

STOMP and STAMP

Stopping the over medication of children, young people
and adults with a learning disability, autism or both

STOMP and STAMP advocacy and the law

A supplement to the STOMP Top Tips for Advocates

STOMP, advocacy and the law

Purpose

This document outlines:

- What the law says about the advocate's role in decisions made about the use of psychotropic medicine.
- The legal duties of health and social care professionals to involve advocates in relation to the use of psychotropic medication.

This paper is intended to assist both advocates and health and social care professionals. It may also be helpful to people who are being prescribed psychotropic medication and their families. It accompanies 'STOMP Top Tips for Advocates' available at www.voiceability.org/for-professionals/stomp

Both this document and the Top Tips guide are intended to provide helpful assistance. They ought not to be relied upon as a statement of the law or as advice on health or medical matters.

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1. Background

STOMP stands for stopping the over-medication of people with a learning disability, autism or both. Specifically, the campaign is about the use of psychotropic medication. STAMP is for children and young people, their families and professionals. It stands for supporting treatment and appropriate medication in paediatrics.

People with a learning disability, autism or both are more likely to be given psychotropic medications than other people. These medications affect how the brain works. They include medications for psychosis, depression, anxiety, sleep problems or epilepsy. Sometimes they are given to people because their behaviour is seen as challenging. These medicines are right for some people but for many others there are different ways of helping them so they need less medicine or none at all.

2. The case for action

There is evidence of widespread prescribing of psychotropic medicines (antipsychotics, antidepressants and hypnotics) for people with learning disabilities. Public Health England estimates that every day 30,000 to 35,000 adults with a learning disability (approximately 1 in 6) are taking psychotropic medicines, when they do not have the health conditions the medicines are designed to treat.

Some uses of psychotropic medicines to manage behaviour that challenges in people with a learning disability are 'off-label' for a licensed medication. This means it is being given for something other than the purposes authorised for that medication.

Use of psychotropic medication can be especially concerning if people take them for too long, or take too high a dose, or take them without good reason.

Psychotropic medication can cause side effects such as:

- significant weight gain
- feeling tired or 'drugged up'
- severe constipation or bowel obstruction
- serious problems with physical health, including organ failure.

The Charity Inquest¹ and the Learning Disability Mortality Review (LeDeR² programme) also report that the inappropriate use of psychotropic medicines can be a significant contributory factor, or the cause, of a person's death, as has been highlighted in the recent case of Oliver McGowan³ and past cases such as that of William (Bill) Johnson⁴.

The vast majority of people with learning disabilities and/or autism are not in hospital. For the most part, according to NICE⁵ they are receiving most or all of their medicines from their GP. The report *Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England*⁶ found widespread prescribing of psychotropic medicines, including prescriptions for multiple medicines from the same and different classes. With the exception of antiepileptic medicines, a high proportion of people had no relevant licensed indications recorded for the psychotropic medicines they were prescribed.

Similarly, in 2016, CQC's *Survey of medication for detained patients with a learning disability*⁷ found 86% of inpatients were prescribed antipsychotic drugs on a regular basis. In more than half of these prescriptions, the individual did not have a diagnosis of a disorder that the drug was intended for.

NICE guidance on *Challenging behaviour and learning disabilities: prevention & interventions*⁸ gives recommendations on the care of people with learning disabilities, autism or both whose behaviour challenges, including the use of medicines. The guidance is that psychotropic 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 others is severe (for example because of harming others or self-injury).

The guidance also makes it clear that when providing support and interventions for people with a learning disability and behaviour that challenges, independent advocacy must be offered to the person and to their family members or carers, as described in the Care Act, Mental Capacity Act and Mental Health Act.

