This is a repository copy of *What do people with intellectual disabilities, their family members and paid carers understand about psychotropic medication? A rapid review*.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/215435/

Version: Published Version

Article:

Cavanagh, D.E. orcid.org/0000-0002-5204-9485, Caton, S. orcid.org/0000-0001-9013-8721, Rawles, J. et al. (4 more authors) (2024) What do people with intellectual disabilities, their family members and paid carers understand about psychotropic medication? A rapid review. Journal of Applied Research in Intellectual Disabilities, 37 (5). e13283. ISSN 1360-2322

https://doi.org/10.1111/jar.13283

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

Received: 6 December 2023 | Revised: 5 July 2024 | Accepted: 9 July 2024
DOI: 10.1111/jar.13283

REVIEW

JARID Journal of Applied Research in Intellectual Disabilities bild WILEY

What do people with intellectual disabilities, their family members and paid carers understand about psychotropic medication? A rapid review

Dawn E. Cavanagh[1] | **Sue Caton**[1] | **Jodie Rawles**[2] | **Katherine Runswick-Cole**[2] | **Chris Hatton**[1] | **Umesh Chauhan**[3] | **Christine Hutchinson**[4]

[1]Department of Social Care and Social Work, Manchester Metropolitan University, Manchester, UK

[2]The School of Education, The University of Sheffield, Sheffield, UK

[3]School of Medicine and Dentistry, University of Central Lancashire, Preston, UK

[4]Learning Disability Services and Autism Services, Lancashire and South Cumbria NHS Foundation Trust, Preston, UK

Correspondence
Dawn E. Cavanagh, Department of Social Care and Social Work, Faculty of Health and Education, Manchester Metropolitan University, Brooks Building, 53 Bonsall Street, Manchester, M15 6GX, UK.
Email: d.cavanagh@mmu.ac.uk

Funding information
National Institute for Health and Care Research (NIHR), Grant/Award Number: NIHR204107

Abstract

Background: People with intellectual disabilities are more likely to be prescribed psychotropic medication than the general population and are frequently prescribed multiple medications. Understanding people with intellectual disabilities and carer perspectives is essential to improving the quality of psychotropic medication prescribing and usage.

Method: A rapid review explored people with intellectual disabilities' understanding of psychotropic medications, as well as family members and paid carers, and how this understanding can be improved.

Results: Twenty-one journal articles were included. Lack of understanding of medication was universal, with participants often unaware of adverse effects, alternatives, and rights around medication. There was also a lack of involvement in decision making for all participants. Some interventions aimed at people with intellectual disabilities or paid carers helped to improve knowledge.

Conclusion: Evaluating how best to improve psychotropic medication understanding for people with intellectual disabilities, family members and paid carers should be a focus for future research.

KEYWORDS
behaviours that challenge, family members, intellectual disabilities, paid carers, psychotropic medication, understanding

1 | INTRODUCTION

Intellectual disability is defined as 'a significantly reduced ability to understand new or complex information and to learn and apply new skills…result[ing] in a reduced ability to cope independently, and begin[ning] before adulthood, with a lasting effect on development' (World Health Organisation, 2017). People with intellectual disabilities in the UK are more likely to be diagnosed with mental illness compared to the general population (Cooper et al., 2007; Deb et al., 2001). However, the proportion of people with intellectual disabilities who have been treated with psychotropic medication (medication that works in the brain and is used to treat mental illness) in the UK (including antipsychotics, antidepressants, anxiolytics and antiepileptics as mood stabilisers) far exceeds the proportion with a recorded mental illness

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.
© 2024 The Author(s). *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd.

J Appl Res Intellect Disabil. 2024;37:e13283.
https://doi.org/10.1111/jar.13283

(Sheehan et al., 2015). Frequent use of psychotropic medications, often in the absence of a formal diagnosed psychiatric disorder, has also been reported in individuals with intellectual disabilities in other countries, such as Norway and Spain (De Kuijper et al., 2010; Folch et al., 2019). Public Health England estimated that at any time around 30,000 to 35,000 adults with intellectual disabilities are prescribed psychotropic medication by their General Practitioner (GP) without appropriate clinical justification (Glover et al., 2015).

The latest information from the *Health and Care of People with Learning Disabilities* dataset shows that people with intellectual disabilities are more likely than people without intellectual disabilities to be prescribed antipsychotics (14.5% vs. 0.9%), including antipsychotics in the absence of a severe mental illness diagnosis (9.1% vs.0.5%), antidepressants (21.2% vs.10.7%), including antidepressants in the absence of a diagnosis of depression (12.0% vs.4.5%) and benzodiazepines (7.1% vs.1.8%) (NHS England, 2022). The Learning Disability Census Report (England) of people with intellectual disabilities in inpatient units in 2015 reported that 72% of people had either regularly prescribed or PRN ('as and when required') antipsychotic medication in the 28 days before the census, while 11% of people had received rapid tranquilising medication (Health and Social Care Information Centre, 2015).

Antipsychotics and other medications are often used off-label (Haw & Stubbs, 2005) and in the absence of a diagnosed mental health condition for people with intellectual disabilities (Sheehan et al., 2015). Off-label prescribing is when a licensed drug is used outside the terms of its marketing authorisation, meaning that the benefits or risks of using the drug in these circumstances has not been examined by a regulatory agency (Haw & Stubbs, 2005). Psychotropic medications are often prescribed to treat behaviour that challenges and, in some instances, they are used as chemical restraint, where medication is used to restrict the freedom of movement of the person by subduing or sedating the individual (Care Quality Commission, 2020). Psychotropic medications are often prescribed to treat behaviour that challenges, which is a descriptive term rather than a diagnosis, with displayed behaviours an expression of distress or a means of communication rather than a mental health condition (Royal College of Psychiatrists, 2016; Sheehan et al., 2015).

The use of psychotropic medication to manage behaviour that challenges is largely unsupported by research evidence (Matson & Neal, 2009; Tyrer et al., 2008) and can detract from non-pharmacological psychosocial and environmental interventions, such as positive behavioural support, which are favoured by the *National Institute Health and Care Excellence* (NICE) for the management of behaviours of concern (National Institute for Health and Care Excellence, 2015). Gore et al. (2013) describe Positive Behavioural Support as a multicomponent framework for developing an understanding of behaviour that challenges based on an assessment of the social and physical context in which the behaviour occurs. Strategies aimed at redesigning the environment and guiding the behaviour of people who provide support are outlined in a positive behavioural support plan aimed at improving the quality of life for the person. People with intellectual disabilities from minority ethnic groups are at greater risk of being given medication for behaviour that challenges than other people with intellectual disabilities (Holmes et al., 2023). It has been suggested that these dispartities may indicate institutional and/or individualised racism within pharmacological practice for these populations (Holmes et al., 2023).

There is also evidence that more women than men with intellectual disabilities are given mental health medication (NHS England, 2022), a trend that is reflected in the wider UK general population (Hassan et al., 2016; Ohayon et al., 1998).

High psychotropic medication usage and psychotropic polypharmacy (when people are taking a number of mental health medications) are also common in this group. A UK cross-sectional population study reported that of 217 people with intellectual disabilities using services almost a quarter (23%) were being prescribed two or more mental health drugs (McMahon et al., 2020). High doses and psychotropic polypharmacy have been found to increase the chances of drug–drug interactions and medication-related adverse events, with common and serious adverse effects including weight gain, obesity, diabetes, extrapyramidal symptoms, seizures and heart problems (Deb et al., 2023). Psychotropic polypharmacy is commonplace for older adults with intellectual disabilities (O'Dwyer et al., 2017), with the probability of being given more psychotropic medication increasing as the person gets older (García-Domínguez et al., 2022). One reason for this greater use could be difficulty with identifying age-associated health conditions such as dementia, which is more prevalent in people with intellectual disabilities and which can develop at a younger age (Cooper et al., 2018). Another reason might be that older adults with intellectual disabilities are more likely to experience major life events and multiple losses due to family bereavement, differences in living circumstances, cognitive decline, greater dependency on others and less autonomy, which can lead to a deterioration in mental health and/or behaviours that challenge (Bond et al., 2019).

Given the risks associated with long-term psychotropic medication use, including extra-pyramidal side effects, involuntary autonomic disturbances, and endocrine and metabolic disorders (de Leon et al., 2009), it is concerning that people with intellectual disabilities also tend to be treated with psychotropic medication for long periods of time (Costello et al., 2022). Reasons for this include the lack of a medication review (Adams, 2019; Costello et al., 2022), limited availability of psychological support and resources, lack of training around positive behavioural support and a high turnover of staff (Adams, 2019). Furthermore, there may be pressure from family carers and staff to continue to prescribe psychotropic medication to manage behaviours that challenge (Branford & Shankar, 2022) or to avoid risk of relapse of behaviours that challenge which could lead to placement breakdown (Adams, 2019) and potential transfer to out of area residential placements or even admission to hospital.

It is possible to reduce or stop long-standing psychotropic medication as part of a medicine optimisation process, which entails the

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

supervised withdrawal of the medication (Branford et al., 2019b). *STOMP (Stopping Over-Medication of People with a Learning Disability, Autism or Both)* is a national project in England, launched in 2016. It aims to reduce overmedication, with a particular emphasis on the health risks associated with this (Branford et al., 2019a), especially considering the *Learning Disability Mortality Review* (LeDeR, 2018) and the finding that inappropriate medication usage can be a significant contributory factor, or the cause, of a person's death. There have been some limited early signs of potential reductions in the prescription of psychotropic medications since *STOMP* was launched (Mehta & Glover, 2019). However, the most recent *Health and Care of People with Learning Disabilities* dataset information suggests that while initiatives such as *STOMP* are having some impact on reducing the numbers of people being prescribed psychotropic medication, the increase in those being prescribed antidepressants suggests there may be a shift in prescribing behaviour (NHS Digital, 2022).

