



# Overprescribing of Psychotropic Medicines in People with a Learning Disability, Autism or Both

A presentation delivered to pharmacy professionals at the Keele Good Practice Day on *Stopping Overmedication of Patients with Learning Disability , Autism or both (STOMP)*  
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**Expert by experience**

What am  
I going to  
talk  
about?

Understanding learning  
disability

Appreciating interventions for  
behaviours that challenge

Evidence of overprescribing  
psychotropic medicines

Addressing overprescribing –  
STOMP, deprescribing

# Firstly, let's discuss some definitions

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- What do we mean by **learning disability, learning disabilities, intellectual disability** and **intellectual disabilities**?
- **Intellectual disability** or **intellectual disabilities** means the same as **learning disability** or **learning disabilities**.
- In the U.K. NHS, social care and educational services in the UK tend to use the terminology **learning disability** or **learning disabilities** whereas other countries and researchers use the words **intellectual disability** or **intellectual disabilities**
- Sometimes **learning difficulties** are confused with **learning disabilities** - **learning difficulties** refer to neurodevelopmental conditions such as dyslexia and dyspraxia
- A person's learning disability may be described as mild, moderate, severe or profound.

# Firstly, let's discuss some definitions

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NICE defines a learning disability as meeting 3 core criteria:

1. lower intellectual ability (usually an IQ of less than 70)
2. significant impairment of social or adaptive functioning
3. onset in childhood.

<https://pathways.nice.org.uk/pathways/learning-disabilities-and-behaviour-that-challenges>

MENCAP, the national charity, define learning disability as

- A reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.
- People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.
- <https://www.mencap.org.uk/learning-disability-explained>

# Firstly, let's discuss some definitions

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- What is “**autism**” ?
- Autism is a lifelong developmental disability which affects how people communicate and interact with the world. One in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK.
- <https://www.autism.org.uk/advice-and-guidance/what-is-autism>
- Around 4 in 10 autistic people have a learning disability.
- <https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/learning-disability-and-autism>

# Terminology

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- Varies
- Speak to service user
- No acronyms eg learning disability NOT LD
- NHS England Guidance
  - <https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/>

# Medicines Optimisation

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- NHS England
- <https://www.england.nhs.uk/medicines-2/medicines-optimisation/>



# Where do people with learning disability live?

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- Principle 1 – medicines optimisation
- Setting:
  - People with learning disability can live anywhere
  - They may live with
    - Relatives
    - On their own in their own home
    - Other people; flat /house share, residential home
    - What is supported living and how does it differ from residential care?
- How are people with learning disability supported?
  - Varies
  - Support may be from relatives or paid cares
  - Some people with learning disability may not have support
  - People with learning disability are supported to make informed decisions about their medicines unless they lack capacity (Mental Capacity Act).



