

STOMP – Next Steps



**The Challenging
Behaviour Foundation**
making a difference to the lives of people with severe learning disabilities

SUMMARY OF BACKGROUND TO THE STOMP/STAMP PROGRAMME

- BBC Panorama Programme - Undercover Care: The Abuse Exposed Winterbourne View (31st May 2011)
- Transforming Care: A National Response to Winterbourne View Hospital (December 2012)
- Winterbourne Medicines Programme. Improving the Use of Medicines in People with Learning Disabilities (April 2014-2015)
- Call to Action letter published by NHS England (14th July 2015) detailing 3 reports:
 - Winterbourne View – Time for Change. Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism (2014)
 - Prescribing of Psychotropic Drugs to People with Learning Disabilities and/or Autism, Public Health England (June 2015)
 - Survey of Medication for Detained Patients with a Learning Disability, CQC (February 2016)
- STAMP programme announced in December 2018



STOMP

Stopping Overmedication of People with a Learning Disability, Autism or Both

- Improve the quality of life of people with a learning disability, autism or both
- Make sure people only receive psychotropic medication for the right reasons and in the right amount
- Improve understanding of psychotropic medicines and when they should or should not be given

STAMP

Supporting Treatment and Appropriate Medication in Paediatrics

- Make the lives of children and young people with a learning disability, autism or both who are prescribed psychotropic medications better
- Make sure that children and young people who need medication can get it for the right reason, in the right amount for as short a time as possible
- Help people to understand more about these medications and have the confidence to ask why they are needed

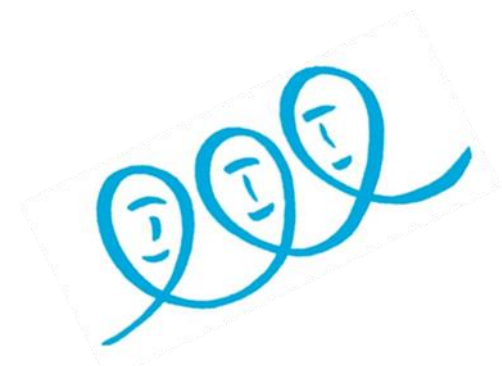


STOMP

- Improve understanding of alternatives to medication
- Make sure that people with a learning disability, autism or both are involved in decisions about their health and treatment

STAMP

- Help make more non-medication treatments and support available
- Make sure the person with their family and paid carers are involved in any decisions to start, stop, reduce or continue taking them
- Get more children and young people with a learning disability, autism or both to have an annual health check starting from the age of 14

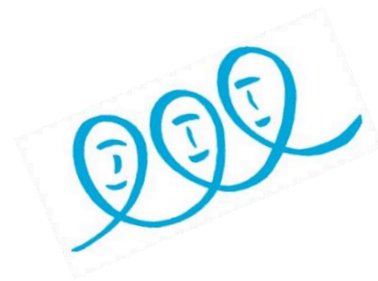


WHY IS STOMP/STAMP IMPORTANT?

Human Rights!

Article 2 Protects your right to life

Public authorities should also consider your right to life when making decisions that might put you in danger or that affect your life expectancy.



WHY IS STOMP/STAMP IMPORTANT?

Human Rights!

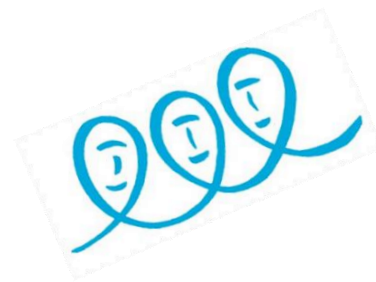
Article 3: Freedom from torture and inhuman or degrading treatment

What is degrading treatment?

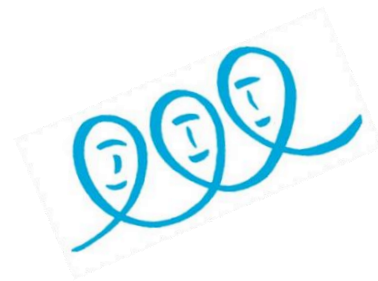
Degrading treatment means treatment that is extremely humiliating and undignified. Whether treatment reaches a level that can be defined as degrading depends on a number of factors. These include the duration of the treatment, its physical or mental effects and the sex, age, vulnerability and health of the victim. This concept is based on the principle of dignity - the innate value of all human beings.



