. Feedback from 13 consultation workshops with 105 stakeholders, for example, academics, practitioners, people with lived experience and their carers/advocates, policy-makers (13 workshops with 105 stakeholders).
3. Primary data from 4 focus groups with 22 carers/family members of people with lived experience.

Literature searches

Scoping searches of the literature were conducted to identify approaches used to prevent and reduce the use of RP and possible explanatory relevant theories. This was done by performing free-text searches on Google Scholar supplemented by forwards and backwards citation tracking from relevant papers and systematic reviews.

The main literature searches were then conducted using six databases: Applied Social Sciences Index and Abstracts (ProQuest), Cumulative Index to Nursing and Allied Health Literature (EBSCO), MEDLINE (Ovid), PsycInfo (Ovid), EMBASE (Ovid) and Web of Science Core Collection (Emerging Sources Citation Index). The search covered evidence from 1 January 2001 up to 21 July 2021 and yielded 16,775 hits, which were then reduced to 14,383, after using EndNote X9's (2013) inbuilt duplication detection function and manual de-duplication. Results were imported to Covidence.

Inclusion and exclusion criteria

For the main search for this review, all study designs and types were included, all healthcare settings providing care for people with a LD and all types of RP and approaches focusing on preventing or reducing their use, with the exception of pharmacological approaches (e.g. medication). In terms of age and diagnosis, only studies reporting on adults (> 18 years old) with a diagnosis of a LD who may also have a diagnosis of autism and/or mental health problems were included.

Screening and article selection

After 14,383 titles/abstracts were independently screened by 6 reviewers, 174 articles remained. Full-text screening was independently conducted by five reviewers. Two reviewers screened each paper at both stages; discrepancies were resolved via online discussions. Fifty-three full-text articles were included in the final synthesis.

The order in which articles was selected for analysis and synthesis was based on relevance and rigour. Relevance pertains to whether a study can contribute to programme theory building and/or testing, and rigour is whether the methods used to generate the relevant data are considered credible and trustworthy (Wong G, Westhorp G, Pawson R, Greenhalgh T. Realist synthesis. RAMESES training materials. *BMC Med* 2013:6).

Supplementary/citations, lead authors, unpublished materials, scholar searches, theories, early examples, and related projects searches

A supplementary, theory-driven search was also conducted between April and June 2022 using the 13-step citations, lead authors, unpublished materials, scholar searches, theories, early examples, and related projects (CLUSTER) technique to maximise identification of relevant literature and theories [Booth A, Harris J, Croot E, Springett J, Campbell F, Wilkins E. Towards a methodology for cluster searching to provide conceptual and contextual 'richness' for systematic reviews of complex interventions: case study (CLUSTER). *BMC Med Res Methodol* 2013;**13**:118; Tsang A, Maden M. CLUSTER searching approach to inform evidence syntheses: a methodological review. *Res Synth Methods* 2021;**12**:576–89]. This resulted in an additional 443 articles that were screened, resulting in 64 articles which were then examined in detail to identify theories that might underpin the findings of the review. Inclusion and exclusion criteria were broad, for example, not limited by age, publication date, diagnosis. These were determined based on findings from the main searches and focused on identifying substantive theories to support the programme theories.

Data extraction and analysis

The extraction and organising of data from each paper were undertaken by two reviewers and any disagreements were resolved by discussion. Full texts of eligible papers were uploaded into NVivo 2020 (QSR International Pty Ltd, Warrington, UK; URL: www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home). Sections from articles were extracted based on relevance with regards to the initial programme theories (IPTs) or information not previously captured but potentially important to consider for the overall programme theory. Inductive, deductive and retroductive thinking was used to code data with regards to contexts, mechanisms and/or their association with outcomes.