Shared decision making ensures that people are supported to make decisions about their treatment that are right for them and is a key component of universal personalised care as set out in the NHS Long term Plan (2019). Despite being disproportionately prescribed psychotropic medication, people with intellectual disabilities are not always aware of their right to be involved in decision making and experience a lack of involvement in the process (Raghu & Patel, 2010). To support shared decision making in people with intellectual disabilities it is important to consider health literacy and accessible information since the extent to which people have appropriate information or feel knowledgeable may influence whether they feel confident participating in decisions (Sheehan et al., 2019). However, research shows that people with intellectual disabilities are not always able to read the labels on their prescribed medication and may struggle to remember verbal information given to them (Fish et al., 2017). This suggests that there is a need for accessible and tailored information about prescribed medication mandated in the Accessible Information Standard (NHS England, 2017) for this group. Research to date suggests that the views of people with intellectual disabilities about psychotropic medication, and how they can be supported to become more involved in decision making, are largely absent. Yet, to empower people with intellectual disabilities and the people who support them to become more confident and effective agents in shared decision making there needs to be greater insight into what people who have been prescribed psychotropic medication understand about their medication and its impact on their lives. A scoping review exploring people with intellectual disabilities' understanding of their prescription medication found that many people had a poor understanding of their prescription medication, including a lack of knowledge about medication names, how to take their medication and the associated risks (Smith et al., 2019).

Accordingly, an exploratory rapid review was carried out to identify and gain a broad overview of the research evidence relating to what adults with intellectual disabilities understand about their psychotropic medication, as well as that of their family carers and those with paid caring responsibilities.

2 | METHODS

2.1 | Ethical procedure

Research ethics approval was sought and obtained from Manchester Metropolitan University Ethics Committee. There were no human subjects.

2.2 | Review approach

Rapid reviews are an emerging type of evidence synthesis, alongside systematic reviews, and scoping reviews. A rapid review aims to be rigorous, whilst providing a more streamlined, efficient and pragmatic approach to evidence synthesis than the systematic review (Moher et al., 2015). This rapid review was designed to provide a comprehensive, yet broad overview of the topic area. Many of the principles of a systematic review were used. Search terms were clearly defined using Boolean principles and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) described the search. The inclusion and exclusion criteria were clearly defined. However, the systematic review process was expedited by making adaptations to some steps, which will be acknowledged and explained below.

2.3 | Identifying the research question

The research question, which was developed following an initial review of the literature and project team discussion was: *Do people with intellectual disabilities, family members and those with paid caring responsibilities, understand psychotropic medication? How can this understanding be improved?*

2.4 | Search strategy

Systematic electronic searches were conducted in April 2023 on the following electronic databases: the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science and PsycInfo. Please see Table 1 for the search terms used in the databases. Initial searches were conducted on MEDLINE and PubMed, but not translated into full searches as there were so few studies relevant to the subject.

A grey literature search was not included because an initial search revealed that a comprehensive search was unlikely to identify literature relevant to the research question.

2.5 | Inclusion and exclusion criteria

Studies were only included if they reported on people's understanding of psychotropic medication from the perspective of people with intellectual disabilities (aged 16 years+), family members or paid carers.

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 1 Search terms.

Search term 1	Search term 2	Search term 3
Search operator	And	And
intellectua* disab* (or difficult* or handicap* or impair*) OR menta* disab* (or deficien* or impair* or retard*or handicap*) OR global developmental delay OR learning (disab* or difficult* or disorder*) OR developmental disab* (or difficult* or delay or retard* or impair* or handicap*) OR multiple disab* (or handicap*) OR profound disab* (or handicap*) or Down* Syndrome	Psychotropic medication* OR Psychotropic drug* OR Mental health medication* OR Mental health drug* OR PRN usage OR Antipsychotic* OR Antidepressant* OR Mood stabiliser* OR Anxiolytic* OR antiepileptic* OR Stimulant*	Side effect* OR Risk* OR Knowledge OR Understanding OR Decision making OR Consent OR Information OR Informed consent OR Health education OR Health literacy OR Adverse effect*

TABLE 2 Framework for recording data.

Type of data	
1	Author
2	Year of publication
3	Study location
4	Study design
5	Study aim(s)
6	Participants
7	Methodology
8	Findings

Studies could also be included if they reported on improving understanding for these groups. The search was restricted to papers published in peer reviewed journals. Empirical research data using either quantitative, qualitative, or mixed methods design were included, as well as case studies. Studies were to be excluded from the rapid review if they included systematic reviews or literature reviews, editorials, commentaries, opinion pieces or reports. Only publications written in the English language were eligible for inclusion. Valuing People (2001) was a new strategy for people with intellectual disabilities for the 21st century, which was based on the principles of rights, independence, choice and inclusion. The document indicated that policy and practice were changing, a key area being mental health. For instance, a key action was for a Mental Health National Service Framework 'to bring new benefits to people with learning disabilities'. (p. 61) Literature published prior to 2000 may therefore not have been relevant to current policy and practice and so the search was limited to the years 2000 to 2023.

2.6 | Study selection

All identified articles were imported into Rayyan, a web-based collaborative review platform, to enable rapid screening of retrieved sources. After duplicates had been removed, titles and abstracts of articles were screened independently, with each article assessed for relevance according to the inclusion/exclusion criteria. A subsample of 15% of abstracts was reviewed by a second reviewer which was conducted in blinding mode. The blinding mode was then removed, and the full-text articles for included decisions were reviewed by both reviewers. There was one disagreement between reviewers which was resolved through discussion with the reviewers and the wider research team until a consensus was reached. The reference lists of all included articles were examined to ensure that all relevant and eligible studies had been identified.

2.7 | Collating, summarising and reporting the results

Papers were read in full and data from the relevant articles was tabulated and summarised by two members of the research team based on Arksey and O'Malley's (2005) framework for recording data (Table 2):

Characteristics of the studies were then reported, for example, country, setting, study design and participant group.

2.8 | Quality assessment

A quality assessment was not carried out as an initial review of the research literature revealed that the number of studies identified from the review were likely to be small. Furthermore, identified papers were likely to include a range of methodological approaches, including qualitative research and/or case studies with small sample sizes that may not have been deemed high quality (but for transparency the methodological approach of identified papers have been included in Table 3).

3 | RESULTS

3.1 | Included studies

Initial searching of electronic databases provided 1135 records. Using the Rayyan tool, 145 duplicates were removed leaving 990 records to screen for relevance based in title and abstract. After title and abstract screening, 22 articles were eligible for full-text screening. Following full-text screening, a further six articles were removed for reasons including:

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 Overview of psychotropic medication knowledge (and interventions to improve knowledge) among people with intellectual disabilities, family members and paid carers.

Author (year), country	Study design	Study aim(s)	Participants	Methodology	Findings
Aman et al. (2007), USA	Quantitative process evaluation	To evaluate a medication education booklet series for people with intellectual disabilities.	$N = 604$ adult respondents, 60% ($n = 361$) of whom were classed by the researchers as having intellectual disabilities.	Standardised 13-item questionnaire containing closed questions distributed to consumers with and without intellectual disabilities via pharmacies, physicians' offices, county boards etc.	Consumers with intellectual disabilities experienced more difficulty in understanding the materials, but satisfaction and understanding were reportedly high overall.
Arscott et al. (2000), UK	Quantitative assessment of knowledge	To explore the knowledge that people with intellectual disabilities had about their mental health medication.	$N = 30$ adults with intellectual disabilities who attended social-education centres, colleges and employment-preparation units in two towns in the West Midlands.	The 31-item Knowledge of Prescribed Medication Questionnaire (KPMQ) was adapted for use with people with intellectual disabilities, with some questions removed and the wording of questions simplified.	Participants had a poor knowledge about some aspects of their medication, especially side-effects, other medications which should not be taken in conjunction with the prescribed medication, and alternatives to medication.
Barratt et al. (2023), Australia	Qualitative arm of larger mixed methods study	To explore disability support workers perceptions of the SPECTROM (Short-term Psycho-Education for Carers To Reduce Over Medication of people with intellectual disabilities) programme and to gain an insight into how they perceive their role in this area of practice.	$N = 10$ participants who supported people with intellectual disabilities within 'group homes'.	Post-intervention semi-structured interviews. conducted virtually following completion of SPECTROM 8 h training. Analysed using thematic analysis.	While participants felt that SPECTROM training improved knowledge and attitudes, they added that without a practice framework consistent reduction in the use of psychotropic medication would be improbable.
Crossley and Withers (2009), UK	Qualitative study	To explore how informed people with intellectual disabilities were about their medication; how they felt about taking long-term antipsychotic medication and the decisions involved in this process.	$N = 8$ adults described as having mild-moderate intellectual disabilities. Residing within an NHS domiciliary service in community homes within the North of England.	Two phased, semi-structured interviews, with the data organised and analysed using grounded theory methodology.	Participants had little knowledge about their medication, beyond knowing their regime. Despite some strong feelings regarding medication and side effects there was a general feeling of acceptance and a belief that nothing could change.
Crowley et al. (2008), UK	Pre/post-test intervention. Pilot	To assess people's understanding about psychosis, their medication, stress and relapse after attending a psycho-education programme, and to improve people's knowledge of their illness.	$N = 8$ adults with a dual diagnosis of psychosis and mild intellectual disability. Recruited from an outpatient population served by a community intellectual disability team.	Two groups were run ($N = 4$ in each group) for six sessions. Groups ran weekly for 1 h 30 min (with one break). Measures of knowledge and self-esteem were completed pre- and post-group.	All participants completed the programme and measures of psychosis knowledge showed increases post-group. The participants were able to understand the concept of psychosis, the need for medication, the role of stress and early signs of relapse.

