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# The UK psychiatrists' experience of rationalising antipsychotics in adults with intellectual disabilities: A qualitative data analysis of free-text questionnaire responses

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## Abstract

**Background:** Overprescribing of off-licence psychotropic medications, particularly antipsychotics, for challenging behaviours in people with intellectual disabilities without a psychiatric disorder is a significant public health concern. In the United Kingdom, the National Health Service England launched an initiative in 2016, 'Stopping Over-Medication of People with learning disabilities, autism or both (STOMP)', to address this concern. STOMP is supposed to encourage psychiatrists in the United Kingdom and elsewhere to rationalise psychotropic medication use in people with intellectual disabilities. The current study aims to gather UK psychiatrists' views and experience of implementing the STOMP initiative.

**Methods:** An online questionnaire was sent to all UK psychiatrists working in the field of intellectual disabilities (estimated 225). Two open-ended questions allowed participants to write comments in response to these questions in the free text boxes. One question asked about the challenges psychiatrists faced locally to implement STOMP, and the other asked for examples of successes and positive experiences from the process. The free text data were analysed using a qualitative method with the help of the NVivo 12 plus software.

**Results:** Eighty-eight (estimated 39%) psychiatrists returned the completed questionnaire. The qualitative analysis of free-text data has shown variation within services in the experience and views of the psychiatrists. In areas with good support for STOMP implementation provided through adequate resources, psychiatrists reported satisfaction in the process with successful antipsychotic rationalisation, better local multi-disciplinary and multi-agency working, and increased awareness of STOMP issues among the stakeholders such as people with intellectual disabilities and their caregivers and multidisciplinary teams, and improved quality of life caused by reduced medication-related adverse events in people with intellectual disabilities. However, where resource utilisation is not optimum, psychiatrists seemed dissatisfied with the process with little success in medication rationalisation.

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**Conclusions:** Whereas some psychiatrists are successful and enthusiastic about rationalising antipsychotics, others still face barriers and challenges. Much work is needed to achieve a uniformly positive outcome throughout the United Kingdom.

**KEYWORDS**

intellectual disabilities, psychotropic medication, questionnaire survey, STOMP, UK psychiatrists

## 1 | BACKGROUND

Three decades ago, Deb and Fraser highlighted that half of the adults with intellectual disabilities received psychotropic medication even after discharge from hospitals to community settings (Deb & Fraser, 1994). This rate remains similar even today (Sheehan et al., 2015). This is despite publications of national (NICE, 2015; Unwin & Deb, 2010) and international guidelines (Deb et al., 2009) on the use of psychotropics in adults with intellectual disabilities. The off-licence prescribing of antipsychotics to address challenging behaviours in the absence of psychiatric disorders in people with intellectual disabilities is a public health concern (Glover et al., 2015). Because of this, in the United Kingdom, NHS England launched a major initiative, STOMP (STopping Over-Medication of People with learning disabilities, autism or both), in 2016 (Branford et al., 2018). STOMP encourages people to have regular check-ups about their medicines, make sure doctors and other health professionals involve people, families and support staff in decisions about medicines, and inform everyone about non-drug therapies and practical ways of supporting people, so they are less likely to need as much medicine if any.

Many people with intellectual disabilities display challenging behaviours such as verbal aggression, physical aggression toward others, property and self (self-injurious behaviour), destructiveness and so on (up to 60%; Deb, Unwin, et al., 2022). These behaviours may be challenging to manage and cause distress to the person with intellectual disabilities, and their caregivers, exclusion of these people from community facilities, community placement breakdown leading to hospitalisation, and lead to restrictive practices such as physical restraint and overuse of psychotropic medications outside their indications to address these behaviours.

Both pharmacological and non-pharmacological psychosocial interventions have been used to address challenging behaviours. The overall evidence for the efficacy of psychotropic medications in improving challenging behaviour in the absence of a psychiatric disorder is weak (Deb et al., 2023). There is growing evidence for the efficacy of non-pharmacological interventions in improving challenging behaviours in people with intellectual disabilities (Bruinsma et al., 2020; Gerrard et al., 2019; McGill et al., 2018). Both national and international guidelines recommend using psychotropic medications only when non-pharmacological interventions, such as positive behaviour support (PBS; Gore et al., 2022) and function-based treatments (Geiger et al., 2010) have failed and the person or others around them are at risk of harm (Deb et al., 2009; NICE, 2015).

