Briefing Paper on Use of Psychotropic Medication in People with Learning Disability

This briefing paper includes the following information:

- Background and summary
- What we know about the inappropriate use of medication for children and adults with learning disabilities
- Published guidance on prescribing antipsychotic medication
- Why it is important to avoid inappropriate medication
- Medication data collection
- Who is at risk of being inappropriately medicated?
- Action being taken to address the issues
- STOMP family carer survey 2019
- Key points in the use of psychotropic medication

Background & summary

It has been known for many years[1] that people with learning disabilities, especially those who display behaviour that challenges, have been prescribed "unnecessary or excess" medication.

Recognition that people with a learning disability, autism or both were at risk of over-medication grew after the BBC Panorama programme about Winterbourne View hospital in 2011. The abuse exposed by Panorama led to the beginning of the Transforming Care Programme, which was a commitment to improving services for

[1] Severe learning disabilities and challenging behaviours: Designing high quality services (1994) Emerson, McGill & Mansell (eds)

people with a learning disability, autism or both to ensure they could live a good life in the community.

The Serious Case Review of the abuse at Winterbourne View Hospital found many people in the hospital were prescribed antipsychotic and antidepressant medication without a diagnosed mental health need. These findings led to a specific recommendation to reduce the use of these medications when there is no diagnostic reason for them to be prescribed.

"*Reducing the use of antipsychotic medication with adults with learning disabilities and autism requires attention. An outcome of the National Dementia Strategy (Department of Health, 2009) was an investment in reducing antipsychotic medication for patients with dementia. Adults with learning disabilities require no less*."[2]

The Department of Health Winterbourne View Concordat Programme of Action (2012, page 16) committed to explore the extent of the issue:

"*We will explore with the Royal College of Psychiatrists and others whether there is a need to commission an audit of use of medication for this group. As the first stage of this the Department of Health will commission by Summer 2013 a wider review of the prescribing of antipsychotic and anti-depressant medicines for people with challenging behaviour to report*."[3]

A series of reports were commissioned, and this led to a NHSE "Call to Action" to stop the inappropriate medication of people with learning disabilities (the STOMP programme).

There are issues with **lack of data** (collected and/or published). In 2015 a report was published that estimated via GP data that between 30-40,000 people with learning disabilities are being prescribed anti-psychotic / antidepressant (or both) medication for which they have no diagnosis. Data collection of medication prescribed for children and adults in inpatient settings is no longer published (it was previously collected in the discontinued Learning Disability Census, the last one was in 2015).

What do we know about the inappropriate use of medication for children and adults with learning disabilities?

Following a CBF letter to the Minister about the use of medication, and a meeting between CBF, psychiatrists and the Chief Pharmaceutical Officer at the Department of Health, 3 reports were commissioned:

[2] Winterbourne View Hospital: A Serious Case Review, 2012, page 142
[3] The Department of Health Winterbourne View Concordat Programme of Action, 2012, page 16

1. A data report using GP prescribing data (Public Health England) *Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners (2015)*
2. A good practice report by NHSIQ – *Improving the use of medicines in people with learning disabilities* (2015)
3. A report of the role of Second Opinion Appointed Doctors (SOAD) (a scheme run by the Care Quality Commission to provide extra scrutiny of the use of medication for people detained under the Mental Health Act): *Survey of medication for detained patients with a learning disability* (2016)

These reports provide limited information about medication of people with learning disabilities who are living in community settings (GP prescribing), and limited information (via the SOAD report) about people with learning disabilities who are detained under the Mental health Act in hospitals – but significant cause for concern.

1. Data report:

A report by Public Health England (2015)[4] "estimated that **on an average day in England, between 30 - 35,000 adults with a learning disability are being prescribed an antipsychotic, an antidepressant or both without appropriate clinical indications (psychosis or affective/anxiety disorder).** A substantial proportion of people with a learning disability who are prescribed psychotropic drugs for behavioural purposes can safely have their drugs reduced or withdrawn".

2. Good practice report

This report considered good practice in 6 sites and identified key themes. The report concluded: *"Across the country, there is a great deal of variation within learning disability services and this does not provide the necessary high quality optimised care for everyone."* It recommended a "call to action" building on the success of a similar approach used for reducing inappropriate medication for dementia patients.

