Psychotropic prescribing in people with intellectual disability and challenging behaviour
Aligning evidence, practice, and policy

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Intellectual disability affects about 1 million people in England. People with intellectual disability are more likely to develop a mental disorder and often have multimorbidity. Appropriate drug treatment of mental illness is important, but recent evidence confirms an over-reliance on psychotropic drugs, particularly antipsychotics, for challenging behaviour when no mental illness has been recorded. Such use is off-licence and unsupported by empirical evidence. Overuse of medication is concerning as people with intellectual disability are more sensitive to unwanted side effects and often lack capacity to consent to treatment. Safe and appropriate use of psychotropic drugs has become a priority for people with intellectual disability, their care givers, and services after revelations of shocking abuse of patient trust and safety, prompting the UK government to review care for this group of patients with complex needs. The serious and systemic failings identified by the review galvanised clinicians across primary and secondary care, and an NHS policy drive, “Stopping over-medication of people with learning disabilities” (STOMP), now entering its second year, aims to ensure the best use of psychotropic drugs. Although the STOMP campaign has kept the issue alive, it is yet to effect real change and there remains much scope for improving prescribing of psychotropic drugs for people with intellectual disability.

It is often possible to reduce or discontinue antipsychotic drugs in people who have been prescribed them long term, but there are associated risks, including unmasking symptoms of mental disorder, withdrawal reactions, and deteriorations in behaviour. Barriers to psychotropic withdrawal include infrequent or ineffective drug reviews, lack of confidence or motivation among general and specialist practitioners, and poor access to specialist psychiatrists or pharmacists to advise on and oversee medication changes. Other important factors in the inappropriate maintenance of psychotropic drugs for challenging behaviour are the lack of supporting evidence for interventions to treat this behaviour and the inconsistent and patchy implementation of alternatives to medication.

Predictors of successful reduction of psychotropic drugs prescribed for challenging behaviour in people with intellectual disability have not been reliably identified, and new research into the risks and potential benefits of using these drugs for challenging behaviour has not been forthcoming. A deprescribing algorithm might be one way of changing practice at scale, but any algorithm must be sufficiently flexible to accommodate the considerable heterogeneity in this patient group. Excessive focus on reducing medication might be discriminatory, for example, if it denies people with intellectual disability appropriate treatment for mental illness.

A pragmatic approach is needed to optimise medication. Within this framework, medication is not viewed as inherently good or bad, but its advantages and disadvantages are considered in relation to an individual's clinical needs, preferences, and life circumstances. People with intellectual disability and their families report feeling deprived of options, excluded from decision making processes, and finding it difficult to ask for more information about psychotropic drugs.

Shared decision making is central to optimising medication. This principle has been little explored in people with intellectual disability but has value in guiding decisions about psychotropic drugs in other people. We should ensure that people with intellectual disability act as partners in their care by enabling access to relevant information and by developing tools that support collaboration, such as tailored patient decision aids.

We must combine new approaches with generalisable knowledge drawn from other populations and initiatives. For example, the STOMP campaign has parallels with the national dementia strategy, which substantially reduced prescribing of antipsychotic drugs for adults with dementia over a relatively short period, although people living in care homes—the most vulnerable group—seem to have benefited less.

Monitoring the effect of STOMP will therefore be essential and is already part of the Royal College of Psychiatrists Centre for Quality Improvement audit programme. Such audits provide benchmarking data and direct future efforts.
We need to invest in more research to clarify the role of pharmacotherapy in the multimodal management of challenging behaviour, with a focus on understanding the causes and mediators of these behaviours and identifying subgroups of people most likely to benefit from psychotropic drugs. Qualitative investigation of the attitudes of patients, carers, and clinicians to drug reductions, alongside explorations of contexts, barriers, and facilitators will help to identify the complex non-clinical and systems factors that influence use of psychotropic drugs.

Changes in prescribing can be difficult to achieve, and the effect of one-off policy interventions should not be overestimated. Meaningful and sustained change in psychotropic prescribing requires a cultural shift in the way that people with intellectual disability are supported by healthcare professionals and broader society.

Other essential elements include commissioning the right care in the right place, providing suitable educational and vocational opportunities, and investing in early intervention and training programmes for families and care staff. If we are serious about improving use of psychotropic medication and valuing people with intellectual disability we must ensure that a clear national strategy combining policy drivers and much needed research investment is prioritised to stop further disadvantage to this patient group.

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