One way of addressing the concern regarding the overreliance on medication to address challenging behaviours is by reviewing current prescriptions carefully and reducing dosage with the view to discontinuing medications where it seems appropriate and safe to do so (Shankar et al., 2019). There have been several publications of successful antipsychotic withdrawal in adults with intellectual disabilities in the United Kingdom and the Netherlands (Ahmed et al., 2000; Branford, 1996; de Kuijper et al., 2014; de Kuijper & Hoekstra, 2018; Gerrard et al., 2019; Shankar et al., 2019; Sheehan & Hassiotis, 2017). According to these studies, total discontinuation of antipsychotic medication has been possible in 25%–61% of adults with intellectual disabilities, and 50% dose reduction in another 11%–19%, although in up to 20% of cases, antipsychotics were re-instated within 3–4 years of discontinuation primarily due to resurgence of challenging behaviour (Deb et al., 2023; Deb, Bertelli, & Rossi, 2022).

Unlike other countries, UK psychiatrists receive specialist training in intellectual disabilities and provide specialised services for psychiatry in intellectual disabilities ([www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)). It is essential to assess the effect of the STOMP initiative on the UK psychiatrists' practice concerning rationalising psychotropic medications in people with intellectual disabilities so that lessons can be learned. Therefore, in this paper, we have presented data on the qualitative analysis of the views of UK psychiatrists on the barriers and successes in implementing STOMP in practice by analysing the free text comments returned in a recent online survey questionnaire.

## 2 | METHODS

An online survey using the STROBE cross-sectional study model was developed through a consultation process by a core team of psychiatrists, pharmacists and academics working in the field of psychiatry of intellectual disabilities, with input from patient representative groups in the United Kingdom.

The questionnaire with a cover letter was emailed to the UK Royal College of Psychiatrists' Intellectual Disabilities Regional Representatives and Training Programme Directors practising in Psychiatry of Intellectual Disabilities. They were asked to forward the questionnaire to the psychiatrists working within their respective regions. The Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists in the United Kingdom supported the survey. The survey was open between 12 October 2019 and 29 February 2020, and three email reminders were sent out to encourage participation.

The survey questionnaire took approximately 10 min to complete. It contained the following main subsections: (a) respondent characteristics; (b) the experience of reducing/withdrawing antipsychotic medications; (c) prescribing habits since the introduction of the STOMP; (d) the structures in place to support the withdrawal process (e) the successes and challenges experienced in withdrawing antipsychotics prescribed for challenging behaviours in adults with intellectual disabilities.

Two questions allowed participants to write their comments in free text boxes. One of these questions asked participants to describe the experience of successes and positive aspects of withdrawing psychotropics. The second question asked participants to describe the challenges they faced while trying to withdraw antipsychotics. Free text responses were used to gain qualitative data.

## 2.1 | Ethics and participation consent

No ethical approval was required as this was a survey of psychiatrists' opinions and did not collect any individual patient data. All potential participants were advised that participation was voluntary with the explicit mention that the response to the survey constituted informed consent, and their replies would be anonymised before analysis.

## 2.2 | Data analysis

Free text responses were transferred to a word document from which they were transferred as a file onto NVivo 12 plus software (<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>). The data were analysed using the following six-step thematic analysis process (a) familiarising with data by reading and re-reading the data and noting down initial ideas; (b) generating initial codes; and (c) searching for themes by collating codes into potential themes, and gathering all data relevant to each potential theme; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report (Braun & Clarke, 2006). Two authors (Bharati Limbu and Shoumitro (Shoumi) Deb) first read the word file to familiarise themselves with the data. The data were then coded to generate initial themes, which were saved as NVivo 12 plus software nodes. The data and nodes were reviewed to develop themes, which were then further refined and reviewed. Once the themes could no longer be refined, themes were then defined, which we have presented in the Results section. Researchers were unknown to the participants and had no direct contact with them as the study was based on an online questionnaire. Two authors (Bharati Limbu and Shoumitro (Shoumi) Deb) independently coded the text for triangulation, providing a good agreement between them, although we did not conduct any statistical analysis for inter-rater reliability. Any disagreement was resolved by further discussion between the authors.

## 3 | RESULTS

We estimate that around 225 psychiatrists working in the speciality of intellectual disabilities in the United Kingdom received the questionnaire, 88 (estimated 39%) of whom returned the completed questionnaire. The estimate of 225 is based on the database of the Royal College of Psychiatrists, UK members showing an interest in joining the Faculty of Psychiatry of Intellectual Disabilities. About 16% of participants have more than 20 years, and 35% have more than 10 years of experience of working as a psychiatrist in the field of intellectual disabilities. Of the participants, 87.5% were consultants, 6.8% were higher trainees, and 5.7% were speciality doctors. The regional distributions showed that 20.5% were working in London, 15.9% in the South West of England, 11.4% in the South East of England, 10.2% in the East Midlands, 6.8% in the West Midlands, 8% in the East of England, 5.7% in the North East of England, 5.7% in Scotland, 4.5% in Wales, 4.5% in Northern Ireland, 4.5% in the Yorkshire and Humber region, and the rest (2.2%) in other areas. Psychiatrists worked with children and adults with intellectual disabilities, in-patients (including the Forensic sector) and in outpatient settings. Although we did not collect data on these, we believe most psychiatrists worked with adults with intellectual disabilities outside the Forensic settings.