# LET'S THINK ABOUT Addressing behaviour that challenges

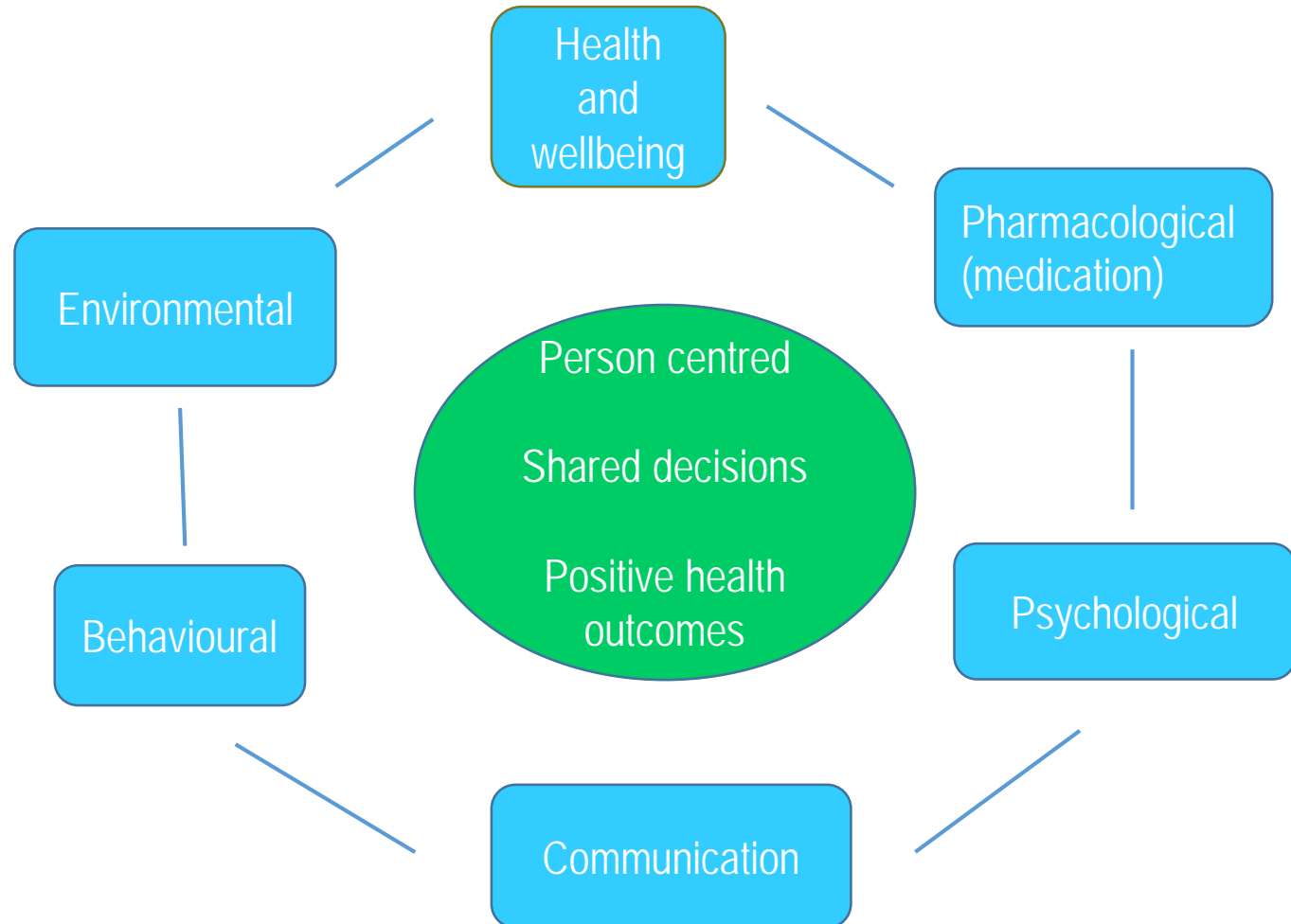
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- What is “challenging behaviour”, “behaviour that challenges”, “behaviours that challenge”?
- Social construct, communication expression or medical diagnosis ?
  - Emerson (2001) : Behaviour which is culturally abnormal and places a person in serious danger and seriously affects their ability to make use community amenities because of its duration, intensity, or frequency
  - NICE NG 11 2015:
    - can include aggression, self-harm, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour, including behaviours which may bring the person into contact with the criminal justice system.
    - more prevalent amongst those with more severe learning disability and those who have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health conditions

# LET'S THINK ABOUT Addressing behaviour that challenges

- Interventions:

- Multidisciplinary
- Complex interventions
- Positive Behaviour Support
- Diagnostic Overshadowing
- National Guidelines e.g NICE



# Health Inequalities

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- People with learning disability experience poorer health outcomes, reduced access to healthcare services, have worse physical and mental health and shorter lifespans compared to people without learning disability (on average people with learning disability die 25 years younger)
- Accessing annual health check that is available to all people with learning disability over the age of 14 on learning disability register
- Increased prevalence of epilepsy
- Higher incidence of mental illness – challenges in diagnosis, ictal psychosis
- Comorbid physical health conditions, may directly impact the number of medicines that are prescribed, potentially giving rise to problematic polypharmacy

# Overprescribing of PSYCHOTROPIC MEDICINES

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- What's the issue?
  - Polypharmacy
  - Adverse Effects – short term and long term effects
  - Lack of monitoring and follow up
  - Long term prescribing of psychotropic medicines
  - Ethical issues
  - Often prescribed without documented mental health diagnosis
  - Off label use of medicines – reasons for prescribing
- What's the evidence?
  - USA 1970s / 1980s legal challenges to the use of psychotropic medicines for the management of behaviour that challenges in people with learning disability
  - Winterbourne View 2011 – BBC Panorama reported abuse at this hospital in Gloucestershire for people with learning disability; 11 staff members went to prison
  - NHS England commissioned reports
  - The NHS Improving Quality pilot improvement project Winterbourne Programme (2015), carried out across six sites in England found that patients, carers and family members did not always understand why psychotropic medicines had been prescribed.

