

'STOMP' and 'STAMP' -The Essential Role of the Health and Care Workforce in Reducing the Reliance on Psychotropic Medication

Summary report

October 2024

# Introduction

ODG

This summary report provides headline findings from the "STOMP' and STAMP'" project undertaken in collaboration by the National Development Team for Inclusion (NDTi), the Voluntary Organisations Disability Group (VODG), Learning Disability England (LDE) and Skills for Care.

The project was funded by Health Education England and took place between 2022 and 2023.

## What is STOMP and STAMP

It is estimated that on an average day in England between 30,000 and 35,000 people with a learning disability, autism or both are taking prescribed psychotropic medication without appropriate clinical justification (NHSE, 2015). This is medication which results in alterations to perception, mood, or consciousness. Long-term use of these medicines puts people at unnecessary risk of a wide range of side effects including weight gain, organ failure and even premature death.

In 2018, NHS England launched STOMP-STAMP to address the use of psychotropic medications for people with a learning disability, autism, or both. **STOMP** stands for the Stopping Over Medication of People with a learning disability, autism, or both and **STAMP** stands for Supporting Treatment and Appropriate Medication in Paediatrics. Both are now commitments within the NHS Long Term Plan involving many organisations to ensure that medication is used appropriately and safely. More information can be found on the NHS England website.

Despite STOMP- STAMP's launch in 2018, a recent Learning Disabilities Mortality Review (LeDeR) report identified that the "inappropriate use of psychotropic medicines can be a significant contributory factor, or the cause, of a person's death" with 8% of individuals taking two or more psychotropic medications at the time of death. This is contra to advice from NICE and suggests that STOMP-STAMP's aim of reducing the use of antipsychotic medication in this population has made limited progress.

Health and social care staff play an essential role in delivering the STOMP - STAMP agenda. This research aimed to explore this potential and identify opportunities to embed STOMP and STAMP across the health and care workforce, to reduce the reliance on psychotropic medication for people with a learning disability and autistic people.

#### The research's objectives were to:



Gauge awareness and understanding of STOMP and STAMP among members of the health and social care workforce;



Explore barriers and challenges to embedding STOMP and STAMP as normal practice across different health and care roles and settings;



Identify opportunities and solutions to improve health and care colleagues' awareness of STOMP and STAMP.

### What we did

To achieve the research objectives this piece of work was guided by a Reference Group made up of people with a learning disability, autistic people, and family carers. This group worked with the project research team to capture data from:



A literature search.

An online survey for health professionals (181), social care professionals (138) and family carers (21).

1:1 conversations with professionals (7)

Round table conversations (2)

### A note on data

It is important to note that the participants in this research are not representative of the health and social care workforce in England. Instead, they are individuals and groups with a vested interested in STOMP-STAMP who have shared their views and experiences to help make change for the future.

This is particularly important to keep in mind when survey data is referred to as participants are positively skewed towards being well informed, having undertaken training and feeling confident in applying STOMP and STAMP which data suggests is not representative of the wider health and social care workforce.

#### **Key Findings**

To date, information about STOMP-STAMP has not reached those who need it.
There are many misconceptions in the health and social care workforce about STOMP-STAMP
Many of the non-prescribing health professionals, social professionals and family carers didn't know that STOMP-STAMP applied to them or that they could use it.
Where training about STOMP-STAMP had been undertaken, professionals reported having the skills, knowledge, and confidence to use STOMP-STAMP in their roles.
There is a need for a designated role within the health and social care workforce, which includes Learning Disability Nurses, to Champion STOMP-STAMP, advocate for individual needs and act as conduit between them, prescribing and non-prescribing professionals.

Whilst there has been a lot of information about STOMP and STAMP published since the start of the projects in 2018; this research suggests that, for the most part, this information hasn't reached those who need it in a way they can use it. As a result, the rate of psychotropic drug prescribing for people with a learning disability, autism or both without a diagnosed mental illness has only fallen by 0.8% in 5 years from 15.8% in 2017/18 to 14.5% in 2021/2022 (<u>NHS Digital, 2023</u>). This is far below what it was hoped the projects would achieve.

Participants suggest that the original call to action in the STOMP - STAMP project being focused on recruiting groups to make a pledge to promote good practice rather than making it a mandatory part of their roles, might offer an explanation as to why its principles have not been enacted in practice. That is, due to the plethora of guidance offered to health and social care professionals on a regular basis, the inherent pressures in both sectors, not least the COVID-19 pandemic falling within the timeframe being discussed, and turnover of staff, non-mandatory information can fall to the wayside.

It is therefore promising to see that STOMP- STAMP has now been incorporated into the NHS plan, which means that all health and social care staff working with people with a learning disability, autism or both will have to incorporate it into their practice.

As many roles in the sector are currently working out what it is they need to do differently with regards to STOMP - STAMP, the remainder of this report aims to provide learning to help inform changes in practice with suggestions for further work that could be done to strengthen its use in the future.

Firstly, we heard from participants that there are misconceptions about STOMP - STAMP held within health and social that need addressing. The most pronounced of these related to the widely held belief that STOMP - STAMP is a turning away from psychiatry, rather than a working more closely with psychiatry to ensure psychotropic medications are used appropriately and in conjunction with other interventions such as Positive Behavioural Support. It is felt that this misconception provides an explanation for additional findings in this research relating to the apprehension of social care professionals and family carers from utilising STOMP - STAMP to address medication concerns.