In the following sections, we have presented data from the qualitative analysis of participants' responses to two questions for which they were allowed to write their comments in free text boxes. We have started with the comments to the question on success stories and positive outcomes of STOMP implementation, followed by the challenges faced by the participants in implementing STOMP.

## 4 | SUCCESSES

When the participants were asked to write their comments in the free text box in response to the question about what the positive experiences were from taking part in the STOMP initiative, the following themes emerged; (a) positive changes in prescriber's attitude and practice concerning antipsychotic prescribing for challenging behaviours, (b) improved local multi-agency working including working with families, (c) better awareness of STOMP issues among the multi-disciplinary team (MDT), GPs, support staff and families, and (d) improved quality of life and decreased medication-related adverse events in people with intellectual disabilities upon withdrawal of antipsychotics.

### 4.1 | Positive changes in prescriber's attitude and practice

Many participants found the process of psychotropic withdrawal satisfying and helpful.

It has had its challenges but it is gratifying to see the benefits.

For some participants, the satisfaction from withdrawing psychotropic medication was not deterred by lack of MDT support or, in some cases, unsuccessful withdrawal.

It is professionally satisfying regardless of whether withdrawal is successful.

This has been a highly challenging and ultimately rewarding experience for me as a new consultant with very little support from the MDT.

Some also felt that the STOMP initiative sets a good example for trainees.

Encouraging overall; provides a good example to trainee psychiatrists....

Many participants reported cases of many successful withdrawals of medication or significant dose reductions.

Several successful cases of withdrawing antipsychotics.

.....managed to withdraw at least 50% of dose in 25% of people....

Encouragingly, these dose reductions did not lead to unwanted effects such as hospital admission.

.....no hospital admissions at the back of antipsychotics withdrawal....

For some prescribers, taking part in STOMP implementation has increased their confidence in deprescribing and not initiating psychotropics in the first place to address challenging behaviours.

It is a good initiative and made me think now for each patient the long term impact.

.....more aware of the risks and more confidence to say no to prescribing....

Overall, the STOMP initiative seems to be encouraging some psychiatrists to be more rational in their psychotropic prescribing.

.....we have become more rational in prescribing.....

One participant highlighted the role of in-patient assessment and treatment unit in rationalising antipsychotics for people who have been receiving them for many years without an appropriate review.

Use of the in-patient environment to complete effective assessments, medication withdrawal and monitoring.

Many participants argued that medication review and rationalisation should be part of their routine clinical activities.

It works really well when considered as part of your routine review in every contact. It helps when you spend some time to explain about STOMP and signpost to information available online....

This should always be considered, this is not a change in practice.

Many participants mentioned that they had been carrying out medication reviews for a long time, even before the launch of STOMP.

It has continued for years before the STOMP initiative.

Some highlighted how the experience of STOMP implementation has led to the exposure of previously unmet needs.

STOMP has been a challenge but also a wonderful opportunity to address unmet need in our people with ID.

One person highlighted the need for working closely with the MDT and the GPs.

It works best when we co work with GP and psychology.

One participant pointed out the need for a full discussion with all stakeholders, particularly the possible causes for the challenging behaviours.

Discussing reasons, allowing time to think and then having a cautious reduction helps.

One participant mentioned how their local initiative to implement STOMP has led to a better assessment of all causes of challenging behaviours, particularly physical causes, many of which were amenable to non-psychotropic treatment. This has eventually helped reduce the overreliance on psychotropic medications to address challenging behaviours.

Recent (Aug 2019) STOMP pilot set up. Identifying underlying physical ill health (e.g. delirium, constipation, pain, UTI) in many patients who had been written off as 'difficult' and medicated for no good reason. These patients are now accessing better physical health input, and their carers are asking for medical reviews/laxatives/urine dipsticks rather than 'more prn'/'increased risperidone'.

## 4.2 | Improved multi-agency and family working

Many participants mentioned how the process of medication rationalisation improved multi-agency working in their local areas.

MDT, multiagency work and people participation (helped).

Major expansion in PBS services and specialist nurse prescribing provision.

In some areas, the process increased multi-agency and multi-professional working and the bonding within the team to achieve the common goal of rationalising psychotropics.

There has been a strengthening of cross agency working with a common goal to improve the quality of lives of people with ID.

For some, explaining the issue to all stakeholders and making relevant information available increased the support for psychotropic rationalisation from families, schools and other agencies.

It helps when you spend some time to explain about STOMP and signpost to information available online. Having MDT support and working closely with GP helps.

.....support from individuals e.g. family, school or health colleagues....(increased).