3. SOAD report:

Second Opinion Appointed Doctors (SOADs), visit people detained under the Mental Health Act. They consider clinical records and opinion from others and decide whether medication to be prescribed for mental disorder is appropriate. CQC was asked to look at the information it had collected about prescribing for people with learning disabilities visited by SOADs. The report examined the information held by the CQC about 945

[4] Public Health England. Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. (2015)

requests, which involved a patient with learning disabilities, submitted between October 2012 and August 2013. The requests were on behalf of 796 individual patients (because, in some cases, a provider clinician submitted more than one request for the same patient during that period).

The people with learning disabilities that the SOADs visited were detained in hospital under the Mental Health Act. It is likely, therefore, that they were those with more severe mental health problems and more severe forms of challenging behaviour.

The main findings were that:

- For **more than a half of the prescriptions, the patient did not have a diagnosis of a disorder for which that drug was a recognised indication**. The research evidence base for prescribing for people with learning disabilities is limited. Manufacturers of medication often do not submit information on their use for people with learning disabilities when they apply for a product license. As a consequence, many of the medications used in treating people with learning disabilities and considered professionally appropriate may not be specifically licensed for this population.
- **Twenty-four per cent of patients were prescribed more than one different psychotropic drug to be given on a regular basis.** When medication prescribed to be given 'as required' is included, **57% were prescribed more than one psychotropic drug; with 40% prescribed five or more drugs.** A psychotropic drug is a one that is capable of affecting the mind, emotions or behaviour.
- Eighty-six per cent of patients were prescribed at least one antipsychotic drug to be given on a regular basis. Eighteen per cent were prescribed more than one antipsychotic drug to be given concurrently on a regular basis. An antipsychotic drug is one that is commonly used to treat a psychotic disorder such as schizophrenia.
- Six per cent of patients were prescribed a 'high dose' of a single type of antipsychotic medication to be given on a regular basis. Thirteen per cent were prescribed a 'high dose' by virtue of the additive effect of more than one type of antipsychotic medication. High dose is defined as **a dose that is above the range recommended by the British National Formulary.** The British National Formulary Survey of medication for detained patients with a learning disability is a guide, and may be departed from if there are sound reasons.
- Twenty-eight per cent of patients had an increased likelihood of being administered a combination of antipsychotic medication equating to a high dose because they were prescribed additional antipsychotic medication to be given 'as required'. We do not know whether or how often this medication was administered.
- SOADs made changes to the overall treatment plan in some 25% of cases (i.e. in 75% of cases they made no change). However, many certified treatment plans

still permitted the administration of multiple psychotropic medications and of high doses of antipsychotic medication.

In 2016, a survey by the Care Quality Commission (CQC)[5] found that inappropriate medication was still a widespread problem. Their survey of people with a learning disability receiving inpatient care found that high numbers of people (86%) were prescribed antipsychotic drugs on a regular basis. More worryingly, they also found that for more than half of these prescriptions, the individual did not have a diagnosis of a disorder for which that drug was for. A study carried out by University College London in 2015 suggests that this is not just an issue for people receiving inpatient care. Of the 33,000 adults with a learning disability in this study, 21% had a diagnosed mental health need, but 49% were prescribed antipsychotic medication.

Guidance on prescribing antipsychotic medication

The National Institute for Health and Care Excellence (NICE) 2015[6] sets out guidelines on how medication should be used for people with a learning disability, autism or both. This includes guidelines about using medication to reduce challenging behaviour and treating people with a learning disability, autism or both who have a mental health need. The guidance is clear that antipsychotic medication should only be used for challenging behaviour if:

- Psychological or other interventions alone do not reduce the challenging behaviour within an agreed time, or
- Treatment for any mental or physical health problem has not led to a reduction in the behaviour, or
- The risk to the person or other is severe (for example because of harming others or self-injury).

Practice guidelines from the Royal College of Psychiatrists also give advice on prescribing psychotropic medication for people with a learning disability, autism or both. This includes the need for regular reviews of psychotropic medication. They advise that if the medication has not had its desired effect in three months, then it should be stopped and other options considered. Best practice would be that alternatives to

[5] How medicines have been given to patients with a learning disability who are kept in hospital under the Mental Health Act, February 2016, CQC

[6] NICE guidelines (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

medication are always considered before and during prescription, as well as after any medication has been reduced or stopped.

Avoiding inappropriate medication is important for a number of reasons:

- It can often be difficult for someone to stop taking psychotropic medication, especially when they have been taking it for a long time due to the effects the medication has on the body.
- Side effects of psychotropic medication can have a negative impact on a person's quality of life and health, including being at risk of significant weight gain or organ failure.
- Although it is uncommon, side effects of psychotropic medication can be serious and even life threatening if not monitored closely.
- Once medication has been prescribed, there can be less motivation to explore alternative interventions such as Active Support, modifying the person's environment or Positive Behaviour Support.
- Inappropriate or over-medication is a restrictive practice, particularly when it is used to sedate a person as a reactive response to behaviour that challenges. The use of restrictive practices should be reduced as much as possible so that people can live with as much freedom as possible.

