



Stakeholder Experiences of Deprescribing Psychotropic Medicines for Challenging Behaviour in People with Intellectual Disabilities

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Manuscripts

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3 1 **Stakeholder Experiences of Deprescribing Psychotropic Medicines for Challenging**
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5 2 **Behaviour in People with Intellectual Disabilities**
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10 4 **Abstract**
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14 6 **Purpose**
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17 7 Evidence of overprescribing of psychotropic medicines to manage challenging behaviour in
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19 8 people with intellectual disabilities has led to national programmes within the U.K to promote
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21 9 deprescribing, such as STOMP (Stopping the Overprescribing of Medication in People with
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23 10 Learning Disabilities, Autism or both). To successfully implement deprescribing initiatives
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25 11 we need to understand how to engage stakeholders in the process.
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31 13 **Approach**
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33 14 In a published systematic review, we reported evidence about the process of deprescribing
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35 15 psychotropic medicines for people of all ages with intellectual disabilities and challenging
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37 16 behaviour. As a part of the original review, we searched for evidence about stakeholders'
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39 17 experiences of the psychotropic deprescribing process which was synthesised and reported
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41 18 within the current study.
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47 20 **Findings**
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49 21 Six studies were identified. Involving carers and people with intellectual disabilities,
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51 22 providing ongoing support, and improving access to non-pharmacological interventions
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53 23 including Positive Behaviour Support may contribute to successful outcomes, including
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55 24 reducing or stopping psychotropic medicines and improved quality of life. Implementing
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3 25 psychotropic deprescribing requires a multidisciplinary collaborative care approach and
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5 26 education for stakeholders.
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9 **27 Originality**

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12 28 There have been no previous reviews of stakeholder experiences of deprescribing
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14 29 psychotropic medications for people with intellectual disabilities and challenging behaviour.
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16 30 The existing literature is scant and further research is needed.
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21 **32 Paper Type**

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23 33 Research Paper
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30 **36 Background**

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32 37 Overprescribing, the use of a medicine where there is a better non-medicine alternative, or the
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34 38 prescription is inappropriate for the circumstances and wishes of an individual, occurs
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36 39 throughout healthcare systems (Ridge, 2021). An estimated 10% of dispensed items are
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38 40 overprescribed in primary care with 15% of people taking five or more medicines a day
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40 41 (Ridge, 2021). Initially, a medicine may be appropriately prescribed, but in the absence of
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42 42 timely review, it may no longer be the best choice. Furthermore, polypharmacy, the
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44 43 prescribing and administration of multiple medicines, and patient cognitive impairment can
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46 44 be problematic and may be associated with medication errors (Duerden et al., 2013,
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48 45 Maidment et al., 2008).
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53 46 Overprescribing can lead to harm by exposing individuals to unnecessary adverse effects of
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55 47 medicines and an increased risk of interactions with other medicines (Ridge, 2021). Equally,
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57 48 overprescribing increases the burden on the person and any family carers supporting them
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3 49 (Duerden et al., 2013, Ridge, 2021, Bennett et al., 2021, Lawson et al., 2022). In 2021, the
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5 50 U.K. Government overprescribing review (Ridge, 2021) recommended expanding the use
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8 51 of structured medication reviews and embedding deprescribing within the prescribing
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10 52 process.

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13 53 Deprescribing, the planned and supervised process of dose reduction or stopping of
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15 54 medication in a safe and effective way (Doherty et al., 2020, Australian Deprescribing
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18 55 Network, US Deprescribing Research Network, 2020, Bruyère Research Institute), is a
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20 56 complex healthcare intervention that looks to address overprescribing. As with prescribing,
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22 57 deprescribing should be a collaborative process within a person-centred and shared decision
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24 58 making framework with the aim of minimising risk of harm from medication whilst
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27 59 achieving improved positive health outcomes (Department of Health and Social Care, 2021).

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30 60 In 2016, NHS England launched the STOMP programme in response to evidence that
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32 61 psychotropic medicines are overprescribed in people with intellectual disabilities for the
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34 62 management of challenging behaviour (Branford et al., 2019, NHS England, Sheehan et al.,
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37 63 2015, Bowring et al., 2017). For example, a report by Public Health England (Glover and
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39 64 Mehta, 2019) in 2015 found that a third of people known to have intellectual disabilities were
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41 65 prescribed at least one psychotropic medicine and more than half of these people did not have
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44 66 a documented mental health diagnosis.

