STOMP: Stopping Over-Medication of People With Learning Disabilities, Autism or both

BEST PRACTICE GUIDE
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CMG is a leading provider of care and support for people with learning disabilities
Foreword

Concerns about overmedication of people with a learning disability, autism or both were first identified as part of the enquiry into the events at Winterbourne View near Bristol. Following this enquiry a programme was established by Dr Keith Ridge the Chief Pharmaceutical Officer for NHS England to identify the extent of the problem of overmedication and the potential for improvement.

This research undertaken by Public Health England and others in 2015 identified that at any time, between 30,000 and 35,000 people with a learning disability are prescribed an antipsychotic, an antidepressant or both by their GP without having the conditions for which the drugs were designed to treat and have been shown to be effective (this is 1 in every 6 people known to their GP as having a learning disability). In addition to these drugs concerns were also raised about the overmedication with other psychotropic drugs such as mood stabilisers, benzodiazepine, sedatives and stimulants. This is clearly a human rights issue that can have a big impact on people’s quality of life as well as a health inequality.

Out of this research came the launch of the NHS England STOMP campaign – Stopping the overmedication of people with a learning disability, autism or both. The goals of STOMP are; to improve the quality of life of children, young people and adults with a learning disability, autism or both, who are prescribed psychotropic drugs; make sure people only receive these drugs for the right reasons and in the right amount; improve understanding of these drugs and when they should, or should not be used; improve understanding of non-drug treatments and support which may help and make sure that people work with their doctor, multi-disciplinary team and the people who support them in making any changes to treatment.

It is very easy for social care organisations to imagine that the prescribing and management of medication (particularly psychotropic drugs) is someone else’s responsibility. However the management of medication is everyone’s business and we are delighted that social care providers have been such enthusiastic supporters of the STOMP campaign. In particular we are indebted to Jill Parker and Rhidian Hughes from the Voluntary Organisations Disability Group (VODG) and Peter Kinsey (Chief Executive of CMG) for inspiring the development of this support material produced by CMG.

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STOMP: Stopping Over-Medication of People With Learning Disabilities, Autism or both

Introduction

I am very proud to share with you CMG and Alderwood’s STOMP Good Practice Guide. STOMP is a national campaign aimed at stopping over medication of people with learning disabilities, autism or both. I think it is shocking that so many people with a learning disability are prescribed medication for treating mental health problems when they have no such diagnosis.

In both CMG and Alderwood we support a number of people whose behaviour has been labelled as “challenging”. This includes people with a diagnosis of autism. We know that many people who are diagnosed with autism can experience heightened anxiety and sensory overload and may have difficulty expressing how they feel. All too often, people with these needs are admitted to hospitals, sometimes under a section of the Mental Health Act. This is in response to their behaviour which we should see as their way of communicating.

We have looked at the stories of people we support where we have managed to help them significantly reduce the amount of psychotropic medication that they receive (this is medication for the treatment of mental health conditions). This includes a number of people who have been discharged from hospitals into our services. Often they have left hospital on very large doses of medication. We have looked carefully at lessons we have learned from these experiences which we are able to share. We have identified a number of important themes and these form the basis of this Good Practice Guide.

I hope you find this Guide informative and useful and most importantly that it is shared widely in order to benefit as many people with learning disabilities as possible across the country.

I would like to thank all of the people we support, their families and staff who are featured in this report and also the people who have helped put this document together. Everyone whose image is featured in this guide has given their consent for its use.

Peter Kinsey,
Chief Executive, CMG

(Alderwood is a subsidiary of CMG)
Overview of STOMP

STOMP: Stopping Over-Medication of People With Learning Disabilities, Autism or both

The main responsibility of any prescriber is to utilise medications appropriately and effectively in order to improve the quality of life of the individuals in their care.

There is clear evidence that a disproportionate amount of people with intellectual disability in community settings are being prescribed antipsychotics and antidepressants.

A recent Public Health England document reports that 17% of people known to have an intellectual disability are being prescribed antipsychotics and 16.9% prescribed anti-depressants (Glover et al 2015).

The British National Formulary guidelines generally require a diagnosis of schizophrenia, mania or a significant depressive illness for these medications to be prescribed appropriately.

It is the case however that many people with an intellectual disability are prescribed these medications without such a diagnosis.

It is thought that 30,000 to 35,000 people with an intellectual disability in a community setting are prescribed these medications without the appropriate indications for their use (Glover et al 2015).

Some individuals in a community setting may present with significant challenging behaviours associated with an increased risk to both themselves and others. There is of course a need to reduce this risk and an apparent solution may be to utilise medication, in many cases antipsychotics, in order to achieve a rapid reduction in behaviours that challenge. This may then be followed by their long term use.

We should therefore have clear evidence to suggest that the use of medication in these circumstances is effective in reducing risk and improving quality of life.

The editorial article in the British Journal of Psychiatry by Glover et al (2014) raises doubts about the effectiveness of medication in these circumstances. The article puts forward evidence that the use of antipsychotic medication in the long term is inappropriate in the management of behaviour that challenges.

It further suggests that in cases where there is no underlying mental illness, the medication is used to treat “the symptom, not the cause.” Additionally, in some cases a reduction in medication is associated with an improvement in presentation.

There is therefore evidence to suggest that the use of such medication does not effectively deal with the underlying problems or significantly improve quality of life.

In addition to this, the long term administration of these medications can be associated with significant side effects and physical health problems.

Such problems may include Parkinson’s like side effects such as movement disorders (Del et al 2008). In addition these medications can be associated with obesity, severe cardiac problems, haematological problems and an increase in the risk of developing diabetes (De Hert et al 2011). This requires special consideration as there is evidence that people with learning disabilities have poorer health than their non-disabled peers (Emerson and Baines 2010).

Any clinician prescribing such medication should have clear evidence of its efficiency and appropriateness in the individual case. Prescribers should therefore weigh up the possible positive effects of a reduction in risk, anxiety and distress with the negative effects of physical health concerns and possible side effects.

Glover et al (2014) do explore the reasons behind the prescription of medication. Clinicians are asked to intervene in intense and high risk situations, typically to avoid hospital admission or placement breakdown. It is important however that management of an acute situation is not routinely followed up by the continued prescription of these medications.

In addition, there are now well developed techniques in the form of Positive Behavioural Support which has been shown to improve the lives of those with intellectual
disability showing challenging behaviours (LaVigna and Willis, 2005).

There is therefore an effective alternative to medication in addressing these issues.

This is substantiated in the NICE Guidelines on the management of people with behaviour that challenges (NICE Guidelines 2015).

The guidelines emphasise the need to consider medication only when psychological intervention is ineffective or the immediate risk is very severe. Medication should be offered in combination with psychological and other interventions. Also, any medication initiated should be monitored regularly and stopped if not associated with a clear improvement in quality of life.

On 1st June 2016 there was an agreement to address this situation. The Royal Colleges of Psychiatrists, GPs and Nursing as well as The Royal Pharmaceutical Society, the British Psychological Society and NHS England all signed a commitment to Stopping Over-Medication of People with Learning Disabilities (STOMP 2016). This has formalised the process and made it a priority for all people working with those with intellectual disability.

**The Psychiatric Interview**

Considering all of the above, the clinician needs to have a thorough understanding of the benefits and adverse effects of the medication in the individual case. There should also be rigorous scrutiny of the need for medication, the effects of other therapies and a clear clinical objective to utilise the minimum dosage of medication, if medication is indicated at all.

All psychiatric interviews should be person centred and providers may be required to support individuals with intellectual disability in order to ensure a clinically effective interview.

Often, the service user is able to provide all necessary information but in some circumstances providers supporting the service user in the interview will be required to supply information on the service user’s behalf.

The following points should be considered by providers when preparing for the Psychiatric appointment:

1. The provider and Psychiatrist should ensure that the individual’s family are aware of and invited to the appointment and are involved in the process from the outset unless this is against the wishes of the service user.

2. The provider should ensure that the support worker accompanying the service user knows them well, preferably for many years. This will enable the support worker to report any changes in the service user’s presentation to the Psychiatrist. The support worker should also have experience of working in the service user’s home and be aware of any changes in personal or social circumstances that may have an effect on the service user’s presentation. The support worker should also have knowledge of any additional physical health problems (for example constipation or urinary tract infection) which may affect the individual.