(Continues)

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 (Continued)

Author (year), country	Study design	Study aim(s)	Participants	Methodology	Findings
de Kuijper and van der Putten (2017), The Netherl-nds.	Quantitative assessment of knowledge and expectations of direct support professionals	Aim was to investigate the knowledge and expectations of support professionals towards effects of psychotropic drug use on behaviour in the people they support.	$N = 194$ support workers in 14 residential facilities.	Two-self-designed questionnaires were used to measure knowledge and expectations.	The majority had unrealistic expectations regarding the positive effects of antipsychotics on cognitive and behavioural functioning, and 94% scored below the cut-off scores regarding knowledge; 60% indicated they needed education and training.
Deb et al. (2021), UK	Field testing and process evaluation using mixed methods	Aim was to develop a training programme, SPECTROM, for support staff to help reduce overmedicate-ion in people with intellectual disabilities and to carry out field testing of SPECTROM including a process evaluation.	$N = 20$ participants (support workers) received SPECTROM training.	SPECTROM was developed using the Experience-based co-design method that included four focus groups and a one-day co-design event. The Management of Aggression and Violence Attitudes Scale-Revised-Intellectual Disabilities (MAVAS-R-ID) and the Psychotropic Knowledge Questionnaire was used for field testing. A semi-structured interview and a feasibility questionnaire were used for process evaluation.	MAVAS-R-ID scores showed a statistically significant improvement in staff attitude to 'medication management' ($p < 0.05$). Psychotropic Knowledge Questionnaire showed statistical post-training improvement in correct responses ($p < 0.05$). Process evaluation data showed that SPECTROM was acceptable, applicable, practical, and relevant to staff practice, and helped to improve self-reflection, knowledge, and support to people with intellectual disabilities.
Deb et al. (2023), UK	Qualitative study	To elicit staff views on the psychotropic use for challenging behaviour to inform the contents of SECTROM resources, such as staff teaching modules.	Support staff ($n = 8$), home managers ($n = 5$) and PBS trainers ($n = 2$).	Two focus groups led by a facilitator using a topic guide. Analysed using thematic analysis.	Some participants felt medication use was justified, but others viewed it as a form of chemical restraint. Most agreed that polypharmacy of psychotropics might lead to side effects. Some acknowledged the lack of shared decision-making involving people with intellectual disabilities and their families. There was universal anxiety about withdrawing the medication.
Donley et al. (2011), Australia	Mixed methods	To explore disability support workers' knowledge of chemical restraint and training needs in relation to its administration. Also explored their perceptions of the support provided by other professionals and family members.	$N = 117$ survey respondents. $N = 6$ interviewees.	Email survey and semi-structured interviews.	The majority of workers felt that they had good support from their co-workers and supervisors to support people who display behaviours that challenge; however, there was a need for more specific information regarding psychotropic medication side effects and alternatives.

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 (Continued)

Author (year), country	Study design	Study aim(s)	Participants	Methodology	Findings
Edwards et al. (2017), Australia	Qualitative study	To explore the views of family members of adults with intellectual disabilities who have been prescribed psychotropic medication to help manage challenging behaviour.	$N = 7$ family members of people with intellectual disabilities with moderate to high support needs.	Semi-structured interviews via face-to-face or the telephone. Thematic analysis was used to organise and analyse the data.	Many viewed medication as having a positive impact. There were some concerns, such as a lack of positive behavioural support plans. There was a need for improved communication with family members and inclusive decision making.
Fretwell and Felce (2007), UK	Quantitative assessment of knowledge. Pilot study	Aim was to explore staff knowledge of anti-psychotic medication for people with intellectual disabilities and their associated side effects.	$N = 22$ carers and $N = 3$home managers.	Completed simple questionnaire to identify people with intellectual disabilities on their caseloads and their current medications.	Knowledge of potential side effects was somewhat limited, with only two having been identified by most respondents. Most felt that the information they received was insufficient and that there was a need for further training.
Hall and Deb (2008), UK	Qualitative study	Aim was to explore the knowledge and views of adults with intellectual disabilities and their carers of medication prescribed for behaviour that challenges.	$N = 20$ adults with mild to moderate intellectual disabilities who attended a psychiatric outpatient clinic.	Structured and semi-structured interviews, with the data analysed using grounded theory analysis.	Few people with intellectual disabilities were fully informed about their treatment. However, the prescribing of such medication emerged as a positive experience. For the few who expressed dissatisfaction, reasons related to perceived lack of role in the treatment decision, their experience of adverse effects, a perceived lack of efficacy and a ‘desire to lead a normal life’.
Heslop et al. (2005), UK	Qualitative, participatory study	Aim was to explore what knowledge people with intellectual disabilities and their carers had about the person's treatment with psychotropic medication.	$N = 21$ people with intellectual disabilities; $N = 20$ carers and $N = 11$ prescribers. Individuals with intellectual disabilities were contacted via the partner organisations and the voluntary and statutory organisations with which they worked.	Semi-structured face-to-face interviews, using grounded theory analysis.	Many carers said that although they knew how to administer the medication, they knew little about why the person was taking it and what the implications might be. Despite this, people with intellectual disabilities made the general assumption that carers would, or should, know everything about their medication. The current provision of information to people with intellectual disabilities and carers was found to be poor, yet many prescribers relied on carers to reinforce information about medications.

(Continues)

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 (Continued)

Author (year), country	Study design	Study aim(s)	Participants	Methodology	Findings
Lalor and Poulson (2013), UK	Qualitative study	Aim was to explore the experiences and attitudes of care staff for adults with intellectual disabilities prescribed psychotropic medication living in long-term residential care.	$N = 8$ full-time, experienced care staff.	Semi-structured interviews. Data were analysed using interpretative phenomenolo-gical analysis.	Staff had a number of concerns, such as the negative impact of medication upon client quality-of-life, the ethical implications of the medications' regime, and a significant lack of training, which meant that they felt frustrated with the organisation.
Sheehan et al. (2019), UK.	Qualitative study	Aim was to explore experiences of psychotropic medication use among people with intellectual disabilities and their families and paid carers.	$N = 14$ adults with intellectual disabilities, $N = 12$ family carers and $N = 12$ paid carers were recruited from specialist psychiatry services, groups, care providers and training organisations in the UK.	Individual, face-to-face, semi-structured interviews. Thematically analysed.	Though people with intellectual disabilities sometimes experienced medication negatively, they were generally not aware of their right to be involved in medication decisions. While family and paid carers described making joint decisions about medication with psychiatrists, lack of involvement was often described. This took three forms in participants' accounts: being uninformed of important facts, insufficiently included in discussions and lacking influence on shaping decisions. Participants described efforts to democratise the decision-making process by gathering information, acting to disrupt perceived power asymmetries, and attempting to prove their credibility as valid decision-making partners.
Sawyer et al. (2019), Canada	Quantitative assessment of knowledge	Aim was to explore the experience of direct care staff involved in managing medication for people with intellectual disabilities.	$N = 152$ direct care staff employed at three agencies providing residential services for individuals with intellectual disabilities across Ontario.	A 15-item online survey, focusing on self-reported knowledge and comfort with psychotropic medication.	62% of staff reported that psychotropic medications were among the top medications regularly taken by people with intellectual disabilities, with behaviour listed as the most reported reason for taking medication. Most staff reported monitoring medication, however, the frequency of monitoring varied. Staff reported feeling knowledgeable about medication use, but most reported a desire for additional training.

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 (Continued)

Author (year), country	Study design	Study aim(s)	Participants	Methodology	Findings
Sheehan et al. (2018), UK	Mixed methods	Aim was to explore the experiences and views of family carers about the management and the use of psychotropic medication to manage behaviours that challenge.	$N = 99$ family carers of people with intellectual disabilities.	Online structured questionnaire created by the Challenging Behaviour Foundation, with some free-text responses.	The decision to prescribe evoked complex emotions in family carers with medication use associated with mixed outcomes. Whilst some family carers felt involved in decisions around psychotropic medication prescribing, others described feeling marginalised and lacking information and influence.
Sheehan et al. (2017), UK	Pre-/post-test intervention	Aim was to establish and evaluate a psychotropic medication group for men with intellectual disabilities on a secure psychiatric ward.	$N = 6$ men with mild–moderate intellectual disabilities on a secure psychiatric ward with a range of psychiatric diagnoses at various stages of recovery.	Participants took part in a psychotropic medication education group, once weekly over 8 weeks. Knowledge and confidence with prescribed medication were assessed by self-report and by a test of medication knowledge (20 true and false statements) pre and post intervention.	There was interest and enthusiasm for the group. Participant feedback was generally positive and most of those who completed the group reported achieving their personal learning goals. There was no significant difference in results of a medication knowledge test at baseline and at the end of the course.
Strydom et al. (2001), UK	Service user consultation	Aim was to inform leaflet design via a service user consultation.	$N = 21$ participants with intellectual disabilities.	Services-user questionnaire to identify gaps in medication knowledge and information sources, followed by four in-depth individual consultations to measure the accessibility and attractiveness of the sample leaflet.	The service-user questionnaire identified that people had difficulties in reading and understanding medication labels and manufacturers' inserts, and overwhelmingly requested a readable leaflet about their medication. Consultation with users revealed that a larger leaflet with pictures, rather than symbols, was preferred, and words and concepts needed adjustment.
Strydom and Hall (2001), U.K.	Randomised controlled trial. Pilot study.	Aim was to assess whether psychotropic medication leaflets improve the knowledge, understanding and satisfaction of people with intellectual disabilities.	$N = 54$ people with "mild to moderate" intellectual disabilities, recruited from two outpatients clinics and three inpatient wards.	Leaflets randomly allocated to one of two groups—both groups received info verbally, but one of the groups also received info about their medications via a leaflet. Authors tested people's knowledge of their medication within 2 days of receiving the information, and again approx. 1 month later.	The leaflets did not significantly improve any aspect of medication knowledge. The leaflet group tended to rate their understanding of the information that they received lower than those in the comparison group. The participants with mild intellectual disabilities in the leaflet group had significantly reduced medication knowledge and understanding.