# OVERPRESCRIBING of PSYCHOTROPIC MEDICINES

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- Winterbourne View - Transforming Care report 2012 highlighted overuse of antipsychotic and antidepressant medicines in people with learning disabilities suggesting that medication reviews are conducted in a timely manner and involve pharmacists, doctors and nurses
  - [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)
- A report by Public Health England in 2015 involving GPs found that 58% of adults with learning disabilities and/or autism receiving antipsychotics and 32% of those receiving antidepressants had no recorded relevant diagnosis of a mental health condition. In addition, 22.5% of prescriptions for antipsychotics included more than one medicine in this class and 5.5% were for doses exceeding the recommended maximum
  - <http://clock.uclan.ac.uk/17970/1/Psychotropic%20medication%20and%20people%20with%20learning%20disabilities%20or%20autism.pdf>
- UK cohort study found that of the 33,016 people reviewed, only 21% of the cohort had a record of mental illness and 25% had a record of behaviour that challenges, however, 49% were prescribed psychotropic medicines.
  - Sheehan R, Hassiotis A, Walters K et al. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. BMJ 2015;351:h4326. <http://dx.doi.org/10.1136/bmj.h4326>
- Behaviour that challenges is often the primary reason for the high rate of antipsychotic prescribing in people with learning disabilities
  - <https://pathways.nice.org.uk/pathways/learning-disabilities-and-behaviour-that-challenges>
  - Deb S, Sohanpal SK, Soni R et al. The effectiveness of antipsychotic medication in the management of behaviour problems in adults with intellectual disabilities. J Intellect Disabil Res. 2007;51(Pt 10):766–777. <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2007.00950.x>
  - University of Hertfordshire. Intellectual disability and health. The use of medications for the management of problem behaviours in adults who have intellectual disabilities. Available at: <http://www.intellectualdisability.info/mental-health/articles/the-use-of-medications-for-the-management-of-problem-behaviours-in-adults-who-have-intellectual-disabilities>

# Overprescribing of PSYCHOTROPIC MEDICINES

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- Are people with learning disability equal stakeholders in decisions around for prescribing of psychotropic medication?
  - Shared decision making
  - Informed Consent
  - Availability of high quality accessible information
  - Management of adverse effects
- Which classes of psychotropic medicines are involved?
  - Winterbourne view highlighted antipsychotics and antidepressants
  - Initially more interest in addressing overprescribing of antipsychotics
  - Recent reports suggest now more prescribing of antidepressants and mood stabilisers

## ADDRESSING OVERPRESCRIBING

1. Stakeholder awareness

2. Reducing initiation of prescribing

3. Linking up with the wider health and social care team re appropriate management and interventions

4. Deprescribing psychotropic medicines prescribed for the management of behaviour in the absence of documented mental health diagnoses

# DEPRESCRIBING (REDUCTION OR DISCONTINUATION)

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- Call to action in 2016
- NHS England's STOMP (Stopping the Overprescribing of Medicines in People with learning disability, autism or both) <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>
- The aim is to reduce inappropriate psychotropic medication prescribing.
- STAMP (Supporting Treatment and Appropriate Medication in Paediatrics) <https://www.england.nhs.uk/learning-disabilities/improving-health/stamp/> launched in 2018
- Identifying individuals who require medication reviews
- Is medication being monitored?
- Tracking patients, clinical audit, quality improvement projects
- Best practice in deprescribing
  - Stakeholder engagement - MDT, social care, family carers, people with learning disability
  - Shared decision making, informed consent
  - Improving health inequalities
  - Improving quality of life
  - Availability of high quality accessible information
  - Management of discontinuation effects
  - Accessibility of other interventions
  - Monitoring, review, follow up



# What does STOMP aim to achieve?

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- Position statement of the Royal College of Psychiatrists, Faculty of Psychiatry of Intellectual Disability 2021
- [https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/position-statement-ps0521-stomp-stamp.pdf?sfvrsn=684d09b3\\_6](https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/position-statement-ps0521-stomp-stamp.pdf?sfvrsn=684d09b3_6)
- Actively exploring alternatives to medication
- Ensuring people with learning disability, autism or both, of any age, and their circle of support, are fully informed about their medication and involved in decisions about their care
- All staff within the organisation have an understanding of psychotropic medication, including why it is being used and its potential side effects
- Ensuring all people are able to speak up if they have a concern that someone is receiving inappropriate medication
- If psychotropic medication is needed, then it is started, reviewed and monitored in line with relevant NICE guidance

# DEPRESCRIBING cautions to consider

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- Removing sedative effects of medicines
- Reduction in sexual side effects
- Reduction of prolactin levels leading to return of menstrual periods, increase in fertility
- Discontinuation symptoms
- Unmasking of undiagnosed mental health condition
- Increase in episodes and intensity of behaviour that challenges - consequences

# Some useful resources

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- NHS England <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>
- CPPE resource <https://www.cppe.ac.uk/programmes/l/learndislc-d-01>
- NICE <https://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities>
- Branford D, Webster A, Shaw C, Gerrard D and Saleem N (2018) Stopping over-medication of people with an intellectual disability, Autism or both (STOMP) Part 1 – history and background of STOMP. Advances in Mental Health and Intellectual Disabilities. <https://doi.org/10.1108/AMHID-02-2018-0004>
- Branford D, Webster A, Shaw C, Gerrard D and Saleem, N (2018) Stopping over-medication of people with an intellectual disability, Autism or both (STOMP) Part 2 – the story so far. Advances in Mental Health and Intellectual Disabilities. <https://doi.org/10.1108/AMHID-02-2018-0005>
- MindEd platform (supported by Health Education England) <https://www.minded.org.uk/>

# Thank you for listening

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- Any questions??

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