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47 67 Our previously published systematic review reported findings addressing the primary review
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49 68 question in accordance with a published protocol
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51 69 (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=158079), looking at the
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53 70 effects of deprescribing psychotropic medicines as a part of a care pathway or treatment plan
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56 71 for people of all ages with intellectual disabilities and challenging behaviour (Adams et al.
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58 72 2023). The review included 54 studies carried out in community and inpatient settings
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3 73 primarily in the UK, the USA and the Netherlands focussing on 3292 people with intellectual
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5 74 disabilities. Our review found that psychotropic deprescribing interventions for people with
6
7 75 intellectual disabilities may lead to dosage reductions and the discontinuation of these
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9 76 medicines. Although negative effects of deprescribing were reported we found there were
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11 77 positive effects on behaviour, mental and physical health which were associated with a
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13 78 multidisciplinary model (Adams et al., 2023).
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17 79 Examining the overall effectiveness of an intervention is essential, but alone is insufficient to
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19 80 fully support the widespread implementation of a complex intervention such as deprescribing.
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21 81 To successfully implement deprescribing initiatives we need to understand how to engage
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23 82 health and social care professionals, family carers and individuals with intellectual disabilities
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25 83 in the process and how they experience deprescribing. An understanding of how the attitudes,
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27 84 beliefs and values of these stakeholders affect decision making and influence behaviour as
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29 85 part of the deprescribing process is a key aspect of this (Darnton, 2008, Moore et al., 2015).
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31 86 Furthermore, a clear understanding of the barriers and enablers to successful deprescribing is
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33 87 important to maximise success and contribute towards the development of clear guidance and
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35 88 policy.
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41 89 Existing published literature reviews have not adequately explored these experiences of
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43 90 stakeholders, regarding deprescribing psychotropic medicines in people with intellectual
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45 91 disabilities. Previous reviews have considered people's experiences of deprescribing in older
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47 92 people (Lundby et al., 2019) and within primary care (Doherty et al., 2020) but have not
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49 93 specifically looked at deprescribing psychotropic medicine use with people with intellectual
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51 94 disabilities.
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55 95 To address this gap in the literature, we had originally included an additional review question
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57 96 in our protocol addressing stakeholder experiences and perspectives on deprescribing
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59 97 psychotropic medicines in individuals with intellectual disabilities and challenging behaviour.
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3 98 We defined stakeholders as people with intellectual disabilities, paid carers, family carers,
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5 99 nurses, healthcare assistants, GPs, psychiatrists, pharmacists, other specialist healthcare
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8 100 professionals and social care professionals. In this paper we report and discuss the findings
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10 101 that emerged from our attempt to consider this review question.
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12 13 102 **Methodology**

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15 103 Full details of the methodology are reported in our previously published systematic review
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17 104 (Adams et al., 2023). To answer the current question in this review, we only included papers
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19 105 that reported outcomes for stakeholders' experiences in terms of attitudes, views and beliefs
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21 106 about psychotropic deprescribing in people with intellectual disabilities.
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24 107 Database searches were updated several times and a final search was completed in November
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26 108 2022. Forwards and backwards reference searching of papers included in our published
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28 109 systematic review (Adams et al., 2023) was also conducted to track citations. Four key
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30 110 researchers, identified as having published several studies in this field over the last 10 years,
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32 111 were contacted to identify any further studies. Trial registries were not searched. Following
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34 112 data extraction using a bespoke data extraction form, studies were individually appraised for
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36 113 risk of bias using the qualitative tool from the Critical Appraisals Skills Programme Tools
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38 114 (CASP; CASP,2015) which consist of ten questions to assess internal and external validity.
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44 45 116 **Data Analysis**

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47 117 We organised our findings into groups which were developed by discussions within the
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49 118 research team. This allowed us to synthesise our findings more easily and draw conclusions
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51 119 from our findings.
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56 57 121 **Findings**

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3 122 We only found two papers through database searching (Kleijwegt et al., 2019, Deb et al.,
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5 123 2020). We found one additional paper through citation searching (Wrein, 2019) and an
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7 124 additional three more via direct author contact (de Kuijper et al., 2022b, de Kuijper et al.,
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9 125 2022a, Deb et al., 2023). Two papers reported results from the same study; one reporting
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11 126 quantitative data (Deb et al., 2020) and the other reporting qualitative data (Deb et al., 2023) .
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15 127 Two studies were carried out in the U.K. (Wrein, 2019, Deb et al., 2020) and three studies in
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17 128 The Netherlands (de Kuijper et al., 2022b, de Kuijper et al., 2022a, Kleijwegt et al., 2019).
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19 129 Two studies (n = 34, n = 88) reported experiences direct from psychiatrists (de Kuijper et al.,
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21 130 2022b, Deb et al., 2020, Deb et al., 2023), two studies (n = 29, n = 8) reported experiences
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23 131 direct from carers (Kleijwegt et al., 2019, Wrein, 2019); and one study (n = 7) reported
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25 132 experiences direct from people with intellectual disabilities (de Kuijper et al., 2022a). There
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27 133 were a range of study types; two mixed methods studies using online questionnaires (de
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29 134 Kuijper et al., 2022b, Deb et al., 2020, Deb et al., 2023), one qualitative study using
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31 135 interviews (de Kuijper et al., 2022a), one qualitative study using semi structured interviews
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33 136 (Wrein, 2019) and one qualitative study using focus groups (Kleijwegt et al., 2019).
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39 137 We organised our findings by grouping data from the included studies into five categories:
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41 138 (1) carer attitudes towards deprescribing, (2) healthcare professional attitudes towards
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43 139 deprescribing, (3) the attitudes of people with intellectual disabilities towards deprescribing,
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45 140 (4) the extent of multidisciplinary team and wider clinical team working, (5) the availability
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47 141 of resources.
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53 143 *Carer attitudes towards the deprescribing process*

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56 144 The involvement of paid carers was seen as vital to the success of deprescribing (Wrein,
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58 145 2019). Overall, there is some evidence from two studies that carers are resistant, at times, to
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3 146 deprescribing due to concerns about a deterioration, their lack of experience (Deb et al., 2020,
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5 147 Kleijwegt et al., 2019), and a feeling that “maybe at times it makes us more risk adverse if
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8 148 we're unsure how the individual is going you know to respond to something maybe we'll
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10 149 think, well let's not do that” (Wrein, 2019) p73 giving rise to therapeutic inertia. Three of
11
12 150 these studies reported on findings regarding both paid and family carers whereas one study
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14 151 reported findings related to only paid carers (Kleijwegt et al., 2019).

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17 152 Despite carer “resistance”, findings from one study reported that there is evidence that paid
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19 153 carers are willing to collaborate on discontinuing antipsychotics where possible, although
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21 154 they feel more confident about achieving dosage reduction rather than total withdrawal. The
22
23 155 concerns raised by paid caregivers about time constraints lead to the perception that
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25 156 caregivers may have limited capacity to effectively manage challenging behaviour
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27 157 exacerbations. (Kleijwegt et al., 2019). However, while this study involved people with mild
28
29 158 intellectual disabilities; people with moderate to profound intellectual disabilities were not
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31 159 included. (Kleijwegt et al., 2019).
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38 39 161 ***Healthcare Professional attitudes towards the deprescribing process***

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42 162 In one online survey psychiatrists reported feeling positive towards deprescribing, reporting
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44 163 that they found the process of antipsychotic deprescribing a rewarding experience, increasing
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46 164 their confidence (Deb et al., 2023). However, the authors reported a low survey response rate
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48 165 meaning that their findings are unlikely to represent the views of psychiatrists working with
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50 166 people with intellectual disabilities broadly. In addition, an association was reported between
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52 167 well-resourced STOMP implementation with psychiatrists reporting satisfaction in the
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54 168 process with successful rationalisation of antipsychotic medication. However, where there
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56 169 was insufficient resource, psychiatrists seemed dissatisfied with the process with limited
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3 170 success in deprescribing antipsychotic medication. In another study, healthcare professionals
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5 171 reported that the lack of stakeholder knowledge of the deprescribing process can be a barrier
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8 172 (de Kuijper et al., 2022b).
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14 174 ***The attitudes of people with intellectual disabilities towards deprescribing***

16 175 There is some limited evidence from one study that people with intellectual disabilities are
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18 176 concerned about psychotropic medication deprescribing in case it leads to the re-emergence
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21 177 of behaviour problems (de Kuijper et al., 2022a). During the interviews in this study,
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23 178 participants expressed the importance of having a good rapport with their doctor. This
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26 179 relationship was important to them because it meant that they felt that their concerns were
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28 180 taken seriously. The participants also emphasised the importance of their own coping style in
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31 181 the success of discontinuing long-term medication, suggesting that the mindset and
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33 182 motivation of a person with intellectual disabilities may be a crucial facilitator in the
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35 183 deprescribing process (de Kuijper et al., 2022a).
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38 184 Evidence from people with intellectual disabilities highlights the importance of accessing
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40 185 approachable physicians who can address issues that may arise during the deprescribing
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42 186 process along with peer, family, and professional support (de Kuijper et al., 2022a).
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45 187 Interviews with people with intellectual disabilities revealed that their understanding of the
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47 188 deprescribing process and the quality of treatment by physicians are important facilitators of
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49 189 deprescribing (de Kuijper et al., 2022a).
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55 191 ***Extent of multidisciplinary team (MDT) and wider clinical team working***

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3 192 Evidence suggested that multiagency working and input from the MDT, nurse prescribers,
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5 193 allied healthcare professionals, social workers and pharmacists enables successful
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7 194 psychotropic deprescribing (Deb et al., 2023, Deb et al., 2020). Similarly, there is evidence
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9 195 from support staff that insufficient availability of multidisciplinary consultation was a barrier
10
11 196 to successful deprescribing (Kleijwegt et al., 2019). Successful deprescribing should
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13 197 incorporate a multi-level approach involving the support of managers at the institutional level
14
15 198 and the creation of favourable conditions at the political and professional level (de Kuijper et
16
17 199 al., 2022b).

200 *Availability of resources*

201 The belief that resources can play a significant role in achieving successful psychotropic
202 deprescribing outcomes was reported in one study (Deb et al., 2023, Deb et al., 2020) where
203 Positive Behaviour Support (PBS) plans were seen as a facilitator to deprescribing. The lack
204 of time, absence of appropriate PBS plans, lack of non-pharmacological interventions for
205 challenging behaviour, and inadequate social care provision were reported as barriers to
206 achieving successful deprescribing (de Kuijper et al., 2022b, Deb et al., 2023).

207 **Discussion**

208 The main finding from this review is the lack of studies reporting upon the stakeholder
209 experience of psychotropic deprescribing in people with intellectual disabilities. It was
210 difficult to find relevant studies, with most of the studies not identified in the initial data base
211 searches. However, the findings extracted from the included studies do provide some
212 valuable insights into stakeholder experiences and perspectives regarding the deprescribing of
213 psychotropic medicines in individuals with intellectual disabilities and challenging behaviour,
214 albeit limited by the lack of a substantial research literature.

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3 215 Carer resistance is significant in the context of the review question as it highlights the balance
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5 216 between implementing deprescribing interventions with caution and the potential benefits of
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7 217 deprescribing. Carer willingness to collaborate (Wrein, 2019), notwithstanding certain
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9 218 limitations, emphasises the importance of involving them in decision-making processes
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11 219 related to medication management. There is a need for effective strategies to address carers'
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13 220 concerns to build confidence, making them feel an equal partner in the deprescribing process.
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15 221 Similarly, concerns expressed by individuals with intellectual disabilities about the re-
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17 222 emergence of behaviour problems upon deprescribing reveal their unique perspective(de
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19 223 Kuijper et al., 2022a). Their emphasis on the doctor-patient relationship and personal coping
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21 224 strategies signifies the importance of shared decision making within a person-centred
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23 225 framework.
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25 226 Collaborative involvement of diverse healthcare and social care professionals is essential for
26
27 227 effective deprescribing in individuals with intellectual disabilities and challenging behaviour,
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29 228 emphasizing the importance of collective psychotropic deprescribing decisions (Deb et al.,
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31 229 2020, Deb et al., 2023). In addition to secondary care healthcare professionals, primary care
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33 230 practitioners including GPs and non medical prescribers have a significant role in the
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35 231 prescribing and deprescribing of psychotropic medicines in people with intellectual
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37 232 disabilities who display challenging behaviour. However inadequate resources can hinder
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39 233 effective deprescribing review (Deb et al., 2023, Deb et al., 2020, de Kuijper et al., 2022b).
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41 234 Commentaries by Deb and colleagues (Deb, 2007, Deb et al., 2009) further emphasise the
42
43 235 significance of the team approach in implementing psychotropic deprescribing. They
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45 236 highlight the barriers faced by general practitioners (GPs) in terms of lack of community
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47 237 support and negative attitudes of care staff.
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3 239 We found in our review that healthcare professionals reported that the lack of stakeholder
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5 240 knowledge of the deprescribing process can be a barrier (de Kuijper et al., 2022b). The
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7 241 commentaries by Deb and colleagues (Deb, 2007, Deb et al., 2009) also stress the
8
9 242 importance of education and support for GPs and carers to consider the withdrawal of
10
11 243 psychotropic medications, even after long-term use.

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15 244 NICE recommends that, during the annual physical health check for individuals with
16
17 245 intellectual disabilities conducted by GPs, it is crucial to consider the potential connection
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19 246 between challenging behaviour and physical health issues (NICE, 2015). This involves
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21 247 reviewing physical health medications and establishing a shared care management plan. GPs
22
23 248 are well placed to review both psychotropic and physical health medications, providing a
24
25 249 holistic, person centred approach to the management of challenging behaviour, including any
26
27 250 subsequent plans for psychotropic deprescribing. Consequently, educational and training
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29 251 initiatives for GPs regarding psychotropic deprescribing should highlight the significance of
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31 252 reviewing both physical health and psychotropic medications.

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36 253 Similar enablers of psychotropic deprescribing have been reported in people living with
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38 254 dementia where training appeared to increase the ability and confidence of care staff to
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40 255 manage challenging behaviour without the need for medication. In addition, a study exploring
41
42 256 supporting deprescribing in older adults in long term care concluded that a key element of
43
44 257 deprescribing success was attracting and sustaining engagement of a wide variety of relevant
45
46 258 stakeholders from across the health system by leveraging best practices in stakeholder
47
48 259 engagement (McCarthy et al., 2022). Furthermore, a systematic review looking at
49
50 260 psychotropic deprescribing in older adults with limited life expectancy reported that patient
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52 261 and relative involvement and the importance of teamwork were associated with successful
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54 262 outcomes (Lundby et al., 2019). These findings are consistent with our findings regarding the
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3 263 level of accessibility and engagement of the MDT can affect the outcome of psychotropic
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5 264 deprescribing interventions in people with intellectual disabilities.
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8 265 Studies looking at deprescribing interventions that are not specific to psychotropic medicines
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10 266 or people with intellectual disabilities reported some similar barriers and enablers to our
11
12 267 study. A systematic review by Reeve and colleagues (Reeve et al., 2013) reported barriers of
13
14 268 non-specific fears about stopping, such as stopping being problematic or being unable to
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16 269 cope, fear about the condition returning or worsening and fear of withdrawal effects. They
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18 270 also reported that a good relationship with the physician facilitated the deprescribing process.
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20 271 Interestingly, a systematic review exploring consumer attitudes towards deprescribing
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22 272 reported that the majority of carers reported that they would be willing for one or more of
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24 273 their care recipient's medications to be stopped if their care recipient's doctor said it was
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26 274 possible (Weir et al., 2022).
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32 275 Due to the low number of studies included in this review, the impact of our findings is limited
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34 276 and therefore it is important to exercise caution in interpreting these findings. The quality
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36 277 appraisal process identified potential bias associated with sampling and recruitment methods
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38 278 across studies, such as direct approaches (de Kuijper et al., 2022b, Deb et al., 2023, Deb et
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40 279 al., 2020), convenience sampling (Kleijwegt et al., 2019) and recruitment by physicians (de
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42 280 Kuijper et al., 2022a).
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46 281 In addition to the small number of included studies and despite there being no restriction on
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48 282 country, three out of the five studies were carried out in the Netherlands (de Kuijper et al.,
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50 283 2022a, de Kuijper et al., 2022b, Kleijwegt et al., 2019) and two studies were carried out in the
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52 284 U.K. (Wrein, 2019, Deb et al., 2020). This may limit the external validity and transferability
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54 285 of the overall systematic review when considering settings in other countries where there may
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56 286 be differences in health policy, practices and access to healthcare.
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3 287 When developing policies, we need to consider stakeholder experiences as this can impact on
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5 288 the uptake and the success of implementing the intervention. Earlier research suggests that
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8 289 carers of people with intellectual disabilities feel they are not sufficiently involved in
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10 290 healthcare decisions by services (Lalor and Poulson, 2013, Chadwick et al., 2013).

291

292 **Conclusion**

293 Our findings suggest that there is very limited data on stakeholder experiences of
294 deprescribing psychotropic medicines as a part of a care plan for people with intellectual
295 disabilities and challenging behaviour. To inform best practice in implementing the
296 psychotropic deprescribing process in people with intellectual disabilities we need to further
297 understand how these experiences impact on the implementation process of psychotropic
298 deprescribing by carrying out further research. Despite these limitations, our review provides
299 a valuable starting point for researchers and practitioners seeking to better understand the
300 complex issues surrounding psychotropic deprescribing in people with intellectual
301 disabilities.

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3 1 **Stakeholder Experiences of Deprescribing Psychotropic Medicines for Challenging**
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5 2 **Behaviour in People with Intellectual Disabilities**
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10 4 **Abstract**
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14 6 **Purpose**
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17 7 Evidence of overprescribing of psychotropic medicines to manage challenging behaviour in
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19 8 people with intellectual disabilities has led to national programmes within the U.K to promote
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21 9 deprescribing, such as STOMP (Stopping the Overprescribing of Medication in People with
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23 10 Learning Disabilities, Autism or both). To successfully implement deprescribing initiatives
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25 11 we need to understand how to engage stakeholders in the process.
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31 13 **Approach**
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33 14 In a published systematic review, we reported evidence about the process of deprescribing
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35 15 psychotropic medicines for people of all ages with intellectual disabilities and challenging
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37 16 behaviour. As a part of the original review, we searched for evidence about stakeholders'
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39 17 experiences of the psychotropic deprescribing process which was synthesised and reported
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41 18 within the current study.
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47 20 **Findings**
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49 21 Six studies were identified. Involving carers and people with intellectual disabilities,
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51 22 providing ongoing support, and improving access to non-pharmacological interventions
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53 23 including Positive Behaviour Support may contribute to successful outcomes, including
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55 24 reducing or stopping psychotropic medicines and improved quality of life. Implementing
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3 25 psychotropic deprescribing requires a multidisciplinary collaborative care approach and
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5 26 education for stakeholders.
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9 **27 Originality**

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12 28 There have been no previous reviews of stakeholder experiences of deprescribing
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14 29 psychotropic medications for people with intellectual disabilities and challenging behaviour.
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16 30 The existing literature is scant and further research is needed.
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21 **32 Paper Type**

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23 33 Research Paper
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30 **36 Background**

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32 37 Overprescribing, the use of a medicine where there is a better non-medicine alternative, or the
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34 38 prescription is inappropriate for the circumstances and wishes of an individual, occurs
35
36 39 throughout healthcare systems (Ridge, 2021). An estimated 10% of dispensed items are
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38 40 overprescribed in primary care with 15% of people taking five or more medicines a day
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40 41 (Ridge, 2021). Initially, a medicine may be appropriately prescribed, but in the absence of
41
42 42 timely review, it may no longer be the best choice. Furthermore, polypharmacy, the
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44 43 prescribing and administration of multiple medicines, and patient cognitive impairment can
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46 44 be problematic and may be associated with medication errors (Duerden et al., 2013,
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48 45 Maidment et al., 2008).
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53 46 Overprescribing can lead to harm by exposing individuals to unnecessary adverse effects of
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55 47 medicines and an increased risk of interactions with other medicines (Ridge, 2021). Equally,
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57 48 overprescribing increases the burden on the person and any family carers supporting them
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3 49 (Duerden et al., 2013, Ridge, 2021, Bennett et al., 2021, Lawson et al., 2022). In 2021, the
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5 50 U.K. Government overprescribing review (Ridge, 2021) recommended expanding the use
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7
8 51 of structured medication reviews and embedding deprescribing within the prescribing
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10 52 process.

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13 53 Deprescribing, the planned and supervised process of dose reduction or stopping of
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15 54 medication in a safe and effective way (Doherty et al., 2020, Australian Deprescribing
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18 55 Network, US Deprescribing Research Network, 2020, Bruyère Research Institute), is a
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20 56 complex healthcare intervention that looks to address overprescribing. As with prescribing,
21
22 57 deprescribing should be a collaborative process within a person-centred and shared decision
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24 58 making framework with the aim of minimising risk of harm from medication whilst
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27 59 achieving improved positive health outcomes (Department of Health and Social Care, 2021).

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29
30 60 In 2016, NHS England launched the STOMP programme in response to evidence that
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32 61 psychotropic medicines are overprescribed in people with intellectual disabilities for the
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34 62 management of challenging behaviour (Branford et al., 2019, NHS England, Sheehan et al.,
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37 63 2015, Bowring et al., 2017). For example, a report by Public Health England (Glover and
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39 64 Mehta, 2019) in 2015 found that a third of people known to have intellectual disabilities were
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41 65 prescribed at least one psychotropic medicine and more than half of these people did not have
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44 66 a documented mental health diagnosis.

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47 67 Our previously published systematic review reported findings addressing the primary review
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49 68 question in accordance with a published protocol
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51 69 (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=158079), looking at the
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53 70 effects of deprescribing psychotropic medicines as a part of a care pathway or treatment plan
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56 71 for people of all ages with intellectual disabilities and challenging behaviour (Adams et al.
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58 72 2023). The review included 54 studies carried out in community and inpatient settings
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3 73 primarily in the UK, the USA and the Netherlands focussing on 3292 people with intellectual
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5 74 disabilities. Our review found that psychotropic deprescribing interventions for people with
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7 75 intellectual disabilities may lead to dosage reductions and the discontinuation of these
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10 76 medicines. Although negative effects of deprescribing were reported we found there were
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12 77 positive effects on behaviour, mental and physical health which were associated with a
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14 78 multidisciplinary model (Adams et al., 2023).

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17 79 Examining the overall effectiveness of an intervention is essential, but alone is insufficient to
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19 80 fully support the widespread implementation of a complex intervention such as deprescribing.
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21 81 To successfully implement deprescribing initiatives we need to understand how to engage
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23 82 health and social care professionals, family carers and individuals with intellectual disabilities
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25 83 in the process and how they experience deprescribing. An understanding of how the attitudes,
26
27 84 beliefs and values of these stakeholders affect decision making and influence behaviour as
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29 85 part of the deprescribing process is a key aspect of this (Darnton, 2008, Moore et al., 2015).
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31 86 Furthermore, a clear understanding of the barriers and enablers to successful deprescribing is
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33 87 important to maximise success and contribute towards the development of clear guidance and
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35 88 policy.

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40 89 Existing published literature reviews have not adequately explored these experiences of
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42 90 stakeholders, regarding deprescribing psychotropic medicines in people with intellectual
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44 91 disabilities. Previous reviews have considered people's experiences of deprescribing in older
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46 92 people (Lundby et al., 2019) and within primary care (Doherty et al., 2020) but have not
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48 93 specifically looked at deprescribing psychotropic medicine use with people with intellectual
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50 94 disabilities.

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55 95 To address this gap in the literature, we had originally included an additional review question
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57 96 in our protocol addressing stakeholder experiences and perspectives on deprescribing
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59 97 psychotropic medicines in individuals with intellectual disabilities and challenging behaviour.
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3 98 We defined stakeholders as people with intellectual disabilities, paid carers, family carers,
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5 99 nurses, healthcare assistants, GPs, psychiatrists, pharmacists, other specialist healthcare
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8 100 professionals and social care professionals. In this paper we report and discuss the findings
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10 101 that emerged from our attempt to consider this review question.
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13 102 **Methodology**

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15 103 Full details of the methodology are reported in our previously published systematic review
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17 104 (Adams et al., 2023). To answer the current question in this review, we only included papers
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19 105 that reported outcomes for stakeholders' experiences in terms of attitudes, views and beliefs
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21 106 about psychotropic deprescribing in people with intellectual disabilities.
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24 107 Database searches were updated several times and a final search was completed in November
25
26 108 2022. Forwards and backwards reference searching of papers included in our published
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28 109 systematic review (Adams et al., 2023) was also conducted to track citations. Four key
29
30 110 researchers, identified as having published several studies in this field over the last 10 years,
31
32 111 were contacted to identify any further studies. Trial registries were not searched. Following
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34 112 data extraction using a bespoke data extraction form, studies were individually appraised for
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36 113 risk of bias using the qualitative tool from the Critical Appraisals Skills Programme Tools
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38 114 (CASP; CASP,2015) which consist of ten questions to assess internal and external validity.
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44 116 **Data Analysis**

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46 117 We organised our findings into groups which were developed by discussions within the
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48 118 research team. This allowed us to synthesise our findings more easily and draw conclusions
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50 119 from our findings.
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55 121 **Findings**

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3 122 We only found two papers through database searching (Kleijwegt et al., 2019, Deb et al.,
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5 123 2020). We found one additional paper through citation searching (Wrein, 2019) and an
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7 124 additional three more via direct author contact (de Kuijper et al., 2022b, de Kuijper et al.,
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9 125 2022a, Deb et al., 2023). Two papers reported results from the same study; one reporting
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11 126 quantitative data (Deb et al., 2020) and the other reporting qualitative data (Deb et al., 2023) .
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15 127 Two studies were carried out in the U.K. (Wrein, 2019, Deb et al., 2020) and three studies in
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17 128 The Netherlands (de Kuijper et al., 2022b, de Kuijper et al., 2022a, Kleijwegt et al., 2019).
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19 129 Two studies (n = 34, n = 88) reported experiences direct from psychiatrists (de Kuijper et al.,
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21 130 2022b, Deb et al., 2020, Deb et al., 2023), two studies (n = 29, n = 8) reported experiences
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23 131 direct from carers (Kleijwegt et al., 2019, Wrein, 2019); and one study (n = 7) reported
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25 132 experiences direct from people with intellectual disabilities (de Kuijper et al., 2022a). There
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27 133 were a range of study types; two mixed methods studies using online questionnaires (de
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29 134 Kuijper et al., 2022b, Deb et al., 2020, Deb et al., 2023), one qualitative study using
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31 135 interviews (de Kuijper et al., 2022a), one qualitative study using semi structured interviews
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33 136 (Wrein, 2019) and one qualitative study using focus groups (Kleijwegt et al., 2019).
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39 137 We organised our findings by grouping data from the included studies into five categories:
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41 138 (1) carer attitudes towards deprescribing, (2) healthcare professional attitudes towards
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43 139 deprescribing, (3) the attitudes of people with intellectual disabilities towards deprescribing,
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45 140 (4) the extent of multidisciplinary team and wider clinical team working, (5) the availability
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47 141 of resources.
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53 143 *Carer attitudes towards the deprescribing process*

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56 144 The involvement of paid carers was seen as vital to the success of deprescribing (Wrein,
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58 145 2019). Overall, there is some evidence from two studies that carers are resistant, at times, to
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3 146 deprescribing due to concerns about a deterioration, their lack of experience (Deb et al., 2020,
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5 147 Kleijwegt et al., 2019), and a feeling that “maybe at times it makes us more risk adverse if
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7 148 we're unsure how the individual is going you know to respond to something maybe we'll
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9 149 think, well let's not do that” (Wrein, 2019) p73 giving rise to therapeutic inertia. Three of
10
11 150 these studies reported on findings regarding both paid and family carers whereas one study
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13 151 reported findings related to only paid carers (Kleijwegt et al., 2019).
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17 152 Despite carer “resistance”, findings from one study reported that there is evidence that paid
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19 153 carers are willing to collaborate on discontinuing antipsychotics where possible, although
20
21 154 they feel more confident about achieving dosage reduction rather than total withdrawal. The
22
23 155 concerns raised by paid caregivers about time constraints lead to the perception that
24
25 156 caregivers may have limited capacity to effectively manage challenging behaviour
26
27 157 exacerbations. (Kleijwegt et al., 2019). However, while this study involved people with mild
28
29 158 intellectual disabilities; people with moderate to profound intellectual disabilities were not
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31 159 included. (Kleijwegt et al., 2019).
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161 ***Healthcare Professional attitudes towards the deprescribing process***

