Positive Behaviour Support & STOMP in Learning Disability Practice

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Aims

To have an awareness of the Positive Behaviour Support Framework and consider how it may be applied to clinical practice.

To discuss the NHS England Pledge of Stopping the Over Medication of People with a Learning Disability, Autism or Both (STOMP).
Objectives

Gain an understanding of the principles of Positive behaviour support (PBS) and the policies this relates to.

Develop an awareness of the motivating factors for behaviours that challenge.
What is Positive Behaviour Support?

A multi-component framework for delivering a range of evidence-based supports to increase quality of life and reduce the occurrence, severity or impact of behaviours that challenge. (NHS LGA 2014)
What is Positive Behaviour Support?

A person can start to exhibit behaviours that are deemed as “challenging” due to many different reasons, dependent on the individual.

It may be due to communication or interaction issues, because of pain or illness, environmental overstimulation or under-stimulation or sensory deficits.
Positive Behaviour Support

The foundations of Positive Behaviour Support (PBS) is a Functional Behaviour Assessment.

This is understanding why the individual exhibits the target behaviour, and addressing the issues to prevent further episodes of behaviours that challenge.
Functional Behaviour Assessment

BEHAVIOUR is a MESSAGE!
Functional Behaviour Assessment

- Everyone communicates through their behaviour regardless of whether or not they have speech.

People:

- Sigh when they are sad.
- Slam doors when they are angry.
- Fidget when they are anxious.
Functional Behaviour Assessment

For people with little or no speech, behaviour becomes the most important way of communicating.
Functional Behaviour Assessment

Maintaining Factors;

Challenging Behaviour is not exclusive to people with learning disabilities.

Similar behaviours occur in almost everyone.

Challenging behaviour serves a purpose or a function for the individual.
Functional Behaviour Assessment

Challenging behaviours are **effective strategies** for obtaining certain activities or events or avoiding certain activities;

- Obtaining tangibles.
- Escaping or avoiding situations.
- Social attention.
- “Self stimulation.”
Positive Behaviour Support Framework

Assess the behaviour

Formulate an understanding of why these behaviours occur

Develop a Behaviour Support Plan

Monitor for effectiveness and review when necessary
Positive Behaviour Support

Positive behaviour support is used in different ways, according to the individual’s requirements, and is considered as a long-term management technique.

It may involve changing environmental factors that may be the root cause of the challenging behaviour, so that the person is able to live a more valued, fulfilled life with better access to services.

(Department of Health 2014).
Jack

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Jack

Jack is 27 years old and lives at home with his Mother and Father.

He is diagnosed with a Severe Learning Disability and ASD. He has significant communication difficulties, although he can make his needs known.

Jack has been known to Learning Disability services since he was a young boy.
Referral to the Team

Originally Jack was referred to the team due to him refusing to leave the confines of his bedroom.

Reports from the screening visit identified 3 priority behaviours when parents were trying to support him with personal care and access to the community:

- Self Injury
- Physical Aggression
- Stripping Clothing
Functional Assessment

Assessment of the priority behaviours was conducted utilising several different methods including direct observations; interviews, record searches (GP records, Care Coordination records and Specialist Behaviour Team records).

The assessment identified the predominant function to Jack’s “behaviour” was negatively reinforced in form of Escape.
What does the Function mean for Jack?

Avoiding requests/demands.
Avoiding activities.
Avoiding people!
Assessment Outcome

However the assessment also identified a pattern in Jack’s presentation particularly over the Autumn and Winter months.

He was prone to chest infections, when suffering from a chest infection Jack would retreat to his bedroom.

Once he had recovered his routines would be altered and would not engage with family or carers.
Assessment Outcome

During the observations it was identified that Jack would grind his teeth and jaw.

He was also suffering from severe toothache!
Support

Jack was wanting to avoid demands placed on him by his family and carers.

But was this due to the pain he was in?

Due to his communication difficulties the only way to express his pain or wanting to be left alone was through behaviour that was originally seen as “challenging”.