(Continues)

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 (Continued)

Author (year), country	Study design	Study aim(s)	Participants	Methodology	Findings
Wilson et al. (2023), Australia	Pre/post-test intervention pilot study	Aim was to test the applicability and preliminary efficacy of SPECTROM, an education programme developed in the UK, in an Australian context.	Pre- and post-training, participants completed surveys on the Psychotropic Knowledge Questionnaire and Management of Aggression and Violence Attitude Scale (which measures staff attitudes towards behaviours that challenge)—Carried out at four time points: pre-training, 2 weeks, 3 months and 5 months post-training.	Thirty-three participants (support workers) attended the training course and completed pre-training and post-training surveys.	Psychotropic Knowledge Questionnaire scores showed statistically significant post-training improvement at all post-training time points ($p < 0.05$). Management of Aggression and Violence Attitude Scale scores were high at pre-training (indicating good attitudes) and did not change significantly at any of the post-training survey time points. A 2-week post training feedback questionnaire reported 80% agreement that the training programme was appropriate, useful and valid.

- Wrong publication type
- Irrelevance to the research question

This resulted in a total of 16 articles. An additional five articles were added to the review from reference searches.

A total of 21 articles were included in the review. The flowchart of the screening process used for the review, including reasons for exclusion, are summarised in Figure 1.

3.2 | Study characteristics

All identified articles reported completed studies, characteristics of which are summarised in Table 3. Out of the 21 studies reviewed, 14 were conducted in the UK (Arscott et al., 2000; Crossley & Withers, 2009; Crowley et al., 2008; Deb et al., 2021, 2023; Fretwell & Felce, 2007; Hall & Deb, 2008; Heslop et al., 2005; Lalor & Poulson, 2013; Sheehan et al., 2017, 2018, 2019; Strydom et al., 2001; Strydom & Hall, 2001) and four in Australia (Barratt et al., 2023; Donley et al., 2011; Edwards et al., 2017; Wilson et al., 2023) and one each in the USA (Aman et al., 2007), Canada (Sawyer et al., 2019), and the Netherlands (de Kuijper & van der Putten, 2017).

Study designs included qualitative studies (Barratt et al., 2023; Crossley & Withers, 2009; Deb et al., 2023; Edwards et al., 2017; Hall & Deb, 2008; Heslop et al., 2005; Lalor & Poulson, 2013; Sheehan et al., 2019); questionnaires (Arscott et al., 2000; de Kuijper & van der Putten, 2017; Fretwell & Felce, 2007; Sawyer et al., 2019), pre/post-test interventions (Crowley et al., 2008; Sheehan et al., 2017; Wilson et al., 2023), mixed methods (Donley et al., 2011; Sheehan et al., 2018); field testing and/or process evaluations using either quantitative or mixed methods (Aman et al., 2007; Deb et al., 2023) one randomised control trial (Strydom & Hall, 2001) and one service user consultation (Strydom et al., 2001). Four of the aforementioned studies were pilots (Crowley et al., 2008; Fretwell & Felce, 2007; Strydom & Hall, 2001; Wilson et al., 2023).

3.3 | Participants

Despite the inclusion criteria being 16 + years, all papers discussed adults (18+) with intellectual disabilities. Data were collected from participants with intellectual disabilities in 10 of the included studies (Aman et al., 2007; Arscott et al., 2000; Crossley & Withers, 2009; Crowley et al., 2008; Hall & Deb, 2008; Heslop et al., 2005; Sheehan et al., 2017, 2019; Strydom et al., 2001; Strydom & Hall, 2001). All 10 studies included participants with mild–moderate intellectual disabilities, while two studies also collected data from participants with severe to profound intellectual disabilities (Heslop et al., 2005; Sheehan et al., 2019). Of these 10 studies, two included paid carers (Hall & Deb, 2008; Heslop et al., 2005), and one family members (Sheehan et al., 2019). Data were collected from family members for two studies (Edwards et al., 2017; Sheehan et al., 2018) and from support staff for nine studies (Barratt et al., 2023; Deb et al., 2021; Deb et al., 2023; Donley et al., 2011; Fretwell & Felce, 2007; de Kuijper & van der Putten, 2017; Lalor & Poulson, 2013; Sawyer et al., 2019; Wilson et al., 2023).

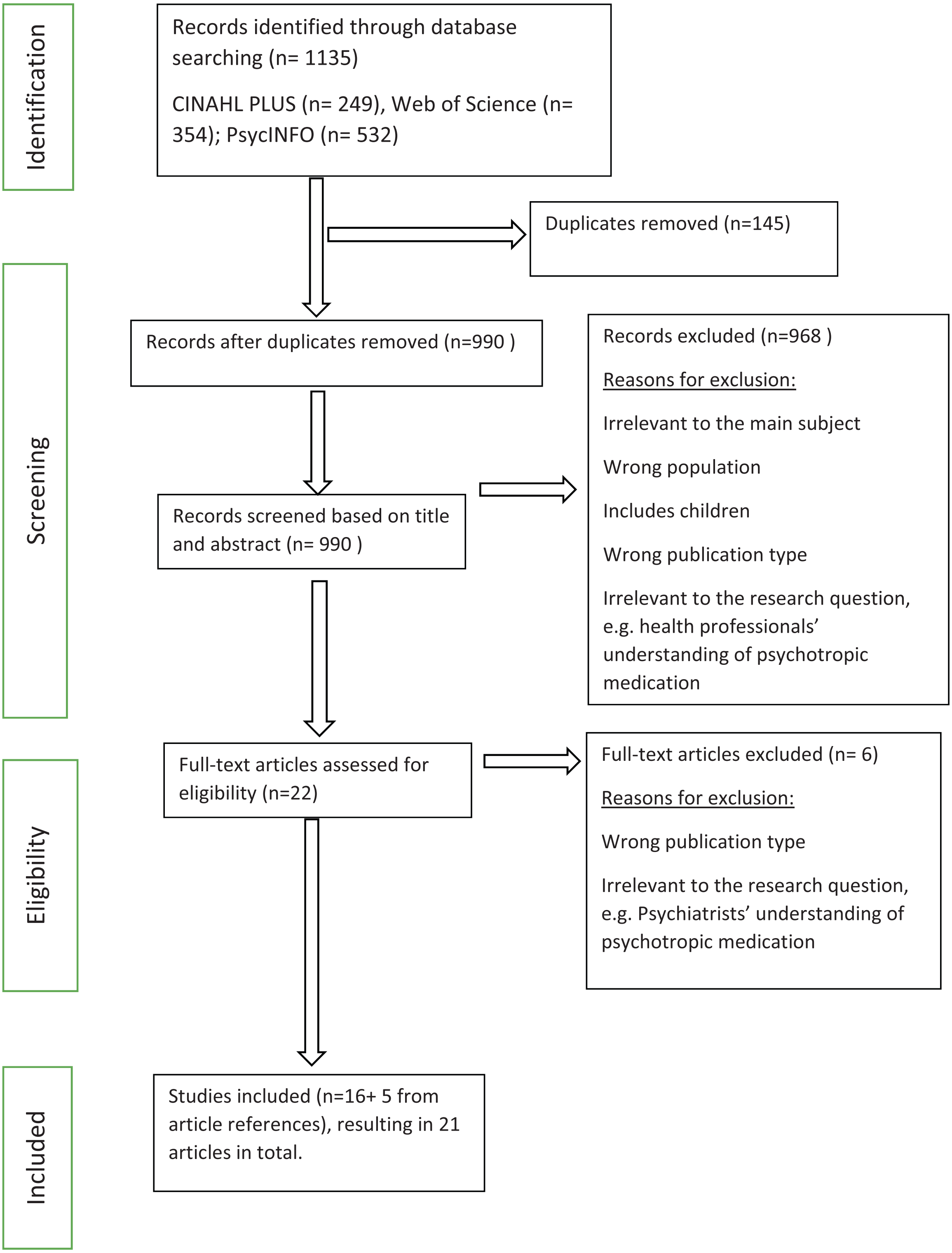

FIGURE 1 Flow chart of psychotropic medication studies from identification to inclusion.

Nine studies specifically stated that participants with intellectual disabilities were taking psychotropic medication (Arscott et al., 2000; Crossley & Withers, 2009; Crowley et al., 2008; Hall & Deb, 2008; Heslop et al., 2005; Sheehan et al., 2017, 2019; Strydom et al., 2001; Strydom & Hall, 2001). One study also included participants who had taken psychotropic medication in their recent past (Strydom et al., 2001). Seven studies cited reasons for participants with intellectual disabilities taking psychotropic medication, such as mental illness (Arscott et al., 2000; Crossley & Withers, 2009; Crowley et al., 2008; Sheehan et al., 2017, 2019; Strydom et al., 2001; Strydom &

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Hall, 2001), epilepsy (Arscott et al., 2000), behaviour (Crossley & Withers, 2009), to treat medical complaints (Arscott et al., 2000) and to decrease side effects (of other medication) (Arscott et al., 2000). In two studies, it was less clear what the reasons were (Hall & Deb, 2008; Heslop et al., 2005).

The studies including participants with intellectual disabilities were conducted in a range of settings such as days services (Sheehan et al., 2019); NHS domiciliary services (Crossley & Withers, 2009), residential care (Lalor & Poulson, 2013); a local mental health resource centre (Crowley et al., 2008), a psychiatric outpatient clinic (Hall & Deb, 2008) and ward (Sheehan et al., 2017).

3.4 | Themes

Literature was organised according to the following three themes:

3.4.1 | Theme 1 understanding of psychotropic medication

People with intellectual disabilities

There were five articles about what people with intellectual disabilities understood about psychotropic medications (Arscott et al., 2000; Crossley & Withers, 2009; Hall & Deb, 2008; Heslop et al., 2005; Sheehan et al., 2019). These articles found evidence that many people with intellectual disabilities had poor knowledge of many aspects of their medication, including the reasons for taking their medication, adverse effects associated with their medication, contraindications, as well as alternatives to medication. For some people this appeared to be because they had not been told about these aspects of their medication (Crossley & Withers, 2009; Heslop et al., 2005; Sheehan et al., 2019). Yet, many people with intellectual disabilities expressed a desire for knowledge (Crossley & Withers, 2009; Sheehan et al., 2019).

Two of the studies reported that participants were highly compliant with their medication regime (Crossley & Withers, 2009; Sheehan et al., 2019), which, in part, may have been due to a lack of knowledge of their medication (Sheehan et al., 2019). Crossley and Withers (2009) conducted eight semi-structured interviews with participants with mild–moderate intellectual disabilities with the findings analysed using grounded theory analysis. The authors devised a model of compliance from the analysis of their findings that proposed that participants' deference towards authority figures and a belief that the ‘doctor knows best’ were key motivators in their passive acceptance of their situation. However, missing from the model was the finding that some participants also felt they had no choice in the situation; therefore, the perceived consequences of non-compliance might also have been an important factor. One participant, for example, reported that there had been some physical coercion when they had refused to take medication in the past. Sheehan et al. (2019) carried out semi-structured interviews with 14 participants with mild–moderate intellectual disabilities as part of a multistakeholder qualitative study, with the data analysed using thematic analysis. The authors argued that their study supported the model of compliance proposed by Crossley and Withers (2009), yet their findings also revealed that some participants feared the consequences of non-compliance (particularly admission to a mental health hospital).

The aforementioned two papers also revealed that people with intellectual disabilities generally did not expect to be included in medication decisions. However, in the Sheehan et al. (2019) study, some participants with milder intellectual disabilities wanted to be involved in decision making, but found that they were excluded despite efforts to assert themselves. No UK articles examined the extent to which people with intellectual disabilities were aware of their rights regarding psychotropic medication and decision making under relevant legislation such as the Mental Capacity Act (2005) (Department of Health, 2005), Mental Health Act 1983 (as amended, most recently by the Mental Health Act 2007) (Department of Health, 2008) or Human Rights Act (1998). No studies explored family members and paid carers' awareness and understanding of this either, nor their knowledge of national guidelines or initiatives.

Family members

Three studies were about what family members understood about psychotropic medication. Two focused on family members' views about psychotropic medication being used to help manage behaviours that challenge (Edwards et al., 2017; Sheehan et al., 2018), while one focused on psychotropic medication being used to help with mental health conditions (Sheehan et al., 2019). Prescribing psychotropic medication evoked complex emotions in family members, such as anger, sadness, disappointment, guilt, and frustration (Sheehan et al., 2018, 2019).

In the Sheehan et al. (2018) study, findings from an online structured survey completed by 99 family members, revealed that prescribing medication for behaviours that challenge was associated with mixed outcomes. Over one-third (38%) of family members reported that they had not been given any information about the medication that had been prescribed and often had to carry out their own research. A lack of information meant that some families did not understand side effects and what to do about these or were not aware of alternatives to medication. Some families felt included in decisions, while others reported feeling marginalised. In Edwards et al. (2017) study, semi-structured interviews were carried out face-to-face or on the telephone with seven family members. In this instance, medication used to help manage behaviours that challenge was viewed as having a positive impact. The latter may have been because the small number of participants were recruited through the Queensland Government Office of the Public Guardian (OPG), Department of Justice and Attorney-General, where a statutory guardian for restrictive practice matters is appointed and makes the decision regarding the use of chemical restraint (CR) for adults with intellectual disabilities. The findings therefore may represent the views of people in contact with that office because there was a perceived need for the use of CR and a belief that it would be of benefit. However, despite families feeling that medication had a positive

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

effect on behaviours that challenge, many also reported having concerns about its use too, including the failure to implement positive behaviour plans to help reduce medication, poor record-keeping, medication being prescribed for the benefits of others rather than the person, as well as side effects and over-medication. Families described not being involved in decisions regarding medication. Families from both studies felt that the intimate and valuable knowledge that they had about their loved ones was overlooked (Edwards et al., 2017; Sheehan et al., 2018).

In the Sheehan et al. (2019) study, semi-structured interviews were conducted with 12 family members of people with intellectual disabilities with a diagnosed mental health condition. Many families recalled that medication was first used during a mental health crisis, a stressful time for the family which can make it difficult to make a confident and informed decision about medication. Some families reported beneficial effects of medication. However, for other family members, long-term experience of medication was less favourable, with medication found to be ineffective, only temporarily effective or blighted by adverse physical side-effects. Other concerns included many medication changes, medication being used too readily, and the absence of psychosocial interventions, which were often considered more appropriate but unavailable due to a lack of resources. Some families questioned whether medication should be used at all for people with intellectual disabilities and/or autism.

All three studies reported a need for inclusive decision-making and better information to help with decision making. Sheehan et al. (2019) reported that some families described attempts to democratise the decision-making process by gathering information, acting to disrupt perceived power imbalances, and attempting to prove their credibility as valid decision-making partners. This was met with various degrees of success.

Paid carers

There were nine articles about what paid carers understand about psychotropic medications. Paid carers (and family carers) reported undertaking several medication related activities such as collecting, storing, and giving medication to the person; determining when to seek professional advice, and mediating interactions between the doctor and the person with an intellectual disability (Sheehan et al., 2019). However, despite their 'frontline' status, the majority of articles found that paid carers did not always understand many aspects of psychotropic medication prescribing and usage, including its purpose (Heslop et al., 2005; Sheehan et al., 2019) and adverse side effects (de Kuijper & van der Putten, 2017; Donley et al., 2011; Fretwell & Felce, 2007; Heslop et al., 2005; Sheehan et al., 2019) and alternatives (Donley et al., 2011). In one study, where paid carers were able to recognise side effects, there was uncertainty and anxiety about how to act on them (Deb et al., 2023). There was also anxiety about withdrawing medication (Deb et al., 2023). In the one study (Sawyer et al., 2019), where staff reported feeling comfortable and knowledgeable about medication use, this was based on self-reported knowledge, which may not have adequately reflected people's actual level of knowledge. Only one study examined staff comfort and knowledge around PRN use (Sawyer et al., 2019), and there was very limited information regarding staff understanding around deprescribing.

In some articles paid care staff (like family members) were shown to have concerns about the use of psychotropic medication, including its potential ethical implications. For example, Lalor and Poulson (2013) explored the experiences and attitudes of care staff for adults with intellectual disabilities prescribed psychotropic medication living in long-term residential care. Data were analysed using interpretative phenomenological analysis. Many staff were concerned by the side effects experienced by people with intellectual disabilities and expressed feelings of frustration, helplessness, and a sense of injustice that there was little they could do to improve the quality of life of the people they supported. In a study using focus groups to explore the perspective of paid carers, there were mixed feelings about whether medication was justified or a form of 'chemical restraint' (Deb et al., 2023).

In one study staff felt they had good support from their co-workers and management to support people with intellectual disabilities (Donley et al., 2011), whereas staff in another study felt that this was lacking (Lalor & Poulson, 2013). However, across the articles, many paid carers felt insufficiently informed about psychotropic medication and expressed a need for further training (Deb et al., 2023; Donley et al., 2011; Fretwell & Felce, 2007; Heslop et al., 2005; Lalor & Poulson, 2013; Sawyer et al., 2019). Despite this, Heslop et al. (2005), who carried out semi-structured interviews with both people with intellectual disabilities ($N = 21$) and paid care staff ($N = 20$), found that people with intellectual disabilities assumed that their carer knew all about their medication. They relied on them to reinforce information about their medication even though the provision of information for paid care staff was poor and there was limited access to alternatives. In a few studies paid carers reported valuing being involved in decision making; however, some experienced difficulties in getting their voices heard by professionals and having a genuine role (Heslop et al., 2005; Sheehan et al., 2019). Some paid carers also acknowledged the lack of shared decision-making involving people with intellectual disabilities and their families (Deb et al., 2023).

3.4.2 | Theme 2 educating people with intellectual disabilities

Interventions that aimed to improve understanding using illustrated leaflets or booklets had mixed results. Aman et al. (2007) found that people with intellectual disabilities experienced more difficulty than people without intellectual disabilities in understanding illustrated booklets, but understanding was reportedly high. However, since the assessment of understanding was based on self-report it is not known the extent to which people were able to assess themselves accurately. Strydom and Hall (2001) examined whether leaflets they had designed (Strydom et al., 2001) improved knowledge and understanding for people with intellectual disabilities. They individually randomised 54 participants with mild to moderate intellectual disabilities to two

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

groups. A control group was given verbal medication information by their nurse or psychiatrist, and a study group was given specifically designed leaflets in addition to verbal information. The leaflets did not significantly improve any aspect of medication knowledge. This may have been because participants had not been supported to understand the leaflets, which according to Chinn (2020) can aid understanding and decision making.