With regards to analysis, a realist logic of analysis following three stages was used: (1) juxtaposition of data sources; (2) reconciling contradictory data; and (3) consolidation of sources of evidence. The first stage involved comparing and contrasting between data presented in different studies. The second stage involved examining results that differ in seemingly similar circumstances, seeking explanations for the different outcomes with a particular focus on contexts. The third stage involved making judgements as to whether findings presented in different sources were adequate to form patterns in developing context–mechanism–outcome configurations (CMOCs) and programme theory. These processes helped in making sense of the CMOCs and overarching programme theory, reducing numbers where possible, and highlighting areas for further exploration. Finally, the overarching programme theory was used to develop

recommendations for improving practice aimed at preventing and reducing RP for people with a LD and comorbid autism or mental health problems.

Consultation with stakeholders

Stakeholder consultation (13 workshops with 105 people) was a key component of this review, in order to (1) discuss and agree on key concepts, definitions, terminology and scope of the review, (2) inform the development and refinement of IPTs, (3) validate CMOCs and programme theories (partial and overarching) and (4) co-develop key recommendations to inform policy and practice change.

Focus groups with carers/family members

Having highlighted the importance of the carers' role in the early stage of this review, a further small-scale study was funded within this project (SWAP), resulting in 4 focus groups with 22 carers to explore how carers perceived their loved one's behaviour (also called 'challenging'); how staff should respond to this behaviour without using RP; and how carers could make more decisions about their loved one's care.

Results

Key findings

This realist review incorporated both primary and secondary data, moving beyond peer-reviewed literature, to unpick why/how approaches used to prevent or reduce RP for people with a diagnosis of a LD who may also have a diagnosis of autism and/or mental health problems might work. Eight CMOCs were formulated and framed within three theory areas/stakeholder groups:

1. people with lived experiences/'the person' and their carers
2. staff
3. the organisation.

Substantive theories were also explored to understand why certain factors are important in reducing the use of RP, for example, self-determination theory and the patient-centred care model (relates to 'the person'); the cognitive appraisal model; the Six Core Strategies, the positive and proactive care model, the high and intensive care model and self-leadership (related to 'the organisation'). This then led to the evolution of the overarching programme theory that explains the whys and hows of preventing and reducing the use of RP for this group of people.

This overarching programme theory indicates that while there are interventions that might work in mental health settings ('what works?'), the 'who?' – people with LDs – is a vital consideration for this to work. Interventions are not always appropriately targeted or tailored for this population; staff are not adequately trained and supported; people lack a voice and the autonomy to enable them to contribute to their care planning and improve their well-being and quality of life (with the help of their loved ones/families, where needed); and organisations fail to recognise these shortfalls. While the circumstances/settings ('in what context?') in which these failures occur are implicit, they are equally important in recognising where the change needs to start – in recognising that RP happen in the context of people with LD who are still currently detained in settings/environments that are unsuitable for their needs, especially mental health hospitals. And they happen in the context of a lack of positive organisational culture, where these practices are used and accepted as the 'norm'.

Findings of this review indicate that there are eight CMOCs which reflect tailored interventions needed to address challenges in the following areas:

- individualised care planning (including autonomy and competency for people with LD/autism)
- communication and person-centred approaches
- stress reduction
- workforce development/training
- reflection and reconnection (including debriefing)
- care delivery reorganisation

- appropriate staffing levels and mix; and
- invested organisations.

Recommendations

Nine key recommendations/suggestions for improvement were co-created as part of this review, grouped by the three theory areas/stakeholder groups identified.

People with lived experience

Individualised care planning

- Care plans, that is positive behaviour support plans should include appropriate interventions according to the person's needs and personal stressors.

Autonomy for people with LD

- Autonomy and competency of people with lived experience should be acknowledged and ensured that they are genuine partners of their care teams.
- Person-centred positive risk-taking should be considered for people with LD, where appropriate, to support their autonomy.

Communication and person-centred approaches

- Different means and support for communication for people with LD should be ensured.
- Family members/carers should be actively encouraged and enabled to provide their expertise to professionals to facilitate person-centred care and communication.