3. Relevant details of medication (i.e. the current MARS sheet) with clear timings of any medication changes must be brought to the appointment. This will include the frequency and reasons for the administration of any “as required” or PRN medication. Details of any other treatments and changes in care plans should also be brought to the interview.

4. The provider should supply the relevant recording charts and other behavioural record tools for scrutiny.
The essence of the interview will be an in-depth review of the use of medication, focusing on the impact of this on the individual's presentation and quality of life. It will also assess the effects of other therapies in order to gain a full picture of the service user's response to medication change. This should be with a view to achieving the minimum dosage of medication and stopping the medication where possible.

The outcome of the psychiatric appointment will then be fed back to the service user's GP to ensure there is a full understanding of the individual's presentation and needs. Any input from the GP should be clarified and agreed in the context of joint working. In addition, an agreement between the GP and Psychiatrist must be developed in order to ensure relevant physical health checks are completed.

**In summary**

STOMP has formalised the need to ensure that individuals with an intellectual disability are not on unnecessary medication. Reduction of medication in a safe and closely monitored way should therefore be a priority of clinicians in primary and specialist care.

There are cases where medication is beneficial and necessary, but prescribers should have clear evidence to show this is the case and medication should routinely be utilised in conjunction with other therapies.

With the development of Positive Behavioural Support we are now moving away from medication as the primary management of behaviour that challenges. STOMP has prioritised this process.

*Dr Craig Forbes is an NHS Consultant Psychiatrist working in The East Hampshire Community Learning Disability Team and is not employed by CMG.*
Committed staff really getting to know the person they support

Linda Fish, Operations Director, Alderwood

We have found that in supporting people with very complex behaviours, it is essential to have highly committed staff who spend time really getting to know and understand the person they support.

Alderwood LLA provides care and education for some of the most challenged people in the country. Everybody who resides at Alderwood has a diagnosis of autism spectrum disorder and behaviour which challenges. Many of our service users have other conditions such as ADHD, Tourettes Syndrome, Bi-polar and more. Over the years we have become recognised as a company who leads the way in this very specialised field. In recent times much of our work has been centred round bringing people out of secure hospitals and back into local communities. In order to do this we need highly skilled staff teams who are committed and determined to support others to have better quality lives.

Everybody working for Alderwood LLA, including company directors, has worked, and still work, hands on with people we support. We ‘hand’ train our staff to this day, as we recognise the need to empower, invest, and put the time and effort into each employee. We have built teams that we are very proud of and we have encouraged them to be very proud of what they achieve in the work place. We are very aware that this work is not for everybody and with each recruitment drive there will be a number who will quickly realise it isn’t for them, but we are very pleased that we have a large number of staff who have been with us since the early days and are as enthusiastic now as they were in the beginning.

New staff members will learn about each person they support. New employees will learn about the service user’s past and how they have got to where they are now. We give them as much information as we can in order for them to understand what makes the service user ‘tick’. They will learn about likes, dislikes, what different behaviours mean, possible triggers to behaviour and so on. They have a senior mentor who checks in with them regularly throughout their first six months and a ‘buddy’ who will train them how to care and support for each of the people residing within the home. This is very much about the service users and how they cope with accepting new faces in their environment as well as new staff members building the necessary confidence. In some cases, this can take a very long time to achieve for both employee and service user. We have some service users and staff members who will never be able to tolerate one another. Our service users can be completely non-tolerant of some people for reasons that are not immediately apparent to others: different smells, voice tones, movement, clothing, colours and all manners of other things may be involved.

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New staff members will learn about each person they support

Highly skilled members of staff do not just walk through our doors. It is sometimes the most unlikely candidates who make the best support staff for our service users. We have people in our care, who, in previous placements, have been supported with 3:1 and 4:1 male staffing only and are now supported by a 5ft tall slightly built female lead worker and one other support staff. It is about who ‘gets it’, who can see the autism beyond the behaviour, who feels passionate enough to stick around and find out how to help the person, who believes that there are much more holistic ways of supporting a person than restraint and medication.
Between the years of 2009 and 2015 we had visited and assessed X at various secure locations across the country. Following each assessment we offered the placing authority a service for X with us, which was continuously turned down due the fact that some people felt that he needed to be detained in a secure environment. X eventually came into Alderwood’s care in October 2015. He is a tall, well built 33 year old man who can be very loud and excitable and can appear intimidating and aggressive to others. X is actually vulnerable in many ways and totally misunderstood. For the majority of his adulthood, X, has survived in various institutions and has been prescribed medication for many different conditions.

For the first time, X is being supported by a specialist autism provider who is delivering the tools he needs to make the world he inhabits a less confusing, less frightening and an easier place to be.

X’s autism affects him profoundly and often causes him to behave in a manner that many people find extremely challenging. Over the years, ever increasing medication has been prescribed to X to deal with these behaviours. As a result, by the time he reached Alderwood, he spent much of his day in a comatose state, due to the sedating side effects of these drugs.

This is some of the cocktail of medication X was prescribed at the time of him coming into our care:

- Quetiapine 125mg twice daily
- Carbamazapine 600mg
- Carbamazapine 400 mg
- Olanzapine 10mg twice daily
- Diazepam 10mg twice daily
- Lanoprazole 30mg
- Methylphenidate XL 90 mg
- Depakote 750mg twice daily
- Loratadine 10mg

- Nitrofurantion 100mg (when not on other antibiotics) PRN
- Peptic liquid 10mls
- Laxido 1 to 2 sachets
- Diazepam 20mg for agitation
- Paracetamol 1 gram
- Ibuprofen 200 mg

It was of vital importance that we filled X’s day with meaningful activity that was risk-assessed and of interest to him. The focus of this activity was to promote his knowledge, understanding, recognition, self-empowerment and independence. He needed a portable pictorial schedule/work system which we taught him how to use. His individual programme would need to tackle the three impairments that made life so difficult for him: communication, social interaction and rigidity of thought.

In order to achieve this, every member of staff chosen to work in X’s transition team completed an intensive training programme which included how ASD affected him, how we would implement a visual communication system, how the principals of PROACT SCIP®, would be instigated and how we would monitor, assess and manage the effects of sensory overload.

Paperwork and information provided by those who have been involved in X’s care for many years advised us that X has been, and still is, prone to severe urine infections and bladder and bowel problems which can cause him significant discomfort and have plagued him since teenage years. An antibiotic is prescribed and administered daily to combat the recurrent infections. Prior to X coming into our care, a core team of Alderwood staff had been trained to perform abdominal massage which X needs regularly. Since October 2015, X has still experienced infections but there has been a significant decrease in incontinence issues and personal hygiene. X has in recent weeks undergone a general anaesthetic in order for medical staff to have a good
look to determine what, if anything, is actually wrong. We are awaiting the results.

Since X came into Alderwood in October 2015, we and our health colleagues have worked together in reducing X’s medication and, in some cases, eliminating some of these drugs. We support our service users to be able to have the necessary blood tests, scans etc which are required to monitor what is happening to their organs. Reducing and eliminating anti psychotic medication must be managed well and it takes all parties concerned in the person’s welfare to work in partnership to monitor closely the effects of withdrawing medication. As medication decreases, the amount of structure and activity increases. Enhanced visual aids, reward systems and transition tools start to become the person’s medicine. You start to see somebody very different emerging. In X’s case a much more active person, a comedian and somebody who has started to feel admiration and respect. X is more motivated and far more engaging. His zest for life has returned and he wants to try new experiences. He is interested in fashion, cars and football. He is back in touch with his mum, sister and his brothers, who he did not see for years.

So far in X’s journey, all PRN medications have been stopped except for Paracetomol. The prescribed doses of Quietapine and Diazapam were carefully reduced via a planned pathway. X’s medication remains under review which will continue to be the case. There is still some way to go for X but his future is looking much brighter and with every day that passes he is making up for all that he missed throughout the years of being in inappropriate environments and over medicated.

