

We support

# STOMP

Stopping over-medication of people  
with a learning disability, autism or both



## Project News

January 2018

New Year greetings from the STOMP delivery group and a warm welcome to the first of our new STOMP updates for project partners and supporting organisations. It's a brief round-up of what's happening around the project. We will send it out every so often to keep you updated. We would love to include news of what YOU are doing to implement STOMP - please send **your** news to [sarah.bowes1@nhs.net](mailto:sarah.bowes1@nhs.net)

The STOMP delivery group is run by the NHS England Learning Disability Programme.

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### New STOMP videos

[Derbyshire Healthcare NHS Foundation Trust](#) has created a set of five short films about STOMP, one each for GPs, psychiatrists, carers, learning disability teams and pharmacists:

[https://www.youtube.com/playlist?list=PL4shZXQ9YqmIFPJX02IWJvhHqdrMf\\_EkO](https://www.youtube.com/playlist?list=PL4shZXQ9YqmIFPJX02IWJvhHqdrMf_EkO)

### Coming soon!

**STOMP project leaflet** – look out for an accessible leaflet about the project, coming out in January!

**Health Care Pledge** – also coming soon - selected NHS Trusts and independent health providers are working to produce a healthcare provider pledge similar to the social care pledge developed by VODG.





The healthcare pledge will focus on what providers can do to put STOMP into practice, including better collaboration with primary care and the use of alternatives to medication. Anyone supported by a healthcare provider and their carers/family members will be able to see what the organisation will be doing in relation to STOMP. The pledge will be tested December - February and will be followed by a launch event (with MiXit performance) scheduled for March 2018.



### **CBF resource for families**

Also coming soon - NHS England has commissioned the Challenging Behaviour Foundation to develop an online resource for families, which will also be available in a printed format. These resources will give families helpful advice at each step of the journey, from the introduction of medication to withdrawal. The resources are based on a consultation we commissioned CBF to carry out with families, who are also involved in producing the resources.

The STOMP delivery group is supporting group member Hazel Griffiths with a **short resource for families** to record test results in a way that is easy and helps with monitoring medication. See Hazel's feature on page 4. And we're working with theatre group MiXit to make **a short video** on STOMP for frontline care staff.



**Pledge partner news** – since the STOMP pledge was launched last year by NHS England, Royal College of Nursing, Royal College of Psychiatrists, Royal College of GPs, Royal Pharmaceutical Society, British Psychological Society and Alistair Burt (then Minister for Community and Social Care), the following professional groups have also become pledge partners:

- Voluntary Organisations Disability Group (VODG)
- British Association of Social Workers
- Royal College of Speech and Language Therapists
- The Learning Disability Professional Senate - includes NHS England, Care Quality Commission, Clinical Commissioning Groups, Challenging Behaviour Foundation, Department of Health, Health Education England
- British Association of Music Therapy
- Royal College of Occupational Therapists
- British Dietetics Association
- British Association of Dance Therapy
- British Association of Drama Therapy

We'll feature partners' work in each edition of this newsletter (see the social care providers work below and the Royal College of Psychiatry work on page 4). Email [sarah.bowes1@nhs.net](mailto:sarah.bowes1@nhs.net) to feature your work.

## Social care pledge going strong!

Voluntary Organisations Disability Group (VODG) has been leading on the pledge for social care providers, which helps providers give the best support possible to people taking psychotropic medicines. In a short space of time, over 120 providers have signed up, supporting over 45,000 people with a learning disability, autism or both!



**Leaflet about visiting the doctor** – VODG has produced an excellent leaflet to help staff, the person and their family prepare for visiting a doctor. It includes an easy read section for people to complete before and during their appointment, as well as a section for their carer/family member to complete beforehand too. It helps make the process of visiting a doctor easier and less stressful and ensures people know what to talk about with regard to psychotropic medicines being taken. This and other resources can be found at [www.vodg.org.uk/campaigns/stompcampaign](http://www.vodg.org.uk/campaigns/stompcampaign).



**In the news** - well done and many thanks to Katy and her support provider, Dimensions, who recently took part in an excellent interview on BBC Radio Solent. Katy talked about her experience of being over-medicated and with staff what is happening to help her lead a good life without medication. Please do let us know of any examples of how you have been raising awareness.



## On the road - MiXit performances

In

In 2017 NHS England commissioned the inclusive theatre company MiXit to devise a play about STOMP, which has been a massive success at conferences. It got a standing ovation at the recent Annual Conference of the Royal College Psychiatrists' Faculty of Psychiatry of Intellectual Disability, and at just about everywhere!