Best Interest

Jack needed to be supported to receive dental treatment. To do this he needed to be with people who he trusted and was familiar with.

It was proposed for Jack to receive dental treatment under general anaesthetic.

However the Best Interest decision was made initially to try and support Jack to the dentist for regular check ups as this was viewed as least restrictive and pose less risk.
Support/Intervention

Jack can become very anxious of the unknown.

Jack’s anxieties can lead to incidents of physical aggression.

Small gradual steps were required to get him to the dentist.
Reinforcers

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Communication/interventions

Social stories

Forward chaining

Desensitisation

Reinforces

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Risk Assessment

What do you think we needed to focus Jack’s risk assessment on to get him to the dentist?
Visits to the dentist

Through the support we were able to get Jack to the dentist.

Reasonable adjustments made were;

- Time in waiting room.
- Familiarity with environment and Dental staff.
- Regular meetings with dental team with awareness sessions of triggers and escalation in anxieties

Although Jack had several check ups we were unsuccessful in him having any treatment.
Reasonable Adjustments

Jack’s toothache got worse, again identified through a deterioration in his behaviour which had a significant impact on his mental health and wellbeing.

There was a chance due to Jack’s behaviour and deterioration in mental health a possible admission to an inpatient unit for intervention.

Jack urgently required treatment under general anaesthetic.
Increase support!

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Reasonable Adjustments & PBS

Meetings with the nursing and dental team were conducted.

A side room was made available with changes to the environment to make it safe for Jack.

All the reinforces identified during the assessment were placed in the room.

Familiar items such as his cup he likes to drink out of were placed in the room.
Risk Assessment Reviewed

What was needed?

Medication?

How to administer anaesthetic?
Day of the Surgery

Over the weekend Jack was prescribed a 3 day course of Lorazepam.

The staff who had supported Jack over the weeks were the ones identified to support him on the day of his treatment.

Risk assessments already conducted on transportation and alternative routes if required to return home.
Dental treatment success
Tees, Esk and Wear Valleys
NHS Foundation Trust

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Lessons learned

A better understanding by professionals of the complexities that Jack has.

This includes an understanding that Jack will be unable to access medical environments without causing him major anxieties.

Asking the question how can we support Jack without provoking anxieties that will cause a deterioration in him accessing the community. (home visits).

Understanding that reasonable adjustments to practice can prevent major incidents and anxieties for a person with complex needs.
Good practice

Multi disciplinary support from health professionals enabled Jack to gain treatment successfully.

Good communication and support for each area supporting Jack meant resources and information was shared appropriately.

Patience – 3 months preparation.
Tees, Esk and Wear Valleys
NHS Foundation Trust

STOMP
Pledge for Healthcare Providers
Stopping over-medication of people with a learning disability, autism or both

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The report into the Winterbourne View Care Home scandal highlighted serious concerns about the reliance on psychotropic medication to control challenging behaviour. Department of Health: Transforming care: A national response to Winterbourne View Hospital. (Dec 2012).
Background

A Public Health England paper scoped the extent of this type of prescribing across GP surgeries and reported that 30,000-35,000 prescriptions per day are issued without a coded clinical indication. *Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England.*
Background

Public Health England highlighted high national levels of prescribing of psychotropic medication in people with learning disabilities compared to the rest of the population.

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.
Background

This highlighted that 30% of all adults with a learning disability or autism were prescribed one or more psychotropic medications in primary care, and 16.2% of adults with learning disabilities or autism received one or more that were not linked to a specified indication.
TEWV’s commitment to STOMP

Dr Neelakandan Murugesan (Durham and Darlington Adult Learning Disability, Clinical Director) signing TEWV NHS Foundation Trusts commitment to the STOMP Healthcare Pledge in April 2018
STOMP’s Pledge & Current Practice within TEWV:

We will ensure that medication, if needed, is started, reviewed and monitored in line with the relevant NICE guidelines.

We will ensure all staff within the organisation has an understanding of psychotropic medication including why it is being used and the likely side effects.