Interventions that aimed to improve knowledge through educational group work had mixed results, with pre-and post-test scores after one educational programme suggesting that the intervention was not effective at increasing medication knowledge (Sheehan et al., 2017). However, the authors acknowledged that this may have been because the participants overestimated their knowledge and skills at baseline which made it difficult to determine any improvements. Knowledge was found to improve with another educational group programme (Crowley et al., 2008). Factors which appeared to aid understanding included information being presented in a variety of formats (for example, drawings and films), information being regularly repeated and only giving people information about the medications they were taking (Crowley et al., 2008).

3.4.3 | Theme 3: Training paid carers

All three articles were about the same training programme, SPECTROM, a Short-Term Psycho-Education programme developed in the UK (Deb et al., 2023) for paid carers to reduce the overmedication of people with intellectual disabilities. Two of the articles evaluated the appropriateness of the SPECTROM training programme in the Australian context. Thirty-three participants attended the training course and completed pre-training and post-training surveys (Wilson et al., 2023). SPECTROM training increased staff knowledge of psychotropic medications, yet loss of participants was high. The qualitative arm of the study (Barratt et al., 2023), which entailed online semi structured interviews, revealed a need for a national practice framework about psychotropic medication reduction to ensure best practice.

4 | DISCUSSION

The aim of this rapid review was to identify and analyse studies that explored the understanding that adults with intellectual disabilities have of their psychotropic medication, as well as family members and those with paid caring responsibilities. There is limited research regarding understanding of psychotropic medication among people with intellectual disabilities. The findings from this review identified five studies addressing this issue, which showed that people with intellectual disabilities often have poor knowledge of many aspects of their psychotropic medication. This included the reasons for taking their medication, adverse effects associated with their medication, contraindications, as well as alternatives (Arscott et al., 2000; Crossley & Withers, 2009; Hall & Deb, 2008;Heslop et al., 2005; Sheehan et al., 2019).

When using NHS services, people have a right to information about their treatment and for that information to be explained in a way that they understand (Mind, 2023). For people with intellectual disabilities who have capacity to make decisions about medication, having access to accessible information is important for making an informed decision about medication prescribing and treatment (Sheehan et al., 2019). Patients receiving information about their medication in a way that they understand also helps to ensure medicines optimisation, so that they can make the best use of their medication (Royal Pharmaceutical Society, 2013). However, the findings from the review suggest that many people with intellectual disabilities are poorly informed about their psychotropic medication (Crossley & Withers, 2009; Sheehan et al., 2019), suggesting that they are not always receiving accessible information directly from healthcare professionals, which may have implications for informed decision making. Aman et al. (2007) found that illustrated booklets improved the understanding of people with intellectual disabilities about their psychotropic medication which suggests that people can improve their knowledge of their medication. However, Strydom and Hall (2001) found that leaflets had no effect on participants' understanding. This may have been because participants were not supported to understand the information contained within them. As Chinn (2020) points out accessibility requires that attention be paid to the interactional practices accompanying the use of leaflets or booklets. Further training may be needed for healthcare professionals to engage directly with people with intellectual disabilities to make sure that they are supported to access and understand information regarding their medication.

The limited resources that exist in the UK about psychotropic medication for people with intellectual disabilities are largely not directed at this population. Resources include a guide for support workers accompanying a person with intellectual disabilities to a GP consultation (VODG, 2017), a web-based resource for families (The Challenging Behaviour Foundation, 2023) and a guide for advocates in relation to the use of psychotropic medication and supporting people to have a better life (Voiceability, 2021). These resources tend to focus on prescribing rather than deprescribing. It is not known how beneficial, well known or used these resources are or the extent to which people with intellectual disabilities were involved in their production. Evaluating how best to improve medication understanding in the intellectual disability population could act as a stimulus for future research.

Although the identified studies do not specifically address whether people with intellectual disabilities understand their healthcare rights relating to psychotropic medication, the findings suggest that they are often not aware of their right to be involved in medication decisions (Crossley & Withers, 2009; Sheehan et al., 2019) and perceive the consultant as having all the power (Sheehan et al., 2019). Future research should evaluate how best to rebalance perceived power asymmetries so that people with intellectual disabilities feel more included and involved in discussions about psychotropic

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

medication. There was some evidence that group education may be appropriate for some people with intellectual disabilities to help improve their understanding so that they can be involved in decisions about their treatment (Crowley et al., 2008). Of course, there are some situations under which a person can be treated without their consent, such as under some sections of the Mental Health Act 1983 (as amended, most recently by the Mental Health Act 2007) (Department of Health, 2008) or if they do not have capacity to decide whether to have treatment and the treatment is deemed to be in their best interests. However, even in these exceptional cases, there is still a responsibility among professionals to maximise people's understanding of the medications they are taking.

This review also revealed that there is little published research reporting the experiences of family members of people with intellectual disabilities who are prescribed psychotropic medication for mental health conditions or to help manage behaviours that challenge. The review identified three papers that included family members (Edwards et al., 2017; Sheehan et al., 2018, 2019). Family members reported being given little information about the medication prescribed to people with intellectual disabilities (Sheehan et al., 2018), meaning that they had little knowledge of side effects (Edwards et al., 2017; Sheehan et al., 2018) or what to do about them (Sheehan et al., 2018). They reported concerns about the long-term use of medication (Sheehan et al., 2019) and the absence of alternatives (Edwards et al., 2017; Sheehan et al., 2018, 2019). No studies were identified regarding educating and/or training family members, suggesting that there is a need for research to evaluate the best way to improve medication understanding in family members.

Some family members also described feeling insufficiently included in decisions relating to psychotropic medication (Edwards et al., 2017; Sheehan et al., 2018, 2019). Sheehan et al. (2019) recommended seeking the views of prescribers and other healthcare professionals which might reveal factors that act as a barrier to family involvement in decisions and be a target for intervention. Paid carers also described valuing decision making in which they had a voice; yet, despite their front-line status some reported feeling excluded (Heslop et al., 2005; Sheehan et al., 2019). None of the identified studies specifically addressed the issue of psychotropic medication use among people with intellectual disabilities, and how these decisions are made, when people lack mental capacity and/or are detained under the Mental Health Act 1983 (as amended, most recently by the Mental Health Act 2007) (Department of Health, 2008).

In the UK reducing the use of psychotropic medication for managing behaviours that challenge, and promoting the development and uptake of alternative interventions, is a national priority (Branford et al., 2019a; Nice, 2015). The NICE guidelines for managing behaviours that challenge advocate that families should be informed and involved in decisions about medication (NICE, 2015). However, the findings from this review suggest that this may not always be reflected in current practice, with family members reporting that they had not been given any information about the medication prescribed and felt left out of decision making (Sheehan et al., 2018). The finding that many family members felt there was no choice but to use medication due to a lack of alternatives raises concerns about prescribing practices and questions the degree to which alternative strategies are being implemented. The review recommended utilising the knowledge of family members (which is often disregarded) to potentially help with the implementation of alternative strategies, which could consequently reduce the use of medication to manage behaviours that challenge.

Despite behaviour that challenges being a significant factor in PRN prescribing (Delafon et al., 2013; Sawyer et al., 2019), this review found one study which included the knowledge of paid care staff about PRN medication (Sawyer et al., 2019). The study found that some staff did not know when side effects were occurring from PRN medication (Sawyer et al., 2019). One benefit of psychotropic PRN medication is that it can be used to respond to a patient's immediate clinical needs rather than the person having to wait for regular dose administration (Harper et al., 2017) However, the disadvantages are that it can contribute to polypharmacy (Delafon et al., 2013), lead to adverse effects (Barr et al., 2018), and increase the risk of morbidity (Barr et al., 2018). Further research is needed to explore how people with intellectual disabilities and their families experience PRN use, so that any gaps in PRN practice might be improved.

Nine out of the 21 studies identified as part of this rapid review collected data from paid carers. Findings from the review revealed that despite undertaking several medication related activities, many paid carers appeared to have a poor understanding of psychotropic medication prescribing and usage (Deb et al., 2023; Donley et al., 2011; Fretwell & Felce, 2007; Heslop et al., 2005; de Kuijper & van der Putten, 2017; Sheehan et al., 2019). Many paid carers reported feeling insufficiently informed about psychotropic medication and expressed a need for further training (Deb et al., 2023; Donley et al., 2011; Fretwell & Felce, 2007; Heslop et al., 2005; Lalor & Poulson, 2013). Wilson et al. (2023) found that training improved staff knowledge around deprescribing, which aims to reduce the use of inappropriately prescribed psychotropic medication. This is promising and illustrates that paid carers can be supported to improve their understanding of psychotropic medication. This review showed that paid carers were often worried about withdrawing medication (Deb et al., 2023) and further training interventions should focus on what staff can do to ensure that the people they support obtain the best possible outcomes from their medication.

5 | STRENGTHS AND LIMITATIONS

A strength of this rapid review was the use of Arksey and O'Malley's (2005) framework for recording data, which allows for transparency and validity. Another strength was the use of a second reviewer to screen a subsample of abstracts, as well as the full-text articles, using Rayaan's blind mode to help eliminate bias.

Several limitations to this rapid review must be acknowledged. First, articles were only included if published between 2000 and 2023. This approach was taken to focus on current practice after the UK Government published the policy paper Valuing People—A new

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Strategy for Learning Disability for the 21st Century (2001), but it is acknowledged that studies prior to 2000 may have offered additional insights. However, many of the studies identified in the reference lists of included studies for this review suggest that prior to 2000 there was a focus on what people with intellectual disabilities understand about their medication living in the long-stay hospital model of care of the 1980s and 1990s. These studies may therefore not be relevant. Some of the studies had small sample sizes. For example, Sheehan et al. (2017) included six participants and Edwards et al. (2017) included seven participants, making it difficult to extrapolate the findings to the rest of the population with intellectual disabilities, their families, and paid carers.