Key messages:
- It is essential to have highly committed staff who spend time really getting to know and understand the person they support.
- Service providers need to empower, invest and put time and effort into supporting each employee.
- New employees should learn about the service user’s past and how they have got to where they are now.
- New employees should learn about a person’s likes, dislikes, what different behaviours mean and possible triggers for behaviour.
- It is good practice to have a senior mentor who checks in with new staff regularly throughout their first 6 months.
The critical importance of a well planned transition

Linda Fish, Operations Director, Alderwood

Increasingly, we are seeing people with very complex needs being discharged from hospital back into community settings under the ‘Transforming Care’ programme. These people are often prescribed high levels of medication. In order for them to transition successfully and for there to be a gradual reduction in medication, it is essential that each person has a tailor made transition plan that helps them adjust from being in hospital to a community setting.

At age 15, F spent 22 months in a private hospital even though her family lived 70 miles away. On admission to hospital F was repeatedly restrained on a daily basis, intra muscular medication was administered and she was placed in seclusion for extended periods of time. These experiences were completely new to her and she found them intensely traumatic resulting in a catastrophic deterioration in her mental state.

At the request of F’s family, NHS England and the local authority, Alderwood LLA carried out an assessment of F’s needs in March 2014. What we found was a very ‘broken’ girl. She looked very frail, gaunt and appeared unresponsive. She was completely naked. Her hands bore nasty red scars where she had been biting. When she finally acknowledged our presence, she spoke in a whisper, “What are your names?”.

For 4 months Alderwood worked free of charge to ensure F had a smooth and thorough transition from the hospital into The Chestnuts (which was our residential school at that time). The transition had to be a success. A lot of thought and planning went into the detail of how we would support F and we needed everybody involved to understand how this would work.

Here are extracts from F's transition.

**Week 1 – Transition task 1 - Growing up, moving on**

Task 1 was a story task whereby F was supported to recognise pictures of herself as a baby, toddler, young girl, adolescent, to the young woman she is today.

Alderwood staff showed her photographs of the family home, past schools and other places F had lived in or visited and encouraged F to use the pictures to prompt her into thinking about what age/stage of her life she was at when she frequented these places. She was also encouraged to interact with the pictures by sticking them into a story book.

The target for this task was to gain F’s understanding of how she grew up and moved on from homes and schools at different stages of her life. The book grew each week of the transition.

**Week 2 – Transition task 2- Things I like to do**

Task 2 introduced lots of activity cards from the everyday things such as domestic duties, hygiene routines, reading and writing, mathematics and so on to trips out and about in the community. F was encouraged to think about each picture and where she would like to place it, either under the heading of LIKE or DISLIKE.

The target was for F to provide Alderwood with the information necessary to build a personalised care plan and timetable. F was involved every step of the way.
Week 3 – Transition task 3 – New local area

Task 3, a matching task, saw F using photographs of landmarks in and around the area where she was to move. She directly matched place names to the photographs on a match board.

F was encouraged to verbalise the words on each photo-card, for example: lake, shop, dentist, The Chestnuts etc. The target was to encourage F to ask questions, share experiences and familiarise herself with the local area as far as possible prior to her move.

Week 4 – Transition task 4 – New area map

Transition task 4 was a puzzle made up of pictures which when pieced together detailed the position of The Chestnuts on a map of the local area.

The target was for F to become familiar with the new local area and The Chestnuts environment.

Week 5 – Transition task 3- Chestnuts building

This puzzle task showed each room in The Chestnuts including F’s bedroom which was bare of bedding, cushions, clothes, etc.

The original plan had been to get F out into the local community by this stage but it did not happen due to the constraints of the hospital. F looked at pictures and chose bed linen, towels etc to go into what would be her room.

Week 6 & 7 – Transition task 6 & 7 – Match staff

Task 6 and 7 was a simple matching task but was completed on two separate boards. Six photo cues of Alderwood staff were matched as one set and six photo cues of people she would associate to the hospital. Staff faces for Alderwood included staff she has already met and some she was yet to meet.

The target was for F to become familiar with the staff from the new provision.

Transition weeks 8 – 9 - 10 and 11

this focussed on staff from Alderwood becoming more confident in their role to the extent of being allocated as F’s staff within the confines of the hospital. This allowed F to really build trust and learn to rely upon their support. By this stage Alderwood staff were using TEACCH/Visual Structure throughout all time spent with F.

Transition week 12

this started with the new staff team covering all shifts at the hospital through to transporting F to her new home. Prior to leaving hospital, F completed all the transition tasks with each one that connected her to hospital being finished. Alderwood staff went through the story book which was started in week one of F’s transition and the choices she had made throughout the journey.

Both F and Alderwood had many obstacles to overcome throughout the transition period but F, who had barely seen daylight in 22 months, came into our care on the 1st September 2014.

Dr Santosh and his team from the Centre for Interventional Paediatric Psychopharmacology based at The Maudsley Hospital, South London, visited F in her new home. Dr Santosh carried out a full assessment of F and decreed that she presented with severe obsessive compulsive disorder in addition to moderate learning disability, autism and Tourette’s syndrome. He recommended that the intra muscular injection be stopped immediately but the same medication be given orally at the dose of 0.5 mg twice a day. He also recommended a reduction of Valproate and Chlorpromazine and set a plan in motion whereby, over several weeks, the medications would decrease and more appropriate medication introduced. The plan was shared with our local Consultant Child and Adolescent Psychiatrist, F’s new local GP and the consultant at the hospital as, at this stage, she was not fully discharged from their care. Alderwood kept very detailed monitoring of F’s progress which was shared with all parties on a weekly basis.

F, was making massive improvements under our care but could still be described as suffering huge anxiety symptoms at times but as her trust in us built she started to turn a corner. By February 2015, we were able to take her to The Maudsley Hospital in London to attend an appointment with her family and Dr Santosh. Everybody was amazed at the difference in her. This was also a land mark day for F because it was the first time in 5 years that she had travelled back into London (where her family live) and was actually able to spend time with them in a park where they had something to eat together. This was a great achievement for F and it was the first tiny step towards getting her back into her family home for visits.

Dr Santosh, remained involved in F’s case and she attended several more reviews at The Maudsley with him. Each time she visited him, both he and his team were astonished at the progress she was making. Visual communication, low arousal environments, a consistent approach and committed staff are as much a medication as anything else prescribed. F does still take some prescribed drugs and she may need to do so for time to come but, the traumatic days of restraint, intra muscular injections and PRN anti psychotics are left in her past and hopefully she will never have to experience that form of treatment again.

F is a beautiful, bright and happy young lady. Every day of her life since being with us she has questioned how long her hair is. In distress, she had pulled her hair out prior to coming to us and was mostly bald when we were transitioning her from the hospital. Her hair is now thick, shiny and half way down her back; the scars on her hands are healed but the memories of medication control and physical restraint remain with her.

Key message

- It is essential that each person has a tailor made transition plan that helps them adjust from being in a hospital to a community setting.
The importance of a healthy lifestyle

Michael Fullerton, Clinical and Quality Director, CMG

As we will appreciate for ourselves, our own decisions about lifestyle and behaviour can have a dramatic effect on how we feel and cope with life stresses. A poor diet, sleep disturbances, lack of exercise, being over or underweight, substance misuse etc can all have an impact on our levels of motivation, self image and social engagement.

The same is the case for people we support. There is a direct link to good mental and physical wellbeing and it is important to educate and encourage people to make positive decisions about lifestyle and personal health.

If people feel good about themselves, they are less likely to present with behaviours which challenge. There are obviously other factors at play with presentations of behaviours which challenge, however a key focus must be on “living well”.

**Nutrition and Hydration**

The two key elements for a healthy diet are

1. Eating the right amount of food for your activity levels

2. Eating a range of foods to consume a balanced diet

Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables. Carers generally have a poor knowledge about public health recommendations on dietary intake (The Health Equalities Framework, 2013).

Therefore, support providers must ensure supporting teams are provided with training and education relating to good nutrition and are able to proactively work with individuals to encourage a healthy eating pattern.