162 In one online survey psychiatrists reported feeling positive towards deprescribing, reporting
163 that they found the process of antipsychotic deprescribing a rewarding experience, increasing
164 their confidence (Deb et al., 2023). However, the authors reported a low survey response rate
165 meaning that their findings are unlikely to represent the views of psychiatrists working with
166 people with intellectual disabilities broadly. In addition, an association was reported between
167 well-resourced STOMP implementation with psychiatrists reporting satisfaction in the
168 process with successful rationalisation of antipsychotic medication. However, where there
169 was insufficient resource, psychiatrists seemed dissatisfied with the process with limited
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3 170 success in deprescribing antipsychotic medication. In another study, healthcare professionals
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5 171 reported that the lack of stakeholder knowledge of the deprescribing process can be a barrier
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8 172 (de Kuijper et al., 2022b).
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14 174 ***The attitudes of people with intellectual disabilities towards deprescribing***

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17 175 There is some limited evidence from one study that people with intellectual disabilities are
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19 176 concerned about psychotropic medication deprescribing in case it leads to the re-emergence
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21 177 of behaviour problems (de Kuijper et al., 2022a). During the interviews in this study,
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23 178 participants expressed the importance of having a good rapport with their doctor. This
24
25 179 relationship was important to them because it meant that they felt that their concerns were
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28 180 taken seriously. The participants also emphasised the importance of their own coping style in
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30 181 the success of discontinuing long-term medication, suggesting that the mindset and
31
32 182 motivation of a person with intellectual disabilities may be a crucial facilitator in the
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35 183 deprescribing process (de Kuijper et al., 2022a).
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38 184 Evidence from people with intellectual disabilities highlights the importance of accessing
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40 185 approachable physicians who can address issues that may arise during the deprescribing
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42 186 process along with peer, family, and professional support (de Kuijper et al., 2022a).
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45 187 Interviews with people with intellectual disabilities revealed that their understanding of the
46
47 188 deprescribing process and the quality of treatment by physicians are important facilitators of
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49 189 deprescribing (de Kuijper et al., 2022a).
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55 191 ***Extent of multidisciplinary team (MDT) and wider clinical team working***

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3 192 Evidence suggested that multiagency working and input from the MDT, nurse prescribers,
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5 193 allied healthcare professionals, social workers and pharmacists enables successful
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7 194 psychotropic deprescribing (Deb et al., 2023, Deb et al., 2020). Similarly, there is evidence
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9 195 from support staff that insufficient availability of multidisciplinary consultation was a barrier
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11 196 to successful deprescribing (Kleijwegt et al., 2019). Successful deprescribing should
12
13 197 incorporate a multi-level approach involving the support of managers at the institutional level
14
15 198 and the creation of favourable conditions at the political and professional level (de Kuijper et
16
17 199 al., 2022b).

200 *Availability of resources*

201 The belief that resources can play a significant role in achieving successful psychotropic
202 deprescribing outcomes was reported in one study (Deb et al., 2023, Deb et al., 2020) where
203 Positive Behaviour Support (PBS) plans were seen as a facilitator to deprescribing. The lack
204 of time, absence of appropriate PBS plans, lack of non-pharmacological interventions for
205 challenging behaviour, and inadequate social care provision were reported as barriers to
206 achieving successful deprescribing (de Kuijper et al., 2022b, Deb et al., 2023).

207 **Discussion**

208 The main finding from this review is the lack of studies reporting upon the stakeholder
209 experience of psychotropic deprescribing in people with intellectual disabilities. It was
210 difficult to find relevant studies, with most of the studies not identified in the initial data base
211 searches. However, the findings extracted from the included studies do provide some
212 valuable insights into stakeholder experiences and perspectives regarding the deprescribing of
213 psychotropic medicines in individuals with intellectual disabilities and challenging behaviour,
214 albeit limited by the lack of a substantial research literature.

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3 215 Carer resistance is significant in the context of the review question as it highlights the balance
4
5 216 between implementing deprescribing interventions with caution and the potential benefits of
6
7 217 deprescribing. Carer willingness to collaborate (Wrein, 2019), notwithstanding certain
8
9 218 limitations, emphasises the importance of involving them in decision-making processes
10
11 219 related to medication management. There is a need for effective strategies to address carers'
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13 220 concerns to build confidence, making them feel an equal partner in the deprescribing process.
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15 221 Similarly, concerns expressed by individuals with intellectual disabilities about the re-
16
17 222 emergence of behaviour problems upon deprescribing reveal their unique perspective(de
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19 223 Kuijper et al., 2022a). Their emphasis on the doctor-patient relationship and personal coping
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21 224 strategies signifies the importance of shared decision making within a person-centred
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23 225 framework.
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25 226 Collaborative involvement of diverse healthcare and social care professionals is essential for
26
27 227 effective deprescribing in individuals with intellectual disabilities and challenging behaviour,
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29 228 emphasizing the importance of collective psychotropic deprescribing decisions (Deb et al.,
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31 229 2020, Deb et al., 2023). In addition to secondary care healthcare professionals, primary care
32
33 230 practitioners including GPs and non medical prescribers have a significant role in the
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35 231 prescribing and deprescribing of psychotropic medicines in people with intellectual
36
37 232 disabilities who display challenging behaviour. However inadequate resources can hinder
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39 233 effective deprescribing review (Deb et al., 2023, Deb et al., 2020, de Kuijper et al., 2022b).
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41 234 Commentaries by Deb and colleagues (Deb, 2007, Deb et al., 2009) further emphasise the
42
43 235 significance of the team approach in implementing psychotropic deprescribing. They
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45 236 highlight the barriers faced by general practitioners (GPs) in terms of lack of community
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47 237 support and negative attitudes of care staff.
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3 239 We found in our review that healthcare professionals reported that the lack of stakeholder
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5 240 knowledge of the deprescribing process can be a barrier (de Kuijper et al., 2022b). The
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7 241 commentaries by Deb and colleagues (Deb, 2007, Deb et al., 2009) also stress the
8
9 242 importance of education and support for GPs and carers to consider the withdrawal of
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11 243 psychotropic medications, even after long-term use.