¹ Inquest: <https://www.inquest.org.uk/oliver-mcgowan-opening>

² LeDeR: <http://www.bristol.ac.uk/sps/leder/>

³ Oliver McGowan: <https://www.theguardian.com/uk-news/2018/apr/16/our-son-died-because-of-arrogant-doctors-family-tells-inquest>

⁴ William Johnson: <https://www.theguardian.com/society/2013/jul/07/call-inquiry-deaths-psychiatric-hospital>

⁵ *Psychotropic medicines in people with learning disabilities whose behaviour challenges*: NICE <https://www.nice.org.uk/advice/kt19/resources/psychotropic-medicines-in-people-with-learning-disabilities-whose-behaviour-challenges-pdf-58757961132997>

⁶ *Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England* http://webarchive.nationalarchives.gov.uk/20160704150153/http://www.improvinghealthandlives.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism

⁷ *Survey of medication for detained patients with a learning disability*: CQC https://www.cqc.org.uk/sites/default/files/20160209-Survey_of_medication_for_detained_patients_with_a_learning_disability.pdf

⁸ *Challenging behaviour and learning disabilities: prevention & interventions for people with learning disabilities who behaviour challenges*: NICE <https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-pdf-1837266392005>

3. Mental Capacity Act

The Mental Capacity Act 2005 (MCA) provides a statutory framework to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over.

Under the Act, there is a duty for NHS bodies to instruct an Independent Mental Capacity Advocate (IMCA) to support and represent the person, 'whenever they (the NHS) are proposing to take a decision about "serious medical treatment" or proposing that another organisation (such as a private hospital) carries out treatment on their behalf⁹.'

The Mental Capacity Act (IMCA) Regulations for England and Wales define serious medical treatment as 'treatment which involves providing, withdrawing or withholding treatment in circumstances where:

- a) in a case where a single treatment is being proposed, there is a fine balance between its benefits to P (the person concerned) and the burdens and risks it is likely to entail for him;
- b) in a case where there is a choice of treatments, a decision as to which one to use is finely balanced; or
- c) the treatment, procedure or investigation proposed would be likely to involve serious consequences for P.¹⁰

The MCA Code of Practice 10.43 makes clear that a decision about serious medical treatment could include a decision about treatments for both mental and physical conditions.

'Serious consequences' are defined in the MCA Code of Practice (10.44) as those which 'could have a serious impact on P, either from the effects of the treatment, procedure or investigation itself or its wider implications. This may include treatments, procedures or investigations which:

- a) cause, or may cause, serious and prolonged pain, distress or side effects;
- b) have potentially major consequences for P; or
- c) have a serious impact on P's future life choices.'

Under the Mental Capacity Act (2005), if someone lacks capacity then any decision made in their best interests should consider the least restrictive option for that person. This means that if two interventions are likely to be similarly effective, the intervention that allows the person the most freedom should be used.

Given the definition of 'serious medical treatment' and 'serious consequences', and the effect that psychotropic medicines can have on a person, we believe that a person who (may) lack capacity to give or refuse consent must have the right to the support and representation of an IMCA. This would be where such treatment is being considered on their behalf and there is nobody appropriate who can be consulted about the decision.

4. Mental Health Act

The Mental Health Act (1983) is the main piece of legislation that covers the assessment, treatment and rights of people, of all ages, with a mental health disorder. People detained under the Act need urgent treatment for a mental health disorder and are at risk of harm to themselves or others.

Under the Mental Health Act (MHA) people who are eligible for an Independent Mental Health Advocate (IMHA) services in England are:

- People detained under the Act.
- Conditionally discharged restricted patients.
- People subject to guardianship.
- People subject to supervised community treatment orders (CTOs).

⁹ Mental Capacity Act 2005 Code of Practice (10.42) <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>

¹⁰ Mental Capacity Act 2005 (IMCA) Regulations 2006 <http://www.legislation.gov.uk/ukSI/2006/1832/regulation/4/made>

Other patients, who are informal, are eligible for IMHA services if they are being considered for section 57 or section 58A treatment (i.e. treatments requiring consent and a second opinion). This includes people under the age of 18 who are being considered for electroconvulsive therapy (ECT).