“For far too long people with learning disabilities have received poor healthcare,” says Sandra Gidley, chair of the Royal Pharmaceutical Society (RPS) English Pharmacy Board. “This group of patients are frequently prescribed antidepressants, sedatives and mood stabilisers in order to manage episodes of ill-health or challenging behaviour, which are not subsequently reviewed. These medicines can cause serious side effects, poor health and even premature death,” she adds.

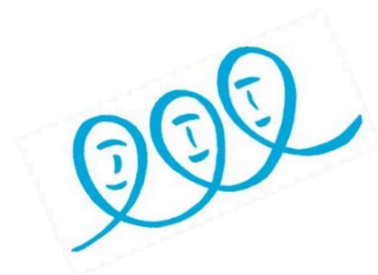


What has been
done so far?



DELIVERY OF STOMP/STAMP TO DATE

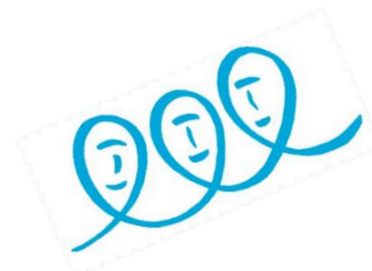
- NHS-produced pledge for healthcare providers
- Raising awareness
 - Events, MiXiT, Blog, Twitter, Newsletters, Email Updates, VODG webpage, examples of good practice
- Resources
 - Information leaflets
- Training
 - Online programme for pharmacists (October 2016)
 - MindEd
 - Spectrom



'NICE' GUIDANCE

- The NICE guideline on challenging behaviour and learning disabilities covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges. It highlights the importance of understanding the cause of challenging behaviour and performing thorough assessments so that steps can be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers.
- The full guideline states that many types of psychotropic medicines have been used to manage behaviour that challenges, including antipsychotics, antidepressants, mood stabilisers and sedatives. Medicines are mostly used to reduce excitation and aggression, despite the limited evidence for efficacy in people with learning disability.

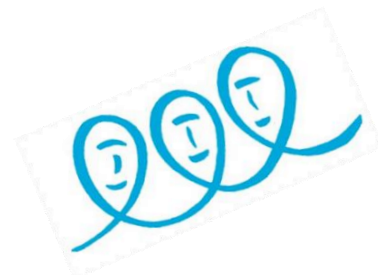
The guidance for the use of medication is already out there in the NICE guidelines. The problem is that it is not being followed sufficiently. So what does one do about that?



THE NEXT STEPS?

- Many of those who should know about the STOMP/STAMP programme do not.
- The delivery of the STOMP/STAMP programme is not always appropriate, for instance, practitioners have withheld pain relief due to a misinterpretation of STOMP/STAMP⁽¹⁾.
- Alternatives and reduction in medication are dependent on the commitment and initiative of individuals, not STOMP/STAMP led⁽²⁾.
- Families are taking responsibility for implementing alternatives and/or reducing medication, with or without knowledge of STOMP/STAMP or input from professionals⁽³⁾.

(1)(2)(3) Source: CBF STOMP workshop with families in March



THE NEXT STEPS?

David Branford, an independent pharmacy advisor on learning disabilities and mental health, said that in recent years there had been a “massive move” away from antipsychotics to other psychotropic drugs, such as antidepressants and antiepileptics.

Branford said that a number of reviews of prescribing have taken place since the (STOMP) campaign was launched in England in 2016.

“The main findings are that STOMP is incredibly good at raising the profile of the issue, but in terms of people systematically reviewing people and taking them off the medicines, there hasn't been a massive change,” he said.