That is, this research found that medication management is often addressed from the 'perspective of risk management' with supporters and family's not wanting to 'change things when they seem to be working'.

In addition, we also found that many non-prescribing health professionals (i.e., pharmacists, nurses, occupational therapists, psychologists, speech and language therapists, arts therapists and physiotherapists), social care professionals and family carers don't know that STOMP - STAMP applies to them or that they can use it. This is felt to perpetuate the consequences of the first misconception detailed above, by reportedly further exacerbating the entrenched power imbalance between these groups. This in turn, is likely to explain why many social care professionals, in particular, don't challenge prescribers as they believe that:

'if a doctor prescribed it, it has got to be right.'

In fact, some participants told us that when social care professionals are made aware of the power STOMP - STAMP gives them to challenge prescribing decisions, they 'are shocked.'

These findings seem to suggest that education about STOMP - STAMP is vital for non-prescribing health professionals, social care professionals and family carers to ensure it can be embedded and utilised in practice. In this research, non-prescribing health professionals and social care professionals who had received training (41%) suggested they found this training useful as it raised their awareness about medication, increased their understanding of how the guidance can be used in practice, and provided them with opportunities to talk to others about how to navigate barriers. These individuals also reported having the skills, knowledge and confidence needed to use STOMP - STAMP in their roles and overwhelmingly stated that they have applied what they learnt in practice (82%).

Unfortunately, none of the family carers (14) reported having received training, but some did suggest that they feel this would be useful.

However, it is not only training for non-prescribing health professionals, social care professionals and family carers that is said to be needed as STOMP-STAMP is embedded, but for prescribing health professionals as well. That is, it was reported that whilst GP's are responsible for reviewing medication, they do not routinely know about STOMP - STAMP. Nor do they necessarily have the knowledge or confidence to review psychotropic medication as this is widely prescribed by psychiatrists. As such, training which dovetails with that provided to non-prescribing health professionals, social care professionals and family carers could be beneficial in this arena. Of the prescribing health professionals who had received training in this research (62%) they highlighted that this training would be most useful if it is delivered at a level relevant to their role, allows them to explore their practice with colleagues, provides high quality practice examples and is refreshed regularly.

### Other learning captured in this research suggests:



ensuring STOMP-STAMP is part of the high quality, structured medication reviews that take place in Annual Health Checks would help embed it in practice.



ensuring pharmacists are able to utilise their increasingly unique position and clinical knowledge to apply STOMP-STAMP.



having a designated role within the health and social care workforce, which includes Registered Learning Disability Nurses, to Champion STOMP-STAMP, advocate for individual needs and act as conduit between them, prescribing and non-prescribing professionals.



addressing the power imbalances within and between different health and social care professionals and settings to allow holistic working to reduce the overuse of psychotropic medication.

Whilst this research hopes that some/all of these practical suggestions will help inform the changes to practice required as part of STOMP-STAMP being part of the <u>NHS Long Term plan</u>, it is important to highlight that they are sat within a wider context that has not been the focus of the project but none the less brought up by participants.

That is, we heard on several occasions, that one of the reasons that STOMP-STAMP has not been successful in reducing the inappropriate prescribing of psychotropic medication is down to the lack of alternatives available to people. For many people, stepping down from psychotropic medication use requires new or additional support from alternative services that are either not available or do not have capacity. Furthermore, we also heard that for many autistic people their journey onto psychotropic medication begins when they are wrongly admitted into a setting that is inappropriate for them and the medication is used to alter mood and/or moderate behaviour.

These findings suggest that there is a much broader piece of work that needs to be undertaken to review the health and social care systems that sit around the specific elements of STOMP-STAMP to allow it to achieve its outcomes.

# What could we do, who could do it, and how do we get them to do it?

We are hopeful that STOMP - STAMP becoming part of the wider NHS Long Term plan will improve its utilisation by the health and social care workforce and lead to an overall reduction in the use of psychotropic medications for people with a learning disability, autism, or both. However, from the findings in this research it is clear that a multi-pronged approach is needed to achieve this outcome. We suggest:



STOMP - STAMP training should be mandated for all tiers health and social care staff working directly with people with a learning disability, autism, or both. This training should:

- be specific to different roles and professions.
- > provide relevant high-quality good practice examples.
- > focus on breaking down misconceptions detailed in this report,
- increase knowledge and confidence.
- be bitesize.
- be refreshed regularly.

It is recommended that the <u>MindEd</u> STOMP - STAMP modules already available are reviewed and embedded within the learning disability and autism training all regulated service providers must ensure their staff receive (<u>Health and Care Act, 2022</u>).



The MindEd STOMP-STAMP modules for family carers should be broadened and widely promoted to encourage their use within this population.



To review and revive the national campaign to raise awareness of STOMP - STAMP to all workforce groups, including family carers, with links to a repository of resources and information.



Learning disability nurses and pharmacists should be utilised for their clinical knowledge and unique position to Champion STOMP-STAMP and act as conduits between individuals, their families, health, and social care professionals.



Personalised, structured medication reviews, including STOMP - STAMP, as part of Annual Health Checks.



More work needs to be done to understand what good looks like in the provision of safe, timely alternative support for individuals to whom STOMP-STAMP applies.