The MHA and the Mental Health Act 1983: Code of Practice 6.12¹¹ details the role of IMHAs which must include supporting patients to obtain information about and understand:

- a) their legal rights under the Mental Health Act
- b) the legal rights which other people (e.g. nearest relative) have in relation to them
- c) the particular parts of the Mental Health Act which apply to them
- d) any conditions or restrictions to which they are subject
- e) any medical treatment that they are receiving or might be given, and the reasons for that treatment (or proposed treatment)
- f) the legal authority for providing that treatment
- g) the safeguards and other requirements of the Act which would apply to that treatment.

IMHAs will also support people to exercise their rights, which can include supporting the person to self-advocate and/or representing the person and speaking on their behalf. IMHAs can support the person to understand their care plans, enable them to raise questions about their care and medication and help them prepare for ward rounds and other meetings. If the person disagrees with the professional who wants to prescribe the medication, the advocate can support the person to request a second opinion concerning their care and treatment. After three months, new and existing medication will be checked by a Second Opinion Appointed Doctor (SOAD) arranged by the Care Quality Commission.

The MHA Code of Practice chapter 20 provides specific guidance on supporting people with learning disabilities and/or autism and stresses the importance of the five overarching principles of the MHA in relation to their care and treatment:

1. Least restrictive option and maximising independence.
2. Empowerment and involvement.
3. Respect and dignity.
4. Purpose and effectiveness.
5. Efficiency and equity.

Psychotropic medication used inappropriately for challenging behaviour without a mental health need can be a restrictive practice, like physical and mechanical restraint and seclusion. This is because it can limit someone's freedom. For example, if someone experiences sedation as a side effect, this impacts on their ability to go out and do the things they enjoy. Therefore, when medication is suggested, less restrictive options should also be considered.

Given the explicit role and functions of an IMHA under the Mental Health Act, advocates have a clear duty to support people in understanding their care and treatment, including the (potential) use of psychotropic medicines and what alternative interventions and options there might be.

5. Care Act

The role of the advocate is detailed in the Care and Support (Independent Advocacy Support) Regulations¹² as assisting the individual in:

- Understanding the process the person is involved in (e.g. the safeguarding, care planning or review process).
- Communicating the individual's views wishes and feelings.

¹¹ Mental Health Act 1983: Code of Practice <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>

¹² Care and Support (Independent Advocacy Support) Regulations 2014 (s5): https://www.legislation.gov.uk/uksi/2014/2824/pdfs/uksi_20142824_en.pdf

- Understanding how the individual's care and support, or support, needs could be met by the local authority or otherwise.
- Making decisions in respect of care and support arrangements.
- Challenging the local authority's decisions if the individual so wishes.

The Care Act advocate must also, as far as is practicable, ensure the individual understands their rights under the Act, ensure those rights are upheld in relation to the functions, and prepare a report for the local authority if they have concerns about the manner in which the assessment or planning function has been exercised or the outcomes arising from it. As with other forms of statutory advocacy, the advocate can access a person's records.

If the person does not have capacity to communicate his or her views, wishes or feelings, then the independent advocate must do so to the extent that they can be ascertained.

Crucially if the person does not have the capacity to challenge a decision made during the assessment, care planning or review then the independent advocate must do so if the advocate considers the decision to be inconsistent with the authority's general duty under Section 1 (2) of the Care Act¹³ - the duty to promote the individual's wellbeing. The wellbeing principle applies in all cases where a Local Authority is carrying out a care and support function, or making a decision, in relation to a person.¹⁴

This means that if psychotropic medication is being considered or is prescribed, that may compromise or is compromising an individual's wellbeing, advocates have a duty to challenge that decision, particularly where there are alternative interventions that address the person's needs with fewer harmful consequences. In doing this, advocates, and all agencies involved, must have regard to the duties specified in Section 1 (3) of the Care Act¹⁵ and 1.14 of the *Care & Support Statutory Guidance*¹⁶.

