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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

Joy Duxbury[1*] Alina Haines-Delmont[2] John Baker[3] Peter Baker[4] Gary Bourlet[5] Elaine Craig[2] James Ridley[6] Rachel Whyte[7] Beth Morrison[8] Michaela Thomson[9] Anthony Tsang[10] and Tella Lantta[11]

[1]Institute of Health, University of Cumbria, Lancaster, UK
[2]School of Nursing and Public Health, Manchester Metropolitan University, Manchester, UK
[3]School of Healthcare, University of Leeds, Leeds, UK
[4]Social Policy, Sociology and Social Research, University of Kent, Kent, UK
[5]Learning Disability England, Birmingham, UK
[6]Greater Manchester Mental Health Trust, Manchester, UK
[7]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
[8]Positive and Active Behaviour Support Scotland, Scotland, UK
[9]Mersey Care NHS Foundation Trust, Prescot, UK
[10]School of Biomedical Engineering & Imaging Sciences, King's College London, London, UK
[11]Department of Nursing Science, University of Turku, Turku, Finland

[*]Corresponding author Joy.Duxbury@cumbria.ac.uk

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This article

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Abstract

Background: There is some evidence to support approaches to reduce restrictive practices in settings for people with a learning disability who may also have a diagnosis of autism or mental health problems. However, there is a significant knowledge gap in how and why such approaches work and in what contexts.

Aim: This study aimed to understand how, why, for whom, and under what circumstances approaches used by healthcare staff to prevent and reduce the use of restrictive practices on adults with learning disability or autism work (or do not work).

Design: The review followed a realist approach. This approach was chosen to understand the mechanisms by which approaches to prevent and reduce the use of restrictive practices work. The review adhered to current Realist and Meta Narrative Evidence Syntheses: Evolving Standards quality and publication standards.

Data sources: 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 and stakeholder consultations.

Review methods: Four main steps were followed: (1) locating existing theories, (2) searching for evidence, (3) extracting and organising data and (4) synthesising the evidence and drawing conclusions. In Steps 1 and 4, the views of stakeholders (academics, key experts, practitioners, people with lived experiences, carers) supplemented systematic searches in electronic databases, supporting the interpretation of results and making recommendations.

Results: A total of 53 articles were included, after screening 14,383 articles. In line with realist methods, eight context–mechanism–outcome configurations and an overarching programme theory were used to explain the why and how of preventing and reducing the use of restrictive practices for people with a learning disability. Restrictive practices commonly occur when people with a learning disability, who display behaviour that can harm or who experience communication difficulties, are detained in environments that are unsuitable for their needs, including mental health hospitals. Furthermore, they happen when staff are inadequately trained, lack person-centred values, struggle to regulate their emotions and display limited communication skills. Restrictive practices happen where there is a lack of adequate staffing, a negative organisational culture, and where they are accepted as the 'norm'. Drawing on these findings, we set out recommendations to include positive risk-taking, greater involvement for families and carers, and targeted training for staff. Organisations need to recognise overuse of restrictive practices and using coproduction and leadership within the organisation to implement change.

Limitations: Many of the papers reviewed were not directly related to people with learning disability, therefore there is a clear need for greater research in this area. Primary research from focus groups has been used to highlight issues and compliment the limited evidence base. While it is recognised that commissioning individualised community approaches is a possible way to reduce the use of restrictive practices, this was beyond the scope of this review.

Conclusions: This review shows that solutions for reducing restrictive practices exist, but that targeted frameworks are lacking and resources to support the implementation of evidence-based strategies in this population and related settings are compromised. More research is needed on how approaches shown to be effective in other settings such as mental health could be tailored for people with learning disability. Furthermore, more research regarding carers' roles is warranted.

Study registration: This study is registered as PROSPERO CRD42019158432.

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Glossary

Abductive reasoning Taking an observation or set of observations and making logical assumptions to explain them. Could be considered a form of 'reading between the lines'.

Advocate A person who puts a case on someone else's behalf.

Context The pre-existing settings, structures, environments, circumstances or conditions that activate behavioural and/or emotional responses (i.e. mechanisms) for those involved.

Context–mechanism–outcome configurations A main structure that is underpinned by the relationship between context, mechanism and outcome by using realist analysis (i.e. how a mechanism is activated by specific context to cause a particular outcome).

Deduction Creating ideas on how behaviour/events might work and testing these ideas in the real world to see if they are true. Could be considered a top–down approach to reasoning.

Emotional cognitive overload model The negative cognitive and emotional manifestations arising from the failure to sufficiently process pertinent input and handle the accompanying mental load.

Generative causation The idea that forces which cause something to happen are activated in particular contexts and may not always be observable.

High and intensive care model An integration of the medical model and the recovery model. This model focuses on contact and crisis prevention and continuity of care between outpatient treatment and acute admission wards.

Induction Making sense of things by observing behaviour or events. Could be considered a bottom–up approach to reasoning.

Initial rough programme theory In a realist review, these are ideas created at the beginning of a research project that attempt to explain how and why the programme(s) of interest is thought to work by describing the context, mechanism and outcomes at play.

Mechanism How individuals or a group respond to, reason about, the resources, opportunities or challenges offered by a particular programme, intervention, approach or process. Mechanisms are hidden, underlying processes that are activated by specific contexts and lead to changes in behaviour.

Middle range theory Theories about the context(s) and mechanism(s) that bring about particular programme outcome(s). Middle range theory is more general than programme theory which means they can be used to guide the implementation of a similar programme in a different setting.

Outcome The changes or behaviours resulting from the interaction between contexts and mechanisms.

Patient-centred care model Treating patients as individuals and as equal partners ensuring that patient values guide all clinical decisions.

Positive and proactive care model Keeps people well and focuses on prevention rather than a cure.

Positive behaviour support plans A documented plan created to help understand behaviour and support behaviour change in individuals with learning disabilities.

Programme theory Theoretical explanations or assumptions about how a particular programme, process, approach or intervention is expected to work that is illustrated as an abstracted description and/or diagram.

Refined programme theory In a realist review, these are the ideas that have been produced after the initial rough programme theories have been tested against the literature and in consultation with stakeholders.

Restrictive practices Deliberate acts on the part of other person(s) that restrict an individual's movement, liberty and/or freedom to act independently. This includes all types of restraint, seclusion and segregation.

Retroductive analysis An analytical process that requires identification of hidden generative causation processes that lie beneath identified patterns or changes in those patterns.

Retroductive thinking A way of making sense of things by identifying hidden causal forces to explain why observable patterns in behaviour/events come about. Unlike abduction, deduction and induction that explain things by using observations, retroduction seeks to find explanations by examining things that are unseen (e.g. love, fear, empathy).

Self-determination theory A motivation theory that humans have three basic psychological needs including, autonomy, competence and relatedness. These underlie growth and development.

Self-leadership concepts The practice of understanding who you are, recognising your desired experiences, and deliberately leading yourself towards them.

Six Core Strategies 1. Leadership towards organisational change 2. Full inclusion of lived experience 3. Using data to inform practice 4. Workforce development 5. Use of seclusion and restraint reduction tools 6. Debriefing techniques.

STOMP Stopping over medication of people with a learning disability, autism or both.

Substantive theory Theories that have been well-established in a particular field that help to explain certain behaviours or outcomes.

SYMPA-ID German-language acronym for 'family systems therapy methods in acute psychiatry, adapted for persons with intellectual disabilities'.

The cognitive appraisal model The subjective interpretation made by individuals to an eliciting event in the environment and their bodily reactions to the event.

Theory-led A realist review is described as theory-led because it will look at programme outcomes to develop theories to explain the patterns, then consult the literature and stakeholders to test the theories. They will also use formal, well-established theories (like self-determination theory) to inform their theory development.

List of abbreviations

BPS	behaviour support plan
CLUSTER	citations, lead authors, unpublished materials, scholar searches, theories, early examples, and related projects
CINAHL	The Cumulative Index to Nursing and Allied Health Literature
DD	developmental disabilities
FTR	fixed-time release
HIC	high and intensive care
HRA	Health Research Authority
ID	intellectual disabilities
IPT	initial programme theory
LD	learning disability
LDE	Learning Disability England
MBPBS	mindfulness/mindfulness-based positive behaviour support
OBM	organisational behaviour management
PABSS	Positive and Active Behaviour Support Scotland
RP	restrictive practices
SDT	self-determination theory
QoL	quality of life

Plain language summary

Restrictive practices such as restraint, seclusion and long-term segregation are sometimes used by healthcare professionals on people who have a learning disability and may also have autism and mental health problems. This is a human rights issue which needs urgent attention. More evidence is needed to show the best ways to support people with a learning disability, and/or additional needs especially when their communication needs are complex which can activate a behaviour that is perceived as challenging.

In this study, we used a 'realist review' which looks at what works for whom best and why (Pawson R. *Evidence-Based Policy: A Realist Perspective*. London: Sage; 2006). We collected information in three different ways: 53 published papers; 13 workshops with researchers and experts including healthcare professionals, people with lived experience, their carers, advocates and policy-makers; and 4 focus groups with 22 carers and family members of people with lived experience.

We found that restrictive practices often happen when people with a learning disability, who display behaviour that can harm or experience communication difficulties, are often detained in environments that are unsuitable for their needs. Staff are commonly poorly trained and supported, and those who are cared for feel that they are not heard, listened to or involved in care planning and discussions about personal preferences.

Ways to improve this included person-centred care planning, with the individual at the centre communicating and using words which people can understand, keeping stress low for everyone, safe staffing levels and organisations which support the changes needed.

Our recommendations include positive risk-taking, greater involvement for families and carers, face-to-face training for staff and staff feeling safe to challenge when needed. Organisations need to recognise overuse of restrictive practices by clearly stating what they are and using coproduction and leadership within the organisation to implement change.

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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Chapter 1 Background

There are approximately 1.5 million individuals with a learning disability (LD) in the UK[1] and up to 60–70% of this population is autistic.[2] Individuals with a primary diagnosis of a LD are more likely to have a wide-ranging number of physical and mental comorbidities that include schizophrenia, epilepsy, depressive disorders, hearing loss and visual impairment.[3] Adults with increased severity of a LD and the presence of communication difficulties have been found to be consistently associated with a higher risk of displaying behaviour that challenges.[4–6] Empirical evidence indicates that the presence of behaviour that challenges is the most prominent characteristic that is linked with incidents of restrictive practices (RP) such as restraint, rapid tranquilisation, seclusion and segregation in these healthcare settings.[7–9]

Despite global consensus to prevent and reduce the use of these controversial practices, these are still commonly used in inpatient and community settings for people with LDs.[10–12] Latest UK statistics indicate that restrictive interventions, such as physical restraint, overmedication and solitary confinement, are still frequently used against the 2060 people with a LD and/or autism who are hospitalised.[13] Barbara Keeley MP,[14] Labour's previous Shadow Minister for Social Care and Mental Health, said while commenting on the CQC Review of Restraint and Seclusion,[15]

> *… the care system has completely failed autistic people and people with learning disabilities who are detained in these unsuitable institutions. The consequences of the use of restrictive practices can result in significant trauma for patients, physical injuries and burnout for staff, frustration and reduced quality of life for carers.*[11,16–18]

The most common approaches used to prevent or reduce the use of RP in LD settings are centred around positive behaviour support (PBS)[19–23] underpinned by a person-centred, trauma-informed approach. These may also cover the implementation of behaviour support plans (BPSs);[24,25] staff training in mindfulness/mindfulness-based positive behaviour support (MBPBS);[26–28] programmes[29] including elements of PBS, Safewards[30] and the Six Core Strategies[31] or organisational behaviour management (OBM) approaches to reducing the use of RP in these settings.[32]

Gaskin *et al.*'s[10] systematic review of 14 single-subject design studies evaluating interventions targeting the reduction of use of RP such as physical and mechanical restraint on people with developmental disabilities (DD) identified a mean reduction in frequency of restraint of over 70% between the baseline and intervention phases. Three types of restraint reduction approaches were reported: (1) those targeting the reduction of restraint with people displaying agitation or aggressive behaviour (e.g. medication to enable night-time sleeping or other medication changes; antecedent assessment and modifying antecedent conditions and behaviour-specific criteria for restraint; involving patients in behavioural support plans); (2) those targeting the reduction of restraint with people who self-harmed (e.g. offering choice to patients regarding staff to work with; fixed-time release (FTR) from restraint; behavioural assessment and treatment; training involving relaxation, increasing time out of restraint, using hands for other activities); (3) those taking an organisation-wide restraint reduction stance (e.g. training on reducing aggression; behavioural training for staff; mindfulness training; OBM including the use of behavioural plans, data-informed practice and contingencies for mechanical restraint). The results were promising for both instances where restraint was used to manage aggression and self-harm, suggesting that it is achievable to reduce the use of RP, even if it is not always clear which intervention influences which outcome and why (given the design limitations and the complexity of these settings). The most successful approaches were the organisation-wide initiatives. Gaskin argues that a key limitation is the lack of evidence with regards to large-scale, multicomponent organisation-wide approaches to reduce RP in these settings, which is more common in the mental health literature.[33–35]

The positive results from Gaskin's review are in line with those reported in Luiselli's review[36] of single-case and small group studies evaluating the implementation of antecedent intervention procedures and FTR contingencies to reduce the use of physical restraint for people with intellectual disabilities in community settings. The first approach implies the assessment and change of circumstances surrounding/associated with restraint, while the second limits the duration of restraint by using a FTR approach.[36] More recently, Sturmey's[37] systematic review concludes that the most effective approach to date in group restraint reduction is mindfulness, although more research is needed to strengthen the evidence, as well as to identify the mechanisms of change (p. 387).

The disparity between existing guidelines and policies to reduce the use of RP on people with LDs and clinical practice points to the need to develop targeted and effective approaches to minimise the use of these practices as well as gather and disseminate the evidence in such a way to enable change in practice. Although existing evidence supports the use of various approaches to reduce RP in settings providing care for people with LDs and autism, there is a knowledge gap of how and why such approaches work and in what contexts. Using a realist review methodology helps us unpick some of the underlying processes/mechanisms that generate the desired outcomes. Additionally, integrating the views of people with lived experience and carers helped us identify new mechanisms and enrich and improve our understanding of existing evidence. This is something that is currently lacking both in primary and secondary research in this area.

While the review covered scoping and main searches of the literature covering relevant theories and approaches used to understand and reduce the use of RP pertaining to a wide range mental health settings (not specifically for people with a LD), the studies included in the formal review reported on findings specific to adults with a primary diagnosis of a LD who may also have a diagnosis of autism or mental health problems/behaviour perceived as 'challenging'. In this report, we used the terminology 'people with learning disabilities' to refer to people in a wide range of mental health settings who have a primary diagnosis of a LD and who may also have a diagnosis of autism or mental health problems.

Chapter 2 Review aim and objectives

The aim of this realist review is to understand how, why, for whom, and under what circumstances approaches used by staff in NHS and independent sector organisations to prevent and reduce the use of RP on adults with a diagnosis of a LD who may also have a diagnosis of autism or mental health problems work (or do not work). This will help inform policy and practice in this area. The review was structured around the following objectives and review questions.

Objectives

1. To conduct a realist review to understand how approaches used in NHS and independent sector organisations work to prevent and reduce the use of RP on adults with a primary diagnosis of LDs.
2. To provide recommendations on the implementation and design of approaches to improve practices aimed at preventing and reducing RP in LD settings.

Review questions

1. What are the causative mechanisms by which approaches that are designed to prevent and reduce RP believed to result in their intended outcomes for adults with LDs?
2. Under what circumstances are these approaches likely to be effective?

Chapter 3 Review methods

A realist approach to evidence synthesis was followed to understand the mechanisms in which approaches to prevent and reduce the use of RP may work. The realist review is an interpretative, theory-driven approach that permits the synthesis of an array of evidence types including qualitative, quantitative and mixed-methods research.[38] Realist methodology recognises how and why context influence outcomes. It is understood that particular contexts activate mechanisms that generate certain outcomes, by providing a narrative based on the evidence of what is most likely to work, how and when.[39]

A realist approach was chosen as one of the main strengths is its capacity to recognise and manage the complexity and heterogeneity of approaches used to prevent and minimise the use of RP in this instance. Instead of focusing on what approaches are used or their effectiveness, a realist review interrogates how these approaches, or their components, produce intended outcomes. A RPT is then developed and supported by substantive theory and expressed at the middle range level. This means the theory is sufficiently broad to allow for transferability of findings to inform the design and implementation of approaches used across different settings.[40,41]

The process of generative causation is iterative and starts with the development and refinement of a realist programme theory of multifaceted approaches or interventions to prevent or minimise the use of RP in adults with LDs. To achieve this, a scoping search of the literature and consultation with stakeholder groups helped us identify the key approaches that are reportedly used. The scope was purposively broad to permit exploration of key approaches. Overlapping components were homogenised and grouped into conceptual labels that facilitated initial data coding. For each conceptual label, a realist logic of analysis was applied to provide an explanatory account of how the interaction between contexts and mechanisms might lead to outcomes. For each conceptual label, mechanism(s) generating certain outcome(s) were identified and in what contexts these mechanisms may be activated.[38,42]

In this review, contexts are defined as pre-existing structures that modify and/or activate the behaviour of mechanisms.[43] Mechanisms are underlying processes or structures that are sensitive to the variation in context; they generate outcomes and are usually hidden.[44]

The plan of inquiry adhered to a detailed protocol based on Pawson's iterative steps of realist reviews: Step 1, locating existing theories; Step 2, searching for evidence; Step 3, extracting and organising data; and Step 4, synthesising the evidence and drawing conclusions (*Figure 1*). The protocol has been published in *PLOS ONE*[46] and the review was registered with PROSPERO (CRD42019158432). We were granted ethical approval by the Health and Education Research Ethics and Governance Committee at Manchester Metropolitan University (Ethics approval number 22510) prior to commencing any consultation and data collection. The focus groups with family members/carers of people with lived experience of LDs/autism and RP were covered by additional ethical approval granted by the Health Research Authority (HRA), including the Yorkshire and The Humber – South Yorkshire Research Ethics Committee (REC reference 22/YH/0247, IRAS project ID 318154).