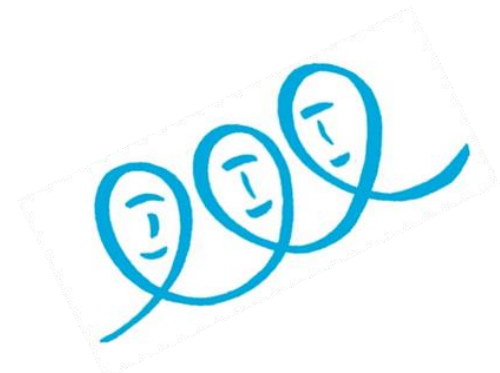
“We need some kind of CQUIN [Commissioning for Quality and Innovation framework], some kind of payment, or legal framework that requires people to be reviewed or taken off [these medicines]; just having campaigns where you raise the issue alone doesn't do it — you need significant incentives and support.”

- David Branford



DISCUSSION GROUPS

- What are the barriers?
- Whose responsibility?
- What needs to be done?
- How will it be done?



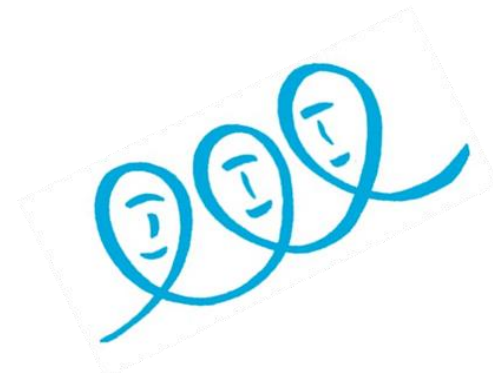
THE NEXT STEPS – What could be done?

- STOMP needs to be kept on the agenda for national and individual decision makers, in governance, social services, care, healthcare, education and other fields.
- Any campaigns should highlight the lived experiences of individuals with learning disabilities and their families
- How can we ensure that the wishes of people with learning disabilities and their families are made central in healthcare decisions?
- What are the practical alternatives to psychotropic medication?
- How can we ensure guidance is actually followed?
- Where overmedication occurs, what needs to be put in place?
 - For practitioners: better diagnostic tools to understand the causes of challenging behaviour
 - For care & support: better understandings of the mental health and environmental causes of challenging behaviour
 - For pharmacists: more understanding & accountability surrounding STOMP



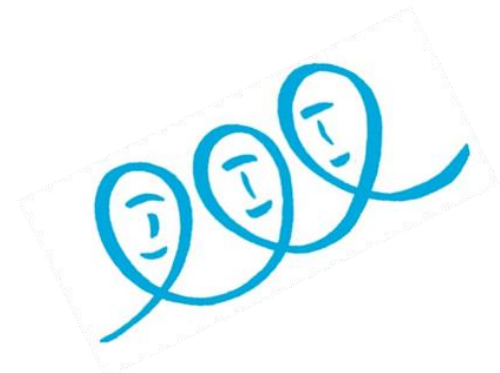
THE NEXT STEPS – Whose responsibility?

- STOMP training developed into training by MindEd, Spectrom – who needs to see this? Support workers/providers, practitioners, government figures, pharmacists? Should STOMP be made a principle of Positive Behaviour Support?
- Who must be held accountable, and who could we reach out to in order to ensure STOMP is on the agenda?
 - Local and central government
 - Royal Pharmaceutical Society
 - Primary Care Physicians
 - Care providers

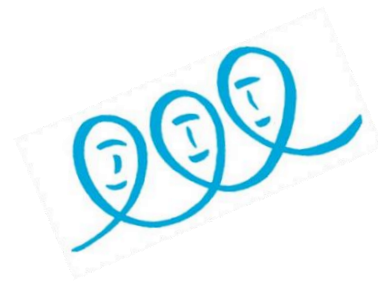


AFTER TODAY

- STOMP/STAMP aims – prompt cards
- CBF STOMP Medication Information Pack
 - 1 x your personal resource
 - 1 x pass to a colleague
 - 1 x pass to a family carer



THE NEXT STEPS



Challenging
BEHAVIOUR
foundation



making a difference

THANK YOU!