We will ensure people with a learning disability, autism or both, of any age are fully informed about their medication and are involved in decisions about their care.

We will work in partnership with people with a LD, autism or both, their families, care teams, healthcare professionals, commissioners and others to stop over medication.

We will actively explore alternatives to medication.

We will maintain accurate records about a person’s health, wellbeing and behaviour.

We will ensure all people are able to speak up if they have a concern that someone is receiving inappropriate medication.

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NICE & STOMP

NICE guidance states that the use of psychotropic medication should be the last resort for managing behaviour which challenges and should only be considered if:

- Psychology or other therapies do not help within an agreed timeframe
- Treatment for a mental or physical health condition has not improved the behaviour
- The risk of harm to the person or others is very severe
A Multi-Disciplinary approach to support the STOMP campaign

“We all need to make it a priority to reduce and stop the use of inappropriate drugs, reduce adverse side effects and potential drug interactions. This is vital to the persons safety and their quality of care”.

NHS England (2016)
Supporting people to speak up if they have a concern about their medication

The goal is to improve the quality of life of people with a learning disability, autism or both by reducing the potential harm of inappropriate psychotropic drugs.

This includes them being used wholly inappropriately, as a “chemical restraint” to control behaviours that challenge, or in place of other more appropriate treatment options.
STOMP making a difference!

Shane is a young man who lives within a residential setting. He was originally referred to the specialist health team from Tees, Esk, and Wear Valleys NHS Foundation Trust (TEWV) due to challenging behaviours that were affecting others.

The team completed a full functional assessment and positive behaviour support (PBS) plan was put in place. This team then liaised with Shane's medication using the principles of Stopping Over Medication People with a Learning Disability, Autism or both (STOMP). Despite any formal mental health diagnosis, Shane was being prescribed the antipsychotic drug Risperidone. He had been taking this from the age of 15 to manage his challenging behaviour.

The wider multi-disciplinary team agreed that Risperidone would be reviewed and gradually reduced over six months. Shane's behaviour (gathered on the identified behaviours that were observed as challenging to others) and these were monitored during this period. The team made regular visits to Shane and those who were supporting him.

Shane is no longer prescribed any medication. His quality of life has improved dramatically and everyone who is close to him has seen a notable difference in all aspects of his life, he is now looking forward to moving into a new supported living home, where he stopped using 'illicit drugs' and has been told 'very happy' and wants to tell the world about STOMP!
STOMP making a difference!

Mark is a 51 year old gentleman who is diagnosed with a Moderate Learning Disability. He lives within a supported living setting where he has lived for 5 years.

Mark was referred to the Specialist Health Team due to an increase in behaviours that others had deemed as “challenging”. There were also concerns of Mark’s mental health.

During the assessment period Mark it was noted that Mark was being administered Diazepam on a regular basis because of periods of “challenging behaviour”. This was concerning for both the Team and his carers at his home.

Further information collated during the assessment it was highlighted that in 2010 Mark had fallen and suffered a broken hip. Mark’s carers were unaware of this incident as the information had not been shared from Mark’s previous home.

Mark has difficulty with his expressive communication and it was questioned whether he had been communicating to others through his behaviour because he was in pain.

We liaised with Mark’s GP where he was prescribed regular pain relief to help Mark with pain he was potentially coming from his hip. Over a 12 week period since the PBS Plans were implemented and the pain relief commenced, Mark did not require any Diazepam to be administered.

The Positive Behaviour Support plans enabled staff that was supporting Mark to understand changes in his mood and appearance which would help indicate he was in pain or he was becoming anxious.
Potential difficulties and barriers to STOMP........

Awareness and Reductions – CAUTION! There may be an initial increase in behaviour as people become more alert.

Concerns and anxieties from family and carers.

Ensuring the correct support from the MDT is available before reductions can take place.

Lack of understanding and experience of alternative approaches such as PBS.
Any Questions

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PBS Video Link

https://youtu.be/1l4Il65WyW8