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1 **Antipsychotic Prescribing in People with Learning Disability:**

2 **Challenges and Pitfalls**

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In this opinion piece we highlight the current concerns of prescribing antipsychotics to people with Learning Disability (PWLD) and propose a system of monitoring of antipsychotic prescribing in General Practice which we argue will reduce inappropriate antipsychotic use.

Learning Disability, synonymous with the term intellectual disabilities (1) affects about 1-2% of the general population (2) and is characterized by significant impairments of both intellectual and adaptive functioning and an onset before 18. (3).

PWLD have high rates of 'challenging behaviour' (CB) - i.e., acts of aggression towards people or property, self-neglect, self-harm and the risk of exploitation (2). CB is a social construct to enumerate a behavioural or mental pattern that may cause suffering or a poor ability to function in life. It is best understood based on learning theory and the principles of applied behavioural analysis. Mental illness is a structured diagnostic concept which encompasses a large range of recognised emotional and behavioural disorders. Mental illness diagnosis requires robust application of the diagnostic schedules. It is reasonable to state that most PWLD with mental illness have CB but majority of PWLD with CB might not satisfy criteria for mental illness. Therefore, the therapeutic approach to CB can be very different from a diagnostic one. However, there is significant overlap between CB and the presence of mental illnesses with the latter also being higher in PWLD than the general population. Deficits in communication, atypical clinical presentations and differences in diagnostic coding methods mean that mental illness can be under-recorded, particularly in those with severe degrees of learning disability (1, 4). This means that the clinician needs to be aware not just of what is observed behaviourally, but also whether there is something underlying diagnostically. A formulation based on both these elements is central to deciding whether there is a need to prescribe medication.

The vast majority of PWLD with CB and/or mental illnesses are seen in primary care. There have been concerns that psychotropic medication is used inappropriately in this group to merely deal with the former (5). It is suggested that about 30-35000 PWLD are on antipsychotics or antidepressants or both without appropriate indications (6) and that the proportion of PWLD treated with psychotropic medication exceeds the proportion with recorded mental illness (7). NHS England has developed a national programme to stop over-medication of PWLD (STOMP) (9). The imperative should be to rationalise clinical practice by carefully balancing the need to stop unnecessary treatment with the possibility of under-treatment that puts the patients or others at risk (1, 4).

Though psychotropic medication can include antipsychotics, antidepressants, mood stabilisers, stimulants or anxiolytics, particular attention has been focused on antipsychotics. With recent data from secondary care, i.e- mental health services, suggesting that antipsychotics are not widely used outside of evidence-based indications in PWLD (8), there is a need to particularly focus on prescribing in primary care.

In general for PWLD, there are 3 major circumstances in clinical practice which lead to antipsychotic prescribing;

1. They have a mental illness with psychotic symptoms
2. They have CB
3. Both of the above

Only acceptable indication is psychosis for the longer term prescribing of anti-psychotics. The rationale for prescribing antipsychotics- either as a definitive diagnosis or as a narrative account of target symptoms has to be clearly recorded (4). This recording appears to be problematic in primary care. While 71% of those PWLD on antipsychotics did not have the diagnosis of a severe mental illness, the comparable figure for the general population though

significantly lower was still 50% (7), suggesting that there is a need to improve the recording of the rationale for antipsychotic prescribing across the board. It is pertinent that in population studies, where ascertainment rates were recorded not just through primary care, the inappropriate prescribing rates for antipsychotics were found to be lower (10).

The Royal College of Psychiatrists has published practice guidelines and four audit standards for prescribing these drugs (4) in PWLD. This includes clearly documenting the indication for prescribing, recording consent or best interests decision-making processes, regularly monitoring treatment response and side-effects and regularly reviewing the need for continuation based on risks and benefits. These four audit standards incorporate the NICE recommendation (11) that if antipsychotics are considered for behaviour that challenges, then it should be only used if psychological or other interventions alone have not produced change within an agreed time or treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or the risk to the person or others is very severe. It also takes account of the NICE guidance ((1, 12) which recommended that:

1. Prescribers should record full details of all medication including the doses, frequency and purpose
2. Record a summary of what information was provided about the medication prescribed to the patient and carers
3. Consider reducing or discontinuing antipsychotics for PWLD who are taking antipsychotic drugs and not experiencing psychotic symptoms and then review their condition
4. Annually document the reasons for continuing the prescription if it is not reduced or discontinued
5. Consider referral to a psychiatrist experienced in working with PWLD and mental health problems.

These recommendations and audit standards can pose a number of challenges in primary care. Firstly, there is the difficulty in changing a long established prescription that may have been the result of an inappropriate need (e.g. antipsychotic to manage acute distress), an appropriate but poorly recorded need (e.g. psychotic symptoms not recorded in patient notes), an unmet need (e.g. chronic social stressors) or resistance from carers, families and sometimes the patients themselves who may either see the medication as a 'quick fix' or genuinely feel that it has helped. Secondly, many primary care prescriptions may well have started as part of recommendations from secondary care. However, 'new ways of working' where psychiatrists and mental health teams handle only "complex" patients while leaving routine follow up and care to primary care has resulted in a large population of people with learning disability who are on repeat prescriptions without review from or access to secondary care services, a group that can be described as the 'vulnerable well'. Finally, any effort to change this status quo requires further resources to meet any unmet needs including access to psychology treatments, social care and other secondary care services.

A range of views exist from primary care on how this problem needs to be tackled –

1. A low threshold be present for referral to specialist teams to manage CB, but this could potentially over-burden specialist services

2. The GP if identifying a mental illness initially prescribes and assess outcomes and then refers if concerns persist. This however could lead to delay in specialised care to a vulnerable adult.

3. If there is concern in the context of uncertain or no obvious co-morbid mental illness to make a referral to specialist community team but this could potentially foster diagnostic overshadowing.

To address the practicalities of this issue, there is a need for close working between primary and secondary care services involving GPs, community pharmacists, specialist learning disability teams and psychiatrists in learning disability. An initiative is under way in Cornwall UK (pop: 550,000) with a pilot project involving all 64 GP practices, community pharmacists and specialist learning disability mental health teams to systematically stratify and reduce the level of antipsychotic prescribing. Using a computer program Eclipse, everyone who has a learning disability, but no other recorded mental illness and registered with a GP in Cornwall has been identified (n = 243). They are stratified from low risk to high risk based on the exposure to numbers and types of psychotropics with those on 2 antipsychotics being at the top (figure 1). Assurance of baseline wellbeing is done using patient/carer held physical wellbeing records (13). To ensure the best possibility of success a STOMP-ID toolkit has been designed to provide assurance of rationalization and if necessary requirement of continuation of medication. Results of this pilot study will clarify the inputs, costs and efficacy of a programme to address this urgent issue that affects some of the most vulnerable people in society. The likelihood of there being a single way in which this current burden can be reduced is unlikely. Outcomes from such pilots are best placed to inform how to develop a unified strategy in future.

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Figure 1: - Risk stratification table for STOMP – ID Cornwall