## 4.3 | Better awareness of STOMP issues among MDT, GPs, staff and families

Because of the local STOMP initiative, in many areas, there is now (a) a better awareness among relevant stakeholders, including MDT and families,

Team members and carers are now starting to believe that medications are not the first step in helping someone with challenging behaviour.

.....carers and family who are aware of STOMP and agreeing to work with the clinicians....

which, according to some, (b) has led to a culture shift.

.....culture shift in the locality....

These initiatives also increased awareness among relevant stakeholders locally of possible harm caused by the long-term use of psychotropic medications and improvement in the quality of life of the person with intellectual disabilities upon withdrawal of psychotropics.

.....there is more awareness of harm of using drugs to manage behaviour....

There are now some local initiatives to increase STOMP awareness among local GPs, and many MDTs are pioneering this work.

The MDT.... is now commenced awareness raising in primary care.

These initiatives also helped increase PBS support for people with intellectual disabilities when needed.

.....we have managed to get a lot of our patients a behaviour support plan and got carers, GP's to think about non-pharmacological ways of managing BtC.

## 4.4 | Improved quality of life

There is an overwhelming consensus that STOMP implementation improves the quality of life for people with intellectual disabilities, including physical health and daily activities.

Better quality of life with service users becoming more alert and not suffering from undue side effects.

.....improvement in physical health and activity....

The improvement in quality of life has almost always been caused by the improvement in medication-related adverse events upon anti-psychotic withdrawal.

.....people get better, not worse. My patients are happier, more alert, and suffering few side effects.

.....a marked reduction in dyskinetic features....

The improvement in medication-related adverse events and the quality of life helped many people with intellectual disabilities to lead a more normal life than before the medication withdrawal.

.....very rewarding seeing people less sedated on a daily basis, getting to know their individual personalities, seeing the improvements in their physical health and skills, for some actually being able to have a conversation with them....

## 5 | CHALLENGES AND BARRIERS

In the analysis of the comments from the participants in the free text box in response to the question of what the main barriers were in implementing the STOMP initiative, the following three main themes

and many subthemes emerged, which are presented in the next section (a) the resource issue including social services; (b) caregivers' attitude toward antipsychotic rationalisation; and (c) prescribers' views and attitude toward STOMP implementation.

## 5.1 | Resource issues

The overwhelming consensus among the participants was that achieving a successful withdrawal is difficult without proper utilisation of resources. One participant was angry that the money is spent on advertising STOMP but not on resources to make it a success.

I am struck by the hypocrisy of this STOMP campaign. So much money is spent on pledges and advertisements but nothing on making the actual process viable.

Some expressed their anger as STOMP implementation is seen as only a psychiatrist's problem. Some participants believe that is because the psychiatry service is available 24 h a day, 7 days a week but not the other professionals' services.

The patient becomes my responsibility as 'the medic' and others can avoid the challenge of a difficult situation.

Why is this only a psychiatry problem? .....the reasons for prescribing are many.

More multidisciplinary team (MDT) support, particularly from clinical psychologists, nurses and behaviour therapists, has been highlighted as the required resources to make the withdrawal of anti-psychotics successful.

We could do better if we have better resourced community teams particularly community nurses and psychology support.

Some have also highlighted the need for more pharmacists and specialist nurse prescribers to help with the STOMP process who can help with collecting data and monitoring progress.

This process needs the support of a pharmacist and behavioural therapist and nurse prescriber to gather the data and support the patients which cannot be provided solely via psychiatric appointments.

Effective joint working with GPs has also been highlighted as necessary by some participants,

Effective joint working with GPs essential.

including raising awareness among the GPs about the STOMP initiative.

At present STOMP awareness in GPs is low.

Some have highlighted the lack of time to do the job properly.

There is an expectation that complex people can be withdrawn of medication without extra resources on top of the normal day job.

The absence of appropriate PBS support at the difficult time of medication withdrawal has been seen as a significant barrier by some to achieving STOMP goals in practice.

It works if service user carers are properly supported with good quality PBS plans, so that if behaviours recur they can be managed with the minimum of distress.

## 5.2 | Social services support

Some have highlighted the issue of social services input and joint working between the health and the social services as the cause for the failure of the STOMP programme.

There is no obligation on social care to support person centred care.

The separation of health and social services locally has made things much more difficult....

The issue of social services support included appropriate, supported accommodation in the community and sometimes day care provision.

The main problems are lack of suitable supported accommodation.

The greatest barrier is funding. There is little daycare....

## 5.3 | Caregiver factors

Some participants highlighted certain characteristics and factors relating to support staff, MDT and sometimes family caregivers that made it challenging to achieve a successful psychotropic withdrawal. The main worries were staff being overstretched and not being supported enough.

....lack of understanding and overstretched care staff....

The issue of lack of staff experience and lack of training has also been highlighted.

We do not have enough in the way of experienced staff and appropriate facilities to support people with BtC, especially in acute situations, and in my view, this continues to lead to difficulty in addressing overprescribing.