Step 1: locating existing theories

Exploratory searches

Identification of approaches

In the first step of the review, we carried out exploratory searches to identify initial literature in this area of work. The purpose of this initial search was threefold: (1) to identify a preliminary overview of the approaches that are used to

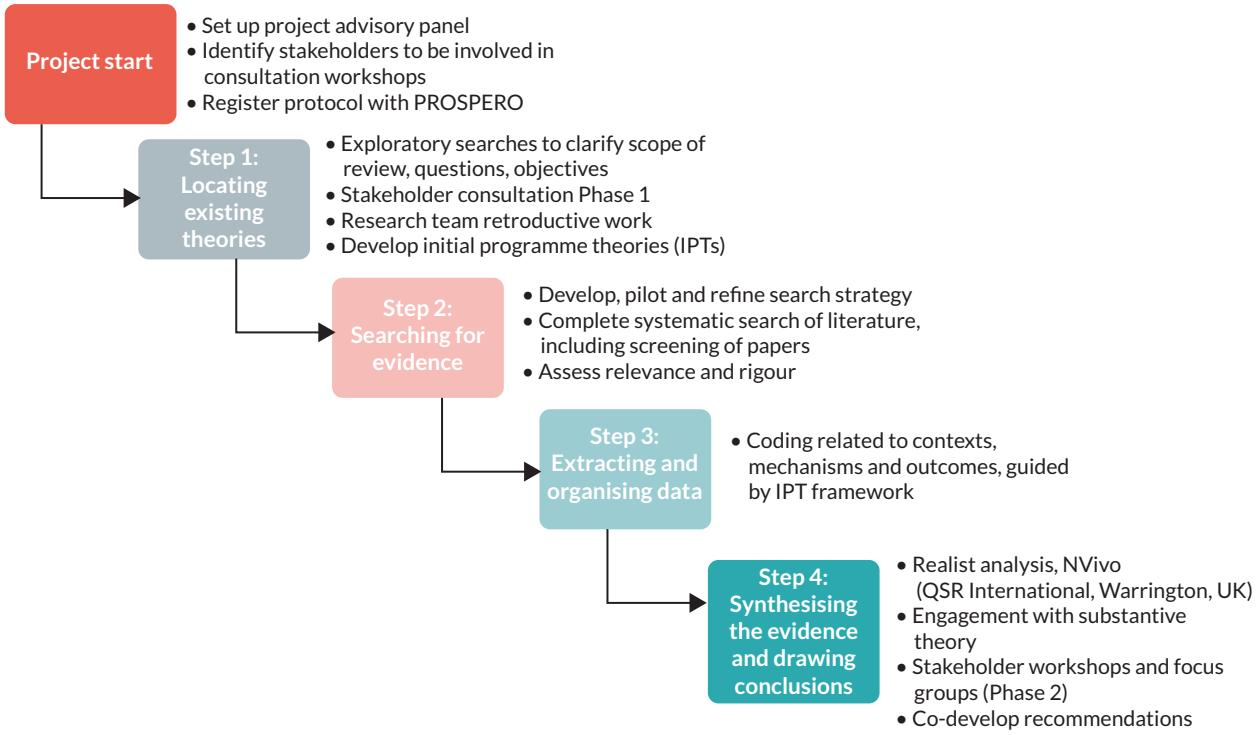

FIGURE 1 Summary of the project approach. *Note*: Some material is reproduced from an open-access article previously published by the research team.[45] This article is published under license to Health Service Delivery Research and is an open-access article distributed in accordance with the Creative Commons Attribution NonCommercial (CC BY-NC 4.0) license, which permits the author and any non-commercial bodies to reuse the material in any non-commercial way they choose under the terms of the licence, without acquiring permission from Health Service Delivery Research (see http://creativecommons.org/licenses/by-nc/4.0/).

prevent and reduce RP, (2) to identify explanations about how approaches designed to prevent and reduce RP use work more generally (i.e. not specific to a LD population) and (3) attempt to identify theories that underpin why certain components are required within existing approaches to achieve desired outcomes. Within such theories, there may be explanations and reasonings with which how an approach was developed (e.g. who designed it and how?) as these may affect outcomes.

The exploratory, scoping searches conducted in Step 1 differ from main search for evidence described in Step 2, in that it aimed to sample the literature to quickly identify the range of approaches and possible explanatory theories that may be relevant. The methods used included elicitation of seminal articles (e.g. Six Core Strategies, Safewards and PBS) from expert recommendations by MC, JD and AH-D and backwards citation searching on seminal articles. Additionally, free-text searches on Google Scholar were performed using keywords that included 'complex intervention', 'reduction', 'restrictive practices' and synonymous terms. This was supplemented with forwards and backwards citation tracking on from relevant systematic reviews identified.

This exploratory search led to the identification of 10 multifaceted approaches designed to prevent and reduce the use of RP in mental health and LD settings. When scrutinising the multifaceted approaches, a member of the team identified overlapping components across the approaches and homogenised them into conceptual labels. This facilitated the sorting/management and categorisation of data. Moreover, it allowed us to see how much data we had for each conceptual label. Judgements were made about what a section of text means and were deductively coded against the conceptual labels. For example, data pertaining to staff training were coded under the *staff training* conceptual label. Once iterative coding of the data was completed, a realist logic of analysis was applied to the data for each conceptual label to develop preliminary CMOCs. To move from multiple granular CMOCs across the conceptual labels, the research team conducted three separate workshops to consolidate CMOCs into three board themes. We reflected on which outcomes related directly to one another, and which are separate. Once we had satisfactorily grouped all the contexts and outcomes, we worked towards considering the 'how' of the theory. The research team grouped, themed and reflected on different potential mechanisms. This led to the development of a number of initial programme theories

(IPTs) that incorporated early assumptions about some of the important or potential contexts that interact with mechanisms to produce particular outcomes. These were further explored in the future phases of the review, including the systematic literature supplementary searches and the stakeholder consultations.

Identification of substantive theories

Additionally, relevant substantive theories were sought based on the articles already retrieved. Substantive theory is an existing and established theory that describes patterns of behaviours at a greater level of abstraction. It can substantiate the inferences made about contexts, mechanisms and outcomes and the configurations between these elements. Provision of an analogy is another function of substantive theory, where causal explanations provided by CMOCs are situated with what is already known from existing literature. Performance improvement pertaining to training and development of healthcare professionals and normalisation of approaches to reduce RP were cited or alluded to in some of the retrieved papers. These theories became an important foundation that informed the conceptualisation of the programme theory development.

Stakeholder workshops (Phase 1: October 2020–July 2021)

A diverse stakeholder group was recruited for the review to use their expert knowledge to inform the development and refinement of the IPTs and, later on, validation of emerging programme theories and CMOCs. In particular, stakeholders discussed and agreed on definitions, terminology and scope of the review; identified potentially relevant factors for Outcomes (O), Mechanisms (M) and Contexts (C); and (later on) validated/sense-checked emerging IPTs and CMOCs. They have also contributed to identifying key recommendations to inform policy and practice change.

Sixty-eight stakeholders have been consulted between October 2020 and July 2021 via nine theory development workshops. These included:

- two workshops with fellow academics and key experts (12 October and 10 November 2020) (*n* = 8)
- two workshops with practitioners such as clinical psychologists, clinical nurse specialists and nurse practitioners, representatives/leads from community and inpatient LD services, primary healthcare facilitators, social work and safeguarding representatives/leads (12 November 2020 and 27 January 2021) (*n* = 17)
- two workshops with self-advocates/people with lived experience in the community organised by Learning Disability England (LDE) (6 July 2021 and 15 July 2021) (*n* = 8)
- two workshops with men and women inpatients in secure LD settings, all with a primary diagnosis of LD with other comorbid diagnoses including autism (June–July 2021) (*n* = 7)
- one workshop with carers of people with LD (24 June 2021) (*n* = 28).

The first couple of workshops (October–November 2020) were predominately comprised of academics or topic experts to discuss a range of views and opinions on the topic. The practitioners and LD staff workshops added diversity that allowed us to address pragmatic aspects of the IPT. The majority of workshop meetings took place online via Zoom (Zoom Video Communications, San Jose, CA, USA) and started with a brief introduction by the review team to introduce stakeholders to the topic under discussion. The discussions were designed to be more open ended; however, as workshops progressed, they focused on particular aspects of the rough initial theory. For example, the fourth workshop had a particular focus on prevention, de-escalation and reflection, whereas the third workshop explored general day-to-day activities of practice that target the prevention/reduction of use of RP.

Five workshops were also conducted with carers and those with LDs. An advocate of LDs, who is the co-founder of LDE; a carer who is a founder of Positive and Active Behaviour Support Scotland (PABSS); and a research practitioner working within inpatient LD services in Mersey Care NHS Foundation Trust led on consultation with three experts by experience groups during the review. Views were sought to:

- identify silenced issues and understand the role of the carer and the service users in the care pathway and the potential reduction in the use of RP
- shape the terminology and language that is used throughout the review, to ensure that information is appropriate and accessible for a lay audience
- sense-check emerging programme theories, with particular focus on mechanisms of change; and

- inform the search strategy for the systematic search of the literature (Step 2).

The additional and valuable information collected via these nine workshops brought a new dimension to the evidence, where approaches to prevent and reduce the use of RP with people with LD should consider:

- behaviour as an expression of need (not a problem and/or a challenging behaviour)
- 'connection before correction' or coercion/use of RP
- coercion/RP use as a treatment failure (not a treatment option)
- a complex approach including the person, their needs and history; therapeutic environment; health professionals' communication and language; physical environment; carers' involvement.

Also, the carers' workshops highlighted two pivotal elements missing in research: (1) the complexity of communication for those with comorbid disabilities that can underpin positive and negative interactions which then dictate the reduction or increase of RP; and (2) the role of carers within the overarching infrastructure of their loved one's welfare system/care pathway. RP use is often regulated by a breakdown in communication.

It is argued that behaviour that challenges is a trigger being activated, a cry for help or an unmet need, compounded by an inability to translate that cry due to LD communicative limitations. RP are then used in reaction. Carers may be the key to facilitating understanding of this and reducing the need for RP.

The review team participated in all the workshop meetings, except workshops with people with LDs/autism, which were moderated by people from LDE and a local NHS trust (both moderators, co-applicants on the LEARN project). The majority of workshops were recorded (apart from the four initial workshops with people with LDs/autism). All participants were informed of the nature of the research, the purpose of the workshops and that they would be recorded via notetaking (where permissible).

Initial programme theories

The initial literature searches, stakeholder consultation, and retroductive thinking among the research team (with input from stakeholders and experts) resulted in the development of a number of IPTs. These included assumptions about how approaches might work (or not) in preventing or reducing the use of RP for people with a LD and what mechanisms may interact with important contexts to produce certain outcomes. These assumptions were organised around three theory areas, that is stakeholder groups/actors involved:

1. people with lived experience of RP (persons with LDs and family members);
2. staff/practitioners on the ground (nurses, healthcare workers, etc.); and
3. organisation/strategy/leaders.

Retroductive thinking or 'retroduction' means 'going back from, below, or behind observed patterns to discover what produces them'.[47] The key role of retroduction at this stage was to unearth causal mechanisms, that is underpinning the causal forces reflecting how people respond (mechanism response) to resources (mechanism resource). These initial assumptions were then used to inform the review searches, especially the supplementary searches, as well as the 'fed-back' and 'fed-forward' from the stakeholder workshops and team meetings to develop the programme theory/theories.

Following on from Step 1 and the development of IPTs, in Step 2 described below, we conducted a systematic main search for the literature, and supplementary searches for identification of substantive theory.

Step 2: searching for evidence

Search strategy

The aim of Step 2 was to identify a body of relevant literature to further develop and refine the IPTs developed in Step 1. The search strategy was designed, piloted and conducted by an information specialist systematic reviewer (AT) with experience of conducting searches for complex systematic reviews. The initial search strategy was guided by consultation with the project management group and the advisory group.

The search strategy was piloted and finalised in MEDLINE (Ovid) using an iterative process of adding, removing and refining search terms in order to achieve a set of results with an appropriate level of sensitivity and specificity (i.e. the search was configured to retrieve a wide range of relevant evidence and to minimise the retrieval of irrelevant evidence).

The initial comprehensive search focused on evidence published from 2001 to May 2021 to align with the publication of a key policy document – 'Valuing People A New Strategy for Learning Disability for the 21st Century' – a White Paper setting out the UK Government's commitment to change practice with the view to improve the life chances of people with LDs.[48]

Main search

A systematic search was conducted on six databases from 1 January 2001 up to 21 July 2021 that included Applied Social Sciences Index and Abstracts (ProQuest), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (EBSCO), MEDLINE (Ovid), PsycInfo (Ovid), EMBASE (Ovid) and Web of Science Core Collection (Emerging Sources Citation Index) (see *Appendix 1*). The search yielded 14,383 results after using EndNote X9's inbuilt duplication detection function and manual de-duplication. These results were then imported into Covidence. For the systematic search, our inclusion and exclusion criteria were broad as we sought to find all study types, ranging from quantitative studies to discussion papers.

Inclusion criteria

- All study designs including commentaries, opinion pieces and editorials.
- Adults (> 18 years old) with a diagnosis of a LD who may also have a diagnosis of autism or mental health problems.
- All healthcare settings (including NHS and independent settings).
- All approaches or interventions that focus on preventing or reducing the use of RP (e.g. all forms of restraint, seclusion, observation and segregation).

Exclusion criteria

- Pharmacological approaches (e.g. medication) to reduce the use of RP.
- Did not address the prevention or reduction of RP.
- Did not contain a LD population.
- Outcome data for adults did not disaggregate from non-adults (i.e. < 17 years old).

After titles/abstracts (n = 14,383) were independently screened by six reviewers (AT, EC, JD, RW, AHD, MT), 174 articles remained. Full-text versions of these articles were retrieved and were independently assessed by five reviewers (AT, JD, EC, JR, AHD). Discrepancies at both stages were resolved via online discussions. Fifty-three full-text articles were included in the final synthesis (see *Appendix 2*, *Figure 8*).

The order in which articles was selected for analysis and synthesis was based on relevance and rigour.[49] 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. Relevance was categorised into low and high relevance. Articles of high relevance were selected for analysis and synthesis first. Articles were considered of lower relevance when their findings were not specific enough for the target group of this review (i.e. adults with a diagnosis of a LD). Specifically, articles were of lower relevance when: (1) adults with a LD were not the primary population or < 50% of the population had a LD diagnosis, (2) insufficient explanation of results pertaining to the prevention or reduction of RP, (3) approach(es) used in articles lacked transparency to allow for replication and (4) articles examined factors or characteristics which are not associated with the prevention or reduction of RP.

Supplementary search

A supplementary, theory-driven search was also performed using the full CLUSTER technique (13 steps) to maximise the identification of relevant literature and theories.[50,51] An additional 443 articles were identified for screening. Inclusion and exclusion criteria for these articles were determined based on findings from the main searches. It was

decided that the screening would focus on identifying substantive theories to support IPTs. Inclusion and exclusion criteria were as follows highlighting a number of key broad approaches of interest:

Inclusion criteria

- All study types.
- All settings.
- All age groups.
- No limits regarding publication date.
- All populations NOT required to focus on people with LD.
- *Those related to people with LD/families/carers*: we were interested in additional information regarding *self-determination theory (SDT)* OR any other theory that could provide explanations for *individualised care plans* (e.g. PBS plans)/*involving persons with LD/families/carers* more in their care planning, *better communication, or providing debriefing* to persons with LD/carers after being subjected to coercion.
- *Those related to staff (all professional groups)*: we were interested in the *emotional cognitive overload model (ECOM), the cognitive appraisal model* OR any other theory that could provide explanations for *stress reduction, staff training or emotional support* (debriefing/support/peer support).
- *Those related to organisation/leadership*: this aspect was found to have less support from theories. So the priority was to find explanations and evidence. The most common examples were the *Six Core Strategies, positive and proactive care model, high and intensive care (HIC) model and self-leadership concepts*. At this point, there were also contexts/mechanism we were interested in such as *leadership, the use of data, organisational investment, evidence-based frameworks* (e.g. *Safewards), staff mix, legislative guidance, and care environment, for example.*
- In addition, we were interested in theories identified in the phase of formulating IPTs but not found/identified directly in the papers reviewed. These included a number of clearly key areas such as the *concept of recovery,*[52] *duty theory and consequentialism*[53] *active support and intensive interaction,*[54] *Normalization Process Theory (NPT),*[55] *Performance Improvement (PI) Theory, Integrated Theory of Health Behaviour Change, Operant Theory, Social Learning Theory, Executive Dysfunction Theory, Yerkes–Dodson Law, and the Arousal Theory of Motivation. These were commonly seen in the literature.*

Exclusion criteria

- No additional information on pre-specified topics/theories.

The CLUSTER searches were completed by one reviewer (AT) and screening was done by five reviewers (TL, JD, AHD, RW, EC). In total, 64 articles were analysed to identify substantive theories.

Step 3: extracting and organising data

The extraction and organising of data were undertaken by two reviewers (AT and TL). Any disagreements were resolved by discussion; however, none occurred.

Full texts of eligible evidence were uploaded into NVivo version 2020 (QSR International Pty Ltd, Warrington, UK; URL: www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home). NVivo is a qualitative data management tool that facilitates data organisation.

All sections (*Introduction*, *Methods*, *Results* and *Discussion*) of the articles have been read and extracted based on what was deemed relevant. Relevancy was twofold: (1) any data from articles that relates or can be related to the IPTs and (2) what is not captured in the IPTs, but may become important to build/expand on the IPTs. Coding of the extracted data was related to contexts, mechanisms and/or their association with outcomes. This approach was inductive, deductive and retroductive. As refinement of the IPTs progressed, we revisited the included articles to search for relevant data that may have been initially missed including new articles that were included from the CLUSTER searches.

An overview of included studies is provided outlining extracted key study characteristics including study design, key findings, and type of approach used to prevent or reduce RP in an Excel spreadsheet.

Step 4: synthesising the evidence and drawing conclusions

A realist logic of analysis was applied that focuses on how the evidence supports, refutes or provides alternative explanations for approaches in preventing or reducing the use of RP.

The process of evidence synthesis was aimed to be achieved using the following three-stage analytic processes:[56] (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 whether similarities between findings presented in different sources are adequate to form patterns in the developing CMOCs and programme theory. These processes facilitate in making sense of the CMOCs and overarching programme theory, reducing the number of CMOCs by consolidation, and highlighting nuances that may act as an avenue for further exploration, if necessary.

The analysis and synthesis stage of the review was an iterative process, and the intent was to understand which mechanisms were activated in different contexts as described in the studies included in the review. Further iterative searching for data can be required at this stage to test particular subcomponents of the programme theory, where evidence may be lacking. In our review, we have conducted iterative searches to locate substantive theories.

Finally, the refined theory was used to develop recommendations for improving practice aimed at preventing and reducing RP for people with LDs in inpatient settings. This happened in our final workshop with stakeholders and topic experts (8 February 2023).

Engagement with substantive theory

Substantive theory for the purpose of realist research operates at a number of different levels to validate inferences made about mechanisms, contexts, outcomes and the configurations between them. It is also useful in adjudicating findings with what is already known on the topic under investigation, to enhance the plausibility and coherence of the arguments made. The first step we took in understanding what theoretical frameworks and ideas would be relevant to the review was to look at existing work on minimising restrictive interventions. Our starting point was the literature collected as part of the exploratory search. This enabled us to consider a wide range of theoretical understandings that could be of potential relevance. A CLUSTER searching approach was used to compile a list of potentially useful and relevant theories in addition to wider team meetings and discussions. In the first instance, theories were largely derived specifically from LD settings, but some theories were later sought to help situate findings in and for a wider context pertaining to RP.

We then compiled a list of theories that could further inform this work and as we retrieved literature more specific to our review questions, we sought links between a number of identified theoretical frameworks and emerging CMOCs. This was done with a view to extend the explanatory potential and usefulness of the overall programme theory developed out of the CMOCs. Some of the theoretical ideas that informed the development of the programme theory were derived from papers retrieved from the literature search, while other theoretical frameworks were sought specifically to cover particular aspects of the phenomena we were attempting to explain.

We therefore used substantive theory to help substantiate and develop inferences made about CMOCs and to enhance plausibility and provide coherence of the arguments made about CMOCs and the data that underpin them.

From CLUSTER searches, 64 articles were identified providing information about potential substantive theories. Related specifically to persons with LDs or family members, this was then isolated to 23 theories. Related to staff, we identified 14 theories, while related to organisation, 12 theories. Some theories could be applied to both persons with LDs and staff, for example the self-efficacy theory. These types of theories were classified based on how they were used in

the articles included. Through team discussions we settled *n* a set number of specific key theories that were more commonly applied to RP identified in the report.