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15 244 NICE recommends that, during the annual physical health check for individuals with
16
17 245 intellectual disabilities conducted by GPs, it is crucial to consider the potential connection
18
19 246 between challenging behaviour and physical health issues (NICE, 2015). This involves
20
21 247 reviewing physical health medications and establishing a shared care management plan. GPs
22
23 248 are well placed to review both psychotropic and physical health medications, providing a
24
25 249 holistic, person centred approach to the management of challenging behaviour, including any
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27 250 subsequent plans for psychotropic deprescribing. Consequently, educational and training
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29 251 initiatives for GPs regarding psychotropic deprescribing should highlight the significance of
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31 252 reviewing both physical health and psychotropic medications.

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36 253 Similar enablers of psychotropic deprescribing have been reported in people living with
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38 254 dementia where training appeared to increase the ability and confidence of care staff to
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40 255 manage challenging behaviour without the need for medication. In addition, a study exploring
41
42 256 supporting deprescribing in older adults in long term care concluded that a key element of
43
44 257 deprescribing success was attracting and sustaining engagement of a wide variety of relevant
45
46 258 stakeholders from across the health system by leveraging best practices in stakeholder
47
48 259 engagement (McCarthy et al., 2022). Furthermore, a systematic review looking at
49
50 260 psychotropic deprescribing in older adults with limited life expectancy reported that patient
51
52 261 and relative involvement and the importance of teamwork were associated with successful
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54 262 outcomes (Lundby et al., 2019). These findings are consistent with our findings regarding the
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3 263 level of accessibility and engagement of the MDT can affect the outcome of psychotropic
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5 264 deprescribing interventions in people with intellectual disabilities.
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8 265 Studies looking at deprescribing interventions that are not specific to psychotropic medicines
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10 266 or people with intellectual disabilities reported some similar barriers and enablers to our
11
12 267 study. A systematic review by Reeve and colleagues (Reeve et al., 2013) reported barriers of
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14 268 non-specific fears about stopping, such as stopping being problematic or being unable to
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16 269 cope, fear about the condition returning or worsening and fear of withdrawal effects. They
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18 270 also reported that a good relationship with the physician facilitated the deprescribing process.
19
20 271 Interestingly, a systematic review exploring consumer attitudes towards deprescribing
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22 272 reported that the majority of carers reported that they would be willing for one or more of
23
24 273 their care recipient's medications to be stopped if their care recipient's doctor said it was
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26 274 possible (Weir et al., 2022).
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32 275 Due to the low number of studies included in this review, the impact of our findings is limited
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34 276 and therefore it is important to exercise caution in interpreting these findings. The quality
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36 277 appraisal process identified potential bias associated with sampling and recruitment methods
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38 278 across studies, such as direct approaches (de Kuijper et al., 2022b, Deb et al., 2023, Deb et
39
40 279 al., 2020), convenience sampling (Kleijwegt et al., 2019) and recruitment by physicians (de
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42 280 Kuijper et al., 2022a).
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46 281 In addition to the small number of included studies and despite there being no restriction on
47
48 282 country, three out of the five studies were carried out in the Netherlands (de Kuijper et al.,
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50 283 2022a, de Kuijper et al., 2022b, Kleijwegt et al., 2019) and two studies were carried out in the
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52 284 U.K. (Wrein, 2019, Deb et al., 2020). This may limit the external validity and transferability
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54 285 of the overall systematic review when considering settings in other countries where there may
55
56 286 be differences in health policy, practices and access to healthcare.
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3 287 When developing policies, we need to consider stakeholder experiences as this can impact on
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5 288 the uptake and the success of implementing the intervention. Earlier research suggests that
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7 289 carers of people with intellectual disabilities feel they are not sufficiently involved in
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9 290 healthcare decisions by services (Lalor and Poulson, 2013, Chadwick et al., 2013).
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292 **Conclusion**

15 292 **Conclusion**
16 293 Our findings suggest that there is very limited data on stakeholder experiences of
17 294 deprescribing psychotropic medicines as a part of a care plan for people with intellectual
18 295 disabilities and challenging behaviour. To inform best practice in implementing the
19 296 psychotropic deprescribing process in people with intellectual disabilities we need to further
20 297 understand how these experiences impact on the implementation process of psychotropic
21 298 deprescribing by carrying out further research. Despite these limitations, our review provides
22 299 a valuable starting point for researchers and practitioners seeking to better understand the
23 300 complex issues surrounding psychotropic deprescribing in people with intellectual
24 301 disabilities.
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