.....training for support staff....

The caregiver issue extended beyond paid caregivers, and many participants expressed concern about the lack of support from the family caregivers in implementing STOMP.

....carers are more nervous when reducing medication....

.....complete withdrawal requires significant buy-in from carers and families....

However, some participants had a very positive experience with the withdrawal and expressed a contrary view that they found the support staff and family caregivers were keen for the person with intellectual disabilities to come off the psychotropic medications.

It is a very positive experience. Most families of people with learning disabilities are keen on medication reduction, as are care home staff etc.

## 5.4 | Clinicians' views and practice

It seems that clinicians' views on and attitudes toward the rationalisation of psychotropic medications, particularly antipsychotics, in treating challenging behaviours in people with intellectual disabilities affect the success rate of STOMP implementation.

Some participants were reluctant to withdraw medication when the person with intellectual disabilities was settled.

Where patients are settled this is low priority.

Many participants have successfully reduced the medication dose rather than achieving complete discontinuation.

A reduction in the dose of psychotropic medication, and/or the frequency of PRN medication, is eminently possible. Complete withdrawal is less common particularly in autism.

.....several people being on lower doses rather than historically unnecessarily high doses....

One participant suggested a cautious approach to antipsychotic discontinuation by slowing down the withdrawal rate.

Slower down titration has better outcomes....

Some participants reminded the readers of an underlying psychiatric disorder's role in challenging behaviours, which will require a thorough assessment of the person from an experienced psychiatrist specialising in intellectual disabilities.

....not all behaviours are just for a reaction/amenable to a PBS plan - if a PBS plan does not work, an open mind about perhaps mental illness accounting for the behaviour.

Some have emphasised the need to carefully explore the person's history as part of their assessment to convince the caregivers of the need for rationalising psychotropics to ensure consistency in the message given by all involved in the process.

It is very important to go back to the history and get the paper notes, and try and convince carers, who are often reluctant. We need to all give the same message.

One participant warned about the potential increase in the use of other classes of psychotropics when antipsychotics were withdrawn, which itself may then become a problem.

I envisage the number of people on other classes of medication may increase as alternatives to antipsychotics. This may lead to concerns about these drugs too.

Some participants provided a rationale for using antipsychotics such as treating anxiety or irritability in people with autism.

....there is a moderately small number of people with autism who gain some benefit in terms of irritability and ritualistic behaviour on low dose antipsychotic medication.

....we have used low dose antipsychotics to treat for example, autistic anxiety.

One participant warned readers about the possibility of adverse events like extrapyramidal symptoms upon withdrawal of antipsychotics.

.....significant orofacial dyskinesia in three elderly patients which did not respond to subsequent interventions....

## 6 | DISCUSSION

The analysis of free-text data has revealed contrasting views from the UK psychiatrists showing variations depending on the areas and services they have worked. Whereas in some areas, psychiatrists are struggling to achieve the STOMP goals because of the lack of local



resources from MDT, social services, PBS support, and so on, in other areas, services have been consolidated locally with better multi-professional and multi-agency working, increased awareness of STOMP issues among the local stakeholders including support staff, GPs and families. This led to successful antipsychotic reduction leading to improved quality of life for people with intellectual disabilities because of reduced medication-related adverse events. Like the current study in the Netherlands, de Kuyper and Hoekstra (2017) found that the doctors' decisions to discontinue antipsychotic medications were influenced not only by clinical factors but also by environmental factors, such as inappropriate living circumstances, attitudes, knowledge and beliefs of the staff and family caregivers on the antipsychotic drug use.

Rationalising antipsychotic medication is a complex process and needs a thorough assessment of the challenging behaviour, the person displaying the behaviours, and a full multi-disciplinary and multi-agency input (Deb et al., 2016). Therefore, where there are ad hoc attempts by psychiatrists to withdraw antipsychotics without the appropriate infrastructures and multi-professional, multi-agency support, the attempts are likely to fail, which may be the experience of some of the participants in this study. Some participants in the current study highlighted the importance of a thorough assessment of not only the environmental factors affecting challenging behaviour but also the physical (Henderson et al., 2020) and mental health issues (Deb, Perera, et al., 2022), as both of them may play a significant role in predisposing, precipitating and perpetuating challenging behaviour (Deb et al., 2016; Deb, Unwin, et al., 2022).

Although in most cases, reduction of dose or total discontinuation of antipsychotics tends to improve the quality of life of the person with intellectual disabilities (Ramerman et al., 2019), the withdrawal process is not without its risks, as is experienced by some of the participants in this study. The withdrawal may lead to deterioration in challenging behaviours in some people with intellectual disabilities (Deb et al., 2023; Deb, Bertelli, & Rossi, 2022).

Some participants highlighted the issue of STOMP training for support staff and families. Caregivers play a pivotal role in influencing the prescribing process (Christian et al., 1999; de Kuyper et al., 2022; Deb, Limbu, et al., 2022; Donley et al., 2012; Kleijwegt et al., 2019; Lalor & Poulson, 2013), which some participants in our study have highlighted. To address the issue of caregiver training, we have recently developed an online training resource backed up by face-to-face workshops (SPECTROM; <https://spectrom.wixsite.com/project>) to help rationalise antipsychotics and other psychotropic medications (Deb et al., 2020). Two small pre, and post-intervention pilot studies of SPECTROM training in the United Kingdom (Deb et al., 2021) and Australia (Barratt et al., 2023; Wilson et al., 2022, 2023) have received good feedback from the trainees and the trainers on the acceptability, practicality, applicability and relevance of SPECTROM to their practice and helped to empower support staff by increasing their knowledge of psychotropic medication and improving attitude toward using medication for challenging behaviour.

Some participants in the current study found input from local pharmacists and nurse prescribers helpful in implementing STOMP. Indeed, a recent study has shown that input from a specialist

pharmacist has helped in implementing PBS plans on the ground and regular monitoring of progress through graphs that led to a successful withdrawal of antipsychotics in more than 60% of 24 participants who were referred to the clinic (Gerrard et al., 2019). The withdrawal rate was significantly higher in the group receiving PBS support than in those not.

In the absence of a specialist pharmacist or a nurse prescriber, it may be possible for the community nurse in the local MDT to provide the support necessary to make the withdrawal successful. However, Unwin et al. (2017) have shown that community nurses are often distracted from their traditional role by being asked to help with many chores, such as helping people with intellectual disabilities with their finances and placement, and so on, that social workers traditionally do. If the community nurses are re-deployed to their traditional role, such as monitoring the person's physical and mental health as well as behaviour, the effect of medication and their adverse effects, and carrying out necessary investigations such as blood tests, ECG and so on, and support direct care staff and families during the withdrawal phase, that should help with the rationalisation of psychotropic medication use in people with intellectual disabilities. The current study highlights the need for a nationally agreed structured withdrawal pathway backed up by training for the prescribers and caregivers (both paid and family caregivers).

As far as we know, this is the first attempt to gather the UK psychiatrists' views directly on their experience of STOMP implementation and rationalisation of antipsychotics in people with intellectual disabilities. This is also the first attempt to gather free text data and analyse them using a standardised qualitative data analysis method. The free text data reflect real-life practice and issues experienced by front-line clinicians in the field, which is necessary to improve clinical practice. Another strength of the study is that the participants included both new and experienced consultants. Another strength is that the study targeted psychiatrists from all parts of the United Kingdom, which is reflected in the differences in their experiences found in the study.

The estimated return rate of the questionnaire of 39% is low but not unexpected for a questionnaire survey like ours. It was impossible to know precisely how many psychiatrists were working in the field of intellectual disabilities and how to reach them all. The lack of a comprehensive database and a mailing list of all those psychiatrists in the United Kingdom working in the field of intellectual disabilities meant we had to depend on the regional representatives to disseminate the questionnaires among their local colleagues. This may have hindered accessing all eligible participants. Because of the small number, it was not possible to stratify the participants according to their age, experience, region of practice and the settings of practice (e.g., children vs. adults vs. in-patients vs. community vs. forensic vs. independent sector). This stratification may have shown different responses from different groups.

## 7 | CONCLUSION

Our findings show that some psychiatrists in the United Kingdom are successful and enthusiastic about rationalising antipsychotics among

people with intellectual disabilities. However, others are still facing barriers and challenges to achieving these goals. Therefore, much work is still needed to achieve a uniformly positive response to rationalising psychotropic medication use in all parts of the United Kingdom.

## AUTHOR CONTRIBUTIONS

Rohit Shankar, Shoumitro (Shoumi) Deb, and Tom Nancarrow conceptualised and designed the study. Bharati Limbu and Shoumitro Deb analysed the free-text data. Shoumitro Deb and Bharati Limbu wrote the first draft of the manuscript, which was edited and approved by all authors.

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## CONFLICT OF INTEREST STATEMENT

Rohit Shankar is a principal stakeholder of the 'SUDEP and Seizure Safety Checklist', a developer of EpSMon, and received institutional and research support and personal fees from LivaNova, UCB, Eisai, Veriton Pharma, Bial and Desitin. Shoumitro Deb, Tom Nancarrow, David Gerrard and Bharati Limbu do not report any conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## REFERENCES

- Ahmed, Z., Fraser, W., Kerr, M. P., Kiernan, C., Emerson, E., Robertson, J., & Thomas, J. (2000). Reducing antipsychotic medication in people with a learning disability. *British Journal of Psychiatry*, *176*(1), 42–46.
- 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*, 1–11. <https://doi.org/10.1111/jar.13070>
- Branford, D. (1996). Factors associated with the successful or unsuccessful withdrawal of antipsychotic drug therapy prescribed for people with learning disabilities. *Journal of Intellectual Disability Research*, *40*(4), 322–329.
- Branford, D., Gerrard, D., Saleem, N., Shaw, C., & Webster, A. (2018). 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.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.
- Bruinsma, E., van den Hoofdakker, B. J., Groenman, A. P., Hoekstra, P. J., De Kuijper, G. M., Klaver, M., & De Bildt, A. A. (2020). Non-pharmacological interventions for challenging behaviours of adults with intellectual disabilities: A meta-analysis. *Journal of Intellectual Disability Research*, *64*(8), 561–578.
- Christian, L., Snyderski, S. M., Singh, N. N., & Poling, A. (1999). Direct service staff and their perceptions of psychotropic medication in non-institutional settings for people with intellectual disability. *Journal of Intellectual Disability Research*, *43*(2), 88–93.
- de Kuijper, G., de Haan, J., Deb, S., & Shankar, R. (2022). Withdrawing antipsychotics for challenging behaviours in adults with intellectual disabilities: Experiences and views of the experts by experience. *International Journal of Environmental Research and Public Health*, *19*, 15637. <https://doi.org/10.3390/ijerph192315637>
- de Kuijper, G., Evenhuis, H., Minderaa, R. B., & Hoekstra, P. J. (2014). Effects of controlled discontinuation of long-term used antipsychotics for behavioural symptoms in individuals with intellectual disability. *Journal of Intellectual Disability Research*, *58*(1), 71–83.
- de Kuijper, G. M., & Hoekstra, P. J. (2017). Physicians' reasons not to discontinue long-term used off-label antipsychotic drugs in people with intellectual disability. *Journal of Intellectual Disability Research*, *61*(10), 899–908.
- de Kuijper, G. M., & Hoekstra, P. J. (2018). An open-label discontinuation trial of long-term, off-label antipsychotic medication in people with intellectual disability: Determinants of success and failure. *Journal of Clinical Pharmacology*, *58*(11), 1418–1426.
- Deb, S., Bertelli, M. O., & Rossi, M. P. (2022). Psychopharmacology. In M. O. Bertelli, S. Deb, K. Munir, A. Hassiotis, & L. Salvador-Carulla (Eds.), *Textbook of psychiatry for intellectual disability and autism Spectrum disorder* (pp. 247–279). Springer Nature. [https://doi.org/10.1007/978-3-319-95720-3\\_11](https://doi.org/10.1007/978-3-319-95720-3_11)
- Deb, S., Bethea, T., Haverkamp, S., Rifkin, A., & Underwood, L. (2016). Disruptive, impulse-control, and conduct disorders. In R. Fletcher, J. Barnhill, & S.-A. Cooper (Eds.), *Diagnostic manual—Intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp. 521–560). NADD Press.
- Deb, S., & Fraser, W. (1994). The use of psychotropic medication in people with learning disability: Towards rational prescribing. *Human Psychopharmacology: Clinical and Experimental*, *9*(4), 259–272.
- Deb, S., Kwok, H., Bertelli, M., Salvador-Carulla, L. U. I. S., Bradley, E., Torr, J., & Guideline Development Group of the WPA Section on Psychiatry of Intellectual Disability. (2009). International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. *World Psychiatry*, *8*(3), 181–186.
- Deb, S., Limbu, B., Crawford, M., & Weaver, T. (2020). Short-term PsychoEducation for Carers to reduce over medication of people with intellectual disabilities (SPECTROM): Study protocol. *British Medical Journal Open*, *10*, e037912. <https://doi.org/10.1136/bmjopen-2020-037912>
- Deb, S., Limbu, B., Unwin, G., Woodcock, L., Cooper, V., & Fullerton, M. (2021). Short-term psycho-education for caregivers to reduce Over-Medication of people with intellectual disabilities (SPECTROM): Development and field testing. *International Journal of Environmental Research and Public Health*, *18*, 13161. <https://doi.org/10.3390/ijerph182413161>
- Deb, S., Limbu, B., Unwin, G. L., & Weaver, T. (2022). Causes of and alternatives to medication for behaviours that challenge in people with intellectual disabilities: Direct care providers' perspectives.