Medication data collection

Data on use of antipsychotic medication and rapid tranquilisation was in the Learning Disability Census but **it is not being collected or published in the MHSDS**. Data has not been published on the use of antipsychotic medication and rapid tranquilisation in inpatient units since December 2015 (the last Learning Disability Census).

"Information on rates of prescribed antipsychotics is not currently published. The 2015 Learning Disability Census of inpatient units reported that 105 out of 165 children aged under 18 in inpatient units (64%) had had prescribed antipsychotic medication in the 28 days before the census."[7]

We regularly hear from families of people with a learning disability about misuse of medication and the devastating effect this can have on individuals. It is difficult to understand why this data is no longer considered important when NHSE has pledged to address the overmedication of people with a learning disability through the STOMP and

[7] Far less than they deserve: Children with learning disabilities or autism living in mental health hospitals. Children's Commissioner, May 2019.

STAMP initiative but will be unable to measure progress for this population that we know are vulnerable without this data.

Data on use of antipsychotic medication and rapid tranquilisation is vital to ensure that the overmedication of people with a learning disability in units is being addressed effectively.

Who is at risk of being inappropriately medicated?

There is now clear evidence that people with learning disabilities are being prescribed inappropriate medication but we know there are particular groups of individuals who are most at risk. As far back as 1994[8] it was well established that individuals who displayed behaviours described as challenging were at greater risk of being prescribed medication inappropriately. The CBF supports many families who raise this as an issue, and in 2016 carried out a survey of 100 family carers, to ask them about the reasons medication was prescribed.

Some of the reasons family carers identified[9] for their relatives being prescribed medication include:-

- **Behaviour described as challenging**
    - *e.g. 'It's a quick fix in the absence of a functional assessment'*
- **Anxiety**
    - *e.g. 'where he lives makes him anxious- the behaviour of the people he lives with, the staff.'*
- **Sleep problem**
    - *e.g. 'He needs to go for a walk daily, for his mental health, behaviour and sleep but it doesn't happen because of staffing'.*
- **To prevent placement breakdown**
    - *e.g. 'It was suggested that unless he was medicated the school could no longer provide for his needs'*
- **Lack of access to local, specialist services before a trigger point**

[8] Severe learning disabilities and challenging behaviours: Designing high quality services (1994) Emerson, McGill & Mansell (eds)

[9] Challenging Behaviour Foundation Survey 2016 and 2019

- *e.g. 'My area has no paediatric learning disability service.'*

Over 90% of families in the CBF report *Stopping Over Medication of people with a Learning Disability, Autism or both (STOMP): a family carer perspective (2016)* said that challenging behaviour was one of the main reasons that medication was prescribed for their relative. However, less than half had a Positive Behaviour Support Plan and families reported that little attention was given to why their relative was displaying behaviour described as challenging.

What action is being taken to address the issues?

In July 2015 NHS England announced a Call to Action followed by the introduction of STOMP. **STOMP** is a programme focused on **- Stopping over Medication of People with a Learning Disability, autism or both**

NHS England led a pledge in 2016 to stop over-medication, which is supported by many organisations in health and social care. This was intended as a 'call to action' and a commitment to reducing the levels of inappropriate medication prescribed for people with a learning disability, autism or both. The goals of STOMP are:

- To improve the quality of life of children, young people and adults with a learning disability, autism or both, who are prescribed psychotropic drugs.
- Make sure people only receive these drugs for the right reasons and in the right amount.
- To improve understanding of these drugs and when they should or should not be used.
- To improve understanding of non-drug treatments and the support which may help and make sure that people work with their doctor, multi-disciplinary team and the people who support them in making any changes to treatment.
- To empower people with learning disabilities, autism or both and their families with the right information and support.

To support the launch of STOMP the Royal Colleges of Nursing, Psychiatrists and GPs, with the Royal Pharmaceutical Society, the British Psychological Society and NHS England produced a toolkit for GPs with guidance on how to identify over-medication and steps to take if someone is prescribed medication that they do not need.
This has been followed by other resources, available on the STOMP webpage[10], along with links to other useful resources and the many organisations that support STOMP.