6. Non-statutory advocacy

The NHS England, ADASS & LGA guidance *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*¹⁷ highlights the importance of people having access to different types of independent advocacy at key points in their interaction with health, education and care services. In addition to the legal right to statutory advocacy, this guidance argues that people should also be offered non-statutory advocacy, which should be available to them either at key transition points and/or for as long as they require at other times in their lives. For example, this could include in preparation for going to or leaving from a specialist hospital.

The role and responsibilities of a non-statutory advocate (professional advocate) are those associated with all types of advocacy and are defined within the Advocacy Code of Practice¹⁸. Non-statutory advocacy means there is no specific legal framework that governs the role. However, depending on the issue the person is presenting with, there is likely to be legislation, national policy or guidance that governs the actual decision or issue at hand which can support the independent advocate in their role.

This is the case with the issues surrounding the use of psychotropic medication which are the same as those discussed under statutory advocacy roles. However, non-statutory advocacy is less time bound, has greater flexibility and can be more responsive in how it operates across different teams of professionals and with different system partners in order to bring about change in the life of an individual. Eligibility for non-statutory advocacy is defined by the advocacy organisation's specific commissioning arrangements and contract for a given area.

¹³ Care Act 2014: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

¹⁴ Care and Support Statutory Guidance (ch. 1): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

¹⁵ Care Act 2014 (s1 (3)): <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

¹⁶ Care and Support Statutory Guidance (1.14): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

¹⁷ Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition 2015 (p.15) <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

¹⁸ Advocacy Code of Practice <http://www.qualityadvocacy.org.uk/wp-content/uploads/2014/03/Code-of-Practice.pdf>

7. Safeguarding

Advocates might witness the frequent use of psychotropic medications to 'calm' residents or patients, or become aware of their use through reading relevant records or in other ways. This could happen in a variety of settings from hospital wards to care homes and other services. This can be a restrictive practice and could deprive someone of their liberty. It could also be an indicator of poor care, if more appropriate options of care and suitably skilled or sufficient staff are not present or apparent. As well as requesting a review of the individual's care plans, such situations may also necessitate raising a safeguarding concern or contacting the CQC, particularly where this practice maybe used on a number of residents/patients in the same place.

For people 18 years old or older, the law and guidance around safeguarding can be found in the Care Act¹⁹ with Chapter 14 of the Statutory Guidance²⁰ being particularly useful. It establishes that adults have a right not to be abused or neglected, and that all agencies working with adults with care and support needs have a duty to work together to ensure the safety of adults who cannot protect themselves. Where an adult may have been abused or neglected, an enquiry should take place to understand what has happened and establish a plan to prevent the person being subject to further abuse. As far as possible, the person should be involved in this enquiry and in decisions that are made about their care.

Whether an issue should be raised as a safeguarding concern will be based on the individual facts, the severity of concerns, the ability of the person to protect themselves and the impact that it has on their life.

For example, where someone might be staying in a care home or hospital and does not have capacity to consent to their medication, they will be unable to protect themselves from overmedication. Whether this person being overmedicated might be considered abuse may depend on a number of factors. These might include, but not be limited to:

- The effect that the medication has had on the person, and whether there was any harm caused. This can include any negative physical effects, but it might also be the fact that the person is unable to engage with people that visit them, build friendships or take part in activities.
- The frequency of this poor practice.
- The intention of the carers when providing the medication.
- Whether there are other people in the same place that are also being overmedicated.

If you have any concerns, you should speak to your line manager. Where you believe it is a safeguarding concern, you will need to follow the Multi-Agency Safeguarding Procedures for your local area to get advice and, if indicated and appropriate, raise the concern.

¹⁹ Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

²⁰ Care and Support Statutory Guidance (ch.14): <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

This document was written by VoiceAbility, with support from NHS England.

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