Stakeholder workshops and focus groups (Phase 2: January–February 2023)

Four additional workshops, one final project meeting and two consultation sessions were also held to discuss and validate the RPTs and to produce recommendations for practice and policy change. In particular:

1. one project meeting (workshop) including the research team, co-applicants, people with lived experience of LDs/autism and policy-makers from the Department of Health and Social Care (8 February 2023) (*n* = 14);
2. four focus groups with carers/family members of autistic people or people with a LD with experience of RP (10 January/12 January/24 January/16 February 2023) (*n* = 22); and
3. two online consultation sessions with a realist review expert.

Project meeting

The project meeting/workshop focused on discussing practice and policy recommendations based on the review results and refined CMOCs. The participants of the meeting were divided into three groups; one for each stakeholder group, that is (1) persons with LD, family members/carers; (2) staff; and (3) organisation and leadership. Simplified CMOCs were presented to the groups and key recommendations that are presented as part of this report's discussion section were formulated.

Focus groups

The four focus groups with carers/family members consisted of mainly mothers of people with a LD and/or autism and a comorbid mental health problem (*n* = 19). Other participants included two fathers and one sister. The focus groups with carers were classed as primary data collection and were governed by separate/additional ethical approvals, to allow for the use of direct (anonymised) quotations from the data. Ethical approval was obtained from the HRA, including the Yorkshire and The Humber – South Yorkshire Research Ethics Committee (REC reference 22/YH/0247, IRAS project ID 318154). All participation was subject to informed consent.

The focus groups explored how carers perceived their loved one's behaviour (also called 'challenging'), how staff should respond to this behaviour, more appropriate ways for staff to communicate and ways in which carers could make more decisions about their loved one's care. Key findings included that 'challenging behaviour' was often misinterpreted by staff as 'attention seeking', so staff don't then meet the needs of the individual which in turn exacerbates distress. This was found to be a systemic issue, that was believed to be deep rooted in practice culture. It was also argued that debriefs of incidents almost never happened, with carers often only receiving a notification of an 'incident'. Carers also stipulated that staff training in isolation does not work and that staff must want to learn, be motivated to change and be supported by the organisation. Most importantly however, families can support staff to understand their loved ones better and how they can prevent or alleviate distress which can lead to the use of RP. Carers can, for example (1) have meaningful contributions in MDT meetings; (2) spend time in organisations, to show staff how they can deal with situations and de-escalate; (3) be involved in developing care plans that work for their person, as blanket restrictions enforced on everybody in the same way do not work.

Online consultation

The consultation with a realist review expert focused on the formulation of our final programme theories and how to integrate substantive theories into the results. Based on these consultations, the logic of the CMOCs was refined, the link to IPTs were enhanced and new theories were integrated into the results.

Chapter 4 Studies included in the review

Characteristics of included studies

Of the 53 articles included, 26 were considered to be of high relevance as previously discussed (see *Appendix 3*, *Table 1*). The remaining papers gave more indirect evidence, for example the population were not mainly people with LDs or the scope was on behaviour that challenges, closely linked to RP and coercion as opposed to minimising RP.

Included articles were from UK (47%, *n* = 25), USA (13%, *n* = 7), Australia (9%, *n* = 5), Canada (9%, *n* = 5), the Netherlands (7%, *n* = 4), Switzerland (5%, *n* = 3), Republic of Ireland (4%, *n* = 2), Brazil (2%, *n* = 1), Germany (2%, *n* = 1) and New Zealand (2%, *n* = 1). They were published between years 2001 and 2020, over half during past 10 years (2013–20) (*Figure 2*).

Various designs and methods were used throughout the included papers. These included surveys and correlational studies (*n* = 10), qualitative studies (*n* = 7), discussion papers (*n* = 8), intervention studies with pre-post measurements (*n* = 7), case studies (*n* = 5), evaluations or descriptions of different programs (*n* = 3), mixed or multimethod studies (*n* = 3), commentary papers (*n* = 2), literature reviews (*n* = 2), one systematic review (*n* = 1), a book chapter (*n* = 1), an audit (*n* = 1), a book review (*n* = 1) and a randomised controlled trial (*n* = 1).

Most of the studies were conducted either at residential care/community care homes (*n* = 17) or in mental health hospital settings (*n* = 16). Other settings included a variety of services for people with LD (*n* = 7) and security settings (*n* = 6). For several papers, the setting was not specified (*n* = 9) as they were more general discussions, for example on a certain topic. In some papers, multiple settings were included. Participants in these papers included people with LD, autism, intellectual disabilities and comorbid diagnoses. The largest number of papers included approaches related to PBS (*n* = 12), or de-escalation (*n* = 6). Other interventions studied or discussed focused on the therapeutic environment, leadership and organisational issues, staff training and single interventions, such as Safewards and No Force First. *Appendix 3*, *Table 1* gives further details about the full characteristics of the studies.

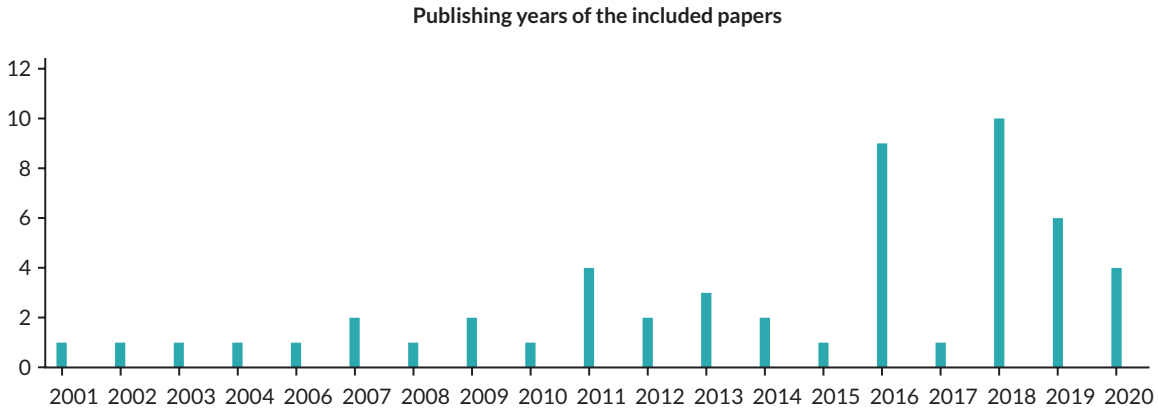

FIGURE 2 Year of the articles included in the review from the main searches. *Note*: The axis refers to number of papers.

Chapter 5 Findings

This realist review incorporates both primary and secondary data, moving beyond peer-reviewed literature to include views and experiences of key players in this field of work, to unpick the why and how of preventing and reducing the use of RP for people with a LD who may also have a diagnosis of autism or mental health problems. It is recognised across the board that restrictive interventions are no longer acceptable 'de facto' practices. This is closely linked to our own positioning and implicitly the context for this review which is threefold. Firstly, RP happen in the context of people with LDs who may display behaviour that can harm or communication difficulties who are often detained in settings/environments which are unsuitable for their needs, especially mental health hospitals. Secondly, they happen in the context where staff are inadequately trained, or do not have the right values/emotional regulation/communication skills or are stressed/burnout. Thirdly, RP happen in the context of a lack of positive organisational culture, where they are used and accepted as the 'norm'. The context for this review (and our key emerging theories) is, after all, the reality for the people involved, that is people with a LD or autism, or staff. It is the environment/backdrop of the interventions/programmes being used.

In this chapter, we present the findings from the analysis and synthesis of the literature reviewed. The chapter is structured around findings regarding the three key levels/stakeholder groups/actors which were identified in Step 1. Here we provide a narrative of findings, followed by a realist analysis containing one or more CMOCs. Illustrative data (i.e. extracts from manuscripts) to support our interpretations in each of the CMOCs. Some of these data derive from quotations presented in relevant articles, other data come from focus groups.

> *The main searches resulted in identifying a range of theories and models to give a rationale explaining why CMOCs work (substantive theories). These substantive theories have been used to support configurations, to substantiate inferences about mechanisms, to validate interpretations of the literature and/or to contribute to the development of programme theory.*

Our review has highlighted how complex factors at human and organisational level influence the use and perpetuation of damaging RP. This relates to a number of theoretical frameworks, a selection of which are outlined including the SDT and the patient-centred care models (the person): the ECOM: self-efficacy theory, the cognitive appraisal model (staff): and the Six Core Strategies, the positive and proactive care framework, the HIC model and self-leadership (organisation; see *Figure 3*).

As noted by others, the use of RP does not occur in isolation but conveys attention to group membership, decision-making and accountability and organisational structures.

This realist review moves beyond identifying barriers of and facilitators to minimising RP to reach an explanation of how and why staff engage with such practices differently under different circumstances. There are three parts of this chapter *Findings*: the first (*Stakeholder Group 1: people with lived experience*) focuses primarily on family members, carers and persons with LD and autism themselves; the second (*Stakeholder Group 2: staff*) presents data from the literature relating to staff with a focus on workforce development and debriefing; while the third (*Stakeholder Group 3: the organisation*) covers organisational influences. In each of these parts, the following sequence is used:

First, we provide a narrative of findings based on our analysis of the data found within the literature. This is then followed by a detailed realist analysis that contains one or more CMOCs. Illustrative data (i.e. extracts from manuscripts) that we have used to make our interpretations and inferences for each of the CMOCs are also provided in each of the subsections. For some CMOCs there is a larger number of supporting quotations from the literature included in the review, while other CMOCs are supported by a smaller set of data. This would provide some indication of the strength with which arguments can be made out of the data included here, but quantity would not be the only consideration. The level of detail and depth within each of the quotations and the confidence with which we can draw inferences from the data also plays a role. Some articles presented a wealth of data (possibly because of reporting flexibility in some journals), whereas others were constrained in the data they could present, therefore limiting the number of data we had available to us. However, this does not mean that arguments cannot be made with adequate strength for CMOCs

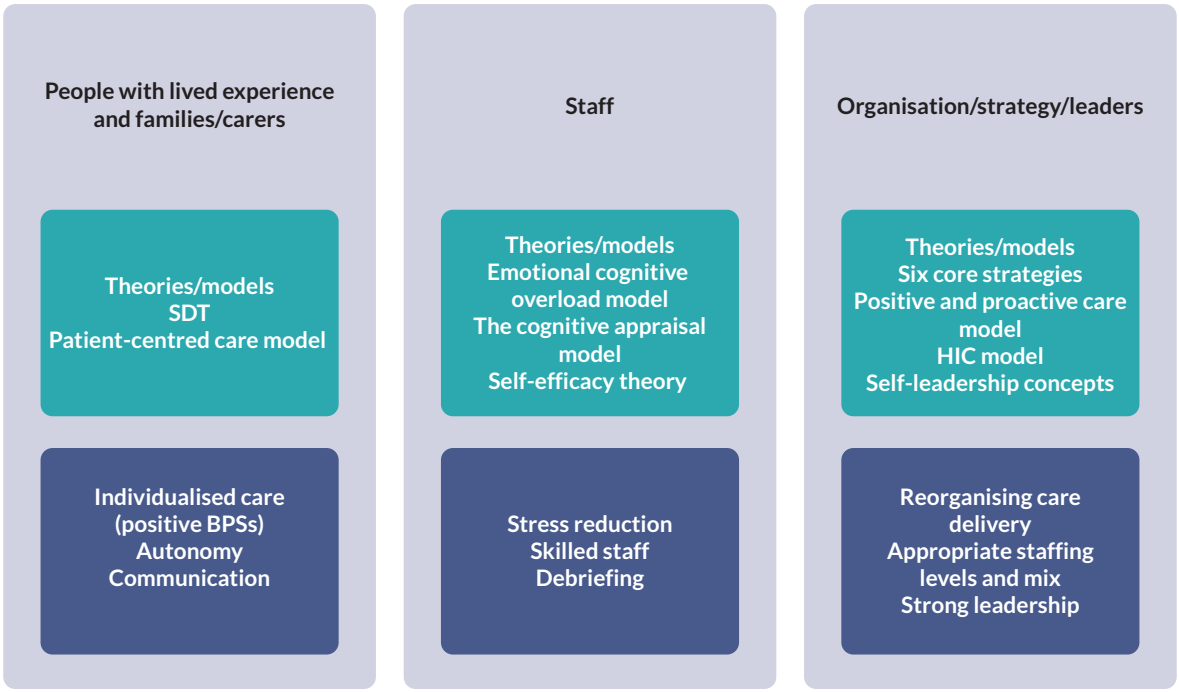

FIGURE 3 Key targeted theories and models underpinning the three theory areas/stakeholder groups.

supported by a smaller set of data, especially when substantiated by relevant theory. Relevant substantive theories have therefore been integrated throughout.

Refined CMOCs after synthesising data are presented in this section. Each area of interest/stakeholder group section begins with a description of the rationale behind CMOCs (substantive theories). After theories, CMOCs are presented followed by relevant extracts from papers included in the review and primary data quotes. CMOCs are then grouped at the end of each section into partial programme theories.

The first set of CMOCs fall within the remit of those with lived experience.

Stakeholder group 1: people with lived experience (people with learning disabilities and families/carers)

People with lived experience are central to the explanation of theories and findings within this review and crucially the importance of personalised care and communication (CMOCs 1 and 2). When exploring this first CMOC, the use and value of care plans are highlighted. SDT[87] is one of the key theories supporting an explanation of why it is important to give more autonomy to people with LD over their own care and to be encouraged and allowed to regulate their own behaviour. Relatedness to staff is also an important element here that could lead to positive outcomes, as people will get motivated to change their behaviour in a positive relationship with staff. The importance of SDT in the lives of people with LD is specifically explored by Di Maggio *et al.*[88]

Context–mechanism–outcome configuration 1: individualised care plans

The first CMOC highlights the importance of person-centred planning.

If individualised care needs are identified within co-created PBS plans (C) that match a person's care and communication needs (identified by a functional assessment) (M), then this can result in the use of person-centred interventions (M). To achieve this people with LD and their families/carers need to be accepted and valued as part of the care team (M). This results in the facilitation of positive lifestyle adaptations, better functionality and a reduction in perceived behaviour that can challenge (O) which in turn could lead to a reduction in RP (O).

This CMOC concentrates on the significance of individualised care. The importance of plans is highlighted in many papers included in this review, for example:

> *Alongside planned Active Support strategies, Positive Behaviour Support includes proactive strategies intended to ensure that the person is consistently having their needs understood and met, so that there is less of a need for them to behave in ways that might be seen as challenging.*[78]

This allows for

> *… lifestyle change and improved quality of life through multi-component treatment plans while decreasing the frequency of challenging behaviour.*[74]

An integral mechanism to achieve positive outcomes is seen as the inclusion of appropriate personalised care interventions:

> *Treatment interventions lead to lasting change in a patient: a new understanding, increased coping skills or enhanced ability to manage the illness.*[89] *Examples are: teaching and reinforcing coping skills, identifying warning signs and symptoms and problem solving around relapse prevention.*[89,61]

One example of how this impacted positively on a person is reported here.

> *His behaviour support plan included activity sampling, picture sequencing to improve the predictability of daily events, reduction of unnecessary speech, and offering him requests using a visual two-way choice format.*[74]

Through the reduction of behaviour that can challenge, it is also possible to reduce RP:

> *Positive behavioural support plans that take a biopsychopharmacosocial approach have been shown to reduce incidents of challenging behaviour.*[70]

Families being accepted and valued as part of the care team, however, rarely occurs, as emphasised in our focus groups with family members:

> *There's this perception that the professionals are the experts and we somehow don't know what we're talking about and the person even less so. Actually, that couldn't be further from the truth. It can only ever be therapeutic if it's a partnership and if that power balance is stabilised and equalised a little bit. Obviously carers, loved ones, family, can help tremendously. We're there not for money*
>
> *Stakeholder focus group 1, participant 6, mother*

Context–mechanism–outcome configuration 2: communication

In this second CMOC, we can see how authentic communication both underpins and builds upon person-centred planning.

When staff communicate with persons with LD in a way that fosters a sense of autonomy to manage their own emotional state (C), by taking account of communication challenges, and with less authoritarian or confrontative interactions (M), then staff will have greater tolerance for behaviours that can harm (or be perceived as 'challenging') (M). This helps to create a trusting relationship (M), where restrictive interventions would not be used in the interest of the organisation, or perceived as punishment (O), conflict would decrease (O), and there would be less incidents requiring the use of approaches such as restraint and seclusion (O).

This second CMOC focuses on how staff in care settings communicate with people with LD communication problems, together with unmet needs, have been seen as a major reason behind conflict and resulting behaviour that challenges:

> *Challenging behaviour is often the result of unmet needs or a communication problem, and not necessarily a direct result of a patient's clinical condition.*[70]
> *It is key to recognise a challenging behaviour as a form of communication. Service users will feel anger and distress in certain situations, as a natural response. Therefore, it is important to understand the activating event and whether physical intervention is the best method of de-escalation in any given situation.*[79]

An unmet need compounded with communication limitations expressed as challenging behaviour has also been highlighted in our focus group with family members:

> *She was definitely fight and flight. She wasn't able to verbalise. She became so traumatised that she was shouting, flapping her hands everywhere, stimming, throwing things. They deemed it as aggressive behaviour. All it was, was communication. They had taken away her scaffolding which she uses to survive really and blaming her for them removing her scaffolding.*
> *Stakeholder focus group 2, participant 2, mother*

Enhancing communication with a person with LD has been a successful strategy to deal with and decrease the use of restrictions in care, as described by support staff in one study:

> *Start a dialogue with the client … Not confront the client … Knowledge of client is helpful in the process of caring.*[80]
> *Participants identified a lack of communication between both parties as the cause of incidents requiring restraint. They suggested that increased communication with staff would improve this situation.*[90]

A literature review about factors that influence nurses' decisions about secluding people with LDs found that persons that were 'hardly approachable' were secluded more frequently and highlighted:

> *This variable clearly suggests an emphasis on the importance of communication in preventing seclusion…*[72]

The interface between contexts, mechanisms and outcomes involving people with lived experience is illustrated in *Figure 4*. This is our first partial programme theory that combines CMOC1 and CMOC2.

Our second group of CMOCs relates to matters influencing staff behaviour including staff stress, training and reflection.

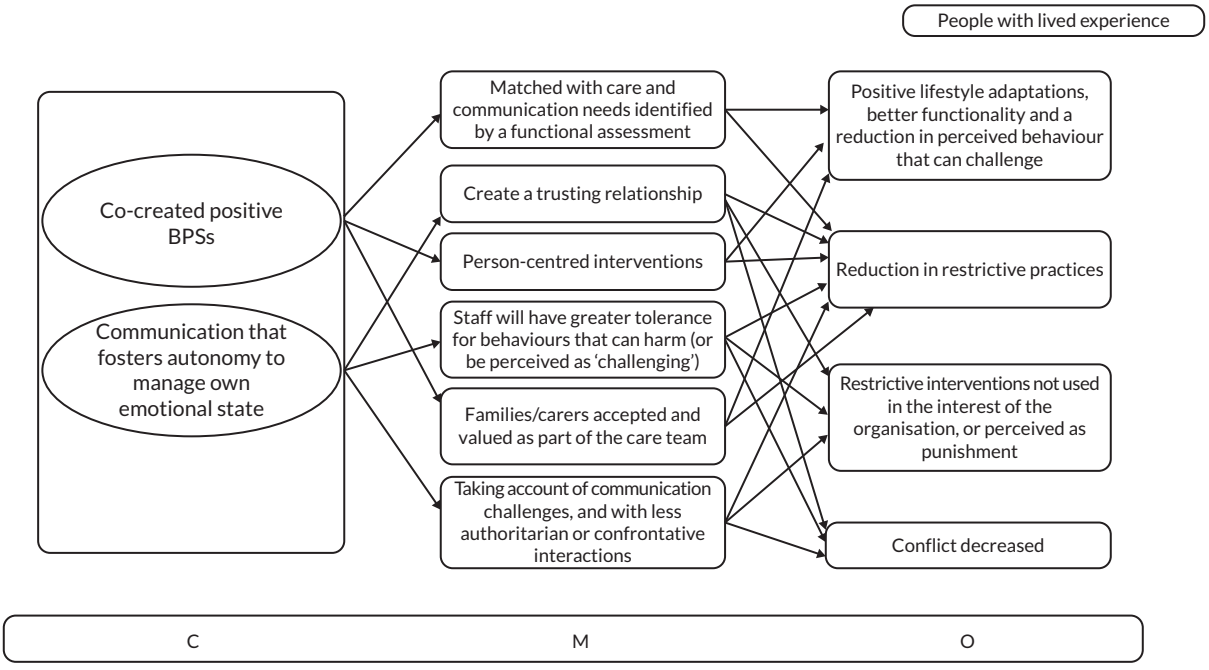

FIGURE 4 The interface between contexts, mechanisms and outcomes involving people with lived experience that contribute to our first partial programme theory (CMOCs 1–2).

Stakeholder Group 2: staff

The role of staff in the minimisation of and indeed the reliance upon the use of RP cannot be underestimated. A number of factors are influential including stress, workforce development and reflective practice.

The importance of workforce development and practices such as debriefing to reduce RP can be in part explained by self-efficacy theory.[91] Self-efficacy is about one's beliefs over their own capacity. It is a foundation for one's motivation, well-being and personal accomplishment. Donat[67] explained the connection between occupational stress, knowledge and competence using self-efficacy theory suggesting that individuals who believe that they can achieve desired outcomes when faced with challenges experience lower levels of fear, frustration, and discouragement when attempting to address those challenges.

Individuals with higher levels of behavioural knowledge and competence will be more effective in their attempts to modify behaviour. They will also be more accurate in judging their capability. Furthermore, they can more effectively recognise when assistance is needed or when expectations need to be modified, a key feature of de-escalation. Thus, they can successfully do more and are more aware of their limitations. This promotes a more effective work environment and lower occupation-related stress. We can then assume that by improving knowledge and skills and increasing a sense of self-efficacy staff will believe in their own capabilities. This will also give them opportunities for reflexive activities such as debriefing, and a positive impact on reducing the use of restrictions will be accomplished.

Self-determination theory may also have a key role in staff performance. Self-efficacy is a result of good education and training, while SDT could explain how it works. It is not just that they are competent, but that they have the autonomy to do things differently in their work. This happens in interaction with peers and persons with lived experience.

Context–mechanism–outcome configuration 3: stress-reduction efforts to mitigate staff burnout

This third CMOC has to do with staff stress and how this needs to be addressed to reduce the use of RP.

If staff work in environments where stress and burnout are highly prevalent, due to factors such as staff shortages, exposure to trauma, and the need to restrain people with LD (C), adopting well-being interventions such as mindfulness (M) can facilitate lower levels of stress and burnout (O). Staff are then more likely to display factors associated with therapeutic communication such as kindness, empathy, and positive interaction with people with LD (O), and so feel more motivated to work (O). Proactive supportive practices have been shown to reduce patient–staff conflict (O), minimise RP (O) and improve standards of care and personal levels of satisfaction (O).

The Emotional Cognitive Overload Model is used to help us understand how individuals become overloaded when they are not able to cognitively process the inputs that they receive. ECOM is defined as the negative emotional and cognitive manifestations resulting from the inability to adequately process pertinent input and handle the associated mental load. This can then result in further stress, impact upon behaviour and burnout.

It has been reported in the literature that staff may have stress and burnout in care environments. Goulding and Riordan[69] reported that nurses who worked in a secure setting for women with LD as an example experience frustration, because they lack formalised support and appreciation:

> *The theme of risk of stress and burnout was also attributed to responses stating that staff did not always feel adequately acknowledged or appreciated for their contribution within the service and that working with the women was very challenging and that working within a female service could be quite isolating.*[69]

The importance of staff well-being and the repercussions it can have for the care they provide was also reflected in our focus groups with carers:

> *The management don't talk to the staff and they don't treat the staff pretty good. So if they're not going to treat the staff very good, how is it going to make the staff feel towards the clients?*
>
> *Stakeholder focus group 4, participant 1, mother*

Supporting staff well-being is important for many reasons but may be directly related to the reduction of RP in care:

> *Staff burnout, low morale and stress may lead to an increase in patient-staff violence and restrictive practices.*[72]
> *Negative evaluations of staff mood included references to staff being bad-tempered and short-tempered. Two participants made reference to staff being 'ratty': 'If you ask them, can you do this, like a trip out, they can be ratty. Say oh you'll have to wait, I'll sort it out the next day'*
>
> *P2.*[64]

A number of interventions are proposed in the literature to address stress and burnout. It is suggested that they could have other positive outcomes too, contributing to a better quality of care:

> *…interventions are based on mindfulness practice, which is linked to increased levels of self-awareness and compassion.*[58]
> *Mindfulness-Based Positive Behavior Support (MBPBS) was more effective than treatment as usual in enabling caregivers to manage their stress, and reduce the use of physical restraint and medications for aggressive individuals in their care. There were reductions in aggression, the need for 1:1 staffing, and staff turnover.*[28]
>
> *Singh et al. 2016*

Context–mechanism–outcome configuration 4: staff training

Our fourth CMOC is related to the importance of workforce development in the reduction of RP.

If all staff teams are trained using methods that have been shown to reduce RP including those that prioritise therapeutic communication skills and the needs of people with LD (C) involving those with lived experience to share their stories and highlight the impact of trauma (M), then staff are more likely to provide person-centred, non-coercive and trauma-informed care (M). They are then more likely to use their learning (M), to adopt alternatives to RP (M), which would decrease the use of such practices (O).

> *There is a lack of education around dealing with violence and aggression: when asked whether respondents had the opportunity to access further educational courses for support to deal with violence and aggression at work, only four out of 23 respondents ticked this box.*[69]
>
> *Goulding and Riordan 2016*

> *We found that several of the hospitals we visited did not employ staff with the necessary skills to work with people with autism who also have complex needs and challenging behaviour. Many, including those working directly with people in segregation, were unqualified healthcare or nursing assistants.*[71]

The importance of staff training was also raised in our stakeholder focus groups with one participant stating:

> *I've seen the most terrible behaviour in the psychiatric hospitals for people that are Autistic because they don't have the training in Autism. The way that they treat someone maybe having a manic episode, interferes with how they are as an Autistic person.*
>
> *Stakeholder focus group 3, participant 1, mother*

In a study conducted in Australia about seclusion and restraint use with people with LD, training and support were highlighted as key areas:

> *Comprehensive training in intellectual disability … about the needs of people who have a disability who are subjected to restraint and seclusion. This type of support to disability workers may help to reduce behaviours of concern and the resulting use of restrictive practices.*[84]

There are some important elements in training that could be interpreted as mechanisms to decrease the use of RP:

> *If direct care staff are intrinsically motivated to provide care that is of the utmost quality and have an understanding that the use of seclusion and restraints is not patient-centered, they will be more likely to benefit from the educational training on alternative strategies to decrease their use.*[61]

Involving people with lived experience in teaching is seen as an important strategy:

> *One way to address this can be by appealing to the human side of employees. One possible teaching strategy may be to use consumer's to help teach the alternative strategies. By using people with mental illness to help educate direct care staff on avoiding the use of seclusion and restraints the organization may interest employees more. The former patients can even share personal stories of their experiences with seclusion and restraint in the hopes of influencing staff to better avoid their use.*[61]

In contrast, it has been argued that training and education do not always reduce the use of RP. There may be multiple complex reasons for this, one being that the context and mechanism were not sufficient to produce the right outcomes.

> *Other studies have shown no change in the use of restraints despite staff education on how to reduce their use.*[61]

Embedding training within broader organisational value-based frameworks and environments is therefore key.

Context–mechanism–outcome configuration 5: reflection and reconnection

This fifth CMOC focuses on recommended reflective practices such as debriefing and learning from events where RP have been used.

If following the use of RP (C) reflective practices such as debriefing are employed (M), then this allows those involved to understand and reflect upon conflict and events (M), share feelings, concerns, learn lessons (M) and revisit BPSs (O). Future conflict could then be prevented, and the use of restrictive interventions minimised (O).

> *A debriefing session should follow as soon as possible after the procedure. This involves gathering of all staff involved in the seclusion/or restraint for the purpose of discussing the events.*[60]

One study suggests that post-incident debriefing is a new practice and may not be sufficiently rooted in services yet in a positive way. It is therefore important that debriefing is introduced with appropriate workforce development:

> *We are just in the process of strengthening our DB [debriefing] process which is weak … at the moment further training in debriefing is needed.*[66]

In the literature, there are examples of staff debriefing, but also an impetus to provide debriefing to persons with LD as part of a behavioural support plan, as opposed to just tick box exercises:

> *Debriefing procedure of individual and witnesses to physical restraint and seclusion/confinement time-out described.*[24] *… Giving service users and staff the opportunity to reflect on adverse events and identify areas for improvement and learning together … is essential.*[77]

The inadequacy of debriefing procedures was echoed in our stakeholder focus groups with participants agreeing that debriefing was rare. One participant said *'Never. Never in eleven years. We would be informed of incidents but never a debrief, never' (Stakeholder focus group 1, participant 1, father)*. This was a strong consensus, and the missed opportunities were highlighted, as exemplified by one carer participating in one of our focus groups:

> *I told them and told them that the medication they put her on would make her violent because she's been on it before and nobody listened to me. So all these restraints and her violence were because they put her on a medication. Had there been a debriefing, I could have informed them.*
>
> *Stakeholder focus group 2, participant 2, mother*

There are different ways and components of successful debriefing and mechanisms of how it works, described for example by Black *et al.*[60] They propose that desirable outcomes should include:

> *The prevention of the future misuse of imposed restrictions (this includes either implementing seclusion and restraint when not appropriate or avoiding these modalities when they are indicated).*[60]

In summary, in combining CMOCs 3–5 to formulate our second partial programme theory (*Figure 5*), one can see the development of the importance of creating positive environments where staff are supported, sufficiently resourced and able to be reflective and learn from previous events and shared information.

Our third focus arising from this review and preliminary work is that of the organisation.

Stakeholder Group 3: the organisation

Organisational-level issues and how care is structured are identified as of significant importance in this review and can impact upon the quality of care and its outcomes. Leadership is key to this process. There are a number of frameworks explaining factors that can affect the quality of care including the Donabedian structure–process–outcome framework.[92] It is evident that reorganising the delivery of care and staffing levels are key structural components in this chain, and that leadership is an integral part of the process, leading to positive care outcomes.[93] The importance of strong leadership is emphasised in, for example, organizational and management theories and will increase motivation and commitment for staff to provide high-quality care. The Six Core Strategy approach is a classic example of this and has an increasing evidence base.

With regards to staff mix, the Framework for Inclusive and Collective Leadership[94] underpins some of the ideology behind CMOC 6. This framework outlines how the notion of collective leadership involves shifting from traditional command-and-control structures and 'heroic' individual leadership towards a model that shares and distributes leadership to wherever expertise, capability and motivation sit within organisations. West *et al.*[95] later argued it gives a rationale for why it is crucial that leaders in health organisations show by example that a culture shift is needed from blame to positive practices and being creative with finding and trying new solutions to address conflict situations:

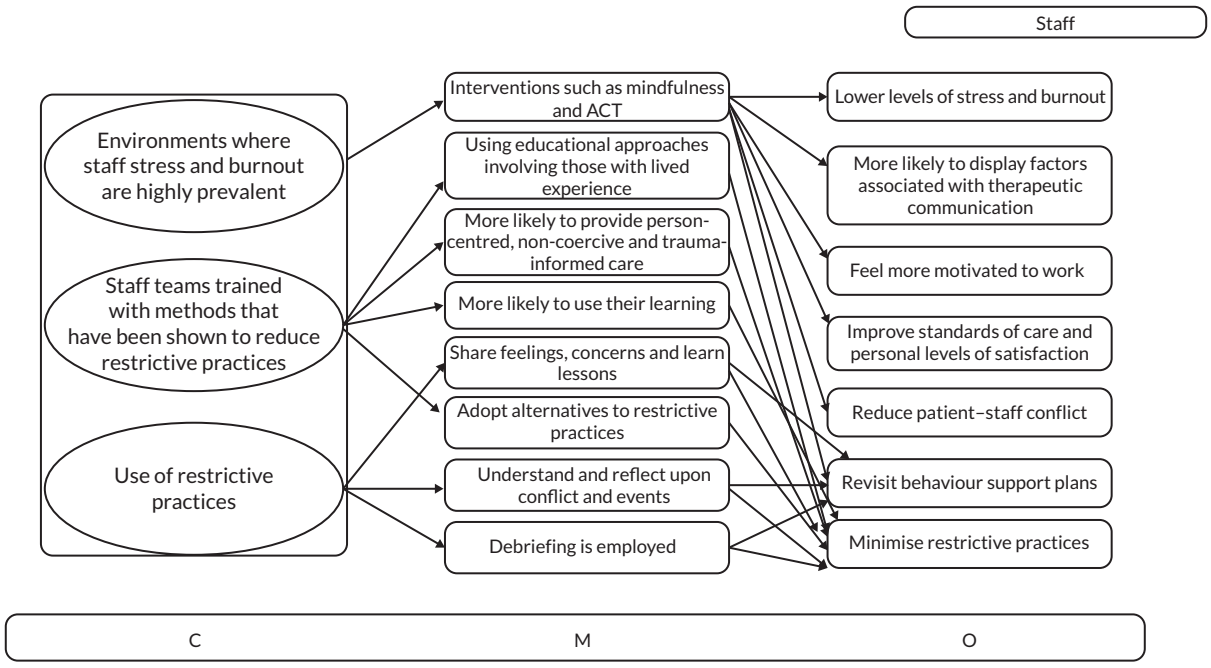

FIGURE 5 The interface between contexts, mechanisms and outcomes staff that contribute to our second partial programme theory (CMOCs 3–5).

> *Attending: being present with and listening with fascination to those we lead. This involves noticing and inquiring about suffering and distress, and challenging approaches oriented to blame and punishment.*

Context–mechanism–outcome configuration 6: reorganising care delivery

The sixth CMOC focuses on rethinking care delivery and reviewing existing practices and care services with a more preventative organisational as opposed to individual lens.

If organisations that use RP routinely (C), review their use in services (M), together with staff and people with lived experience and families/carers (M), and reorganise care using evidence-based approaches, such as the HIC model, Safewards and the Six Core Strategies to reduce coercion (M), then the use of RP could be reduced in the long term (O).

> *Organisational factors … Many of these strategies centre on the structure of the organisation itself: the need for strong leadership, successful reporting, recording and reviewing practices in regard to the collection of data, and the development of those people working within the organisation.*[86]
> *… an institutional philosophy advocating reduced SR use.*[73]

> *Thus, the reconstruction of beliefs, attitudes, and behaviors of professionals can be promoted by sharing perspectives among staff and patients, as well as critical-reflective educational interventions and changes in organizational policies and culture.*[82]

In our focus groups with carers, they repeatedly reported organisations unwillingness to review practice alongside carers, despite their advocacy for working together:

> *If organisations genuinely wanted to have all of that understanding of the individual to help them get better then they could very easily find ways to build up communication links with carers and loved ones and to have that joint way of working. But actually, my experience is that that's not the case. Particularly in inpatient services, it's out of sight, out of mind. They don't really fully understand what the goals of care even are. They're just ticking boxes and going through the motions.*
>
> *Stakeholder focus group 1, participant 6, mother*

Examples of organisational-level programs include the HIC model:

> *The HIC-model integrates the medical model and the recovery model and focuses on contact and crisis prevention and continuity of care between outpatient treatment and acute admission wards.*[81]

The Six Core Strategies take a more overarching organisational approach highlighting multiple factors including data-informed practice and leadership:

> *Clinical teams agree how they will use data. The value and richness of such data is apparent to clinical teams as requests for different data sets were used to monitor, plan and review the impact of PBS plans.*[29]

Many of these approaches reflect the impetus arising from the DH Positive and Proactive framework.[96] The purpose of this guidance was to support the development of service cultures and ways of delivering care and support which better meet people's needs and which enhance their quality of life (QoL). It provides guidance on the delivery of services together with key actions that will ensure that peoples' needs are better met, which will reduce the need for restrictive interventions and promote recovery. It aims to radically transform culture, leadership and professional practice to deliver care and support which keeps people safe.

Context–mechanism–outcome configuration 7: ensuring appropriate staffing levels and balanced staff mix

The seventh CMOC focuses on the importance of appropriate and sufficient staffing.

If there are sufficient and permanent staff (C), taking account of a balance of staff gender, skill mix and experience (M), then there are greater opportunities for staff to be available to address the individual needs of people with LD (M), and to facilitate preventative actions (M). Experienced and educated staff may promote more evidence-based methods (M) meaning that RP could be minimised (O).

> *There are also reasons for restraining that are not client-related, but are related to organisational boundaries. Support staff have reduced possibilities to give good care due to limited working time and staff shortage.*[80]
> *Nursing assistants had a greater perception about the importance and necessity of restraint. This perception was related to the reduced knowledge of alternatives for the management of aggressive behavior and greater sense of vulnerability to suffer aggression.*[82]

It has been suggested that a mix of both junior and senior staff is necessary for the reduction of RP:

> *Greater variability supports the development of competency outlined by Benner;*[97] *less experienced staff learn from and challenge more experienced staff and therefore promote best practice.*[98] *Greater experience is inversely associated with seclusion use ($p \leq 0.001$), supporting the idea that the greater the experience of the main carer, the less seclusion is used.*[72]
> *In one study participants perceived young staff as lacking experience and knowledge to support them effectively. Often this resulted in a lack of mutual respect: Conversely, some participants felt that older members of staff lacked motivation: They've been here so long that they've had enough of the job.*
>
> *P8*[64]

Context–mechanism–outcome configuration 8: strong, committed and compassionate leadership

Our eighth and last CMOC is related to leadership in care settings. It has been rated as one of the most important, single strategies in reducing RP in services for people with LDs.

If compassionate and thoughtful leadership is strong, both operationally and strategically (C), then there will be less conflict on the wards (O). This is because when leaders engage in positive role modelling (M), work within open and transparent environments (M), and communicate clear expectations, staff are more able to prioritise direct care demands (O) and promote high-quality and person-centred interactions with people with LD (O). This will reduce the need to reactively rely upon the use of RP (O).

> *One of the four most important factors for reducing RP has been suggested to be frontline practice leadership…*[66]
> *The main leadership characteristic that participants identified as having contributed to the reduction in SR was the ability to unify staff efforts.*[73]

Of critical importance are leadership behaviours demonstrated at a senior level. In the first instance, a clear organisational statement identifying restraint reduction as a key priority is paramount. Then, backing up ambitions with capacity and resources, captured and job planning facilitates the intentions into good practice.[29]

Suggestions as to how leadership should be embedded into practice have been made:

> *For example, leadership requires: a designated senior board-level manager to collect and collate data regarding RP and ensure and agree RP training and standards are discussed and agreed at the most senior management level.*[66]
> *Violence is less frequent and less severe when a unit has strong leadership, clearly defined rules, clear expectations, and a predictable schedule of groups and activities.*[61]

> *Core competencies and expertise in engagement and collaboration can serve effective leadership. Working ethically in a caring role and can take its toll on the workforce. Clinical psychologists are well placed to work at an organisational level to provide training and supervision for front-line staff and carers.*[58]

Further it is argued that there should be a clear organisational-level statements about and a vision for reducing RP:

> *Also of critical importance are the leadership behaviours demonstrated at the most senior level. In the first instance, a clear organisational statement identifying restraint reduction as a key priority is paramount. Then, backing up such a statement with appropriate capacity and resources, captured within job planning processes, facilitates the translation of good intention to good practice.*[29]

The interface between contexts, mechanisms and outcomes that contribute to our third partial programme theory with regards to organisation is illustrated in *Figure 6*. Our final partial programme theory highlights the significance of reflexive and appropriately resourced organisations where leaders are committed to 'connection before correction' as an underlying trauma-informed and human rights-orientated philosophy. Compassionate and visible leadership is paramount in this instance as outlined in models such as the Six Core Strategies.

Overarching programme theory

Having outlined our eight emerging CMOCs and three partial programme theories, we now synthesise our work to present an overarching programme theory. To summarise, our programme theory of reducing the use of RP in NHS and independent sector settings that consolidates the relationship between the eight CMOCs emerging from the data is illustrated in *Figure 7*. Three broad interconnecting key theory areas (stakeholder groups) were identified early on to support the need for investment and change for people with lived experience (individuals with LDs and their family members/carers), staff and at organisational level in order to minimise RP for people with a LD who may also have a diagnosis of autism or mental health problems.

In the development of our overarching programme theory, analysis and synthesis of the literature was guided by a number of perspectives including substantive theories as outlined, where deemed relevant. This was used to support configurations and consolidate inferences about mechanisms and to validate interpretations of the data and contribute to programme theory development and refinement. Specifically, three interrelated key components were seen to be central to our programme theory comprising aspects related to the person with lived experience (and their families), staff and the organisation and how they influence and impact upon the use of restrictive interventions in LD settings and how they might be minimised by adopting inter-related person-centred practices within organisational change

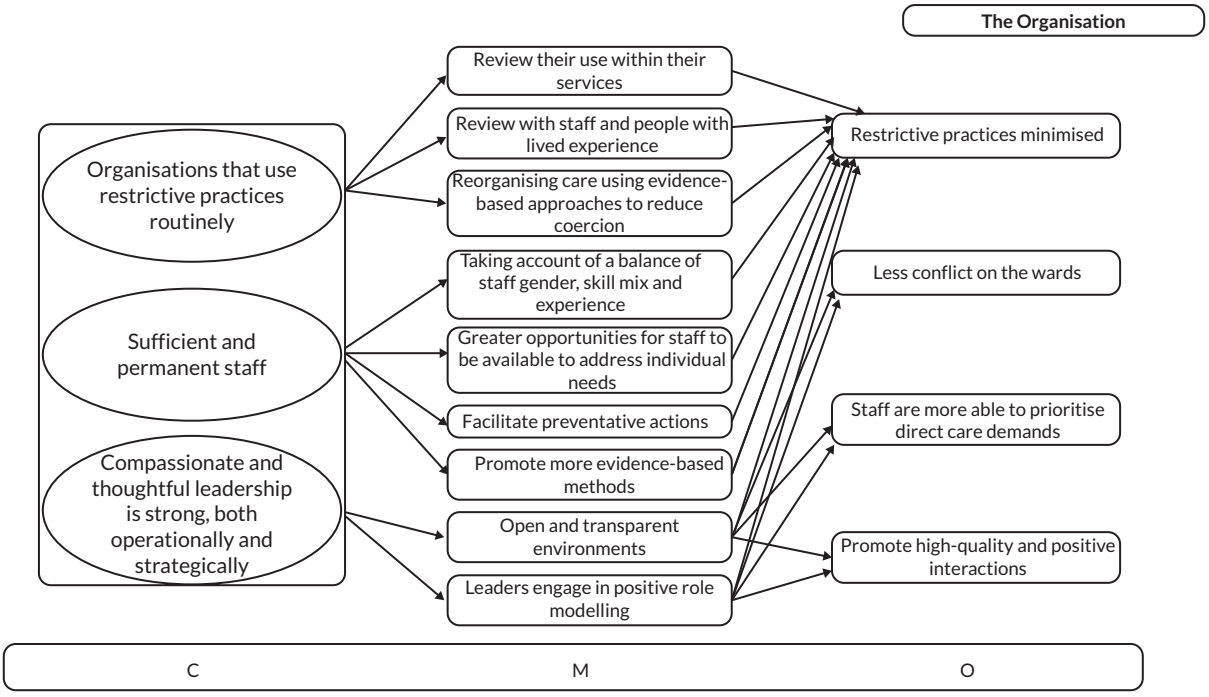

FIGURE 6 The interface between contexts, mechanisms and outcomes that contribute to our third partial programme theory regarding the organisation (CMOCs 6–8).

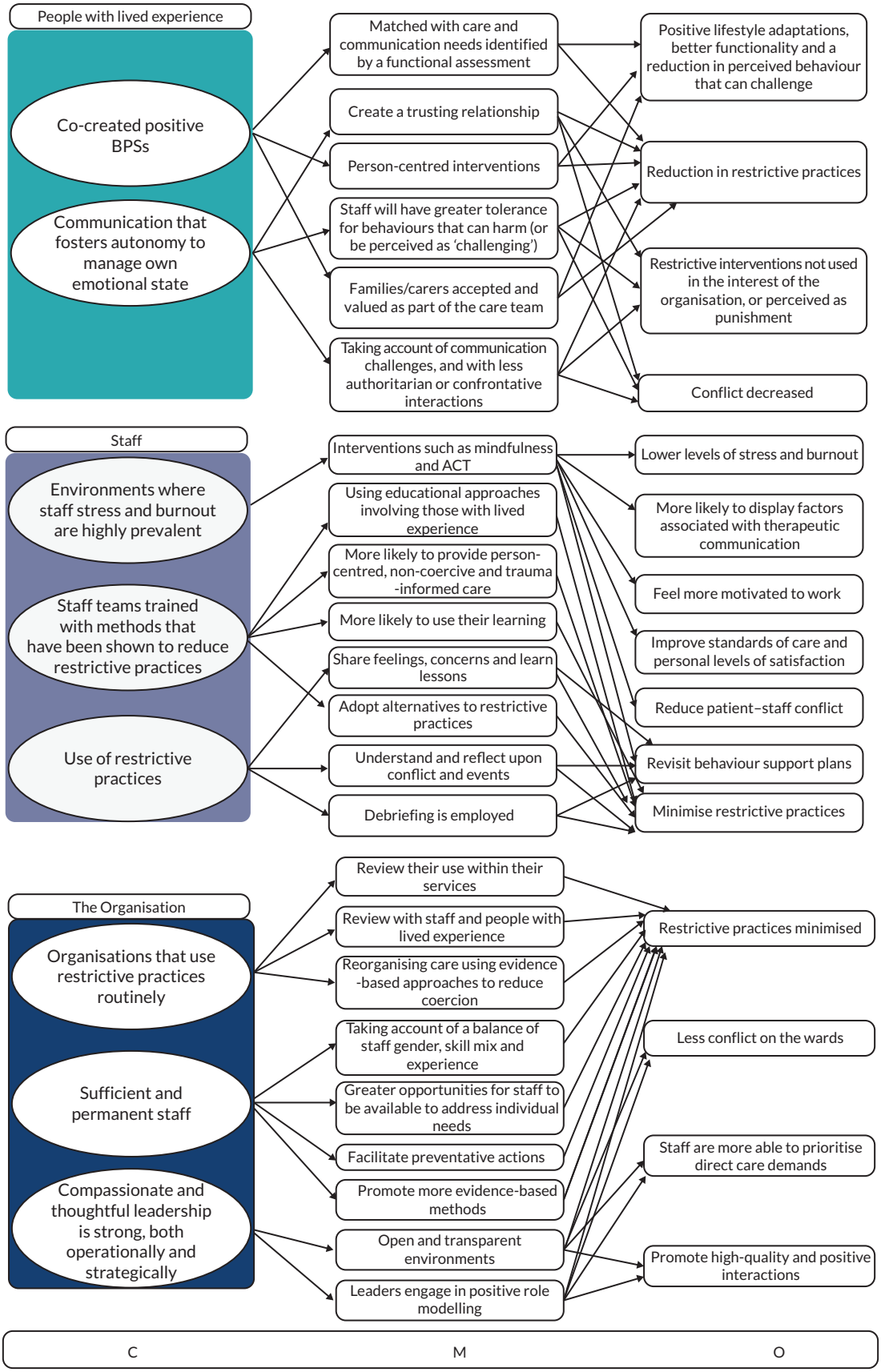

FIGURE 7 Summary of our programme theory of reducing the use of RP in LD care settings that consolidates the relationship between the eight CMOCs.

underpinned by compassionate leadership practices and with people at the heart of practices. Our programme theory also explains what drives challenges to embedding such practices within organisations such as staff burnout, a lack of engagement with carers and persons with lived experience and the over-reliance of non-person-centred approaches.

Bringing the literature and theories together in addition to findings from focus groups, it was clear that with regards to people with lived experience, strategies including effective communication, autonomy and care planning underpinned by theories of SDT and person-centred care models are central to effective relational working. Secondly, the importance of addressing staff needs, both professionally and personally, given the intensity of the environments they work in, warrants structured reflexive approaches such as debriefing and related workforce development. In addition, self-determination should not be looked at solely as a matter of individual attitude, but the management and culture of the organisation need to give permission to frontline staff to do the right thing. The importance of this is further highlighted by underpinning theories such as the ECOM, the cognitive appraisal model and self-efficacy theory. Each emphasises the impact of stress and need for learning and support. This is then further illustrated by the final piece of the jigsaw, the organisation which needs to address person-centred care delivery initiatives, ensure sufficient and supported staffing models and above all subscribe to and invest in strong and authentic thought leadership. Theoretical and complex organisational models include the Six Core Strategies, positive and proactive care, the HIC model and concepts related to self-leadership and moderation.

These interconnected components are multidirectional in that they are both interdependent and reliant upon each other and representative of the need for an overarching reflexive systems approach.

As discussed in the literature reviewed, outcomes result from the inter-relationships between the important contexts in which care takes place in within LD settings. For example, our programme theory indicates that while there are interventions that have been shown to work in mental health settings in reducing RP (*what works?*), for example, the six Six Core Strategies, and Safewards, the *'who'* in these settings is significant, in this case, people with LDs, because of the contexts and mechanisms at play. For example, interventions might not work in reducing the use of RP because of staff stress and burnout that can be associated with working in complex environments without the necessary workforce development and skill mix. Fundamentally, there appears to be a lack of understanding about peoples' needs – commonly referred to as 'challenging behaviour' and the imminent need for specialist targeted training for staff about those with LDs and autistic people. This in turn can translate as organisational failure to recognise these key differences, and in particular the need to understand expressions of unmet need. The importance of highlighting and recognising the role of family members/carers and to include them as advocates in their loved one's care and in workforce development is a key way forward.

Our review indicates that where staff work in and do not have adequate training and support in challenging environments, they are more likely to experience high levels of stress and have extended absences. Positive practice therefore needs to be relational involving family members to advocate for their loved ones and help bridge gaps (at ward/staff and organisational levels) for a better understanding of communication needs and the reduction of triggers that could escalate the use and over-reliance of RP on adults with LDs in NHS and independent sector settings.

Chapter 6 Discussion

Summary of key findings

The aim of this realist review was to understand how, why, for whom, and under what circumstances approaches used by healthcare organisations work to prevent and reduce the use of RP on adults with LDs or autism. This review comprised several steps, including a systematic literature review, two rounds of stakeholders' consultations with fellow academics, key experts in the area, practitioners and persons with a primary diagnosis of LD and family members/carers, the identification of substantive theories, wide systematic literature searches and realist interpretation of the data. While we adopted a robust methodology in conducting this review, there are limitations that warrant consideration when considering the findings. Firstly, given the complex nature of the area under investigation, it is clear from the findings that it was sometimes difficult to untangle both the settings examined and the approaches adopted. Secondly, given the parameters of the review in line with timelines and funding we focused largely on the inpatient setting which meant that the important interface between primary and secondary care was not within the scope of the project. The importance of non-inpatient environments, while implicit in some of the findings, was not therefore, explicitly covered in this work. Finally, implications relating to the status of individuals under the Mental Health Act were not directly examined albeit influential with regards to some of the CMOCs discussed.

Throughout these extensive steps, eight CMOCS were formulated and framed within three theory areas/stakeholder groups: people with lived experiences and their carers, staff, and the organisation. Emerging CMOCS were discussed with various stakeholders to sense-check and validate findings. We also explored substantive theories to understand more deeply, why certain mechanisms are important and decrease or diminish the use of RP. This then led to the evolution of our programme theory into a narrative that explains the why and how of preventing and reducing the use of RP for people with LD and/or autism.

To demonstrate this, the team granulated the overarching programme theory using the actors/stakeholders involved into a narrative that brings together all the primary and secondary findings from this review. In brief, RP happen in the context of people with LD who may display behaviour that can harm or communication difficulties and who are often detained in settings/environments that are unsuitable for their needs, especially mental health hospitals. Secondly, they happen in the context where staff are inadequately trained, do not have the right values/emotional regulation/communication skills or are stressed and experience burnout. Thirdly, RP happen in the context of a lack of adequate staffing or sufficient resources and organisational cultures, where they are used and accepted as the 'norm'. This is known as 'closed cultures'. This lens is synonymous with Beard and Barter's[58] micro, meso and macro levels for promoting compassionate cultures within LD services.

People with LD are often inappropriately detained for displaying behaviour that challenges and not always because of a mental health problem. This fundamental flaw means behaviour that challenges is often the manifestation of a trauma activate or an unmet need, compounded by an inability to translate that need due to the non-typical, communicative limitations that people with LD have.[99] While this error in detention is being reviewed under the current Mental Health Act and programmes such as HOPES, this still does not help the 2030 inpatients with a LD in hospitals today.[71,100]

Restrictive practices happen in closed cultured/toxic organisations where they are used as the 'norm'.[81,101] In these places, staff often perceive challenging behaviour as attention seeking and a constant risk, inappropriately using RP as a punitive first, not last resort.[63,102] Hence the 'rules' of the institution (i.e. in what situations people are restrained) are not centred around the sensory needs of the individual and need revised. Punitive and/or ill-fitting rules not accounting for the individual's sensory needs exasperate a closed culture of excessive petty regulation perpetuating the activated use of RP. This is compounded by lack of dynamic risk assessments dehumanising the person by labelling them dangerous/harmful.[65]

Consequently, people are often locked in long-term segregation with no access to outside space, in inhumane, unsanitary living conditions.[72,62,85,103] Significantly, the carer focus group noted this heightened distress and causes the

person to develop new harmful behaviours not seen before as an attempt to cope, hence perpetuating the vicious cycle.[71] In addition, there are often no care plans that aim to reintegrate these people back into the ward or indeed the community risking institutionalisation.[104] Detailed experiences of this are found in Advonet and CHANGE's[104] 'Lived Experience of Restraint, Seclusion & Segregation' report commissioned by the CQC.

There is now a growing body of research concurring with the focus group data that state the importance of involving carers in as partners in care.[105–107] Specifically, carers hold the key to their loved one's communication style and needs. However, carers are often pushed out of their loved one's care decisions, are made to feel guilty and/or are labelled as 'challenging parents'. Despite holding the keys to interpreting their loved one's behaviour/needs they are often completely excluded and silenced. Due to the lack of community care, people are often placed in hospitals hundreds of miles from their loved ones meaning there is little or no accountability for the care being provided.[108,75] There, closed cultures foster harmful, toxic-cultured hospitals.[71] CQC's idea that 'closed cultures' form a breeding ground for RP could be challenged if family carers served as observers and whistleblowers. Family carers identify and are recognised as potentially helping with person-centred planning but not in this broader monitoring role.

Through involving carers/family members in their loved one's care, staff can gain insight into the service user's communication style and better understand what behaviour corresponds with what expression of need. This 'connection before correction' approach would equip staff to understand individual triggers and responses and identify how to appropriately prevent and/or de-escalate what previously would have been deemed harmful behaviour.[65] This resonates with findings from Clarkson *et al.*[64] who found that patients valued relationships with staff who exhibited qualities such as honesty, trust, and a caring nurturing manner because it enabled individuals to feel safe. RP were prevented as a result. People would then be seen as less of a risk, feel more humanised, understood and seen by staff increasing both their well-being and subsequently the staff's.[70,80,72,81,59]

As supported by Ashworth *et al.*,[57] findings stated that RP happen in the context where staff are inadequately trained, and/or do not have the appropriate values/emotional regulation/communication skills to work with people with comorbid mental health challenges and LD.[83] The lack of specialised training in how to communicate/understand peoples' non-typical communication styles leave staff disempowered and ill-equipped.[69,83] Individuals feel RP are used as a punishment which fractures the therapeutic relationship.[52] In addition, debriefing is often a box-ticking exercise continually blaming the person removed from the staff response. Accumulatively, this creates high levels of stress/burnout with high staff turnovers and sickness leave.[109]

Invested, positive organisations address power imbalances by placing the person with LD at the helm of its care.[71] They give voice to the individual, through their carer/family member, and gain insight into their communication style and sensory needs to better understand what behaviour corresponds with what expression of need.[70] Constructive debriefing includes carers/family members and is used as a reflective tool for learning and re-connecting.[109] Incident reviews and support are essential. This re-defines challenging/harmful behaviour, takes stigmatic labels off people and with appropriate co-created training, can be operationalised and rolled out to create systemic change.[70,69,65] The focus group data suggested developing individual communication passports as a one way of operationalising this.

Invested, positive organisations can also lead to a reduction in RP.[72,71,65] However, hospitals are still an unsuitable environment/setting for the sensory needs of people with LD.[106] Currently, there are few appropriate community mental health services available for people with LD. Hence, they are placed in mental health hospitals within settings/environments that are unsuitable for their needs. This often activates behaviour that challenges or can harm as a result of the unsuitable environment. People therefore live in a constant state of stress/distress. RP happen due to the perpetuating display(s) of behaviour that can harm caused by unmet needs.[104]

Total elimination of RP requires research to co-design mental health support outside the walls of hospitals inside the community.[74,76] However, due to the over-reliance of inpatient care an interim community facing plan is needed for the backlog of people still in hospital.[106] These people must receive high-quality, trauma-informed, person-centred, specialised care that includes carer/family members. Care must be accountable and empower staff to adequately meet their needs while supporting them on their journey back into the community. Examples of this, can be seen in Mersey Care's NHS Foundation Trust, HOPE(S) Model (www.merseycare.nhs.uk/hopes-model).

This realist review, in line with Pawson and Tilley's[44] description, asserts that it is not interventions (resources) that create change, rather, people create change. And mechanisms are ways in which people respond to resources. Our programme theory indicates that, while there are interventions that work in mental health settings (*what works?*), the *'who'* – people with LDs – is a vital component for this to work. Interventions are not always appropriately targeted or tailored for this population; staff are not adequately trained and supported; the people with LDs, autism and other comorbidities lack a voice and the autonomy to enable them to contribute to their care planning and improve their well-being and QoL (with the help of their loved ones/families, where needed); organisations still fail to recognise these shortfalls.

And while the *context/circumstances/settings 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'.

In summary, NHS and independent sector settings where people with LD are cared for are complex care environments, and thus reducing the use of RP is likely to require complex interventions, involving different stakeholders and interventions/approaches as our programme theory suggests. For example, Riley[77] concluded that the reduction of RP requires a carefully selected combination of interventions such as PBS, Safewards and data-informed practice, alongside leadership and a well-developed and mixed workforce. Organisations, staff and person-centred level changes need long-term investment and, positive outcomes go beyond the reduction of RP but require personalised care for people with LD and their families, improved well-being for staff and more suitable care organisations. These findings point to a number of implications for how best to support practitioners and organizations to reduce RP with and for those who are the most vulnerable in society.

Recommendations for practice

Living free from RP is a human right for people with LDs. This review clearly shows that some solutions exist, but that comprehensive and cohesive frameworks are missing and the resources to ensure the implementation of evidence-based strategies are lacking, especially for this population.

There is a global shortage of health-care workers, especially nurses working on the frontline. Recruiting and retaining an appropriately trained and prepared workforce is therefore essential. It is recognised that workplaces where there are high levels of conflict, foster an overuse of RP, and that high staff turnover, a reliance upon temporary staff, stress and burnout are more prevalent in these settings. Therefore, investing in interventions/approaches that have been identified as having research-based outcomes is key.

In line with the CMOCs identified and the programme theory, our findings indicate that appropriately tailored interventions need to address challenges in the following areas:

i. individualised care planning (including autonomy and competency for people with LD/autism)
ii. communication and person-centred approaches
iii. stress reduction
iv. workforce development/training
v. reflection and reconnection (including debriefing)
vi. care delivery reorganisation
vii. appropriate staffing levels and mix
viii. invested organisations.

The following recommendations are proposed to capture these key areas of work, grouped by the three stakeholder groups identified in this review:

People with lived experiences

Individualised care planning

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

Autonomy for people with learning disability

- 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 allowed 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 is crucial to ensure 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 or may develop 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 and education 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. Therefore, 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 is recommended.
- Training for post-incident reviews including debriefing and post-incident support is recommended.

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; 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 monitor 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.

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 value-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 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.

Recommendations for future research

The findings of the papers included in this review (n = 53) were not always directly related to people with LD; therefore, more research and evidence is needed on how different approaches shown to be effective in mental health settings could work in LD settings, and if necessary, how they might be tailored to be successful and sustainable. The theory we have identified is deemed to be sufficiently broad to allow for transferability of findings to inform the design and implementation of approaches used across different settings.[31,110] More focused research is clearly needed with regards to the CMOCs highlighted in this review focussing on organisations, staff and workforce development and the specific needs of those with lived experience and their families. A significant gap is that family members and carers' needs and involvement are rarely addressed, thus research on their perspectives is warranted going forward.

Chapter 7 Equality, diversity and inclusion

Equality, diversity and inclusion core principles have been taken account when undertaking this project and reporting its results (here and elsewhere). It is important to note that this review reports on secondary data, that is peer-reviewed papers already published; therefore, the use of language and terminology in some sections of the report had to mirror that of the papers included in the review. However, through our in-depth consultation with stakeholders, especially people with lived experience and their carers, we have agreed on adapting the terminology used in this report to reflect a wide range of opinions and concerns regarding which terms are not considered appropriate, for example 'challenging behaviour', 'service users'.

Our review is already addressing a significant health inequality for people with a LD who may also have autism or mental health problems. There was no need to split results to indicate differences between groups based on the level of burden associated with the use of RP. The purpose of the review was to identify ways to prevent this from happening in the first place.

While this report captures the results of a realist review – methodology which can sometimes be hard to understand – we have developed a short lay/easy read summary of our report that was co-developed with people with lived experience of LD or autism to make sure that key messages from the review are accessible and can be disseminated widely, beyond the academia.

Our research team included people with lived experience of a LD who have contributed to the project throughout, including co-developing recommendations for practice and policy change. Our team was carefully put together to reflect a wide range of expertise and experience, including all genders, ages, expertise regarding the methodology (e.g. realist reviews), the topic (e.g. LDs, autism, RP in mental health settings, human rights), experience of having managed or contributed to previous National Institute for Health and Care Research-funded studies or other studies in this area of work, experience of caring for somebody with a LD or autism who has been subject to the use of RP, experience as practitioners/healthcare professionals and engaging with LD communities. Junior research assistants were supported in developing their skills and experience, including attending training, developing posters/briefings, presenting findings at national and international conferences, and contributing to emerging peer reviewed papers.

As highlighted in *Chapter 8* engaging with people with lived experience was at the core of our research, helping the team conducting the review to make it meaningful and accessible at all its stages.

Chapter 8 Patient and public involvement

In-depth consultation with people with lived experience has taken place to inform all aspects of the review. The research team included two co-investigators experts by experience, one advocate for people with LDs, and one mother of a person with LDs who has also had experience of RP. Their involvement in the research was essential in helping the team: (1) understand and use appropriate terminology, (2) choose means of disseminating findings and enabling discussions during the project meetings, (3) select inclusion and exclusion criteria for the review, (4) validate emerging programme theories and identify gaps, (5) identify best practice and ways to improve both policy and practice and (6) to co-design recommendations. Our overarching Advisory Group also comprised people with lived experience and their views and input were being incorporated in the research at all stages.

In addition, a number of workshops were conducted with people with lived experience, to inform the development of the IPTs, as well as the validation of the merging programme theory and CMOCs. For example, two workshops with eight self-advocates/people with lived experience in the community organised by LDE were conducted during the early stages of the review (July 2021). Two additional workshops with seven men and women inpatients in secure LD settings, all with a primary diagnosis of LD with other comorbid diagnosis including autism were conducted within the same timeframe (June–July 2021). One workshop with 28 carers/family members of people with LD was also conducted (June 2021). These were led by an advocate of LDs, who is the co-founder of LDE; a carer who is a founder of PABSS; and a research practitioner working within inpatient LD services in Mersey Care NHS Foundation Trust.

These workshops aimed to (1) identify silenced issues and understand the role of the carers/family members and the service users in the care pathway and the potential reduction in the use of RP; (2) shape the terminology and language used in the review, to ensure that information is appropriate and accessible for a lay audience; (3) sense-check IPTs; and (4) inform the search strategy for the systematic search of the literature (stage 2). Findings from these workshops were further complemented by those emerging from the last stakeholder consultation event bringing together researchers, practitioners, people with lived experience and policy-makers to validate emerging programme theory and coproduce recommendations to inform practice and policy change.

Chapter 9 Conclusions

This review highlights that LD settings are complex care environments, and thus reducing the use of RP is likely to require complex interventions, involving different stakeholders and interventions/approaches as our programme theory suggests. Organisations, staff and person-centred level changes need long-term investment, and positive outcomes go beyond the reduction of RP but require personalised care for people with LD and their families, improved well-being for staff and more suitable care organisations.

The previous government's failure to support people in the community is a national scandal, and the poor and restrictive practices used in these 'hospital units may amount to an abuse of their human rights.' As a response, public spending was allocated for research in the field of RP, but there was no priority at the time, specifically given to people with LDs and comorbid mental health challenges. Since the report 'Out of Sight – Who Cares?'[103] a huge spotlight has shone on these failures. Their findings are a direct parallel of this review. They summarise that

> *immediate action is needed to put an end to the abuses in human rights that we have seen. This action must be owned and led from the top by the new government, delivered by local systems working together, and involve people and their families to ensure the needs of the individual are met.*[103]

Subsequently, public funding has now increased in this field by over £90M and change has begun. This includes (though not exhaustively) a £40M investment from the NHS Long Term Plan[15] to improve crisis support for people with LDs in the UK; and a £74M Community Discharge Grant[111] to accelerate the discharge of people from hospitals back into the community. The Mental Health Act Reform Bill[112] limits the scope under which people with a LD can be detained for treatment under section 3 of the Act. This means that people with a LD will only be detained if a co-occurring mental health condition is identified by clinicians, ending the use of the Act to detain people who display challenging behaviour. The Health and Care Act[113] introduced new requirements for registered providers to ensure that staff receive specialised training on LD, which is appropriate to their role. While positive change has begun this is still despite the system not because of it.[114]

The fundamental long-term challenge of re-designing care outside of the hospital walls remains. So does the interim challenge of getting people out of long-term segregation and providing adequate care with a clear pathway back into the community. The 2022 'Building the Right Support for People with a Learning Disability and Autistic People Action Plan'[115] is a promising start. It holds the government and public services accountable with a commitment to keep people in hospitals safe and increase accountable, high-quality care. Similar to this review findings, the recommendations to do this include: reducing RP and providing targeted support for people in long-term segregation to move into the community or a less restrictive setting as appropriate. Most importantly, this Action Plan seeks long-term to reduce reliance on inpatient care by ensuring suitable community support is made available for people with LDs. There is now an explicit research call released seeking research teams to re-design long-term support for people with a LD outside the walls of a hospital setting in a way that better meets their needs.[116] Many of the recommendations and findings from this review could be used to inform that work.

While future narratives are necessary for systemic transformation, we cannot lose short-term sight of those stuck in the harmful and distressing cycle of inadequate care of services failing to meet their needs. They are still subjected to RP every 15 minutes with no care plans that aim to reintegrate them back into the community, risking institutionalisation. With these in mind, this review clearly shows that solutions for reducing RP exist, but comprehensive and cohesive frameworks are missing and the resources to ensure the implementation of evidence-based strategies are lacking. This review findings echo 'The National Learning Disability and Autism Programme'[117] research agenda requiring more evidence on how different approaches shown to be effective in mental health settings could work in LD settings, and if necessary, how they might be modified to be successful and sustainable. Furthermore, a significant gap is that carers' needs are rarely addressed, thus research on their perspectives is warranted going forward. 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.

Additional information

CRediT contribution statement

Joy Duxbury (https://orcid.org/0000-0002-1772-6874): Conceptualisation (equal), Data curation (equal), Formal analysis (equal), Funding acquisition (equal), Investigation (equal), Supervision (lead), Validation (equal), Visualisation (supporting), Writing – original draft (equal), Writing – reviewing and editing (equal).

Alina Haines-Delmont (https://orcid.org/0000-0001-6989-0943): Conceptualisation (equal), Data curation (equal), Formal analysis (equal), Funding acquisition (equal), Investigation (equal), Supervision (equal), Validation (equal), Visualisation (equal), Writing – original draft (equal), Writing – reviewing and editing (equal).

John Baker (https://orcid.org/0000-0001-9985-9875): Conceptualisation (supportive), Funding acquisition (supportive), Validation (equal), Writing – reviewing and editing (equal).

Peter Baker (https://orcid.org/0000-0003-1421-9639): Conceptualisation (supportive), Funding acquisition (supportive), Validation (equal), Visualisation (supporting), Writing – original draft (equal), Writing – reviewing and editing (equal).

Gary Bourlet: Conceptualisation (supporting), Funding acquisition (supporting), Validation (equal), Writing – reviewing and editing (equal).

Elaine Craig (https://orcid.org/0000-0002-4252-3956): Conceptualisation (equal), Data curation (equal), Formal analysis (equal), Funding acquisition (equal), Investigation (equal), Supervision (lead), Validation (equal), Visualisation (equal), Writing – original draft (equal), Writing – reviewing and editing (equal).

James Ridley (https://orcid.org/0000-0001-6337-9597): Conceptualisation (supporting), Funding acquisition (supporting), Validation (equal), Writing – reviewing and editing (equal).

Rachel Whyte (https://orcid.org/0000-0002-0568-4339): Data curation (equal), Formal analysis (equal), Investigation (equal), Validation (equal), Visualisation (supporting), Writing – original draft (equal), Writing – reviewing and editing (equal).

Beth Morrison (https://orcid.org/0009-0007-4903-4315): Conceptualisation (supporting), Funding acquisition (supporting), Investigation (equal), Validation (equal), Writing – reviewing and editing (equal).

Michaela Thomson (https://orcid.org/0000-0002-7849-1466): Conceptualisation (supportive), Data curation (supporting), Formal analysis (supporting), Funding acquisition (supporting), Investigation (supporting), Validation (equal), Visualisation (supporting), Writing – original draft (supporting), Writing – reviewing and editing (equal).

Anthony Tsang (https://orcid.org/0000-0002-2735-7515): Data curation (equal), Formal analysis (equal), Investigation (equal), Validation (equal), Visualisation (supporting), Writing – reviewing and editing (equal).

Tella Lantta (https://orcid.org/0000-0001-7715-7573): Data curation (equal), Formal analysis (equal), Investigation (equal), Validation (equal), Visualisation (supporting), Writing – original draft (equal), Writing – reviewing and editing (equal).

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Data-sharing statement

This is a review and therefore the data generated is not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

Ethics statement

This research has received approval from the Health, Psychology and Social Care Research Ethics and Governance Committee at Manchester Metropolitan University (Ethos approval number 22510) on 30 October 2020. The focus groups with family members/carers of people with lived experience of LDs/autism and restrictive practices were covered by additional ethical approval granted by the HRA, including the Yorkshire and The Humber – South Yorkshire Research Ethics Committee (REC reference 22/YH/0247, IRAS project ID 318154) on 15 December 2022.

Confidentiality and anonymity

The primary data included in this review (i.e. focus groups with family members of people with complex needs and/or experience of restrictive practice) were covered by ethical approval granted by the HRA, including the Yorkshire and The Humber – South Yorkshire Research Ethics Committee (REC reference 22/YH/0247, IRAS project ID 318154). Data from the focus groups were managed and shared in a way that safeguarded the confidentiality and anonymity of participants and were consistent with the terms of consent signed by participants.

Information governance statement

Manchester Metropolitan University is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. This research project was compliant with the UK Data Protection Act and the UK's General Data Protection Regulation with regards to the collection, storage, transfer and disclosure of personal information and upheld the laws core principles.

Under the Data Protection legislation, Manchester Metropolitan University is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here (www.mmu.ac.uk/data-protection/dppolicy).

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/PGAS1755.

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Publication

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Appendix 1 Main literature search strategies

Database: Applied Social Sciences Index and Abstracts

Date searched: 21 July 2021

Hits: 3189

1. (ab(PICA) OR ab(Mental* Handicap*) OR su("learning disability") OR su(SU "adult") OR su(SU "mental deficiency") OR su(SU "Autism Spectrum Disorder") AND su(SU "neurodevelopmental disorder")) OR (ab(Intellect* disabilit* OR ID) OR ab(Learning disabilit* OR LD) OR ab(Learning disorder*) OR ab(Challenging behavior* OR behavior* of concern OR behavior* that challenge*) OR ab(Aggressive behavior*) OR ab(Developmental disabilit*) OR ab(Development disorder*) OR ab(Intellect* NEAR/2 impair*) OR ab(mental* retard*) OR ab(autism OR ASD))
2. ab(Mental health OR psyc* OR forensic OR secure* OR locked NEAR/5 inpatient* OR ward* OR unit* OR hospital* OR center* OR centre* OR department* OR clinic* OR organization OR institutionalized) OR ab(Treatment OR assessment NEAR/1 unit*)
3. mechanical* OR "physical* restrain*" OR "manual* restrain*" OR observ* OR segregat* OR Medication OR chemical OR Rapid tranquili?ation OR sedat* OR PRN OR "blanket rule*" OR "blanket restriction*" OR Seclus* OR Seclude* OR Restrain* OR restrict* OR Coerci* OR Coerced OR SU "Patient isolation" OR Practice* OR intervention* NEAR/2 restric* OR "clinical hold" OR "therapeutic hold*" OR "physical intervention*" OR "Solitary confinement" OR Clinical NEAR/2 hold* OR Rapid NEAR/3 tranq* OR Forced NEAR/3 medic* OR Forced NEAR/3 sedat* OR Forced NEAR/3 drug* OR Lock* NEAR/3 door* OR Lock* NEAR/3 room* OR Lock* NEAR/3 ward* OR Patient* NEAR/3 isolat* OR Consumer* NEAR/3 isolat* OR Service user* NEAR/3 isolat*
4. "Safewards" OR "no force first" OR train* OR educat* OR learn* NEAR/2 staff OR "six core strategies" OR "REsTRAIN YOURSELF" OR "Engagement model" OR "Improvement model"
   "crisis intervention" OR "PDSA" OR "joint crisis plans" OR Restrain* OR restrict* NEAR/3 reduc* OR "De-briefing" OR "debriefing" OR "post-incident review" OR "post-seclusion review" OR "post-restraint review" OR "post-seclusion counselling" OR safe OR comfort OR sensory NEAR/2 room* OR "sensory modulation" OR trauma-informed NEAR/3 approach* OR "trauma-informed care" OR "positive behavior support" OR Reduc* OR Declin* OR Decreas* OR Prevent* OR Minimi* OR Eliminat* OR Diminish* OR Shorten* OR calm down or soft word* or talk down OR Open door polic* OR Person-center* NEAR/2 approach OR Person-centre* NEAR/2 approach OR "Personalized support" OR "individualized care" OR De-escalat* OR deescalat* OR Mindfulness* OR Behavioral intervention* OR "Non-pharmacological intervention" OR "Recovery-based practices" OR "Program* management" OR Risk assessment* OR "Text mining analysis" OR "Rapid restraint analysis" OR RRA OR "Methodical work approach" OR MWA OR "Relational Neurobehavioral Approach"
5. 1 AND 2 AND 3 AND 4

Database: CINAHL

Date searched: 21 July 2021

Hits: 742

1. Intellect* disabilit* OR ID
2. Learning disabilit* OR LD
3. Learning disorder*
4. Challenging behavio#r* OR behavio#r* of concern OR behavio#r* that challenge*
5. Aggressive behavio#r*
6. Developmental disabilit*
7. Development disorder*

8. Intellect* N2 impair*
9. mental* retard*
10. autism OR ASD
11. PICA
12. Mental* Handicap*
13. neurodevelopmental disorder
14. adult
15. MH"learning disability"
16. MH "mental deficiency"
17. MH "Autism Spectrum Disorder"
18. Setting
19. (Mental health OR psyc* OR forensic OR secure* OR locked) N5 (inpatient* OR ward* OR unit* OR hospital* OR center* OR centre* OR department* OR clinic* OR organi?ation or institutionali?ed)
20.
21. Treatment OR assessment *N* unit*
22.
23. Restrictive practices
24.
25. mechanical* OR physical* restrain* OR manual* restrain*
26. observ*
27. segregat*
28. Medication OR chemical
29. Rapid tranquili?ation OR sedat* OR PRN
30. "blanket rule*" OR "blanket restriction*"
31. Seclus* OR Seclude*
32. Restrain* OR restrict*
33. MH "Patient isolation+"
34. Coerci*
35. Coerced
36. (Practice* OR intervention*) N2 restric*
37. "clinical hold" or "therapeutic hold*"
38. "physical intervention*"
39. "Solitary confinement"
40. Clinical N2 hold*
41. Rapid N3 tranq*
42. Forced N3 medic*
43. Forced N3 sedat*
44. Forced N3 drug*
45. Lock* N3 door*
46. Lock* N3 room*
47. Lock* N3 ward*
48. Patient* N3 isolat*
49. Consumer* N3 isolat*
50. Service user* N3 isolat*
51. Interventions to reduce
52. "Safewards"
53. "no force first"
54. (train* OR educat* OR learn*) N2 staff
55. "six core strategies"
56. "REsTRAIN YOURSELF"
57. "Engagement model"
58. "Improvement model"
59. "crisis intervention"

60. "PDSA"
61. "joint crisis plans"
62. Restrain* OR restrict* N3 reduc*
63. "De-briefing" OR "debriefing"
64. "post-incident review"
65. "post-seclusion review"
66. "post-restraint review"
67. "post-seclusion counselling"
68. (safe OR comfort OR sensory) N2 room*
69. "sensory modulation"
70. trauma-informed N3 approach*
71. "trauma-informed care"
72. "positive behavio$r support"
73. Reduc* OR Declin* OR Decreas* OR Prevent* OR Minimi* OR Eliminat* OR Diminish* OR Shorten*
74. calm down or soft word* or talk down
75. Open door polic*
76. Person-center* N2 approach
77. Person-centre* N2 approach
78. "Personali?ed support" OR "individuali?ed care"
79. De-escalat* OR deescalat*
80. Mindfulness*
81. Behavio$ral intervention*
82. "Non-pharmacological intervention"
83. "Recovery-based practices"
84. "Program* management"
85. Risk assessment*
86. "Text mining analysis"
87. "Rapid restraint analysis"
88. RRA
89. "Methodical work approach"
90. MWA
91. "Relational Neurobehavio#ral Approach"

Database: EMBASE

Date searched: 21 July 2021

Hits: 4601

1. Intellect* disabilit* OR ID
2. Learning disabilit* OR LD
3. Learning disorder*
4. Challenging behavio?r* OR behavio?r* of concern OR behavio?r* that challenge*
5. Aggressive behavio?r*
6. Developmental disabilit*
7. Development disorder*
8. Intellect* adj2 impair*
9. exp learning disability/
10. exp mental deficiency/
11. exp Autism Spectrum Disorder/
12. adult
13. neurodevelopmental disorder exp neur disorder/ = million(s) and neur disorder/= 69k.

14.
15. mental* retard*
16. autism OR ASD
17. PICA
18. Mental* Handicap*
19.
20.
21. Setting
22. (Mental health OR psyc* OR forensic OR secure* OR locked OR assessment OR treatment) adj5 (inpatient* OR ward* OR unit* OR hospital* OR center* OR centre* OR department* OR clinic* OR organi#ation or institutional-i#ed)
23.
24. ((Assessment or treatment) adj unit*)
25.
26.
27.
28. Restrictive practices
29.
30. mechanical* OR physical* restrain* OR manual* restrain*
31. observ*
32. segregat*
33. medication or chemical
34. Rapid tranquili#ation OR sedat* OR PRN
35. blanket rule* OR blanket restriction*
36. Seclus* OR Seclude*
37. Restrain* OR restrict*
38. Exp Patient isolation/
39. Coerci*
40. Coerced
41. Practice* OR intervention* adj2 restric*
42. clinical hold* or therapeutic hold*
43. physical intervention*
44. Solitary confinement
45. Clinical or therapeutic adj2 hold*
46. Rapid adj3 tranq*
47. Forced adj3 medic*
48. Forced adj3 sedat*
49. Forced adj3 drug*
50. Lock* adj3 door*
51. Lock* adj3 room*
52. Lock* adj3 ward*
53. Patient* OR consumer* adj3 isolat*
54. Service user adj3 isolat*
55.
56. Interventions to reduce
57. Safewards
58. no force first
59. staff train* OR education OR learning OR train* or educat* or learn* adj2 staff
60. six core strategies
61. ReSTRAIN YOURSELF
62. Engagement model OR improvement model OR crisis intervention OR PDSA OR joint crisis plans
63. Restrain* OR restrict* adj3 reduc*

64. De-briefing OR debriefing OR post incident review OR post seclusion review OR post restraint review OR post-seclusion counselling
65. safe OR comfort OR sensory adj2 room*
66. sensory modulation
67. trauma-informed adj3 approach*
68. trauma-informed care
69. positive behavio?r support OR PBS
70. Reduc* OR Declin* OR Decreas* OR Prevent* OR Minimi* OR Eliminat* OR Diminish* OR Shorten*
71. calm down or soft word* or talk down
72. Open door polic*
73. Person-center* adj2 approach
74. Person-centre* adj2 approach
75. Personali#ed support OR individuali#ed care
76. De-escalat* OR deescalat*
77. Mindfulness*
78. Behavio?ral intervention* OR non-pharmacological intervention OR recovery based practices OR program* management
79. Risk assessment*
80. Text mining analysis OR rapid restraint analysis OR RRA
81. Methodical work approach OR MWA
82. Relational Neurobehavio?ral Approach OR RNA

Database: MEDLINE

Date searched: 21 July 2021

Hits: 513

1. Intellect* disabilit* OR ID
2. Learning disabilit* OR LD
3. Learning disorder*
4. Challenging behavio?r* OR behavio?r* of concern OR behavio?r* that challenge*
5. Aggressive behavio?r*
6. Developmental disabilit*
7. Development disorder*
8. Intellect* adj2 impair*
9. exp learning disability/
10. exp mental deficiency/
11. exp Autism Spectrum Disorder/
12. adult
13. neurodevelopmental disorder exp neur disorder/ = million(s) and neur disorder/= 69k.
14.
15. mental* retard*
16. autism OR ASD
17. PICA
18. Mental* Handicap*
19.
20.
21. Setting
22. (Mental health OR psyc* OR forensic OR secure* OR locked OR assessment OR treatment) adj5 (inpatient* OR ward* OR unit* OR hospital* OR center* OR centre* OR department* OR clinic* OR organi#ation or institutional-i#ed)

23.
24. ((Assessment or treatment) adj unit*)
25.
26.
27.
28. Restrictive practices
29.
30. mechanical* OR physical* restrain* OR manual* restrain*
31. observ*
32. segregat*
33. medication OR chemical
34. Rapid tranquili#ation OR sedat* OR PRN
35. blanket rule* OR blanket restriction*
36. Seclus* OR Seclude*
37. Restrain* OR restrict*
38. Exp Patient isolation/
39. Coerci*
40. Coerced
41. Practice* OR intervention* adj2 restric*
42. clinical hold* OR therapeutic hold*
43. physical intervention*
44. Solitary confinement
45. Clinical or therapeutic adj2 hold*
46. Rapid adj3 tranq*
47. Forced adj3 medic*
48. Forced adj3 sedat*
49. Forced adj3 drug*
50. Lock* adj3 door*
51. Lock* adj3 room*
52. Lock* adj3 ward*
53. Patient* OR consumer* adj3 isolat*
54. Service user adj3 isolat*
55.
56. Interventions to reduce
57. Safewards
58. no force first
59. staff train* OR education OR learning OR train* or educat* or learn* adj2 staff
60. six core strategies
61. ReSTRAIN YOURSELF
62. Engagement model OR improvement model OR crisis intervention OR PDSA OR joint crisis plans
63. Restrain* OR restrict* adj3 reduc*
64. De-briefing OR debriefing OR post incident review OR post seclusion review OR post restraint review OR post-seclusion counselling
65. safe OR comfort OR sensory adj2 room*
66. sensory modulation
67. trauma-informed adj3 approach*
68. trauma-informed care
69. positive behavio?r support OR PBS
70. Reduc* OR Declin* OR Decreas* OR Prevent* OR Minimi* OR Eliminat* OR Diminish* OR Shorten*
71. calm down or soft word* or talk down
72. Open door polic*
73. Person-center* adj2 approach
74. Person-centre* adj2 approach

75. Personali#ed support OR individuali#ed care
76. De-escalat* OR deescalat*
77. Mindfulness*
78. Behavio?ral intervention* OR non-pharmacological intervention OR recovery based practices OR program* management
79. Risk assessment*
80. Text mining analysis OR rapid restraint analysis OR RRA
81. Methodical work approach OR MWA
82. Relational Neurobehavio?ral Approach OR RNA

Database: PsycInfo

Date searched: 21 July 2021

Hits: 1394

1.
2. Intellect* disabilit* OR ID
3. Learning disabilit* OR LD
4. Learning disorder*
5. Challenging behavio?r* OR behavio?r* of concern OR behavio?r* that challenge*
6. Aggressive behavio?r*
7. Developmental disabilit*
8. Development disorder*
9. Intellect* adj2 impair*
10. exp learning disability/ - this was not used because it is not a subject heading in PsycInfo
11. exp mental deficiency/
12. exp Autism Spectrum Disorder/
13. adult
14. Exp neurodevelopmental disorder/
15.
16. mental* retard*
17. autism OR ASD
18. PICA
19. Mental* Handicap*
20.
21.
22. Setting
23. (Mental health OR psyc* OR forensic OR secure* OR locked OR assessment OR treatment) adj5 (inpatient* OR ward* OR unit* OR hospital* OR center* OR centre* OR department* OR clinic* OR organi#ation or institutionali#ed)
24.
25. ((Assessment or treatment) adj unit*)
26.
27.
28.
29. Restrictive practices
30.
31. mechanical* OR physical* restrain* OR manual* restrain*
32. observ*
33. segregat*
34. medication

35. Rapid tranquili#ation OR sedat* OR PRN
36. blanket rule* OR blanket restriction*
37. Seclus* OR Seclude*
38. Restrain* OR restrict*
39. Exp Patient isolation/ - NOT A valid subject heading – used patient isolation instead
40. Coerci*
41. Coerced
42. Practice* OR intervention* adj2 restric*
43. clinical hold
44. physical intervention*
45. Solitary confinement
46. Clinical adj2 hold*
47. Rapid adj3 tranq*
48. Forced adj3 medic*
49. Forced adj3 sedat*
50. Forced adj3 drug*
51. Lock* adj3 door*
52. Lock* adj3 room*
53. Lock* adj3 ward*
54. Patient* adj3 isolat*
55. Service user adj3 isolat*
56.
57. Interventions to reduce
58. Safewards
59. no force first
60. staff train* OR education OR learning OR train* or educat* or learn* adj2 staff
61. six core strategies
62. ReSTRAIN YOURSELF
63. Engagement model OR improvement model OR crisis intervention OR PDSA OR joint crisis plans
64. Restrain* OR restrict* adj3 reduc*
65. De-briefing OR debriefing OR post incident review OR post seclusion review OR post restraint review OR post-seclusion counselling
66. safe OR comfort OR sensory adj2 room*
67. sensory modulation
68. trauma-informed adj3 approach*
69. trauma-informed care
70. positive behavio?r support OR PBS
71. Reduc* OR Declin* OR Decreas* OR Prevent* OR Minimi* OR Eliminat* OR Diminish* OR Shorten*
72. calm down or soft word* or talk down
73. Open door polic*
74. Person-center* adj2 approach
75. Person-centre* adj2 approach
76. Personali#ed support OR individuali#ed care
77. De-escalat* OR deescalat*
78. Mindfulness*
79. Behavio?ral intervention* OR non-pharmacological intervention OR recovery based practices OR program* management
80. Risk assessment*
81. Text mining analysis OR rapid restraint analysis OR RRA
82. Methodical work approach OR MWA
83. Relational Neurobehavio?ral Approach OR RNA

Database: Web of Science Emerging Sources Citation Index

Date searched: 21 July 2021

Hits: 6336

1. Intellect* disabilit* OR ID OR Learning disabilit* OR LD OR Learning disorder* OR Challenging behavio$r* OR behavior* of concern OR behavio$r* that challenge* OR Aggressive behavio$r* OR Developmental disabilit* OR Development disorder* OR Intellect* NEAR/2 impair* OR mental* retard* OR autism OR ASD OR PICA OR Mental* Handicap* OR ”learning disability” OR “adult” OR “mental deficiency” OR “Autism Spectrum Disorder” OR “neurodevelopmental disorder”
2. Mental health OR psyc* OR forensic OR secure* OR locked NEAR/5 inpatient* OR ward* OR unit* OR hospital* OR center* OR centre* OR department* OR clinic* OR organi?ation OR institutionali?ed OR Treatment OR assessment NEAR/1 unit*
3. mechanical* OR “physical* restrain*” OR “manual* retrain*” OR observ* OR segregat* OR Medication OR chemical OR Rapid tranquili?ation OR sedat* OR PRN OR “blanket rule*” OR “blanket restriction*” OR Seclus* OR Seclude* OR restrict* OR Coerci* OR Coerced OR “Patient isolation” OR Practice* OR intervention* NEAR/2 restric* OR “clinical hold” OR “therapeutic hold*” OR “physical intervention*” OR “Solitary confinement” OR Clinical NEAR/2 hold* OR Rapid NEAR/3 tranq* OR Forced NEAR/3 medic* OR Forced NEAR/3 sedat* OR Forced NEAR/3 drug* OR Lock* NEAR/3 door* OR Lock* NEAR/3 room* OR Lock* NEAR/3 ward* OR Patient* NEAR/3 isolat* OR Consumer* NEAR/3 isolat* OR Service user* NEAR/3 isolat*
4. “Safewards” OR “no force first” OR train* OR educat* OR learn* NEAR/2 staff OR “six core strategies” OR “RESTRAIN YOURSELF” OR “Engagement model” OR “Improvement model” OR “crisis intervention” OR “PDSA” OR “joint crisis plans” OR Restrain* OR restrict* NEAR/3 reduc* OR “De-briefing” OR “debriefing” OR “post-incident review” OR “post-seclusion review” OR “post-restraint review” OR “post-seclusion counselling” OR safe OR comfort OR sensory NEAR/2 room* OR “sensory modulation” OR trauma-informed NEAR/3 approach* OR “trauma-informed care” OR “positive behavio$r support” OR Reduc* OR Declin* OR Decreas* OR Prevent* OR Minimi* OR Eliminat* OR Diminish* OR Shorten* OR calm down or soft word* or talk down OR Open door polic* OR Person-center* NEAR/2 approach OR Person-centre* NEAR/2 approach OR “Personali?ed support” OR “individuali?ed care” OR De-escalat* OR deescalat* OR Mindfulness* OR Behavio$ral intervention* OR “Non-pharmacological intervention” OR “Recovery-based practices” OR “Program* management” OR Risk assessment* OR “Text mining analysis” OR “Rapid restraint analysis” OR RRA OR “Methodical work approach” OR MWA OR “Relational Neurobehavio$ral Approach”
5. 1 AND 2 AND 3 AND 4

Appendix 2 PRISMA diagram

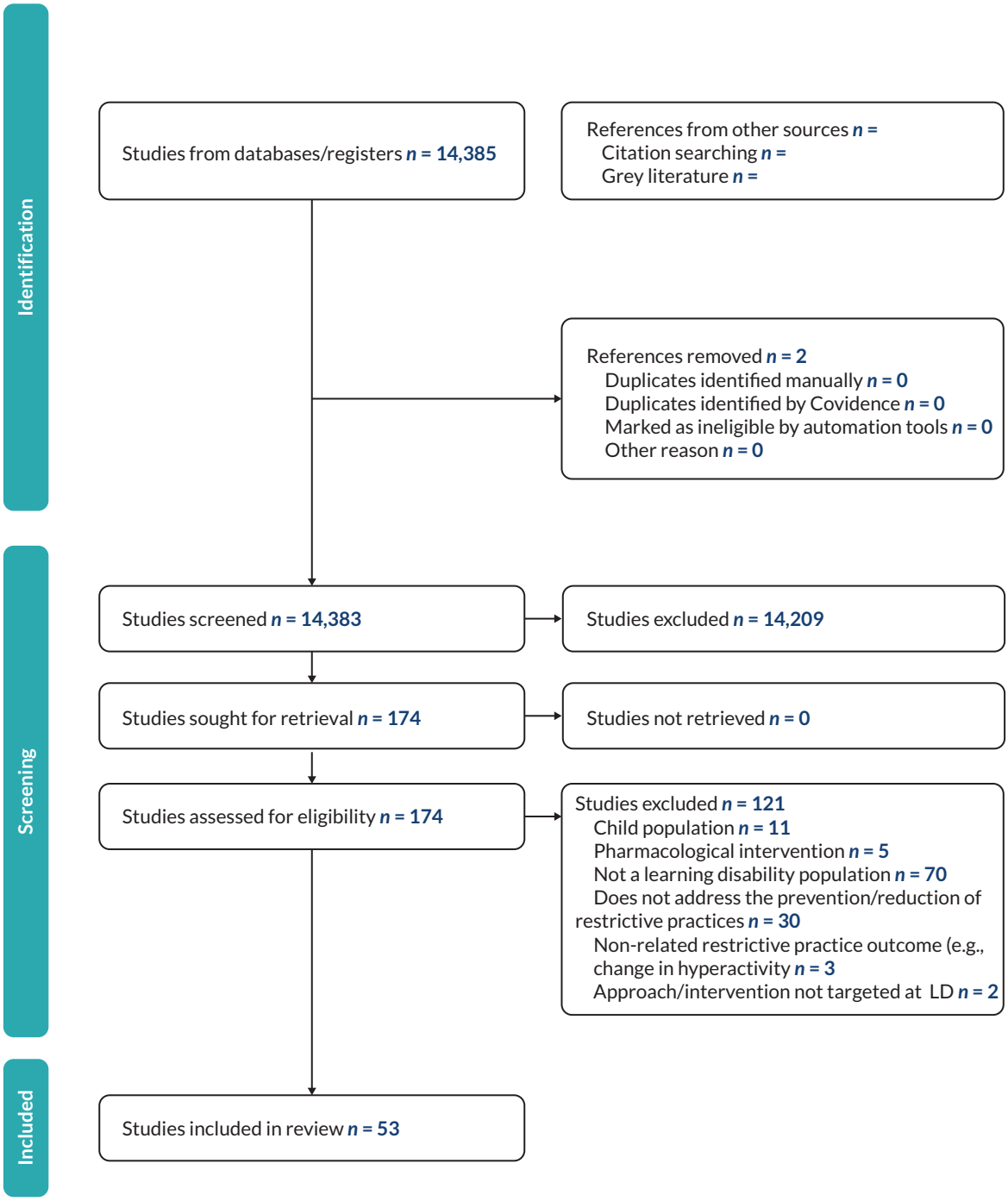

FIGURE 8 Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram for the LEARN review: main search.

Appendix 3 Relevance and rigour of included studies

TABLE 1 Relevance and rigour of included studies

Article ID	High relevance	Low relevance	Rigour	Miscellaneous notes
Allen *et al.*[22]	✓		✓	Rich background detail of the PBS model including case example specific to LD deriving from a separate study
Ashworth *et al.*[57]		✓	✓	No explicit mention of training targeting reduction of RP, only on relevant/important staff attributes
Beard and Barter[58]	✓		✓	Theoretical background paper that divides concepts into micro, meso and macro levels directly relevant to IPT
Bisconer *et al.*[59]	✓		✓	LD was the primary population of target with detailed methodology of approach used
Black and Greenwald[60]		✓	×	Not specific to LD as it discusses multiple populations with very thin descriptions of approach to reduce RP
Bybel[61]		✓	✓	Multiple diagnoses but author confirmed 'some had intellectual disability diagnosis'
Chaplin[62]		✓	×	Narrative review that does not predominately focus on RP reduction
Chaplin *et al.*[63]		✓	✓	De-escalation was not explicitly used in the reduction of RP, it was used to manage with incidents
Chartier *et al.*[24]	✓		✓	Participant characteristics outlined with detailed methodology of approach used
Clarkson *et al.*[64]	✓		✓	Rich qualitative study that includes a section on data analysis plan and reflexivity
Connolly *et al.*[65]	✓		✓	Rich description of the PBS model that is useful for programme theory refinement
Deveau and Leitch[66]		✓	✓	Findings are not exclusive to the LD population
Donat[67]		✓	✓	Findings are not specific enough for the LD population
Feldman *et al.*[68]		✓	✓	Relevant findings to the LD population with a range of severity in LD diagnosis (e.g. borderline, moderate and profound)
Fish and Hatton[52]	✓		✓	Qualitative findings relevant to the LD population; in-depth description of alternative to restraint
Gaskin *et al.*[10]	✓		✓	A review with findings specific to the LD population with description of approach used in each study aimed at reducing seclusion and/or restraint
Goulding and Riordan[69]		✓	✓	Thin description of how RP is reduced in a LD population and lacking detail in methods of analysis
Hext *et al.*[70]	✓		✓	Rich details on approaches (e.g. de-escalation and BPPS-PBSPs)
Hughes and Lane[53]	✓		✓	Contains relevant key information to facilitate the refinement and building of the IPT with a specific focus on the LD population
Javaid *et al.*[25]	✓		✓	Detailed case study outlining how a PBS plan can reduce the use of medication
Joyce[71]		✓	✓	Thin description of approach(es) to reduce RP. Commentary is not entirely specific to the LD population.
Kernohan[72]		✓	×	Delineation of methods are not clear (e.g. screening procedures). CASP were not reported in results despite being mentioned in the methods. Synthesis also not outlined.