[10] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

In 2018 STOMP STAMP (Supporting Treatment and Appropriate Medication in Paediatrics)[11] was launched to focus on the medication needs of children with learning disabilities, autism or both.

STOMP family carer survey 2019

As part of the STOMP work, CBF carried out a survey of family carer experiences in 2016 (see page 6). As a follow up, a further survey was issued in 2019, and 110 family carers of people with learning disabilities told the Challenging Behaviour Foundation about their relative's use of psychotropic medication in the past year. The findings have been submitted to NHSE and have not yet been published. Key findings are:

- 30% family carers said STOMP had made a difference to them and 25% said it made a difference to their relative. This indicates the work of the STOMP programme is beginning to have a positive impact on medication use for people with learning disabilities, autism or both; however more work is needed to produce more positive impact.
- The most common reason identified by family carers for medication being suggested for their relative was behaviour described as challenging, with 67% reporting this in 2019. This compares to a figure of 93% in the survey 2 years previously, which suggests some improvement in prescribing patterns.
- Half the family carers who responded said their relative was offered no alternative interventions to medication.
- For those who a best interest decision under the Mental Capacity Act 2005 was applicable to decide whether to prescribe medication, 44% of family carers reported that a best interests meeting was either not held or the family weren't aware/invited, therefore the decision-making process did not follow the Mental Capacity Act Code of Practice.
- 19% of family carers to report that psychotropic medication had a negative impact on their relative.

[11] https://www.england.nhs.uk/learning-disabilities/improving-health/stamp/

Key points in the use of anti-psychotic medication

Many children, young people and adults with a learning disability continue to be subjected to over medication, with the negative consequences that it entails.

There is a lack of data about the use of medication.

Reasons for prescribing are still not in line with NICE guidance, with challenging behaviour a leading cause for introducing psychotropic medication. Decision making processes continue to be varied, with a significant way to go to full compliance with the Mental Capacity Act for individuals who are not able to consent to medication themselves.

There are 3 key areas to address:

- Prevention of inappropriate medication use – timely information, interventions and support to prevent the use of inappropriate medication
- Support and regular monitoring and reviews of people taking medication appropriately
- Reduction / stopping use of medication when it is being inappropriately prescribed (and support to do so).

Whether alongside medication or in place of it, it is essential that person-centred, **proactive strategies** are used to support people with learning disabilities and / or autism and behaviours that challenge to live a fulfilling and rewarding life.

Families and professionals should work together to reduce over-medication. Family carers of people with learning disabilities and autism are important stakeholders in all aspects of their relative's life and support, including the use of medication.

Families can help to prevent or reduce over-medication by:

- Understanding their relative, their needs and their behaviour
- Their long-term perspective, including medical history and past responses to interventions
- Asking relevant questions on behalf of their relative
- Challenging health and social care professionals
- Motivation and persistence to improve quality of life and health of their relative.

There needs to be a co-ordinated and sustained drive to improve the quality of care and support for people with learning disabilities and / or autism and behaviours that

challenge in all areas of their life and reducing inappropriate use of medication is an important part of this.

Although the STOMP work is included in the NHS 10 year plan, it is unclear as yet how the work will be taken forward.

Useful links and references

- Stopping over-medication of people with a Learning Disability, Autism or both. The Challenging Behaviour Foundation (2016) https://www.challengingbehaviour.org.uk/learning-disability-assets/stompfamilycarerperspective210517.pdf

- Medication Pathway for families of people with learning disabilities, autism or both who are prescribed or may be prescribed psychotropic medication. https://medication.challengingbehaviour.org.uk/

- Summary of the June 2017 Challenging Behaviour National Strategy Group meeting. Summary of the meeting, actions arising, and workshop discussions. Good background information on the issues around medication. https://www.challengingbehaviour.org.uk/driving-change/information-from-meetings//16th-june-2017.html

- NICE guidelines (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges https://www.nice.org.uk/guidance/ng11

- Winterbourne Medicines Programme: Improving the use of medicines in people with learning disabilities. NHS Improving Quality Report April 2014 – April 2015. https://webarchive.nationalarchives.gov.uk/20160805132941/http:/www.nhsiq.nhs.uk/media/2671659/nhsiq_winterbourne_medicines.pdf

- Survey of medication for detained patients with a learning disability. Care Quality Commission (February 2016) https://www.cqc.org.uk/sites/default/files/20160209-Survey_of_medication_for_detained_patients_with_a_learning_disability.pdf

- Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Public Health England. (2015) https://webarchive.nationalarchives.gov.uk/20160704150153/http://www.improvinghealthandlives.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism