

Stopping Over-Medication of People with a Learning Disability, Autism or Both (STOMP)

a family carer perspective

December 2016



**making a difference
to the lives of people with
severe learning disabilities**

Contents

Introduction and background.....	2
Focus of this report.....	3
About the Challenging Behaviour Foundation.....	4
Methodology.....	4
Profile of family carers contributed to this report.....	5
Who is at risk of inappropriate medication?.....	5
Prescribing rationale.....	6
Decision making process.....	8
Impact of medication.....	10
Alternatives to medication.....	11
Information, resources and training family carers currently have access to when medication is suggested or prescribed for their relative.....	12
What must happen now?.....	14
Conclusion.....	18

Acknowledgements

This report is dedicated to the family carers who were prepared to share their story and the experiences of their relatives. It was impossible not to be moved when they spoke of how inappropriate medication had impacted so negatively on their relative's quality of life. The dedication of family carers who have often fought for years to try and affect change is humbling. They have told their stories countless times in the hope it will make a difference; that telling their stories would stop somebody else's family from having the same negative experience as them. For many family carers, their relative's life has remained unchanged since the announcement of the Call to Action in July 2015.

Thank you to Ben Briggs and Paula Smith from NHS England who supported the delivery of this project.

Foreword

by Anne Webster, Clinical Lead and Carl Shaw, Learning Disability Expert Adviser, NHS England

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, this is 1 in every 6 people known to their GP as having a learning disability. As well as these drugs, concerns were also raised about the overmedication with other psychotropics such as mood stabilisers, benzodiazepine, sedatives and stimulants. This is a human rights issue that has an impact on people's quality of life and that of their carers, as well as a health inequality.

Out of the research came the launch of the NHS England STOMP campaign, which stands for Stopping the Overmedication of People with a Learning Disability, Autism or both. The goals of STOMP are:

1. To improve the quality of life of children, young people and adults with a learning disability, autism or both, who are prescribed psychotropic drugs.
2. Make sure people only receive these drugs for the right reasons and in the right amount.
3. To improve understanding of these drugs and when they should or should not be used.
4. To improve understanding of non-drug treatments and the 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.
5. To empower people with learning disabilities, autism or both and their families with the right information and support.

We are pleased to see the outcome of the early stages of this piece of work being carried out by CBF as a core part of STOMP. This was commissioned in year one of the project and provides a baseline of families' experiences and serves to reinforce why this work is so important.

As an outcome of this early work by CBF and alongside other work streams now underway as part of STOMP including work with professional groups, prescribers and social care providers, an information pathway is being developed for families to support them and their loved ones where psychotropic medication is being considered or is already prescribed. This will be available online, to support families when they need it, by providing information and signposting. Further work on gathering families' experiences again to measure progress will take place in year three of the programme. We look forward to working together with CBF and others to see STOMP make a real difference for people with a learning disability, autism, or both, and their families.

Introduction and background

There is a well-publicised history highlighting the poor care and abuse (Silent Minority, 1981) of people with a learning disability and autism spectrum disorder (ASD), with those who are considered to have behaviour described as challenging and/or a mental health need at greater risk of being subjected to restrictive practices.

The most recent high profile scandal screened by BBC Panorama in 2011 exposed the shocking treatment of patients at Winterbourne View Hospital (Undercover Care: The Abuse Exposed, 2011).

The Serious Case Review following the Winterbourne View scandal found that many patients were prescribed antipsychotic and antidepressant medication with no diagnosis of a mental health need to support their use. This resulted in a specific recommendation to reduce the use of antipsychotic and antidepressant medication.

“Reducing the use of antipsychotic medication with adults with learning disabilities and autism requires attention. An outcome of the National Dementia Strategy (Department of Health, 2009) was an investment in reducing antipsychotic medication for patients with dementia. Adults with learning disabilities require no less.”

(Winterbourne View Hospital: A Serious Case Review, 2012, page 142)

The Department of Health Winterbourne View Concordat Programme of Action (2012, page 16) committed to explore the extent of the issue:

“We will explore with the Royal College of Psychiatrists and others whether there is a need to commission an audit of use of medication for this group. As the first stage of this the Department of Health will commission by Summer 2013 a wider review of the prescribing of antipsychotic and anti-depressant medicines for people with challenging behaviour to report.”

Further scrutiny of prescribing practices, evidenced the widespread inappropriate medication of people with learning disabilities and ASD.

Key findings of the **Care Quality Commission (CQC) Survey of medication for detained patients with a learning disability (2016)** reported that:

- For more than half of the prescriptions, the patient did not have a diagnosis of a disorder for which that drug was a recognised indication.
- 86% of patients were prescribed at least one antipsychotic drug to be given on a regular basis.
- 6% of patients were prescribed a high dose or a single type of antipsychotic medication to be given on a regular basis. 13% were prescribed a high dose by virtue of the additive effect of more than one type of antipsychotic medication.

A report by Public Health England (2015) *“estimated that on an average day in England, between 30-35,000 adults with a learning disability are being prescribed an antipsychotic, an antidepressant or both without appropriate clinical indications (psychosis or affective/anxiety disorder). A substantial proportion of people with a learning disability who are prescribed psychotropic drugs for behavioural purposes can safely have their drugs reduced or withdrawn”.*

In July 2015 NHS England announced a Call to Action followed by STOMP.

Focus of this report

The Challenging Behaviour Foundation (CBF) was responsible for ensuring that the Call to Action 2015 and STOMP engaged family carers of people with a learning disability and autism.

“Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. Even when people leave home, they do not leave the family. Families continue to offer a lifetime of involvement, support and advocacy.” (Valuing People Now, 2009)

and was asked to carry out a small piece of work to:

- Provide a voice for family carers to share their lived experience when medication is suggested or prescribed for their relative.
- Carry out an audit to identify what information, resources and training family carers currently have access to when medication is suggested or prescribed for their relative.

Whilst the emphasis of this report is about inappropriate or over medication, family carers cautioned against a narrow focus which may result in a reduction in the use of one restrictive practice but an increase in another restrictive practice.

“If somebody has been prescribed medication because they have behaviour described as challenging and the cause of the behaviour is because they don’t like the person they are living with, then withdrawing medication is not going to help. There is a real likelihood that there will then be a reliance on other restrictive interventions, such as physical restraint or seclusion. In two years’ time, there may very likely to a Call to Action regarding physical restraint.”

Family carers felt passionately that there needs to be a co-ordinated and sustained drive to improve the quality of care and support for their relative in all areas of their life and reducing inappropriate use of medication is an important part of this.

About the Challenging Behaviour Foundation

The CBF is the only UK charity focussed on the needs of people with a severe learning disability with behaviour described as challenging and those who support them. There are three strands to the CBF's work:

1. Information and support: Developing and sharing a range of accessible, practical information and resources to equip and empower families and professionals, to promote early intervention and prevention, support families whose relatives are at risk, and provide casework to families in complex situations.
2. Campaigning and influencing: Informed by family support work, this strategic work focuses on ensuring that children and adults with a severe learning disability and behaviour described as challenging and their families are included, engaged and represented in policy and practice at a national, local and individual level.
3. Promoting best practice: There is a range of evidence and practice that demonstrates how children, young people and adults with a severe learning disability and behaviour described as challenging can be supported to have a good quality of life within their local community. The CBF is committed to actively sharing and promoting evidence based best practice, including working with researchers and practitioners.

Methodology

Family carers were offered the opportunity to contribute in a range of ways:

- In depth telephone interviews
- On-line survey. Family carers were also offered the option to fill in a hard copy or supported to fill in the survey via a telephone interview with a CBF family support worker.
- CBF email network
- Focus group
- Social media

There were three key limitations to involving family carers:

1. Tight deadline, exacerbated by running the consultation period during the summer period when family carers had limited availability due to personal holidays, caring responsibilities (e.g. relative on school holiday, home from college).
2. Limited budget.
3. Initial reluctance from family carers to contribute because past experience has led them to believe that their views are not listened to and their feedback does not result in any change.

“I’ve told my story countless times. Why will it make a difference this time?”

Despite this over 100 family carers shared their views and experiences.

Profile of family carers who contributed to this report

Although the highest response was from parents, siblings spoke poignantly about assuming the role of advocate for their relative.

“Dad is dead and mum is frail so the responsibility is with my brother and me. I don’t know how they did it for over 50 years. I am already exhausted, anxious about the future, frustrated by the lack of progress, angry at not being included in decisions or listened to and still my brother is not having a good life.”

Family carers were fearful about their relative’s welfare should there come a time when there were no family members to campaign on their behalf. They were aware that in the absence of a family carer, few people with a learning disability had access to an independent, specialist (learning disability and ASD) advocate.

The remit for this project was the views and experience of family carers of relatives with a learning disability and ASD. Although the CBF recognises that inappropriate medication is also a concern for family carers of children and adults without a learning disability, their views and experience are not included in this report.

People with a learning disability and/or autism who expressed an interest in contributing their views and experience were referred to the charity CHANGE who carried out a parallel project for self-advocates.

Family carer representation included existing members of the CBF and those who have had no previous contact with CBF.

Who is at risk of inappropriate medication?

The most common profile of the relatives represented in this report is male with a severe learning disability, ASD diagnosis and behaviour described as challenging, but it includes experiences of family carers of males and females of all ages and levels of learning disability.

Inappropriate medication is not restricted to the learning disability and ASD population but for the families who took part in this work, prescribing for their relative starts earlier (age range 5 – 72 years old) and is for longer

“My brother, now 72 years old, lived in a hospital setting for 37 years and was prescribed Largactil throughout this whole period. Our family were not informed of the reason for the medication but my guess would be that it was to calm him. The staff had 40 residents to care for in each villa.”

and typically involves polypharmacy:

“He is on 300mg zuclopenthixol decanoate once a week administered by injection/ 50mg of levothyroxine am /PRN lorazepam 2mg twice daily - 4mg max - administered orally or by injection/10mg olanzapine am administered orally - max dose 40 mg.”

increasing the likelihood of significant health problems and decreasing overall quality of life as a result of side effects.

The introduction of medication was more likely from age 11 years old onwards, peaking between the ages of 16 – 25 years old.

Once medication had been introduced family carers felt their relative became embroiled in a never ending cycle of different, increased or additional medications.

“My son is currently, and has in the past, been prescribed a great many different medications. At present he’s on 7 different medications – including PRN. I’ve lost track of the total number of different types of different medications but it’s probably in the region of approx. 20 different drugs.”

Prescribing rationale

The main reasons identified by family carers for suggesting, prescribing or increasing medication for their relative were:

Behaviour described as challenging (93% of respondents), with physical aggression towards others reported as most prevalent. Despite this high rate, less than half of relatives had a positive behaviour support plan and little attention was given to identifying the cause for the behaviour described as challenging. Less than 20% had a functional analysis carried out or a baseline of behaviours recorded.

“It’s a quick fix in the absence of a functional assessment.”

Mental health need (32% of respondents) with anxiety the highest diagnosis. Family carers were aware of the risk of their relative developing a mental health need but felt that in the absence of preventative measures and a proper investigation into the potential cause of deterioration in mental health (biological, psychological, social, and environmental) medication was the “lazy option”.

“His dad died – they were close – just medication offered for his low mood – no counselling.”

“Where he lives makes him anxious – the behaviour of the people he lives with, the staff.”

Family carers felt that those supporting their relatives did not always account for their individuality and it was convenient to use mental health to explain their relative’s presentation:

“He has always been lively and energetic. He’s got a spark. It should be embraced not described as manic.”

“My brother is quiet, likes to spend time on his own. It doesn’t mean he is depressed.”

Threat of placement breakdown accounted for 22% of people in our survey being inappropriately medicated. Although unhappy with medication as a solution, family carers felt alternative options could be traumatic and contribute to an increase in behaviour described as challenging or impact negatively on their relative's mental health.

“The 28 day rule made our decision for us - we would not have agreed if time constraint hadn't been so tight. Once we moved her to a more appropriate placement we managed to wean her off and build appropriate strategies.”

“It was suggested that unless he was medicated the school could no longer provide for his needs.”

Sleep problem (30% of respondents), with family carers able to offer a potential reason.

“He needs to go for a walk daily, for his mental health, behaviour and sleep but it doesn't happen because of staffing.”

“They let him sleep until midday, then he can't sleep at night.”

Lack of access to local, specialist services before a trigger point.

“The local CAMHS service have been involved for 7 years. She has had five different consultants. Medication has not been reviewed at appropriate intervals. They don't know about her condition, ask me millions of questions and don't do anything practical. My area has no paediatric learning disability service.”

Family carers were able to predict trigger points when medication was more likely to be suggested, prescribed or increased:

- Crisis situation (a significant episode of behaviour described as challenging)
- Change in provision (change in status of care provider, for example from care home to supported living, reduced staffing)
- Any type of unplanned transition (starting school, move from children to adult services)
- Leaving the family home permanently
- Bereavement or loss (death of family member, change of familiar staff)
- Adolescence/puberty
- Admission to an inpatient service (assessment and treatment unit)

“Awful. 27 years at home he had no medication.” (Describing the introduction of medication.)

“He was over-medicated and ended up on several drugs - he came out worse than he went in.”

Decision making process

The professional most likely to suggest medication was a psychiatrist (65%), followed by either a psychologist or care provider (15%). In some instances the professional suggesting medication did not have a learning disability or ASD background.

“We got an urgent appointment with CAMHS via my amazing learning disability nurse. However the doctor who we saw (was lovely) but had no experience of learning disability and he openly admitted it would be hard for him to manage.”

Only 8% of requests for medication were made directly by a family carer.

For half of relatives prescribed medication the professional responsible did not know them very well or at all.

Whilst 76% of family carers said they were involved in discussions about medication for their relative this was not always meaningful and they did not agree with the final decision to prescribe.

“Loathed it. Last resort, but now I realise we should have taken him out of school aged 5 rather than medicate him. I'm angry and deeply upset. I cry in the night over it. He was only 5.”

“My views were ignored and I felt, and still feel, that everyone involved wants my relative to remain on Citalopram. My relative hasn't been seen by a GP for over two years yet remains on this drug. All have agreed however that my relative is not depressed.”

Remaining involved in discussions and decisions about their relative's care and support was a challenge, which increased if their relative no longer lived at home, or was in a placement far from home.

“I think it's much harder for the relatives of people who don't live with them to be involved in decisions about their care, particularly where the relative may live some distance away. This makes it much harder to be involved in initial decisions about medication but also to be involved in trying out alternative forms of help e.g. PBS. Where the relative lives away everything has to be done through someone e.g. the care home manager and much depends upon trusting that person to want to change.”

Frequently, family carers agreed to medication under pressure because they feared the consequences if they did not.

“Very unhappy but feel that there is no choice at the moment because I do not want my son to end up in a care home or hospital where he will not be looked after properly. He has already had a terrible experience in a psychiatric ward so I don't trust the staff to keep him safe.”

For 61%, prescribing took place without consideration of capacity and consent and in the absence of a best interests meeting. If relatives were living away from the family home, family carers were often only informed after the decision to medicate or guessed because of a change in their relative's presentation.

"I was very shocked when I found out. Our family realised that he was very lethargic in comparison to his 'normal' hyperactivity."

Some relatives were administered medication without their knowledge.

"Crushed and mixed up with maple syrup."

For one relative, refusing medication resulted in him being treated inhumanely.

"He has refused so they inject him under restraints. Three people hold my son so the doctor can inject him."

The most common medications prescribed from highest to lowest were:

- Risperidone
- Lorazepam
- Aripiprazole
- Citalopram
- Diazepam
- Fluoxetine

with polypharmacy common.

Medication was regularly prescribed before exploring other explanations for a change in behaviour or mental health.

"Lazy diagnosis. He was suffering from acid reflux."

Impact of medication

Few family carers said that medication had resulted in a positive outcome for their relative. Instead they gave emotive narratives about the way medication has been devastating and life changing for their relative because of the side effects experienced.

“High prolactin levels and sexual dysfunction, delayed puberty, extreme weight gain and off the scale anger and agitation.”

“Heart palpitations, muscle twitches, feeling anxious, wobbly, fuzzy head and massive weight increase.”

“Drooling, constipation, incontinence, obesity, tardive dyskinesia.”

“Diagnosed with osteopenia, risperidone affects prolactin levels which can affect calcium levels, recognised by GP that this is likely side effect.”

“Constant rapid eye blinking, agitation, restlessness, unable to keep still, dilated pupils, different person. Felt it was cruel giving him drugs that made behaviour worse including through the night and that he had no capacity to understand they were having such a drastic effect on his brain.”

“Zombie, walking in to walls, difficulty speaking.”

Despite this, a consistent approach to monitoring and reviewing medication was poor and in the absence of functional analysis, baseline measures and a clear rationale for the medication prescribed it was impossible to confirm that medication was reducing behaviour described as challenging or improving mental health.

“Went for years when he was a teenager without a review. Regularly reviewed in last 2 years.”

“Not since 2013 when psychiatrist put her on non-urgent list.”

94% of family carers were unaware of the Glasgow Antipsychotic Side Effects Scale and only 27% were asked to record side effects in another format. Family carers took responsibility for recording side effects and then had to try and get somebody to listen to them.

“I tell the doctors, social workers, no one cares. They take no notice.”

For some family carers expressing concern backfired and resulted in an increased dose, change, or an additional medication.

“Dosage was reviewed for the medication that caused extreme drowsiness. Medication was changed for the one causing extreme lactation.”

Witnessing distressing side effects was intolerable for some family carers and in the absence of any support from professionals they felt they had no other option but to withdraw medication independently.

“It took us a year. We withdrew it drop by drop. We saw him come alive. But I didn’t sleep at night, worried about whether I was doing the right thing and hoping nothing would go wrong.”

“I have now withdrawn all medication at a sensible rate. He has been off them for over a year and all side effects except the weight gain have gone. He is more coherent.”

Once introduced withdrawal of medication could be impossible.

“A vicious circle has taken place over many years, whereby medication has been prescribed to address the problems caused by medication. This has caused an accumulation of medication because all medication has some negative effects, so there's always the need to address them. This is the same for the medications which are prescribed to address 'side effects' as for the ones prescribed to address the so-called original condition. Over the years medication has been changed, added too, taken away. They increase doses in what can only be described as a brutal manner, and change from one medication to another too quickly. Safe reduction and withdrawal has to be done very slowly. When it's done too quickly the withdrawal effects are mistaken for a re-emergence of the so-called mental illness.”

Alternatives to medication

Family carers were often able to predict the reason for a change in behaviour and/or mental health need and identify an alternative to medication being introduced, changed or increased.

“Dental treatment required - 4 teeth removed and fillings.”

For 16% of relatives it was felt that because their relative was in crisis there was no time to introduce alternatives and half of relatives were just not offered any alternatives.

“Nothing else was offered even though I asked for alternatives other than medication.”

When alternatives were considered they were rarely consistently delivered or sustained.

“She (professional) suggested things but the staff didn't implement any of them, required extra work, e.g. pictures and cards to help explain staff leaving and new staff starting which he finds difficult to cope with.”

“We only got to the stage where the initial assessment was done, but no solution offered. I have lost count of how many times this has occurred over the years, or the amount of ABC charts and the likes I have completed.”

Less than half of relatives had proactive strategies in place, for example, using a person centred approach, having a positive behaviour support plan and a health action plan which included a regular/annual check-up by a GP and prompt access to medical treatment.

Information, resources and training family carers currently have access to when medication is suggested or prescribed for their relative

It is recognised that access to current and relevant information, resources and training is vital to family carers when medication is suggested or prescribed for their relative to support an informed decision..

Three key phases were identified when family carers are more likely to seek information, resources or training:

1. A proactive/early intervention approach:
 - when relatives are identified as having the potential to develop behaviour described as challenging and/or a mental health need
 - behaviour described as challenging and/or a mental health need is emerging.
2. At the point when medication is suggested for their relative.
3. Medication is already prescribed:
 - but is not resulting in any improvement
 - and is causing side effects
 - and a change in medication is suggested
 - and an increase in current medication or an additional medication is suggested.

An audit by the CBF, in partnership with family carers, identified a lack of local and national information, resources and training specifically for family carers about the use of medication for people with a learning disability and ASD.

Professionals who suggested or prescribed medication did not proactively signpost family carers to information, resources or training. Family carers reported that they were typically left to do independent research, for example about the potential side effects of a medication or rely on the generic leaflet which comes as standard with medication.

“I read the leaflet and researched myself. I don't think company carers particularly look out for these things.”

In addition to an audit, a review of information and resources, which were mostly aimed at professionals, was carried out by a family carer focus group. Feedback included:

- When the target audience is not family carers the use of medical terminology/jargon is a problem.
- Documents were lengthy and it was difficult to extract information relevant for a family carer.
- The reader needs to have English as their first language.
- A reading age above the national average is required.
- The questions family carers were likely to have (e.g. how to challenge a decision, how to request alternatives to medication) were not addressed.
- The availability of a hard copy was not always clear - how to obtain one and if there was an associated cost. The same applied for copies in a different language or alternative format.
- Many of the documents needed updating.
- It was not always easy to manipulate text on a tablet for family carers who require a different coloured background due to dyslexia, or a larger font due to a visual impairment.
- The key search words used by family carers during internet searches did not always result in a “hit”.

Family carers mentioned the following resources available from the CBF as valuable:

Family support. The opportunity to:

- Talk through a decision about medication and how they could be involved
- Discuss other interventions
- Discuss the causes of either behaviour described as challenging and/or mental health need and how to address
- Have help to decipher information and resources about medication when family carers were not the target audience
- Be signposted to further relevant information

Information sheets

- Written specifically for families and available electronically or as a hard copy free of charge
- Opportunity to read through and then discuss with family support if required

CBF Training

- Proactive approach to understanding behaviour described as challenging and supporting change including focus on reduction of restrictive practices and introduction of Positive Behaviour Support

DVDs

- Positive Behaviour Support
- Communication
- Available free of charge to family carers

Family carer email network

- Opportunity to share personal circumstances and read about the experiences of other family carers, both positive and negative.
- Safe and monitored environment

CBF website and social media

- Access to current information specifically for family carers

Included in the literature reviewed by the focus group was a copy of Mary O’Toole’s “Draw my Care – DoLS”. Feedback about this format was positive, including:

- Flow chart style made it easy to understand and apply to personal situation
- Simple language
- Unbiased information
- Role of family carers clearly acknowledged

What must happen now?

Family carers welcomed the Call to Action and STOMP but expressed frustration and anger at how long change is taking. Every additional day their relative is unnecessarily taking medication is another day of debilitating side effects.

Family carers were easily able to articulate what good practice looks like. The experiences and insight they shared from all aspects of this piece of work form the basis of the recommendations of this report. The first 8 recommendations involve the wider system for STOMP to consider, and CBF will also refer these to the Transforming Care Delivery Board. Recommendations 8- 11 are issues which STOMP can take forward.

Recommendation 1:

There should be a team approach whenever medication is suggested, introduced, changed or increased, acknowledging family carers as an equal and valued stakeholder. Where appropriate, for example if there is no family carer involvement or the person with a learning disability requests, there should be involvement of an independent, specialist (learning disability, ASD) advocate.

Good practice example: Under the Care Act (2014), local authorities must arrange an advocate if people have substantial difficulty in being fully involved and if there is no-one appropriate available to support and represent their wishes.

Recommendation 2:

Family carers and their relatives should have access to local, specialist early intervention as soon as it is recognised that there is the potential for behaviour described as challenging and/or a mental health need to reduce the likelihood of restrictive practices being introduced, including the use of medication.

Good practice example:

- <http://pavingtheway.works>
- “Consider parent-training programmes for parents or carers of children with a learning disability who are aged under 12 years with emerging, or at risk of developing, behaviour that challenges” (NICE pathway: Interventions for people with learning disabilities and behaviour that challenges; 2015).

Recommendation 3:

Care and support should be delivered following comprehensive assessments (e.g. communication, health, sensory, functional analysis) which underpin plans (e.g. positive behaviour support plan, person centred plan, communication passport, health action plan) that are regularly updated and followed. This aim is to reduce the risk of behaviour described as challenging and/or a mental health need developing or deteriorating and the subsequent risk of medication being introduced as a solution.

Recommendation 4

Alternatives to medication should be proactively identified and available to prevent the development of or increase in behaviour described as challenging or decline in mental health. These should include:

- Therapeutic interventions (occupational, intensive interaction, music, sensory integration)

Good practice example: “The OT support which my son has had over the years has definitely been very helpful - he enjoys it and relates well, on a 1:1 basis with the OTs. He is now relating well to the support worker at the withdrawal charity as well.” (Family carer)

- Maintenance of good physical health through regular checks and always first eliminating pain as a cause for behaviour described as challenging and/or a change in mental health.

Good practice example:

Cardiff Health Check for People with a learning disability (1998).

Regular use of measures such as the Face, Legs, Activity, Cry, Consolability (FLACC) measure and/or the Non-Communicating Children’s Pain Checklist-Revised (NCCPC-R) measure.

- Maintenance of good mental health by ensuring the following are in place:
 - good physical health, acknowledging biological causes (e.g. side effects from medication, sensory impairment) and reducing risk factors
 - psychological support (there are currently limited outlets for expression of emotional needs)
 - social support (to address poor quality of life - current or historic)
 - environmental issues (e.g. reducing restrictive environments such as an inpatient setting; psychological therapies and people who have intellectual disabilities (BPS))

Good practice example:

“All parties involved with my son were consulted by his psychologist to eliminate the likelihood of a physical cause.” (Family carer)

Learning disabilities, identifying and managing mental health problems (NICE QS142, 2017)

- Pre-emptive action of trigger points. Families recommended the development and standard introduction of a “Crisis Plan”.

Recommendation 5

Robust commissioning of education, social and health services, which correlate strictly with the needs identified through assessments and plans, and provided by a skilled workforce trained in positive behaviour support, mental health needs and learning disability, and the role of and alternatives to medication.

Good practice example: “The current care home manager is opposed to medication other than as a very last resort to prevent serious self-harm. She has been brilliant in training her staff to understand and communicate with my daughter and find effective ways of defusing her anxiety. Consequently she is far happier and calmer these days.” (Family carer)

Recommendation 6

To support families in their role, they should have their own carer’s assessment and the recommendations followed and should include:

- A support package which minimises crisis

Good practice example: “Respite was increased to one night overnight respite per week.” (Family carer)

- Additional support during periods of crisis
- Professional family support

A proactive approach to supporting family carers will allow them to continue in their role for longer and reduce the probability of a decision about medication being made during a period of crisis.

Recommendation 7

A suite of information, resources and training specifically for family carers and/or their advocates should be developed to support an informed decision when medication is suggested or prescribed. Information, resources and training should be easily available, provided in a range of formats, independent, regularly updated and free of charge to family carers.

Good practice example: “We found the leaflets and resources from the Challenging Behaviour Foundation really helpful.” (Family carer)

A family carer specific step-by-step good practice guide was suggested covering what to do when medication is suggested, what to do if medication is already administered, what to do if changes are proposed.

Recommendation 8

Family carers wanted a commitment from prescribers to adhere to current good practice guidance including: Reducing inappropriate psychotropic drugs in people with a learning disability in general practice and hospitals in 2016 (), Using medication to manage behaviour problems among adults with a learning disability (Deb et al, 2006), NICE pathway: Challenging behaviour and learning disabilities (2015). They wanted to be equipped to effectively challenge practice that was not in line with this guidance.

Recommendation 9

STOMP to clarify who monitors medication use that may be initiated via education professionals and settings. CQC and Ofsted to ensure that joint inspections of local areas regarding provision of support for children and young people with special education needs and/or disabilities includes examining and reporting prescribing practices of medication related to behaviour described as challenging and/or mental health needs.

Recommendation 10

CQC to consider whether a service, which does not follow current good practice guidance (Recommendation 8) can be judged good or outstanding in any of the 5 domains: Safe, Well Led, Responsive, Caring and Effective.

Recommendation 11

If it is agreed by all that medication should be prescribed, family carers would like to see a medication pathway which records information such as:

- The rationale for the medication
- Evidence based reason for the medication identified including a functional analysis
- The potential side effects and what will happen if they there are experienced
- Monitoring and reviewing procedures including a baseline measure to identify whether medication is making a difference
- Alternative interventions including what will happen if medication does not result in an improvement.

Recommendation 12

A commitment from NHS England to provide regular updates and progress reports, about what is happening locally and nationally, following the Call to Action (2015) and STOMP. Information should be disseminated as widely as possible and in a range of formats to ensure it reaches as many family carers as possible.

Conclusion

Sadly, this report, based on the views and experience of over 100 families confirmed again that children, young people and adults with a learning disability and ASD continue to be subjected to restrictive practices, including the inappropriate use of medication, with significant negative consequences for the individual. This is despite a pledge in July 2015 from NHS England promising rapid and sustained action to tackle the over-prescribing of psychotropic drugs to people with learning disabilities after three separate reports highlighted the need for change. For many families their relative is still being inappropriately medicated and for some families their relative's situation has worsened.

The report also highlights the lack of information, resources and training available to family carers when their relative is at risk of being prescribed medication as a solution for behaviour described as challenging and/or a mental health need. Family carers are frequently expected to make life changing decisions on behalf of their relative, often during periods of crisis, in the absence of relevant, current and independent information, resources and training. With access to the right knowledge, family carers will be better equipped to consider and advocate for alternatives to medication or challenge a decision.

Last word ...

"If I could change one thing it would be access to early intervention. If I had known when my son was a child what I know now, my son's journey would have been different. I would have ensured that he developed a formal communication system which allowed him to tell us what he wanted, what he didn't want, when he was in pain. Now I know that behaviour described as challenging means an unmet need. Nobody gave me any advice on how to parent a child who wasn't going to follow the usual developmental milestones. Knowledge is power."

"I would make prescribers more accountable. Maybe take an American approach and consider litigation. That might make them think twice before prescribing."

"Please listen to me. I've been around since she was born."

"I made sure I was involved at every step and the professionals involved were happy to include me. It meant my son's diagnosis of bi-polar led to appropriate medication and an improvement in his quality of life. Everybody listened to me and I had access to either my son's psychiatrist or a nurse to discuss any concerns, eg side effects."

"Every generation has something they are embarrassed about. For our generation I think we will look back in shame at the way we have treated people with a learning disability."

"It's never too late to get it right. Our current psychiatrist is amazing. At a meeting, we went round the table – there were many of us – and we all introduced ourselves and then she asked for our feedback first and listened! She held everybody in the room accountable for the actions required to ensure my son's quality of life improved and drove it forward. She agreed with us that hospital was not the answer, that he needed to be in his own home which met his specific needs."

References:

Care Quality Commission, (2016). Survey of medication for detained patients with a learning disability. Available at: http://www.cqc.org.uk/sites/default/files/20160209-Survey_of_medication_for_detained_patients_with_a_learning_disability.pdf

Deb, S., Clarke, D., and Unwin, G. (2006). Using medication to manage behaviour problems among adults with a learning disability. *Quick reference guide*. Birmingham: University of Birmingham, Royal College of Psychiatrists and Mencap.

Department of Health, (2012). DH: Winterbourne View Review Concordat: Programme of Action.

Department of Health (2009). Valuing people now: a new three-year strategy for people with learning disabilities. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf

Drawmycare (marytoole10). "@keritayler @irwinmictchel @IMPUBLICLAW @InclusionNorth @Rescare_Charity @SteveBroach oops final version #Stress pic.twitter.com/NcZBV6rgkh". 16 July 2014, 8.11 p.m. Tweet. Available at: <https://twitter.com/MaryOToole10/status/489487401811988480/photo/1>

Flynn, M. (2012). Winterbourne View Hospital: a serious case review. *South Gloucestershire Safeguarding Adults Board*.

Kerr, M., Welsh Centre for Learning Disabilities (1998). Cardiff Health Check for People with a Learning Disability. Available at: http://www.easyhealth.org.uk/sites/default/files/Cardiff_Health_Check.pdf

National Institute for Health and Care Excellence, (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Available at: <https://www.nice.org.uk/guidance/ng11>

National Health Service, (2016). Stopping Over-medication of people with learning disabilities. Available at: <https://www.england.nhs.uk/wp-content/uploads/2016/06/stopping-over-medication.pdf>

Nice.org.uk. (2017). *Learning disabilities: identifying and managing mental health problems | quality-statements | Guidance and guidelines | NICE*. [online] Available at: <https://www.nice.org.uk/guidance/qs142/chapter/Quality-statements>.

Public Health England /CPRD (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. Available at:
http://www.improvinghealthandlives.org.uk/securefiles/160419_1226//Psychotropic%20medication%20and%20people%20with%20learning%20disabilities%20or%20autism.pdf

Silent Minority, (1981). *Documentary, Associated Television, London. Directed by Nigel Evans.*

Undercover Care: The Abuse Exposed, (2011) *Documentary, Panorama, British Broadcasting Company, London.*