TABLE 1 Relevance and rigour of included studies (*continued*)

Article ID	High relevance	Low relevance	Rigour	Miscellaneous notes
Larue *et al.*[73]	✓		✓	
Lee *et al.*[54]	✓		✓	Highly detailed case study with a person diagnosed with LD
Luiselli *et al.*[36]	✓		✓	Highly detailed case study with a person diagnosed with LD
McClean *et al.*[74]	✓		×	Case series with rich detail of each individual. Approach for each individual was also delineated. Lacks a detailed methodology to allow replication.
Merineau-Cote and Morin[75]		✓	✓	Thin description/explanation of how approach(es) can reduce restraint and seclusion
Morrissey *et al.*[76]		✓	×	Thin explanation for the reduction of seclusion. Also, approach used (i.e. therapeutic communities) was poorly described.
Riding[29]	✓		✓	In-depth details of the approaches used to reduce restraint with strong discussion section relevant for programme theory refinement
Riley *et al.*[77]		✓	×	Contains relevant information regarding approaches to reduce RP but the target population is not exclusive to LD
Robinson[78]	✓		×	Personal/professional opinion not supported by evidence/citations
Singh *et al.*[28]	✓		✓	Thorough details of methodology including explanations of results
Smethurst[79]		✓	×	Conceptually thick and thin descriptions
van der Meulen *et al.*[80]	✓		✓	Rich description of topic of interest in conjunction with LD population
van Melle *et al.*[81]		✓	✓	LD comprises minority of the whole sample (i.e. 2%)
Vedana *et al.*[82]		✓	×	Mixed population, hence lower relevance. Delineation of analysis methods is brief. Does not mention whether analysis was conducted at a semantic or latent level. Also, attributed incorrect label to Braun and Clarke's TA – 'reflexive TA' is the correct attribution.
Vere-Jones[83]		✓	×	News article. Professional/personal opinion that is not substantiated with evidence that is readily available in the article.
Webber *et al.*[84]		✓	×	Comparing RP between two groups but minimisation of RP was not the primary outcome. Some elicitation of reduction discussed and explored, nonetheless. Lack of detail regarding BPSs and treatment plans – no definition, characteristics not outlined.
Webber *et al.*[85]		✓	✓	Examined factors (i.e. individual and organisational) associated with the use of seclusion rather than a direct approach. Methodology outlined in great detail. Slight misinterpretation of results (i.e. odds ratio)
White[86]		✓	×	Book review. Thin descriptions of topic of interest. Personal/professional opinions are not substantiated.

BPPS, behavioural support plans that adopt a biopsychopharmacosocial approach.
Notes
Relevance = Whether or not articles contained data that can be used to contribute to programme theory development and refinement.
Rigour = Whether methods used to generate the data can be considered credible/trustworthy?
Low relevance = (1) when findings were not specific enough for the target group in this review (adults with LD), (2) insufficient explanation of results pertaining to the reduction of RP, (3) approach(es) used in article to reduce RP lacked transparency to allow for replication, (4) examined factors or characteristics associated with the reduction of RP rather than a direct approach.

Appendix 4 Characteristics of included studies

TABLE 2 Characteristics of included studies

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Allen *et al.*[22]	2016	UK	Case study example	To report the dissemination and adoption of PBS within treatments programmes at regional and national levels in the UK	Care home	LDs	PBS	Physical intervention (restraint) and medication	The use of physical intervention (restraint) reduced from four to zero and the use of 'required' medication from 19 to 2
Ashworth *et al.*[57]	2016	UK	Evaluation of a training programme using verbal feedback and free text boxes on evaluation sheets	To present the development and evaluation of a training package for staff members on awareness of an adapted DBT programme designed for individuals with ID	Medium-secure psychiatric hospital	ID	Adapted DBT programme	N/A	An increase in self-reported knowledge, confidence and motivation related to the seven aspects of training were reported by the trainees
Beard and Barter[58]	2016	UK	Commentary paper	To discuss the role of clinical psychologists in promoting compassionate cultures within LD services	N/A	ID	Micro-level (e.g. the self), meso-level (e.g. leadership) and macro-level (e.g. social structures)	N/A	N/A
Bisconer *et al.*[59]	2006	USA	Case study (pre-and post-design)	To examine the role of nursing in implementing a behaviour plan in a psychiatric hospital	A ward consisting of 20 patients between the ages of 23- and 64-year-olds	Chronic and persistent mental health illness and complex medical problems	Behaviour plan	Restraints, PRN medication and 1 : 1 special observation	Overall decrease in the frequency of restraints, PRN medication and 1 : 1 special observation
Black and Greenwald[60]	2019	USA	Book chapter	Discussed the implementation, documentation and discontinuation of seclusion and restraint for patients	N/A	N/A	Debriefing and periodic progress notes	Restraint, seclusion and 1 : 1 observation	N/A

continued

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Bybel[61]	2011	USA	Literature review and survey questionnaire	To investigate if teaching staff evidence-based alternatives for restraints and seclusion had any effect on the use of coercive measures	Freestanding psychiatric hospital	Mixed population of major depression, schizophrenia, bipolar disorder, eating disorders and ID	The role of leadership and educational training	Restraint and seclusion	A significant inverse correlation between the number of staff trained and number of seclusion and restraint events
Chaplin[62]	2011	UK	Literature review	To summarise research into psychiatric services for adults with ID with a focus on inpatient care	General and specialist psychiatric services and emergency psychiatric services	ID	Staff training	Restraint, seclusion and PRN medication	Qualitative research has contributed to a better understanding of patients' and carers' experiences. RP still need addressing
Chaplin *et al.*[63]	2009	UK	Correlational study	To explore incidents reported and subsequent use of restrictive procedures and whether specific types of incidents and restrictive procedures were associated with presence of clinical psychopathology	Six-bedded, non-secure unit in a psychiatric hospital in South-East London	ID with comorbid diagnoses	De-escalation	Physical restraint, medication, sanctions or surveillance	Psychiatric diagnosis was not associated with involvement of incidents. Physical assault was the most common incident associated with physical restraint. De-escalation was most frequently associated with less serious incidents such as verbal abuse and theft
Chartier *et al.*[24]	2020	Canada	Prospective cohort (observational)	Preliminary clinical outcome evaluation on the impact of QAM-compliant BSPs on challenging behaviour, use of intrusive measures, and staff acceptance	Five community group homes of 14 individuals	ID	QAM-compliant BSPs	Physical restraint	Physical restraint decreased by 64% by the 12-month post-QAM BSP

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Clarkson *et al.*[64]	2009	UK	Qualitative focus group and interview study	To explore the perceptions of service users regarding direct support staff	Residential forensic service	LDs who have offended or are considered at risk of offending	Emotional relationship between service users and staff and staff characteristics	Physical restraint	Participants valued a consistent, familiar staff team with meaningful interpersonal relationships based on qualities such as honesty and trust. Staff attributes such as immaturity and inexperience increased discontentment and were perceived as unsupportive, resulting in vulnerability and frustration
Connolly *et al.*[65]	2019	UK	Discussion paper	To describe new mandatory training standards and an alternative approach to restrictive interventions to prevent or reduce behavioural crisis from occurring	N/A	Mental health conditions, autism, dementia and LDs	PBS and RRN training standards	N/A	N/A
Deveau and Leitch[66]	2019	UK	Survey questionnaire	To examine the extent to which aspects of positive and proactive care were being implemented in services for people with LD	Hospitals, private sectors, social services and charities/ housing associations that supported a total of 23,805 service users or students	LDs	Positive and proactive care	Physical restraint, seclusion, being escorted and PRN medication	Frontline staff and managers were perceived to be important in reducing RP. Collected data on RP were seen to be generally accurate. Uncertainty was shown in relation to goals and activities required to provide post-incident reviews
Donat[67]	2003	USA	Correlational study	To evaluate a variety of interventions considered to be associated with the successful reduction of seclusion and restraint	Public psychiatric hospital	Schizophrenia, schizoaffective disorderincludingcomorbidity that includes mild mental retardation	Administrative review, behavioural consultation team, review procedure, behavioural assessments and plans, improving staff–patient ratio	Restraint and seclusion	The reliance on the use of seclusion and restraint reduced by 75% based on the average hours per month during the first year compared to the average hours per month during the final year

continued

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Fish and Hatton[52]	2017	UK	Ethnography (observations and interviews)	To explore women's experience of physical restraint in locked wards and their staff in the North of England	Three wards at a NHS LD secure unit	LDs (women only)	Interpersonal relationship and de-escalation	Physical restraint	Positive relationships between staff and service users can reduce the need for restraint
Gaskin *et al.*[10]	2013	Australia	Systematic review	To investigate whether the use of seclusion and restraints on people with DD can be reduced	N/A	DD with comorbid diagnoses	Choice of staff member responsible for care, building rapport, mindfulness-training programme and OBM	Restraint	Broad variations in the magnitude of effect sizes and percentage of reduction in restraint use. Effects were more pronounced where restraint use for self-harm was targeted compared to restraint use for agitation and aggression
Goulding and Riordan[69]	2016	UK	Literature review and questionnaire with follow-up focus groups	To explore the perceived needs of junior nurses working with women with LD	Secure forensic ward containing a variety of units of varying levels of security	LD	Staff peer support	Seclusion	The findings indicated that emotional support needs for staff are important following incidents of violence and aggression. Staff indicated that peer support to be made available and that they receive adequate education relating to gender-specific issues and the use of seclusion
Hext *et al.*[70]	2018	UK	Discussion paper	To raise awareness of RP and provide a way forward	LD and mental health settings	LD and mental health conditions	De-escalation and BPPS	Restraint, seclusion and rapid tranquilisation	Adoption of early de-escalation skills in therapeutic relationships may help reduce challenging behaviours and situations. Tailored BPPS-PBSPs could reduce costly observation, improve patient experience and protect patient's liberty

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Hughes and Lane[53]	2016	Republic of Ireland	Discussion paper	To explore physical restraint use and misuse in ID settings, as well as the ethical, legal and political issues associated with its use	ID services	ID	National policy and nursing ethics	Physical restraint	N/A
Javaid *et al.*[25]	2020	UK	Case study	To describe how a PBS plan was used to reduce anxiety and challenging behaviour in a person with autism	LD inpatient unit	LD and ASD	PBS	Medication	Decrease in lorazepam usage following reduction in frequency of challenging behaviour
Joyce[71]	2020	UK	Discussion paper	To examine the extent to which inpatient services deliver good practice in treatment and care, and where this is not happening, the extent to which they are subject to effective governance	N/A	LD	Staff training, therapeutic environment and PBS	RP	N/A
Kernohan[72]	2016	UK	Literature review	To explore the factors that may influence a nurse's decision to use seclusion when supporting a person with LD	N/A	LD	N/A	Seclusion	Patient factors, staff factors and organisational and environmental factors influence decisions on use of seclusion

continued

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Larue *et al.*[73]	2018	Canada	Retrospective case series based on patient files and focus groups (with management staff)	To identify factors contributing to the reduction of SR use for patients with ID, mental illness and severe behavioural disorders	Tertiary psychiatric facility	ID with comorbid diagnoses	Leadership characteristics, organisational culture, family involvement, tools to support clinical judgement and therapeutic environment	Restraint and seclusion	A myriad of contributory factors were identified ranging from unity staff efforts, involvement of families to a therapeutic environment
Lee *et al.*[54]	2019	UK	Case study	To demonstrate how PBS can be used as an alternative to psychotropic medication to improve the QoL of an individual with a LD and behaviour described as challenging	Residential home	LD	PBS STOMP	Psychotropic medication	The adoption of PBS increases QoL and decreases the use of antipsychotic medication
Luiselli *et al.*[36]	2002	USA	Case study	To document the adjustment and 7-year evaluation of therapeutic maintenance of an individual with mental retardation and multiple psychiatric disorders	Community habilitation setting	LD with multiplepsychiatric disorders including atypical psychosis and borderline PD	Multicomponent behaviour support intervention	Mechanical restraint	The use of mechanical restraint was successfully discontinued and physical restraint was reduced to near-zero levels
McClean *et al.*[74]	2007	Republic of Ireland	Case series	To evaluate the implementation of PBS for five people with the most severe challenging behaviours in community-based settings	Community-based settings	LD with comorbid diagnoses	PBS	Psychotropic medication	Medication rates reduced by 66%

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
van Melle *et al.*[81]	2020	The Netherlands	Audit of patient health records	To present the associations between high and intensive care model fidelity and seclusion rates in acute psychiatric wards	32 closed acute psychiatric wards	Variety of diagnoses including schizophrenia, developmental disorder and autism and ID	High and intensive care	Seclusion and forced medication	No relationships were found between the presence of an intervention plan and the use of restrictive measures. The presence of a de-escalation plan was associated with physical restraint
van der Meulen *et al.*[80]	2018	The Netherlands	Qualitative interview study and analysis of clinical files	To examine how people with moderate ID perceive and evaluate restrictions applied to them in daily care and to what extent do they agree with these restrictions?	Residential and family-home settings	ID	N/A	Restrictions in five domains of daily life (eating, hygiene, social contacts, means of communication and bedtimes)	Significant differences in the reduction of seclusion were observed between the two groups at the 6- and 12-month post-intervention stage
Mérineau-Côté and Morin[75]	2013	Canada	Survey questionnaire	To identify personal and environmental factors related to the use of restrictive measures among persons with ID living in the community	Residential settings (e.g. specialised resource homes and group homes)	LD with comorbid diagnoses	Intervention plan and de-escalation plan	Physical restraint, mechanical restraint and seclusion	Overall, there were no clear trends in the frequency of restrictive measure use. However, restraints and seclusions initiated by staff were about two times more frequent in group homes with ASD and about 53 times more frequent than in group homes without ASD
Morrissey *et al.*[76]	2012	UK	Controlled quasi-experimental	To present preliminary evaluation of a planned therapeutic community service intervention in a secure setting for men with mild ID and PD over a 12-month period	Four residential units with 48 beds	PD with ID	Therapeutic environment	Seclusion	52% reduction in rapid tranquilisation. 42% reduction in physical restraint and use of seclusion. Elimination of prone and mechanical restraint

continued

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Riding[29]	2016	UK	Intervention study	To describe the nature and impact of a restraint reduction strategy implemented within a secure LD service in response to the national Positive and Safe programme	Medium- and low-secure services for adults with a LD	LD	Safewards, PBS and data-informed practice	Physical restraint, prone restraint, mechanical restraint, seclusion and rapid tranquilisation	Relatively high intellectual level, low adaptive functioning and the presence of challenging behaviours were found to be significant predictors of restraint. Specifically, behaviours other than actual aggression proved to be predictor of restraint
Riley *et al.*[77]	2018	UK	Discussion paper	To discuss the principle of recovery-focused care	Mental health care and LD services	N/A	No Force First	RP	Restraint was the method of intervention used most commonly by nursing staff to intervene in violent incidents involving both women and men. Rapid tranquilisation was more likely to be used following actual or threatened violence in females than males. Men were more likely to be subjected to seclusion than women. Women viewed interventions as punishment and expressed intense anger and anxiety
Robinson[78]	2019	UK	Commentary with questionnaire survey	To provide commentary on an article from the perspective of Dimensions, a national provider of social care support to people with LDs and/or autism	A range of unspecified settings	LD and/or autism	Dimension STOMP campaign	Psychotropic medication	MBPBS was significantly more effective than TAU in reducing the use of physical restraints and emergency medications

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Singh *et al.*[28]	2016	USA	RCT	To evaluate the comparative effectiveness of MBPBS and TAU for caregivers in a congregate care facility for individuals with severe and profound IDD	Large congregate care facility	IDD	MBPBS	Physical restraints and emergency medication	Restraints of freedom were found to be centred around the basic elements of life of the client (e.g. eating and sleeping). Communication with the client and knowing the client are methods of decreasing daily restraints of freedom
Smethurst[79]	2016	UK	Discussion paper	To explore how physical restraint breaches four ethical principles (respect for autonomy, non-maleficence, beneficence and justice)	N/A	LD	Staff training, care plans and debriefing	Physical restraint	A higher implementation of the high and intensive care model had lower seclusion hours per admission hours and less forced medication events compared to wards with a lower implementation level of high and intensive care model
Vedana *et al.*[82]	2018	Brazil	Qualitative interview study	To understand the experiences and perceptions of nursing staff about physical restraint in psychiatric units	Two psychiatric units from a general hospital	*Variety of diagnoses including ID and psychiatric conditions	Reducing environment risks, staff training and verbal and attitudinal management	Physical restraint	Physical restraint was perceived to be challenging, risky and unpleasant, and associated with dilemmas and conflicts
Vere-Jones[83]	2007	UK	Interview paper	To report the English Trust that challenged physical restraint	10-bed acute inpatient wards	LD and mental health conditions (e.g. paranoid schizophrenia)	Strategies for Crisis Intervention and Prevention	Physical restraint	N/A

continued

TABLE 2 Characteristics of included studies (*continued*)

Author(s)	Year	Country	Study design/ methods	Aim/objectives	Sample/setting	Population (targeted)	Aspect/type of approach to prevent or reduce the use of RP	RP	Main relevant findings
Webber *et al.*[84]	2010	Australia	Retrospective analysis of audits of restrictive interventions	To describe the characteristics and use of restrictive interventions on people with a compulsory treatment order when compared to those who were also subjects to restrictive interventions but were not subjects to compulsory treatment orders	Government and community service organisations including residential accommodation services and respite services	ID with comorbid diagnoses (e.g. autism and psychiatric disorders)	N/A	Mechanical restraint, chemical restraint and seclusion	A higher proportion of those on compulsory treatment orders were subjected to seclusion than the matched group. However, similar proportions were observed in both groups regarding mechanical and chemical restraint
Webber *et al.*[85]	2014	Australia	Retrospective analysis of restrictive interventions	To examine individual and organisational factors on the use of seclusion in disability services	Community settings (e.g. residential services), congregate care and institutional facilities (e.g. respite services)	ID with comorbid diagnoses (e.g. autism and psychiatric disorders)	N/A	Mechanical restraint, chemical restraint and seclusion	Presence of comorbidities (i.e. autism or psychiatric disorders) and harm to others were positively associated with seclusion. Organisational factors such as people who lived in an institution or who lived within the community were at increased odds of being secluded than those who were housed in other settings such as day and respite services
White[86]	2015	Australia	Book review	To review a book aimed at providing a framework to assist organisations in reducing their reliance on RP	N/A	ID	PBS	RP	N/A

AROC, Aggression and Restriction Observation Checklist; ASD, autism spectrum disorder; BPPS, behavioural support plans that adopt a biopsychopharmacosocial approach; DBT, dialectical behavioural therapy; ID, intellectual disabilities; IDD, intellectual and developmental disabilities; PD, personality disorder; PICU, Psychiatric Intensive Care Unit; PRN, pro re nata; QAM, quality assurance measures; TAU, treatment as usual.

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