6 | CONCLUSIONS

Presently, research regarding an understanding of psychotropic medication in the intellectual disability population is limited, with the review identifying five studies on this issue. Literature was even more sparse for families, with just three papers addressing family members' knowledge. Psychotropic medication understanding was poor among many participants with intellectual disabilities, their family members and paid carers. Many reported feeling excluded from prescribing and usage decisions. This review made several recommendations for improving psychotropic medication understanding and evaluating how best to improve psychotropic medication knowledge should be a focus for future research.

AUTHOR CONTRIBUTIONS

Dawn E. Cavanagh: Led the review; wrote the first draft, review and editing. **Sue Caton**: conceptualisation; original draft preparation; review and editing. **Jodie Rawles**: Literature search and review; original draft preparation. **Katherine Runswick-Cole**: conceptualisation; writing – review and editing. **Chris Hatton**: Conceptualisation; writing – review and editing. **Umesh Chauhan**: Conceptualisation; writing – review and editing. **Christine Hutchinson**: Conceptualisation; writing review and editing.

ACKNOWLEDGEMENTS

The present authors would like to acknowledge the sponsorship of the Lancashire and South Cumbria NHS Foundation Trust. They would also like to acknowledge the contribution of all research participants for sharing their experiences.

FUNDING INFORMATION

This project is funded by the National Institute for Health and Care Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR204107). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

For the purpose of open access, the authors have applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising from this submission.

ORCID

Dawn E. Cavanagh https://orcid.org/0000-0002-5204-9485
Sue Caton https://orcid.org/0000-0001-9013-8721
Chris Hatton https://orcid.org/0000-0001-8781-8486

REFERENCES

Adams, D. (2019). Polypharmacy and deprescribing in people with learning disabilities. *Journal of Prescribing Practice*, *1*(6), 296–300.

Aman, M. G., Benson, B. A., Farmer, C. A., Hall, K. L., & Malone, K. M. (2007). Project MED: Effects of a medication EDucation booklet series for individuals with intellectual disabilities. *Intellectual and Developmental Disabilities*, *45*(1), 33–45. https://doi.org/10.1352/1934-9556(2007)45[33:PMEOAM]2.0.CO;2

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Arscott, K., Kroese, B. S., & Dagnan, D. (2000). A study of the knowledge that people with intellectual disabilities have of their prescribed medication. *Journal of Applied Research in Intellectual Disabilities*, *13*(2), 90–99. https://doi.org/10.1046/j.1468-3148.2000.00010.x

Barr, L., Wynaden, D., & Heslop, K. (2018). Nurses' attitudes towards the use of PRN psychotropic medications in acute and forensic mental health settings. *International Journal of Mental Health Nursing*, *27*(1), 168–177. doi:10.1111/jpm.1260

Barratt, M., Jorgensen, M., Deb, S., Limbu, B., Donley, M., Buchholtz, M., Smith, V., & Wilson, N. (2023). Staff perceptions following a training programme about reducing psychotropic medication use in adults with intellectual disability: The need for a realistic professional practice framework. *Journal of Applied Research in Intellectual Disabilities*, *36*(3), 486–496. https://doi.org/10.1111/jar.1307

Bond, L., Carroll, R., Mulryan, N., O'Dwyer, M., O'Connell, J., Monaghan, R., Sheerin, F., McCallion, P., & McCarron, M. (2019). The association of life events and mental ill health in older adults with intellectual disability: Results of the wave 3 intellectual disability supplement to the Irish longitudinal study on ageing. *Journal of Intellectual Disability Research*, *63*, 454–465. https://doi.org/10.1111/jir.12595

Branford, D., Gerrard, D., Saleem, N., Shaw, C., & Webster, A. (2019a). Stopping over-medication of people with intellectual disability, autism or both (STOMP) in England part 1-history and background of STOMP. *Advances in Mental Health and Intellectual Disabilities*, *13*, 31–40.

Branford, D., Gerrard, D., Saleem, N., Shaw, C., & Webster, A. (2019b). Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2 – The story so far. *Advances in Mental Health and Intellectual Disabilities*, *13*(1), 41–51. https://doi.org/10.1108/AMHID-02-2018-0005

Branford, D., & Shankar, R. (2022). Antidepressant prescribing for adult people with an intellectual disability living in England. *The British Journal of Psychiatry*, *221*, 488–493. https://doi.org/10.1192/bjp.2022.34

Care Quality Commission. (2020). Out of Sight-Who Cares? A review of restraint, seclusion, segregation for autistic people, and people with a learning disability and/or mental health condition. Retrieved from cqc.org.uk

Chinn, D. (2020). An empirical examination of the use of easy read health information in health consultations involving patients with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *2*, 232–247. https://doi.org/10.1111/jar.12657

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Cooper, S., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *The British Journal of Psychiatry*, *190*(1), 27–35. https://doi.org/10.1192/bjp.106.022483

Cooper, S.-A., Hughes-McCormack, L., Greenlaw, N., McConnachie, A., Allan, L., Baltzer, M., McArthur, L., Henderson, A., Melville, C., McSkimming, P., & Morrison, J. (2018). Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study. *Journal of Applied Research in Intellectual Disabilities*, *31*(Suppl. 1), 68–81. https://doi.org/10.1111/jar.12386

Costello, A., Hehir, C., Sharma, D., Hudson, E., Doody, O., & Kelly, D. (2022). Management of psychotropic medications in adults with intellectual disability: A scoping review protocol. *HRB Open Research*, *4*, 30. https://doi.org/10.12688/hrbopenres.13170.2

Crossley, R., & Withers, P. (2009). Antipsychotic medication and people with intellectual disabilities: Their knowledge and experiences. *Journal of Applied Research in Intellectual Disabilities*, *22*, 77–86.

Crowley, V., Rose, J., Smith, J., Hobster, K., & Ansell, E. (2008). Psycho-educational groups for people with a dual diagnosis of psychosis and mild intellectual disability: A preliminary study. *Journal of Intellectual Disabilities*, *12*(1), 25–39. https://doi.org/10.1177/1744629507086606

de Kuijper, G., Hoekstra, P., Visser, F., Scholte, F. A., Penning, C., & Evenhuis, H. (2010). Use of antipsychotic drugs in individuals with intellectual disability (ID) in The Netherlands: Prevalence and reasons for prescription. *Journal of Intellectual Disability Research*, *54*, 659–667.

de Kuijper, G., & van der Putten, A. A. J. (2017). Knowledge and expectations of direct support professionals towards effects of psychotropic drug use in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *30*(Suppl. 1), 1–9. https://doi.org/10.1111/jar.1235

de Leon, J., Greenlee, B., Barber, J., Sabaawi, M., & Singh, N. N. (2009). Practical guidelines for the use of new generation antipsychotic drugs (except clozapine) in adult individuals with intellectual disabilities. *Research in Developmental Disabilities*, *30*(4), 613–669. https://doi.org/10.1016/j.ridd.2008.10.010

Deb, S., Limbu, B., Unwin, G., Woodcock, L., Cooper, V., & Fullerton, M. (2021). Short-term psycho-education for caregivers to reduce overmedication of people with intellectual disabilities (SPECTROM): Development and field testing. *International Journal of Environmental Research and Public Health*, *18*(24), 13161. https://doi.org/10.3390/ijerph182413161

Deb, S., Roy, M., & Limbu, B. (2023). Pharmacological management of psychopathology in people with intellectual disabilities and/or autism spectrum disorder. *BJPsych Advances*, *1-12*, 322–333. https://doi.org/10.1192/bja.2022.61

Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, *45*, 495–505. https://doi.org/10.1046/j.1365-2788.2001.00374.x

Delafon, V., Kiani, R., Barrett, M., Vahabzadeh, A., Vaidya, H., Walker, G., & Bhaumik, S. (2013). Use of PRN medication in people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *7*(6), 346–355. https://doi.org/10.1108/AMHID-05-2013-0032

Department of Health. (2005). *Mental capacity act*. HMSO.

Department of Health. (2008). *Code of practice: Mental health act 1983*. The Stationery Office. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084597?IdcService=GET_FILE&dID=170799&Rendition=Web

Donley, M., Chan, J., & Webber, L. (2011). Disability support workers' knowledge and education needs about psychotropic medication. *British Journal of Learning Disabilities*, *40*, 286–291.

Edwards, N., King, J., Watling, H., & Hair, S. A. (2017). Qualitative exploration of psychotropic medication to manage challenging behaviour in adults with intellectual disability: Views of family members. *Advances in Mental Health and Intellectual Disabilities*, *11*(5–6), 207–218. https://doi.org/10.1108/AMHID-06-2017-0027

Fish, R., Hatton, C., & Chauhan, U. (2017). "Tell me what they do to my body": A survey to find out what information people with learning disabilities want with their medications. *British Journal of Learning Disabilities*, *45*(3), 217–225. https://doi.org/10.1111/bld.12196

Folch, A., Salvador-Carulla, L., Vicens, P., Cortés, M. J., Irazábal, M., Muñoz, S., Rovira, L., Orejuela, C., González, J. A., & Martínez-Leal, R. (2019). Health indicators in intellectual developmental disorders: The key findings of the POMONA-ESP project. *Journal of Applied Research in Intellectual Disabilities*, *32*, 23–34. https://doi.org/10.1111/jar.12498

Fretwell, C., & Felce, D. (2007). Staff knowledge of the side effects of anti-psychotic medication. *Journal of Applied Research in Intellectual Disabilities*, *20*(6), 580–585. 1360–2322. https://doi.org/10.1111/j.1468-3148.2006.00356.x

García-Domínguez, L., Navas, P., Verdugo, M. Á., Arias, V. B., & Gómez, L. E. (2022). Psychotropic drugs intake in people aging with intellectual disability: Prevalence and predictors. *Journal of Applied Research in Intellectual Disabilities*, *35*(5), 1109–1118. https://doi.org/10.1111/jar.12996

Glover, G., Williams, R., Branford, D., Avery, R., Chauhan, U., Hoghton, M., & Bernard, S. (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Public Health England. PHE standard publication template (uclan.ac.uk).

Gore, N. J., McGill, P., Toogood, S., Allen, D., Hughes, C., Baker, P., Hastings, R. P., Noone, S., & Denne, L. (2013). Definition and scope for positive behaviour support. *International Journal of Positive Behavioural Support*, *3*(2), 14–23. Retrieved from (PDF) Definition and scope for positive behaviour support (researchgate.net).

Hall, S., & Deb, S. (2008). A qualitative study on the knowledge and views that people with learning disabilities and their carers have of psychotropic medication prescribed for behaviour problems. *Advances in Mental Health and Learning Disabilities*, *2*(1), 29–37. https://doi.org/10.1108/17530180200800005

Harper, L., Reddon, J. R., Hunt, C. J., & Royan, H. (2017). PRN medication Administration in a Geriatric Psychiatric Hospital: Chart review and nursing perspective. *Clinical Gerontologist*, *40*(5), 392–400. https://doi.org/10.1080/07317115.2017.1311287

Hassan, L., Senior, J., Webb, R. T., Frisher, M., Tully, M. P., While, D., & Shaw, J. J. (2016). Prevalence and appropriateness of psychotropic medication prescribing in a nationally representative cross-sectional survey of male and female prisoners in England. *BMC Psychiatry*, *16*(1), 346. https://doi.org/10.1186/s12888-016-1055-7

Haw, C., & Stubbs, J. (2005). A survey of off-label prescribing for inpatients with mild intellectual disability and mental illness. *Journal of Intellectual Disability Research*, *49*, 858–864. https://doi.org/10.1111/j.1365-2788.2005.00723.x

Health and Social Care Information Centre. (2015). *Learning disability census report England 30 September 2015 experimental statistics*. Health and Social Care Information Centre. NHS England. https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-census-report/learning-disability-census-report-england-30th-of-september-2015

Heslop, P., Folkes, L., & Rodgers, J. (2005). The knowledge people with learning disabilities and their Carers have about psychotropic medication. *Tizard Learning Disability Review*, *10*(4), 10–18. https://doi.org/10.1108/13595474200500033

Holmes, R., Kearney, L., Gopal, S., & Daddi, I. (2023). 'Lots of black people are on meds because they're seen as aggressive': STOMP, COVID-19 and anti-racism in community learning disability services. *British Journal of Learning Disabilities*, *52*(1), 1–10. https://doi.org/10.1111/bld.12541

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Lalor, J., & Poulson, L. (2013). Psychotropic medications and adults with intellectual disabilities: Care staff perspectives. *Advances in Mental Health and Intellectual Disabilities*, *7*(6), 333–345. https://doi.org/10.1108/AMHID-03-2013-0017

Learning Disabilities Mortality Review (LeDeR) Programme. (2018). *Annual report. December 2017. Bristol. Norah fry Centre for Disability Studies*. University of Bristol. LeDeR_Annual_Report_2018 published May 2019.pdf (bristol.ac.uk).

Matson, J. L., & Neal, D. (2009). Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. *Research in Developmental Disabilities*, *30*(3), 572–586. https://doi.org/10.1016/j.ridd.2008.08.007

McMahon, M., Hatton, C., & Bowring, D. L. (2020). Polypharmacy and psychotropic polypharmacy in adults with intellectual disability: A cross-sectional total population study. *Journal of Intellectual Disability Research*, *64*, 834–851. https://doi.org/10.1111/jir.12775

Mehta, H., & Glover, G. (2019). *Psychotropic drugs and people with learning disabilities or autism*. Public Health England.

Mind. (2023). Health and social care rights. Retrieved from Your healthcare rights – Mind.

Moher, D., Stewart, L., & Shekelle, P. (2015). All in the family: Systematic reviews, rapid reviews, scoping reviews, realist reviews, and more. *Systematic Reviews*, *4*, 183. https://doi.org/10.1186/s13643-015-0163-7

National Institute for Health and Care Excellence (NICE). (2015). Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges [NG11]. London, UK.

NHS Digital . (2022). Health and care of people with learning disabilities, experimental statistics 2021 to 2022 – NDRS (digital.nhs.uk).

NHS England. (2017). *Accessible information standard*. www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality

NHS England. (2019). The NHS long term plan. https://www.longtermplan.nhs.uk/

O'Dwyer, M., Peklar, J., Mulryan, N., McCallion, P., McCarron, M., & Henman, M. C. (2017). Prevalence, patterns and factors associated with psychotropic use in older adults with intellectual disabilities in Ireland. *Journal of Intellectual Disability Research*, *61*(10), 969–983. https://doi.org/10.1111/jir.12391

Ohayon, M. M., Caulet, M., Priest, R. G., & Guilleminault, C. (1998). Psychotropic medication consumption patterns in the UK general population. *Journal of Clinical Epidemiology*, *51*(3), 273–283. https://doi.org/10.1016/s0895-4356(97)00238-2

Raghu, R., & Patel, P. (2010). Ethical issues of psychotropic medication for people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *4*(3), 34–38. (PDF) Ethical issues of psychotropic medication for people with intellectual disabilities (researchgate.net).

Royal College of Psychiatrists. (2016). Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: Practice guidelines. Faculty of Psychiatry of Intellectual Disability. Faculty Report.

Royal Pharmaceutical Society. (2013). *Medicines optimisation: Helping patients to make the most of medicines*. Accessed via NHS England » Medicines optimisation.

Sawyer, A., Lake, J., & Lunsky, Y. (2019). Direct care staff knowledge about medication for individuals with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *13*(3/4), 144–151. https://doi.org/10.1108/AMHID-01-2019-0002

Sheehan, R., Hassiotis, A., Strydom, A., & Morant, N. (2019). Experiences of psychotropic medication use and decision-making for adults with intellectual disability: A multistakeholder qualitative study in the UK. *BMJ Open*, *9*(11), e032861. https://doi.org/10.1136/bmjopen-2019-032861

Sheehan, R., Hassiotis, A., Walters, K., Osborn, D., Strydom, A., & Horsfall, L. (2015). Mental illness, challenging behaviour, and psychotropic drug and prescribing in people with intellectual disability: UK population-based cohort study. *BMJ*, *2015*(351), h4326. https://doi.org/10.1136/bmj.h4326

Sheehan, R., Kimona, K., Giles, A., Cooper, V., & Hassiotis, A. (2018). Findings from an online survey of family carer experience of the management of challenging behaviour in people with intellectual disabilities, with a focus on the use of psychotropic medication. *British Journal of Learning Disabilities*, *46*, 82–91. https://doi.org/10.1111/bld.12216

Sheehan, R., Rochester, J., Hafesji, F., Kyambadde, R., & Gravestock, S. (2017). Developing a psychotropic medication education group on a secure ward for men with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *11*(4), 155–164. https://doi.org/10.1108/AMHID-04-2017-0010

Smith, M. V. A., Adams, D., Carr, C., & Mengoni, S. E. (2019). Do people with intellectual disabilities understand their prescription medication? A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *32*(6), 1375–1388. https://doi.org/10.1111/jar.12643

Strydom, A., Forster, M., Wilkie, B. M., Edwards, C., & Hall, I. S. (2001). Patient information leaflets for people with learning disabilities who take psychiatric medication. *The British Journal of Learning Disabilities*, *29*(2), 72–76. https://doi.org/10.1046/j.1468-3156.2001.00108.x

Strydom, A., & Hall, I. (2001). Randomized trial of psychotropic medication information leaflets for people with intellectual disability. *Journal of Intellectual Disability Research*, *45*(Pt 2), 146–151. https://doi.org/10.1046/j.1365-2788.2001.00329.x

The Challenging Behaviour Foundation. (2023). Medication pathway. The Challenging Behaviour Foundation. Retrieved from About this resource – Medication Pathway (challengingbehaviour.org.uk).

Tyrer, P., Oliver-Africano, P. C., Ahmed, Z., Bouras, N., Cooray, S., Deb, S., Murphy, D., Hare, M., Meade, M., Reece, B., Kramo, K., Bhaumik, S., Harley, D., Regan, A., Thomas, D., Rao, B., North, B., Eliahoo, J., Karatela, S., … Crawford, M. (2008). Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: A randomised controlled trial. *Lancet*, *371*(9606), 57–63. https://doi.org/10.1016/S0140-6736(08)60072-0

VODG. (2017). *Preparing to visit a doctor to talk about psychotropic medication*. VODG. Retrieved from VODG | Preparing to visit a doctor to talk about psychotropic medication.

VoiceAbility. (2021). Preventing over-medication. STOMP top tips for advocates. VoiceAbility. Retrieved from STOMP-2021B.pdf (voiceability.org).

WHO. (2017). Definition: Intellectual disability. http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

Wilson, N. J., Barratt, M., Jorgensen, M., Limbu, B., Donley, M., Buchholtz, M., Smith, V., & Deb, S. (2023). Training support workers about the overmedication of people with intellectual disabilities: An Australian pre-post pilot study. *Journal of Intellectual Disability Research*, *67*, 519–530. https://doi.org/10.1111/jir.13023

How to cite this article: Cavanagh, D. E., Caton, S., Rawles, J., Runswick-Cole, K., Hatton, C., Chauhan, U., & Hutchinson, C. (2024). What do people with intellectual disabilities, their family members and paid carers understand about psychotropic medication? A rapid review. *Journal of Applied Research in Intellectual Disabilities*, *37*(5), e13283. https://doi.org/10.1111/jar.13283

14683148, 2024, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13283 by University Of Sheffield, Wiley Online Library on [01/08/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License