Staff

Stress-reduction efforts to mitigate burnout

- Investing in positive workplace cultures and a stable workforce are crucial to ensure the staff feel supported.
- Interventions should be implemented to target stress reduction among staff to mitigate burnout; these could be both preventive (e.g. mindfulness training) and provided as care for staff who already have developed burnout symptoms.

Workforce development

- Training for staff should focus more on continuing education on topics such as human rights, person-centred and trauma-informed approaches rather than short courses on physical interventions (see The Restraint Reduction Network Training Standards: https://restraintreductionnetwork.org/know-the-standard/).
- There should be face-to-face training, whenever possible, to allow staff to interact and learn in a social environment. eLearning in isolation in care settings might be challenging due to environmental constraints, high work pressure and inadequate staffing resources. A blended approach is needed.
- Staff should be supported and encouraged to pursue further education to enhance their communication skills in situations that can challenge.

Reflection and reconnection

- Debriefing in isolation may have a negative connotation due to blame culture and focus on treatment failures. A more positive approach focusing on learning lessons through reflection and post-incident reviews should be implemented involving people with lived experience and family members/carers in the process.
- Organisations should ensure that there is training for post-incident reviews including debriefing and post-incident support.

Organisations

Care delivery reorganisation

- Currently, not all organisations recognise their overuse of restrictive interventions. Organisations should therefore define what RP are as a starting point for reorganising delivery of care, and then record these to enable data-informed practice and change.
- Organisations should implement good, practical models for coproduction to be able to involve people with lived experience, carers and staff to review their services and implement changes.
- Organisations should consider using implementation and improvement models to support sustainable outcomes of evidence-based interventions.
- Organisational evidence-based strategies to minimise the use of RP such as the Six Core Strategies and Safewards should be more widely integrated and adopted across a range of care settings.

Appropriate staffing levels and a balanced staff mix

- Good human resources require workplaces to be attractive and rewarding to healthcare staff.
- Organisations need to invest in staff, recognise their value and provide environments where they feel supported.
- A balanced staff mix is needed, and values-based principles should be key to recruitment.

Strong, committed and compassionate leadership

- Leaders need to be fully informed and drive the implementation of key standards such as the Restraint Reduction Network (RRN) training standards and employ a strategy for roll-out.
- Managers with specialised education in leadership and management to drive and oversee everyday practice in LD settings should be a priority.

Conclusion

This review highlights that settings providing care for people with a LD are complex care environments, and thus reducing the use of RP is likely to require complex interventions, involving different stakeholders and approaches as our programme theory suggests. Organisations, staff and person-centred level changes need long-term investment. These findings point to a number of implications for how best to support practitioners and organisations to reduce RP with and for those who are the most vulnerable in society.

While significant work is still needed for systemic transformation, we cannot lose sight of those stuck in the harmful and distressing cycle of inadequate and inappropriate care in services failing to meet their needs. Some are subjected to RP every 15 minutes with no care plans to reintegrate them back into the community.

> *'People feel stuck in the system […] The focus must be on meeting people's individual needs. We need to move onto ensuring services fit around people rather than trying to fit people into services that can't meet their needs.' (How CQC Identifies and Responds to Closed Cultures. 2022. URL: How CQC identifies and responds to closed cultures – Care Quality Commission).*

Future work

This review findings echo 'The National Learning Disability and Autism Programme' (NIHR. *23/77 National Learning Disability and Autism Programme Demand Signalling*. 2023.) research agenda requiring more evidence on how different approaches shown to be effective in NHS and independent sector settings could work in LD settings, and if necessary, how they might be tailored to coproduction to be successful and sustainable. A significant gap is that carers' needs and

perspectives are rarely addressed, thus more research in this area is warranted. At the heart of all future work must be a clear interface between the individuals and their family, the workforce and the organisational infrastructure and approach.

Study registration

This study is registered as PROSPERO CRD42019158432.

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