- International Journal of Environmental Research & Public Health*, 19, 9988. <https://doi.org/10.3390/ijerph19169988>
- Deb, S., Perera, B., Krysta, K., Ozer, M., Bertelli, M., Novell, R., & Sappok, T. (2022). The European guideline on the assessment and diagnosis of psychiatric disorders in adults with intellectual disabilities. *European Journal of Psychiatry*, 36, 11–25.
- Deb, S., Roy, M., & Limbu, B. (2023). Pharmacological management of psychopathology in people with intellectual disabilities and/or autism spectrum disorder. *British Journal of Psychiatry Advances*, 1–12. <https://doi.org/10.1192/bja.2022.61>
- Deb, S., Unwin, G. L., Cooper, S.-A., & Rojahn, J. (2022). Problem behaviours. In M. O. Bertelli, S. Deb, K. Munir, A. Hassiotis, & L. Salvador-Carulla (Eds.), *Textbook of psychiatry for intellectual disability and autism Spectrum disorder* (pp. 145–186). Springer Nature. [https://doi.org/10.1007/978-3-319-95720-3\\_7](https://doi.org/10.1007/978-3-319-95720-3_7)
- Donley, M., Chan, J., & Webber, L. (2012). Disability support workers' knowledge and education needs about psychotropic medication. *British Journal of Learning Disabilities*, 40(4), 286–291.
- Geiger, K. B., Carr, J. E., & LeBlanc, L. A. (2010). Function-based treatments for escape-maintained problem behavior: A treatment-selection model for practicing behavior analysts. *Behavior Analysis in Practice*, 3(1), 22–32.
- Gerrard, D., Rhodes, J., Lee, R., & Ling, J. (2019). Using positive behavioural support (PBS) for STOMP medication challenge. *Advances in Mental Health and Intellectual Disabilities*, 13, 102–112.
- 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*.
- Gore, N. J., Sapiets, S. J., Denne, L. D., Hastings, R. P., Toogood, S., MacDonald, A., & Williams, D. (2022). Positive behavioural support in the UK: A state of the nation report. *International Journal of Positive Behavioural Support*, 12(1), 4–39.
- Henderson, A., Mcskimming, P., Kinnear, D., McCowan, C., McIntosh, A., Allan, L., & Cooper, S. A. (2020). Changes over a decade in psychotropic prescribing for people with intellectual disabilities: Prospective cohort study. *British Medical Journal Open*, 10(9), e036862.
- Kleijwegt, B., Pruijssers, A., de Jong-Bakker, L., de Haan, K., van Os-Medendorp, H., & van Meijel, B. (2019). Support staff's perceptions of discontinuing antipsychotics in people with intellectual disabilities in residential care: A mixed-method study. *Journal of Applied Research in Intellectual Disabilities*, 32(4), 861–870.
- Lalor, J., & Poulson, L. (2013). Psychotropic medications and adults with intellectual disabilities: Care staff perspectives. *Advances in Mental Health and Intellectual Disabilities*, 7, 333–345.
- McGill, P., Vanono, L., Clover, W., Smyth, E., Cooper, V., Hopkins, L., & Deveau, R. (2018). Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support. *Research in Developmental Disabilities*, 81, 143–154.
- 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* (Vol. 11). NICE Guideline <https://www.nice.org.uk/guidance/ng11>
- Ramerman, L., Hoekstra, P. J., & de Kuijper, G. (2019). Changes in health-related quality of life in people with intellectual disabilities who discontinue long-term used antipsychotic drugs for challenging behaviors. *Journal of Clinical Pharmacology*, 59(2), 280–287.
- Shankar, R., Wilcock, M., Deb, S., Goodey, R., Corson, E., Pretorius, C., & Alexander, R. (2019). A structured programme to withdraw antipsychotics among adults with intellectual disabilities: The Cornwall experience. *Journal of Applied Research in Intellectual Disabilities*, 32(6), 1389–1400.
- Sheehan, R., & Hassiotis, A. (2017). Reduction or discontinuation of antipsychotics for challenging behaviour in adults with intellectual disability: A systematic review. *Lancet Psychiatry*, 4(3), 238–256.
- Sheehan, R., Hassiotis, A., Walters, K., Osborn, D., Strydom, A., & Horsfall, L. (2015). Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *British Medical Journal*, 351, h4326. <https://doi.org/10.1136/bmj.h4326>
- Unwin, G., & Deb, S. (2010). The use of medication to manage behaviour problems in adults with an intellectual disability: A national guideline. *Advances in Mental Health and Intellectual Disabilities*, 4, 4–11.
- Unwin, G., Deb, S., & Deb, T. (2017). An exploration of costs of community-based specialist health service provision for the management of aggressive behaviour in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 316–325.
- Wilson, N. J., Barratt, M., Jorgensen, M., Limbu, B., Donley, M., Buchholtz, M., Smith, V., & Deb, S. (2022). *Short-term psycho-education for caregivers to reduce overmedication of people with intellectual disabilities (SPECTROM): An Australian feasibility study* (pp. 1–6). School of Nursing and Midwifery, Western Sydney University. <https://doi.org/10.26183/q7fe-h221>
- Wilson, N., Barratt, M., Jorgensen, M., Limbu, B., Donley, M., Buchholts, 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*. In Press.

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