Equally, it is important that people are encouraged to consume adequate fluids each day. Adequate water intake supports medicines to work effectively, in addition to assisting in preventing a wide range of conditions e.g. pressure ulcers, urinary infections, heart disease, low blood pressure and diabetes.

It is important that support staff are aware of how much fluids an individual should drink in an average day; studies have tried to establish a recommended daily fluid intake (NHS Choices website), but it can vary depending on the individual and factors such as age, climate and physical activity.

A good rule is to drink enough fluid so that you’re not thirsty for long periods, and to steadily increase your fluid intake when exercising and during hot weather. Passing clear urine is a good sign that you’re well hydrated.

In social care settings it may be appropriate to closely monitor a person’s fluid intake, especially if the person is at risk of dehydration, is not able to initiate getting a
drinking for themselves and/or the person is at risk from the type of fluids they consume e.g. lots of high calorie/caffeine based drinks, high energy drinks or alcohol.

**Physical Exercise**

Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health’s minimum recommended level. People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity (The Health Equalities Framework, 2013).

Regular physical exercise will have a number of health benefits: it can help make you feel good about yourself, help to control weight, is good for health promotion and stimulates the production of endorphins – which make you feel happy and exhilarated. So exercise is not only good for you, but it makes you feel happy!

Encourage people to engage in physical exercise every day. The important thing is to encourage a person to engage in activities that are motivating for them, at a pace the person is comfortable with and that is likely to be sustained. If a person has any chronic health conditions such as heart disease, diabetes or obesity, support the person to have a consultation with their GP prior to any new exercise programme.

People may benefit from the generation of new ideas for activities they may engage with, perhaps with exposure to ‘taster’ sessions, and really importantly being supported by good role models. Therefore encouraging staff teams to be fit and healthy is equally important for support providers.

Physical exercise should be enjoyable, therefore focusing on what a person enjoys doing is essential. So for example, if a person enjoys gardening, this can be a key physical exercise activity as well as a job or hobby.

**Other Key Health Factors**

There are a range of other lifestyle factors that impact positively or adversely on a person’s wellbeing. This includes but is not restricted to quality of sleep, use of substances (e.g. alcohol, tobacco, drugs), sexual practices and any risky behaviours e.g. self-injurious behaviours, self neglect. It is important that a thorough assessment and review of a person’s lifestyle is included in compiling their Health Action Plan.

In developing a Health Action Plan with a person, a good health assessment must take place. Local Community Learning Disability Teams may prefer that you use the Health Assessment Tool they have developed. An excellent alternative would be to make use of the ‘Health Equalities Framework (HEF) – an outcomes framework based on the determinants of health inequalities’ (NDTI, 2013).
D lives in a residential service in South London and is 44 years of age. He has a mild learning disability and moved to the home from a hospital setting, following an admission for a presentation of verbal and physical aggression directed at others. D has always been a keen sportsman and eager to be involved in a wide range of activities such as the gym, football and bike riding.

After several changes of staff at the service and with new management in place, it was noted that D’s activity levels had started to reduce and he was regularly found sleeping on the sofa, declining most activities and increasing his smoking. When interacting with D he appeared to be very delayed in his response and physical movement. It was felt that this inactivity may be linked with increasing his psychotropic medication due to a number of incidents of physical aggression.

The service contacted the local Mental Health and Learning Disability team to arrange a medication review with his Consultant Psychiatrist.

At the time of this appointment, D was prescribed the following medication:

- Chlorpromazine 150mg in the morning & 200mg at night
- Quetiapine 300mg at night
- Carbamazepine 400mg at night
- Procyclidine 5mg at night
- PRN – Chlorpromazine 50mg

After discussion with D, the Psychiatrist reduced D’s night time Chlorpromazine by 50mg to reduce the sedative side effect D had been experiencing. The Psychiatrist asked staff to observe any increases in negative emotions for D. Staff also made a referral to CMG’s Positive Behaviour Support Team (PBS) so that a PBS plan could be put in place for D.

At the time of his follow up appointment, D’s motivation levels had improved a little but he was still falling asleep during the day. Lifestyle measures and diet improvements were also discussed at the appointment to help improve his mood and energy levels. The Psychiatrist also reduced D’s morning Chlorpromazine by a further 50mg to further improve daytime drowsiness.

Staff made a referral to a dietician via D’s GP and D and his Keyworker agreed a comprehensive Healthy Lifestyles Plan which included attending the gym, eating healthier food choices, reducing his smoking and alcohol intake and drinking less bottles of fizzy drink. During this time, D was socialising quite a lot at a local pub with a friend, and it is known that alcohol can reduce the effectiveness of medication. Staff kept records of D’s progress in all areas so they could pass this information back to the Psychiatrist.

With continued progress, D returned to the Psychiatrist and his Chlorpromazine was reduced by a further 50mg. D continued to make progress with his lifestyle choices and was noticeably more alert. He had cut down on his visits to the pub and subsequent alcohol intake and had stopped smoking. Blood tests showed abnormal fasting plasma glucose and D was referred to the Dietician for further investigation. As a result staff once again discussed the importance of diet with D, the difficulties and complications of diabetes and in particular reducing his sugar intake by drinking less fizzy drinks. The Psychiatrist offered extra support from the Community Learning Disability Team.

The team worked alongside D to complete a Health Equality Framework assessment. With this compiled, a multi-disciplinary team (including the PBS Practitioner), agreed a new Health Action Plan to work alongside D’s PBS Plan.
D continued to increase his motivation and energy levels and joined a local football team where he plays regularly as a goalkeeper. He has also taken on a role with the local football stadium as a steward during matches. D continues to feel more alert. He is diagnosed with Type 2 Diabetes which he is controlling well.

He is no longer prescribed Chlorpromazine, including as a ‘PRN’ medicine, and his Procyclidine has been discontinued. Staff are working with the multi-disciplinary team to reduce the Quetiapine now, as D has progressed so positively and feels so much healthier and alert.

Key messages:

• It is important to educate and encourage people to make positive decisions about lifestyle and personal health.

• If people feel good about themselves, they are less likely to present with behaviours which challenge.

• Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet.

• Support providers must ensure that staff teams are provided with training about good nutrition and are able to proactively work with individuals to encourage a healthy eating pattern.

• It is important that people are encouraged to consume adequate fluids each day.

• Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health’s minimum recommended level.

• It is important to encourage a person to engage in activities that are motivating for them at a pace the person is comfortable with and that is likely to be sustained.

• In developing a health action plan with a person, a good health assessment must take place.
The role of positive behaviour support in really understanding an individual

Lynsey Way, MSc Psychologist/PBS Team Manager, CMG

Positive Behaviour Support (PBS) is defined as ‘A multi-component framework for developing an understanding of behaviour that challenges’ (Gore et al 2013). PBS is now recommended as best practice by the Royal College of Psychiatrists, The Royal College of Speech and Language Therapists and The British Psychological Society. It is also recommended by the Department of Health, NHS England and Skills for Care, and also by the All Wales Challenging Behaviour Community of Practice. Essentially the goals of PBS are to enhance a person’s quality of life and reduce behaviour that may be considered challenging. A PBS approach involves producing a comprehensive and detailed assessment of a person’s needs, skills and behaviours and then designing strategies, reviewing and adjusting support styles and environments to increase competence and quality of life of the individual, thereby reducing challenging behaviours. Collaboration is an essential part of a PBS process. Successful implementation depends on the PBS professional working in partnership with the individual, families, staff and other stakeholders in gathering information and designing strategies.

People with learning disabilities may present with challenging behaviours due to several factors: difficulties with social skills, communication skills, problem solving, self occupying, learning new skills and low impulse control may have a role in the development of negative social interactions and behaviours of concern. It is estimated that 12-17% of people with learning disabilities display some challenging behaviours (Marshall 2014). Strategies implemented in a PBS process may include teaching new skills, developing communication resources, finding new opportunities for and promoting meaningful activities, improving physical wellbeing, increasing structured choices, implementing changes in physical environments or increasing social networks.

PBS is likely to include training for people supporting an individual and will also focus on practice leadership to develop staff understanding and working practices in social care settings. A PBS framework is not a static cure however, it must be continued and developed over time. If the support and strategies required for positive behaviour to occur are not supported consistently, or if the person’s needs change, the behaviours of concern may return or increase. Whilst this may make PBS sound costly, research shows that overall PBS costs less and has greater positive outcomes than other models of behaviour management (Hassiotis et al 2009).

The use of anti-psychotic medication for people with learning disabilities who display behaviours that
The goals of PBS are to enhance a person’s quality of life and reduce behaviour that may be considered challenging.

Successful implementation of a PBS framework for service providers of residential care and supported living for people with learning disabilities and behaviours that challenge requires a whole organisation approach. The complex needs of individuals being supported requires skilled and competent staff who understand the individual and their behaviour, adequate and appropriate resources and buildings that are an appropriate fit for the person.

The process of PBS involves the gathering and analysis of data about the person; this may include data obtained through interviews with people that know the person well, direct observations of the person, and analysis of behavioural charts. This data is then used to inform PBS planning and strategy design. However it can also be used to provide detailed evidence which may inform the decision making of multi-disciplinary professionals in reducing medication and preventing hospital admissions.
It was late Spring when A was referred to the CMG PBS team. She was a lady in her late forties who had a long-term history of challenging behaviours and whose staff team had been finding it increasingly difficult to support her. She had a diagnosis of moderate learning disability, autism and epilepsy and had experienced some very difficult and traumatic events in her past. She had also spent long periods of time in hospital and was currently receiving 5 anti-psychotic medications, 2 further anti-convulsant medication, and 3 medications that managed high blood pressure, osteoporosis and hypothyroidism. At times A was having to take 17 tablets at a time. She found this very difficult because she had no teeth and it was often a time when she was likely to become anxious. She was also administered 69 doses of Lorazepam as and when needed in the month of the referral. A was expressing several behaviours of concern at the time of referral: physical aggression, screaming, self harming, property damage, refusing to wash, eat or go out of the service and urinating/defecating in her bedroom.

The assessment took around 6 weeks to complete and involved interviewing staff who knew A well, meeting her family and discussing her history with them, doing several hours of observation, spending time with A completing some simple tasks, and analysing the behaviour charts in the service for the previous 12 months. The challenging behaviours did not detract from the fun and enjoyable character A is; she has a wonderful sense of humour, tells some outrageous stories and is fascinated with things that sparkle. The staff whilst clearly worn out were dedicated to offering A support and would go the extra mile to try and alleviate her distress and understand her behaviour.

The results of the assessment identified the following factors involved in A’s behaviour:

- Her physical health was not good, she had frequent skin infections, difficulties with digestion and bladder infections. This resulted in the use of antibiotics, creams and other temporary medicines. The impact of her refusal to wash and incontinence compounded the health issues. It had become a negative cycle.
- She was reacting in a distressed way to the noise and demands produced by other tenants.
- She was reacting in a distressed way to being prompted to have personal care or any sort of demands on her time. Staff were so motivated to help her that they would repeatedly prompt and become stressed when she would refuse. The more they prompted the more distressed A was becoming.
- She was not communicating as effectively when distressed as she was able to when calm.

The staff team attended training on total communication, active support and person centred planning. The PBS plan was written by the staff team and the PBS practitioner in collaboration. Finally, PBS training was delivered to staff focusing on A and her needs. The plan included taking a low demand approach, altering her accommodation to reduce the noise and impact of other tenants and teaching A to use some visual communication and to be able to tell staff when she was ready for support. In addition, a full health review was conducted and some changes to the way personal care was delivered were introduced. The staff team were also asked to record A’s mood on a 5-point scale, where a 5 was extremely distressed and challenging behaviour occurred and a 1 was very calm, engaged and happy.
Six months later and the total Lorazepam dosages administered for the month had reduced by 97%. In the first month A’s mood was scored as a 5 over 40% of the time. In the fourth month that was down to under 13% of the time, and by the 10th month it was down to under 1%. A also increased the number of baths and showers she had and her access to the community and her health improved slowly but significantly. Due to the data collected, the health team were able to start considering reviewing and changing her long term medications. By the end of the year, A had reduced to one anti-psychotic medication and one anti-convulsant medication. Longer term changes to the building she lives in are planned to enable her to continue growing her confidence and independence in a quiet and structured environment, whilst being able to access social events and activities on her own terms.

Key messages:

- Strategies implemented in a PBS process may include teaching new skills, developing communication resources and promoting meaningful activities.
- Practice leadership is essential to develop staff understanding and effective engagement with service users.
- Understanding why behaviours occur and teaching functionally equivalent skills will prevent the behaviour from occurring longer term.
- Successful implementation of a PBS framework requires a whole organisation approach.
- Understanding a person’s behaviour may require a functional assessment.
Effective monitoring is the key to reducing medication

Michael Fullerton, Clinical and Quality Director, CMG

It is essential, in line with STOMP and the psychotropic drug prescribing practice guidelines (Faculty of Psychiatry of Intellectual Disability, 2016) that all prescriptions of psychotropic medication must be reviewed and evaluated on an ongoing basis. This is preferably every 3 months or less, at a minimum 6 monthly or indeed upon request from the person, their carers/family or other professionals and always in line with NICE quality standards.

Service providers should have systems in place to check the prescription of regular and “as required” psychotropic medicines for people being supported. The systems should include monitoring of the effectiveness of medication reviews and to ensure that the prescription of such medicines is overseen by secondary care, or if overseen by a GP, that the GP has a special interest or expertise in this area. Equally regulators and commissioners should ensure a focus on this area when quality checking.

Service managers should be aware of the psychotropic drug prescribing practice guidelines (Faculty of Psychiatry of Intellectual Disability, 2016) and should advocate as necessary for the person being supported, if it is felt that the person is not being provided with effective review and evaluation of the prescribed medicines.

Within these guidelines, prescribers have access to a ‘self-assessment framework’ which allows the prescriber to audit their own prescription of psychotropic medicines including the rationale for the prescription, consent to treatment procedures, the frequency and effectiveness of monitoring and whether a review of the need or discontinuation has taken place.

To assess and review the rationale and ongoing need for a prescription, a service provider must ensure effective and consistent information is compiled for medication reviews to allow the prescriber to assess and make judgements about the appropriateness of the prescription. The service manager is instrumental to ensuring effective coordination of reliable information to be shared at any medication review. The manager must prepare for the review well in advance, ensuring the support team are recording related observations about the person prescribed the medicine i.e. presentation of any behaviours of concern, evidence of concerns about lifestyle/psychological/physical wellbeing e.g. sleep disturbances, lack of motivation, concerning eating habits, weight gain/loss/fluctuations, excessive fluid consumption, complaints of regular headaches etc etc. The service must ensure effective systems are in place for support teams to record relevant day to day information which is then analysed by the manager to establish trends, progress and concerns over time.

Critically, when ‘as required’ psychotropic medicines are prescribed, the service manager must ensure an effective system (in conjunction with the pharmacist) to record the administration and result, every time the ‘as required’ medicine is offered and consumed by the person.

Trends in relation to moods and/or behaviours of concern may be monitored and analysed by a
Service managers should be aware of the psychotropic drug prescribing practice guidelines

behavioural or mental health practitioner e.g. PBS practitioner. Should this be the case, the practitioner should also be providing updates and reports based on their analysis to the prescribing doctor to ensure effective information sharing and partnership working. The practitioner and/or manager must also outline to the prescriber what current behavioural and/or psychological interventions are in place with an update of progress and difficulties experienced with these interventions.

When decisions are made that a prescription of psychotropic medicine is not appropriate or justified, a clear and safe plan for reduction and discontinuation should be made with the person, their family, support team and other relevant health and social care professionals. A multi-disciplinary meeting is useful to ensure excellent communication between all parties, and that each person understands their role in positively engaging with the person prior to and during any medication reduction as well as clarity of what structures will be in place to monitor the reduction/discontinuation.

Prescribers are actively encouraged to use structured tools when monitoring the prescription of psychotropic medicines including when medicines are being reduced/discontinued. The tools of choice need to be easy to use and could include:

- LUNSERS (Liverpool University Neuroleptic Side Effect Rating Scale) – used to record side-effects (www.reach4resource.co.uk/node/104).
- CGI (Clinical Global Impression Scale) – this is freely available online and can be administered quickly by a clinician who knows the person well.
- HoNOS (Health of the Nation Outcome Scale) – this monitors change over time (Royal College of Psychiatrists, 2016).

Service managers play a key role in monitoring the impact of medication reduction. Specific monitors can include:

- Daily diary notes: good quality observations in relation to the person’s mood, levels of motivation, engagement with others/activities, food and drink offered/consumed/declined, sleep patterns. The Manager should have a system of monitoring the quality of written content, coaching support staff to maintain high standards of recording and also ensuring the service is able to escalate concerns quickly.
- Mood charts: such charts, completed daily can assist in monitoring the person’s emotional coping mechanisms on a day to day basis. The manager and allied health professionals can use these charts alongside daily diaries, Behavioural Charts and/or self help diaries to analyse possible reasons for specific moods/fluctuations.
- Behavioural charts: these should be completed upon the presentation of a specific behaviour of concern and used by the PBS practitioner or equivalent to analyse why a particular behaviour may be occurring. If the behavioural presentation coincides with a medication reduction/discontinuation plan, this does not necessarily mean the plan needs to stop. However, the support and other interventions may need to be reviewed.
- Sleep diary: in circumstances in which a person’s sleep may be affected by a medication reduction, a sleep diary will aid the tracking of any concerns and a sleep hygiene plan can be developed as appropriate.
- LUNSERS (Liverpool University Neuroleptic Side Effect Rating Scale): This is designed to indicate the extent of side-effects experienced by people medicated with neuroleptic medicines. It is designed as a self rating tool but also can administered by healthcare professionals. There is a licence cost if a non-publicly funded healthcare professional is using the tool.
- Self help reporting: the person being supported should have frequent opportunities to report on any changes they are experiencing with a medication reduction/discontinuation plan. This can be arranged through an accessible self reporting process, frequent interviews with the person via the manager or their keyworker or using a specific tool. A guided self help diary such as the SAINT (Self Assessment and INTervention, Eddie Chaplin et al, 2014) may prove beneficial to support the person to focus on day to day moods/thoughts and feelings and provide an ongoing means of monitoring these and how the person responds/copes.
R is 55 yrs of age. He currently lives in a supported living service, having previously spent many years living within hospital environments and a residential care home.

R, due to incidents of ‘behaviours which challenge’ e.g. physical and verbal aggression directed at others and personal self neglect, has been prescribed numerous psychotropic medicines over a number of years.

R was prescribed 10mg Olanzapine daily, along with 700mg Chlorpromazine and 70mg Clopixol. He was also prescribed 15mg Procyclidine to counter the side effects of the Olanzapine. These medicines were prescribed in the absence of a diagnosed mental health condition.

R had recently been experiencing mobility problems, resulting in several falls within his home and out in the community. Following an appointment with his GP, he was referred to physiotherapy and occupational therapy.

Following initial assessment from the occupational therapist and a community learning disability nurse, he was also referred to psychiatry to review his psychotropic medication as it was felt that the amount he was taking may be affecting his mobility.

The psychiatrist reduced his Olanzapine by 2.5mg per week until it was discontinued completely. This had an immediate effect on R’s mobility and cognitive ability, he was more alert and much less unsteady on his feet and was making decisions and choices that previously he would have needed a lot of support and motivating to do, using his initiative rather than waiting for a support staff to give him options.

R also had regular physiotherapy sessions and was given daily exercises which he completed routinely, and it was noted by the physiotherapist that his movement was improving.

Following a further review by his psychiatrist, she recommended also reducing his Chlorpromazine by an initial 100mg at night and also his Procyclidine by 2.5mg initially. This is being monitored and reduced slowly, and is still ongoing with extremely positive effects for R. There has been no adverse impact to date in terms of how R copes with everyday stresses.

When the plan to reduce the medication was made, the manager introduced a mood chart for staff each day to record how R was coping with his emotions, this was monitored and analysed at the end of each week by the manager, alongside daily diary entries to check what activities R was engaging in, if there were any variations in his diet and sleep patterns. Information relating to this analysis was sent by email to psychiatry and the involved PBS practitioner.

The manager spent a lot of time working closely with support staff to monitor interactions staff had with R, to ensure his PBS plan was being followed consistently and also to closely monitor at first-hand how R was coping with the medication changes.

R had agreed to complete a daily self help diary (SAINT), to record each evening how his day had been, any problems or stresses he experienced and how he coped with these. At the end of each week he sat with his keyworker to reflect back on his diary and how he managed stressful situations. This allowed R to reflect back on when he used his ‘best’ coping strategies. R was really chuffed about reflecting on his positive progress and the fact that he was having to take less tablets. Most evident in terms of monitoring R’s response to less medication was how sharper his mind was, how much more understandable his speech was and also that he was no longer experiencing the falls. R’s life has improved significantly since this process started, and it is not yet finished.
Key messages:

- All prescriptions of psychotropic medication must be reviewed and evaluated on an ongoing basis. This is preferably every 3 months or less, at a minimum 6 monthly.

- Service providers should have systems in place to monitor the prescription of regular and ‘as required’ psychotropic medicines for people being supported.

- Service managers should be aware of the psychotropic drug prescribing practice guidelines.

- The service provider must ensure that effective and consistent information is compiled for medication reviews.

- The service must ensure effective systems are in place for support teams to record relevant day to day information which is then analysed by the manager to establish trends, progress and concerns over time.

- The manager must ensure there is an effective system to record the administration and result every time “as required” medication is given.

- When decisions are made that a prescription of psychotropic medication is not appropriate or justified, a clear and safe plan for reduction and discontinuation should be made.

- Prescribers are actively encouraged to use structured tools when monitoring the prescription of psychotropic medicines.
The need for effective partnership working between support providers, families and clinicians

Michael Fullerton, Clinical and Quality Director, CMG

In our experience, it is essential that there is effective partnership working between social care providers whose staff support people with learning disabilities, families and the clinicians who provide guidance and treatment to meet the needs of those individuals. Key to this is mutual respect and good communication.

The inappropriate prescription of psychotropic medicines is a critical issue to focus on for both the population of people currently prescribed such medicines (in the absence of a mental health condition), and for future generations.

A significant number of people with learning disabilities can present with ‘behaviours which challenge’. Understanding the functions of the ‘challenging behaviour’ can often be complicated due to the person’s communication difficulties, potential physical health issues, a variety of environmental factors and potential presentation of mental health disorder (which can often present atypically in a person with a learning disability).

Psychiatry will typically take a lead in assessing and overseeing the clinical support of a person with a learning disability presenting with ‘behaviours which challenge’. This oversight may be in partnership with a behavioural specialist, psychology, speech and language therapy etc, depending on the needs of the person.

Detailed assessment and formulation will be required by all involved clinicians. Some service provider organisations have dedicated Positive Behaviour Support (PBS) or Applied Behaviour Analysis (ABA) practitioners who will take a lead on behavioural functional assessment, liaising with local clinicians, otherwise a clinician from the local community team should lead this input.

Should the prescription of psychotropic medication be considered, this should be by a prescriber ‘…who is competent in the care of people with intellectual disability’ and in line with ‘Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines’ (Faculty of Psychiatry of Intellectual Disability, 2016).

If there is a diagnosis of a mental health disorder, then treatment should follow relevant NICE guidelines for that condition. If no mental health disorder is present, then the prescription of psychotropic medication should be avoided, except for short term circumstances in which there is a serious risk of harm to the person and/or others, while other non-pharmacological plans are developed and implemented. In such instances, a drive to reduce and eliminate the psychotropic medicine must be a key focus.
A resilient partnership relies on everyone working together

The use of psychotropic medication, prescribed on an ‘as required’ basis is often misunderstood by support teams, typically as it is difficult to determine when it is appropriate to offer this. This can lead to ‘over or under’ use unless there is explicit direction from the prescribing doctor. If service providers do not feel they have sufficient guidance from the prescriber, they have a responsibility to voice and rectify that.

As with regularly prescribed psychotropic medication, there should be a commitment to remove ‘as required’ psychotropic medication for people who are not prescribed this to alleviate mental health symptoms.

It is essential that clinicians genuinely engage with and listen to the person, their families/advocates and service providers. The opinions and experiences of all stakeholders are important, and any interventions will only ever be successful if agreed and understood by all involved. Person centred approaches are essential, as is evidenced compliance with the Mental Capacity Act 2005 (where relevant).

Clinicians must focus on the skill and knowledge base of those individuals who will be tasked with following through with agreed interventions. So, if this is a staff team, an analysis of the training needs of each individual team member is essential.

PBS plans and other plans such as communication plans, intensive interaction plans and skill development plans, must be accessible and understandable to the supporting team. In addition, the team should be able to articulate the plan, follow the plan in a safe environment through role play and evidence following the plan in real life situations. There is little to be gained by a clinician providing inadequate or complicated information, support or training to a supporting team as the interventions will be unlikely to prove successful.

Time invested in effective sharing of knowledge and skill is important to the successful implementation of plans, as is ongoing monitoring of practice. Managers of support services take responsibility as practice leaders for ensuring plans are implemented and followed consistently. Periodic Service Review (PSR) is an effective and positive way of providing a visual, clearly defined quality assurance system.

Clinician/provider/family partnership and communication ensures effective monitoring of progress. A resilient partnership relies on everyone working together, with the person’s best interests central to all support strategies.

Embedding PBS requires a competent workforce, led by a skilled manager. The manager or practice leader will shape the vision and attitudes of the service and must ensure effective role modelling. The clinicians will rely on the manager to ensure that good quality monitoring and data collection is maintained. For example, behavioural charts/incident reports being recorded consistently upon presentation of a ‘behaviour of concern’ so that the clinician can complete ongoing and accurate analysis of the effectiveness or otherwise of the PBS and other plans.

Clinicians and behavioural practitioners should set up systems which allow for regular reporting via PSRs, ensuring transparency of ongoing monitoring and the ability to respond to early indicators of relapse or changes in the person’s behaviours. Early intervention in such circumstances may avoid the problem becoming a crisis.

Positive monitoring will also detect successes, for example increases in life or coping skills, reductions in ‘behaviours which challenge’ or restrictions in place. It is important as a network to acknowledge and celebrate successes which empower an individual and lead to enhanced self esteem and confidence.
Preparing for a psychiatric medication review

John is a manager of a supported living service. He is aware that T has an appointment this month with his consultant psychiatrist. John reminds T’s keyworker, Sarah, and asks that this is discussed with T in his keyworker meeting, in advance of the appointment.

Sarah meets with T 2 weeks before the appointment and discusses the appointment with him. To ensure T understands what to expect, what will be discussed and what he will need to think about, Sarah writes a social story with T to support him in understanding what will happen at the appointment. To assist this, they read through the notes from the last appointment and go through all the medicines that T is prescribed by the psychiatrist. They discuss if T feels the medicines are benefiting him or not, and if he thinks he is experiencing any of the side effects of the medicines.

John, in the meantime, contacts T’s PBS practitioner and they complete an analysis of all behavioural charts and incident reports related to T over the last 3 months. Alongside his sleep and mood charts, they ensure that all this information is compiled in time for the appointment. John ensures that he is available on the day of the appointment to accompany T to this. John asks T if he is agreeable for his parents to go to the appointment as well, which he is. John then supports T to invite his parents.

On the morning of the appointment, John uses the social story to discuss with T what will happen at the appointment and asks if he has any questions he wants to ask the psychiatrist. T has a couple of questions and John makes a note of these to ensure they are not forgotten.

John remembers to take T’s medication sheet, medication profile (which indicates the start date of any medication/medication changes etc), behaviour/sleep/mood analysis, T’s PBS plan and the notes of T’s questions.

The appointment is held with everyone stating their views. An agreement is reached to start reducing one of T’s psychotropic medicines with a view to eliminating this. John makes a note of the plans with clarity on what monitoring systems need to be in place when the medicine is being reduced.

On return to the house, John ensures all supporting staff are made aware of the agreements reached in the appointment and outlines the plans for reduction.
Key messages:

- Mutual respect and good communication is key to effective partnership working.

- If there is a diagnosis of a mental health disorder, then treatment should follow relevant NICE guidelines for that condition.

- There should be a commitment to remove ‘as required’ psychotropic medication for people who are not prescribed this to alleviate mental health symptoms.

- It is essential that clinicians genuinely engage with and listen to the person, their families/advocates and service providers.

- PBS and other plans must be accessible and understandable to the supporting team and the team should be able to clearly articulate the plan.

- Time invested in effective sharing of knowledge and skill is important to the successful implementation of plans.

- Periodic Service Review (PSR) is an effective and positive way of providing a visual, clearly defined quality assurance system.
Listening to families is essential

Paul’s story
Geoff and Lucy Mozdzer (parents)

Our son Paul was sectioned in early 2014 and was admitted to a local psychiatric hospital after suffering a severe mental breakdown and being totally unable to function on even a basic level of daily living. Whilst within their care, Paul was administered a cocktail of various anti-psychotic drugs in addition to an already high level of medication.

Whilst in the hospital we had numerous meetings with various doctors but no structured plan was put in place other than the increase of medication to keep Paul sedated in a non functioning state.

This only achieved further problems leading to Paul being unable to carry out the most basic daily tasks of eating and washing. This is an example of just how dysfunctional Paul had become in early 2014.

After discussions, it was agreed that Paul could not return to his original placement and that residential care with CMG would be more appropriate. We expressed our desperation at the high level of anxiety that Paul was presenting and the toxic cocktail of medication that was distancing our son even further from us.

Paul moved to CMG's Stubbington Lane service in May 2014 and after six months of exceptionally challenging behaviour, a glimmer of hope started to appear with the start of a reduction and rationalisation of administered medication and care and support given by staff.

With continual improvement in Paul's well-being and reduced levels of anxiety and behaviour, the home started to introduce small life changes to Paul. Small for us but huge steps forward for Paul eg. days out and weekends home. This we are convinced yet again is down to the reduction in medication and the continued support from staff that has allowed Paul to become a more confident young man who with expert care is now starting to experience and enjoy the life which he deserves.

Moving on into 2016, with small continued but positive progression in Paul's well-being and confidence, those small steps are at last now turning into large strides and we are now at a point where we truly feel we are getting our son back.

Paul has now progressed from a totally unacceptable high level of medication to a suitable level which allows him to lead and enjoy life to the full.

To the system Paul was just another patient with complex life-long problems which they seemed fit to address by administering a huge cocktail of drugs, but we his parents knew that underneath all of that was our son was KIND, CARING, LOVING and GENTLE.

So began a fight to get our son back. We fought long and hard and met with psychiatrists, psychologists, social workers and doctors trying to make them see our point of view and how this was not right. It was hard and emotionally draining but we knew we couldn't give up. We had to fight for our son. Paul couldn't do it, so we had to. Finally, after 4 years we have at last, with help, secured a placement for Paul with an exceptional team of professional like-minded people and Paul’s outstanding progress and the vast reduction in medication is testament to this.

The fight was worth it, we have our son back. He is happy and enjoying his life which is all we ever wanted for him. Without doubt the love we have for our son, our refusal to give up and our sheer determination not to accept what we knew deep down was wrong is the major factor in getting our son back.

Sadly, not everyone with these sort of problems has someone to fight their cause and stand up and say there are far better alternatives. DRUGS ARE NOT THE ANSWER!

Key message
- It is essential that we listen to families who know their loved one best. All too often, relatives can be labelled as difficult or overly anxious.
Matthew’s story
Robin and Isabelle Garnett (parents)

Our son Matthew has autism and several other neurological conditions including extreme generalized anxiety. He is severely affected by his autism and when he was 14, his behaviour became so unpredictable, desperate and challenging that he reached crisis point, resulting in him being sectioned.

Initially, Matthew was sectioned for 12 weeks, during which time we were told that he would be assessed, treated and receive autism-specific care. Tragically, this did not happen. Instead, Matthew spent the next six months without assessment, treatment or appropriate care in a psychiatric intensive care unit, miles away from home, before a bed became available in the unit that had accepted his referral on the day he was sectioned.

Matthew spent 15 months under section, during which time, his mental and physical health deteriorated further. Matthew refused to get up in the mornings, he lost an alarming amount of weight, pulled out his hair, and frequently ‘froze’, unable to speak or move. He was contained in a basement ward with little natural light, repeatedly restrained and secluded, with little meaningful activity structured into his day. We watched, powerless, as our son became progressively more paralysed by anxiety, frozen in fear. We were told the only way to reduce this anxiety was through medication. However, Matthew refused to take the anti-psychotic tablets that were given to him, and so he was routinely subjected a fortnightly trauma of being restrained by 5-6 adults and injected with drugs.

As the months dragged on, we had numerous meetings with various doctors but felt that our attempts to explain our son as a human being with strengths and significant needs fell on deaf ears. We knew our son to be loving, enthusiastic and keen to learn. Instead, we were told that our son was ‘callous’ and ‘belonged in a hospital, pure and simple’. We were told containment and medication should be the approach.

Yet Matthew deteriorated catastrophically, and we became more and more concerned about his safety and wellbeing. It got to the point that we feared for our son’s life. Terrifyingly, we felt marginalized and powerless to protect our son – even at the most basic level. Matthew thought he was in prison, and to us, it felt like he was being punished for being autistic. Rather than his behaviours being seen as communication of what he might not be coping with, or struggling to understand, Matthew was medicated and secluded. To us, it felt Matthew was being treated as a criminal, rather than a vulnerable young person severely affected by autism.

By some miracle (it truly felt that way), we obtained a second opinion from a Neuro-developmental and Mental Health Team with autism expertise and found out about Alderwood LLA. And thankfully, after months of fighting for our son, knocking on as many doors and researching as much as we could, Matthew at last left a secure Mental Health hospital and stepped into his new home in November 2016. From that moment on, Matthew’s life was turned around.

Thanks to the autism-specific, highly structured, person-centred and low arousal approach at Alderwood, Matthew is flourishing. The progress he is making is exceeding our wildest hopes for him. He is out in the community every day, participating in meaningful and motivating activities. He is supported to form constructive peer relationships. He is learning vital life skills such as how to wash himself, shop for the things he needs and cook food he likes. He has returned to a healthy weight, no longer pulls out his hair and is able to speak much more fluently. His anxiety levels have dramatically reduced and he is hardly freezing. Most importantly, he is no longer restrained, injected or contained. Indeed, he is off section and no longer prescribed anti-psychotic medication at all.

We now feel that Matthew’s needs are understood. Staff continually strive to make reasonable adjustments and to teach him the skills he needs to be able to adjust to the neuro-typical world. Staff have a deep understanding of Matthew’s individual profile of strengths and difficulties and, crucially, communication between Alderwood staff and us parents is excellent. We are considered very much part of the team.

The state recognises that hospitals are an inappropriate environment for people with autism and / or learning difficulties. For us, the progress Matthew is making at Alderwood is incontrovertible proof of this. And moreover, it is less costly.

Our last words are Matthew’s:

“I used to be in a bad place, I used to have injections... But now it’s better because I do lots of nice things here. There are some nice people here. And my favourite is football man! There are lots of people I like here. We do lots of nice things. We do football. And I like Liverpool.”

(Matthew and his mum and dad, Isabelle and Robin, recently appeared in Channel 4’s documentary: Under Lock and Key).
Fauzia’s story
Shanana Hussain (Aunt)

My niece, Fauzia, is 20 years old. She has a learning disability and autism and spent 22 months in an assessment and treatment unit (ATU). You may have seen her in Channel 4’s Dispatches documentary saying she is “never going back, never going back”. Since leaving the ATU she has come a long way from those dark painful days.

At discharge Fauzia was a traumatised 17-year-old girl who had spent 22 months in isolation in hospital where she had been subjected to experiences never endured before or since leaving. Experiences I defy anyone to endure and not be damaged by. Let alone if you are a vulnerable child with autism, learning disability, Tourette’s, ADHD and severe anxiety.

By the time she left on Monday 1st September 2014, the day she chose to “finally leave for good”, she had pulled her hair out, she was underweight, she had self-harm scars she inflicted on herself in pure distress on the backs of her hands. She had barely left her room let alone the hospital grounds in nearly two years.

During her admission Fauzia was prescribed high doses of antipsychotic medication as a monthly injection and daily tablet. In addition “PRN” medication had been used regularly as a chemical restraint during her 22 months as an inpatient. This was by injection or by tablets and commonly during physical restraint or threat of restraint and seclusion. Regularly during our family visits, Fauzia she was over sedated and struggled to remain awake.

What was striking was the lack of coherent behavioral interventions to manage Fauzia’s behaviours. What was shocking was the profound lack of understanding of Fauzia’s neurodevelopmental difficulties and resulting behaviours and emotional distress.

This ignorance led to misdiagnosis which meant they justified the administration of high doses of antipsychotics, restraint and seclusion. Once Fauzia was then persistently sedated and a ghost of her former self, this was given as evidence of the effectiveness of the medication.

Recalling that time is hard, difficult to remember; the sheer desperation and deep sense of panic watching her disintegrate in front of us. Fauzia never cried as a child, not really. She has a high pain threshold and a fierce energy for life. But she cried in this ATU. All she ever asked was when is she coming home. Her autistic speech and behaviours became more pronounced, her verbal interactions were very repetitive.

My training and job as a Consultant Child and Adolescent Psychiatrist did not help. It should have, but it did not.

What did help occurred one year into Fauzia’s admission as I was giving up hope that I would be able to do anything to change the situation for her.

I was put in touch (via the Tizard Centre) with Viv Cooper the CEO at the Challenging Behaviour Foundation (CBF) who along with charities like MENCAP have been supporting families and campaigning to get people like Fauzia out of these units and back into their community. Viv was the first person who really understood that this was a disaster. An utter nightmare, a failed system of care for people with a learning disability who through no fault of their own were being housed in institutions such as these and or are being overmedicated as a means of managing their behaviours that challenge.

It then took another year of the right people coming together, numerous meetings, letters, the minister of social care, NHS England London, various reviews, a dedicated Mental Health Act solicitor (the second one), the local Social Services submitting two safeguarding referrals, a tenacious independent reviewing officer (the third one), support from charities like CBF and last but most important an excellent community based care provider, Alderwood, who were able to offer a place to Fauzia.

When we first met the people from Alderwood, we thought it was too good to be true. Their staff weren’t fazed by the most challenging descriptions of Fauzia’s behaviours. Not intimidated by the huge secure institution Fauzia was an inpatient in and their bureaucracy. The Alderwood team worked tirelessly for four months to prepare for Fauzia’s transition out of ATU to the care of a team who really do understand Fauzia and hence care for her. The change in her was like moving from night to day.
Alderwood placed a safe structure of positive behaviour strategies around Fauzia based on an understanding and a constant review and assessment of her behaviours.

We were lucky; Fauzia was seen by a Dr Santosh on discharge, a real CAMHS neurodevelopmental expert who diagnosed Fauzia correctly with severe OCD, not psychosis. Fauzia came off all depot medication within month of discharge. She has never had PRN medication or restrained since and is currently on a low dose antipsychotic medication to treat her severe Tourette’s.

She is now out in the community daily; shopping, cooking, dancing, playing sports, visiting adventure parks, weekend visits with her family. Her days are full and structured; she is happy and developing into the young woman she was always meant to be.

There are over 3,000 people with a learning disability, autism and challenging behaviour stuck in in-patient settings across the country. These are places people should be sent to for a short period of “assessment and treatment” but are spending on average almost five years there where they are at heightened risk of abuse and neglect. Physical restraint, seclusion and overuse of anti-psychotic medication are all common practices.

Fauzia’s experience is not unique. There are so many families still battling to get their children and loved ones out of these institutions that can destroy people’s lives and that of their families.

How we care for people with a learning disability in this country needs to change. My niece has to try every single day to forget what happened to her. For many, this is still a reality with no end in sight.

(Fauzia and her family, recently appeared in Channel 4’s documentary: Under Lock and Key).
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