There is a schedule of performances planned for 2018 (see page 5), and if you would like to showcase STOMP and MiXit at a conference or event, please email [sarah.bowes1@nhs.net](mailto:sarah.bowes1@nhs.net).



**Carl's news** - Hello, my name is Carl Shaw, I am a Learning Disability Expert Adviser in the Improving Health and Quality team at NHS England and I co-lead the STOMP project with Anne Webster. You can [read our blog](#) here. In our team we now have 3 part time pharmacists who job share - David Branford, David Gerrard and Nigget Saleem – please do contact us if we can help you in any way by emailing [sarah.bowes1@nhs.net](mailto:sarah.bowes1@nhs.net).

We are pleased to work with family carer adviser Hazel Griffiths on our STOMP delivery group (see page 5). The delivery group also includes psychiatrist Ken Courtenay, regional NHS England reps Siobhan Lendzionowski, Susan Fox and Elaine Ruddy and representatives from our children and young people and sustainable

improvement teams. Amongst many other things, Jill Parker, our VODG representative on the group, has designed a STOMP board game (like snakes and ladders) which is a big hit in workshops!



## STOMP spotlight - Royal College of Psychiatrists

The Royal College Psychiatrists' Faculty of Psychiatry of Intellectual Disability has resources on its [website](#) promoting the STOMP work to its members. This includes professional resources and a faculty pledge to stop the over use of medication by, for example, promoting awareness of STOMP, training materials, the monitoring of treatment of prescribing, and the importance of involving people and their families in person-centred treatment planning.

As part of their pledges, all the partners undertake to promote the STOMP campaign on their websites and at conferences, for example, and to support their members with guidance on how STOMP can best be implemented by their professional members. Look out for further examples of how partners are doing this in future editions, and please email [sarah.bowes1@nhs.net](mailto:sarah.bowes1@nhs.net) to share your good work in this way.



## Children and Young People –

### *The right medication, at the right time, for the right reasons*

After highly productive meetings last year, the children and young people's team in the NHS England Learning Disability Programme identified key areas for delivering the STOMP message for children and young people, using a variety of approaches: case studies, social Media, parent carer networks; and professional groups and networks. The team is working with the Royal College of Paediatricians and Child Health and the British Academy of Childhood Disability, to develop this work.



## Hazel Griffiths – family carer adviser to STOMP

As a nurse and mum, I was shocked when my son, who has autism, became over-medicated. But I was determined to help him, and to help other families in a similar position.

My son was 19 when he had an acute reaction to stress due to living away from home. Without a definitive diagnosis he ended up on five different psychotropic medicines. We became very worried about his rapid weight increase, emotional bluntness, increase in liver function blood tests, blood sugars, movement disorder and catatonia.

After a traumatic time when had to get him out of a hospital 200 miles away, we found a development psychiatrist and a consultant psychologist in the community, who specialise in autism. The GP was fantastic and devised a health care plan with all of us.

Over time, we slowly reduced his medication, starting with the antidepressants, and within months his blood sugars and LFTs returned to normal levels, and his weight returned to normal.

My son now enjoys a happy, safe life in the community. We support him using positive behaviour support, inclusion and the love of his family. While medications can sometimes be helpful, we feel it is vital that adults with a diagnosis of autism, in fact, anyone in this situation, are regularly monitored. If side effects outweigh benefits, this should be acted on rather than leaving people on these drugs for years and years, when perhaps they are not needed.

As part of my work on the STOMP project, I am designing a short resource which allows families to record test results in a way that is easy to understand and helps with monitoring medication. It should be ready early 2018.

## The North regional STOMP steering group



has written a STOMP audit tool that has been completed by CCGs in the north. It was produced to provide the region with a baseline position of how CCGs are delivering the five regional STOMP priorities. The results will be used by the steering group and Transforming Care Partnerships to identify any areas of support that CCGs need. It also shows the impact of the STOMP programme in the North. Contact [Siobhan.lendzionowski@nhs.net](mailto:Siobhan.lendzionowski@nhs.net)

**STOMP is featuring at a number of upcoming events –** email [sarah.bowes1@nhs.net](mailto:sarah.bowes1@nhs.net) for information, to send us your diary dates or to invite us to speak



23 January	STOMP Social Care Conference Birmingham
27 February	North West Regional Conference Blackpool
6 March	Transforming Communities event Birmingham
8 March	NAS Professional Conference Harrogate
9 March	Yorkshire & Humber Conference Leeds
13 March	Learning Disabilities: Fulfilling Potential & Supporting Better Lives conference Manchester
March	STOMP healthcare pledge launch TBC
11 April	National Autistic Society Conference Birmingham
10-11 May	BILD PBS event TBC

**Thank you for reading this – we look forward to hearing from you!**