Stopping over-medication of people with intellectual disability, Autism or both (STOMP) in England part 1 – history and background of STOMP

David Branford, David Gerrard, Nigget Saleem, Carl Shaw and Anne Webster

Abstract

Purpose – The programme – Stopping the over-medication of people with an intellectual disability, Autism or Both (STOMP) is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However, despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View not only raised concerns about the overuse of antipsychotic drugs but of antidepressants and multiple psychotropic drug use. The purpose of this paper is twofold: Part 1 is to present the history and background to the use of psychotropic drugs in intellectual disabilities, autism or both; and Part 2 presents the progress with the STOMP programme.

Design/methodology/approach – The review tracks the various concerns, guidelines and attempts to tackle the issue of over medication of people with intellectual disability autism or both.

Findings – The review identifies that despite the many studies and guidelines associated with the prescribing of psychotropic drugs for people with an intellectual disability, autism or both the practice is common. Programmes that minimise the use of psychotropic drugs involve a full use of the multidisciplinary team and an availability of alternative methods of managing challenging behaviours.

Originality/value – STOMP is part of an English national agenda – Transforming care. The English Government and leading organisations across the health and care system are committed to transforming care for people with intellectual disabilities, autism or both who have a mental illness or whose behaviour challenges services. This review identifies many studies, programmes and guidelines associated with psychotropic drug use for people with an intellectual disability, autism or both.

Keywords Autism, Intellectual disability, Learning disability, Polypharmacy, Call to action methodology, Psychotropic drugs

Paper type Literature review

Introduction and background

The programme – Stopping the Over-medication of people with an intellectual disability, Autism or Both (STOMP) is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However, despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View (an assessment unit for people with an intellectual disability, autism or both who demonstrated challenging behaviours) not only raised concerns about the overuse of antipsychotic drugs but of antidepressants (South Gloucestershire Safeguarding Adults Board, 2012). This paper – Part 1 presents the history of psychotropic drug use for people with an intellectual disability, autism or both and the background to STOMP. Part 2 (Branford et al., 2018) STOMP – the story so far presents the approach adopted to reduce over medication (the “Call to Action”) and the progress so far at the half way stage.
Historical concern about the use of psychotropic drugs for people with an intellectual disability autism or both

People with an intellectual disability. Psychotropic drugs are widely prescribed for people with an intellectual disability. Since the 1970s concern has been expressed that the prescribing of psychotropic drugs is excessive, inappropriate and potentially harmful. The concern is fuelled by:

1. studies that show high prescribing rates for such drugs;
2. studies that demonstrate a significant reduction in such prescribing following close scrutiny by either physicians, pharmacists or drug review committees; and
3. failure of studies to clearly associate the prescribing of psychotropic drugs with their indication – either mental illness or challenging behaviours.

Surveys of prescribing for people with an intellectual disability

Surveys of the prescribing of psychotropic drugs for people with an intellectual disability who lived in institutional care became common following an initial study by Lipman of 109 institutions in the USA. That study demonstrated that 51 per cent of residents were prescribed at least one psychotropic drug. Aman and Singh (1988) reviewed 35 such USA based surveys and concluded that typically 30–50 per cent received a psychotropic drug of which antipsychotic drug prescribing was the main component. In addition 25–45 per cent received an antiepileptic drug.

There were far fewer studies in the UK. However, the most comprehensive were those undertaken by Fischbacher (1987) of 509 residents of an institution for people with an intellectual disability in North and West Lothian (Scotland) and Branford (1994) of 486 residents in Leicester. Psychotropic drug use is shown in Table I.

There are few early studies of the prescribing for people with an intellectual disability who were cared for in the community. A variety of different methods were used to identify such people which led to great variance in the results. The results were also dependent on whether smaller institutional style facilities in the community were categorised as “living in the community”. The results from two UK studies (Branford, 1994) and by far the largest survey involving the population of 35,000 people with an intellectual disability living in New York who received services are shown in Table II.

In addition to surveys of whole populations attempts have also been made to understand the drug use for specific syndromes or behaviours. Deb et al. (2015) reviewed 100 people with an intellectual disability who attended at clinic with aggressive behaviours. They showed 90 per cent to be on psychotropic drugs. They showed that not only the use of psychotropic drugs is common among adults with ID who attend psychiatric clinics for aggressive behaviour, the use of polypharmacy of psychotropic medications in general and high dose of antipsychotics in particular are equally prevalent. There was no significant association with demographic variables such as physical health conditions or psychiatric diagnosis.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Percentage receiving psychotropic drugs Clarke et al.</th>
<th>Percentage receiving psychotropic drugs Branford (1994)</th>
<th>Percentage receiving psychotropic drugs Jacobson</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution</td>
<td>40.2</td>
<td>44</td>
<td>39.9</td>
</tr>
<tr>
<td>Community based care settings</td>
<td>19.3</td>
<td>19</td>
<td>24.8</td>
</tr>
<tr>
<td>Living with family</td>
<td>10.1</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>
Drug review programmes

Although there are many surveys of the use of psychotropic drugs by people with an intellectual disability there are fewer studies comparing the prescribing patterns before and after an active drug review programme. Of the older USA studies one showing the greatest change was a seven year programme using rigidly mandated guidelines. It demonstrated a reduction and maintenance of antipsychotic drug use from 41 per cent of an institutional population to 12 per cent (Findholt and Emmett, 1990). The study used a drug review committee with the specific remit to manage the use of psychotropic drugs. The committee involved a team of psychologists, pharmacists, nurses and physicians.

Other drug review programmes have been reported in the UK (Branford, 1996a, b; Ahmed et al., 2000). A 2014 Dutch (De Kuijper et al., 2012) study investigated the effects of controlled discontinuation of antipsychotics prescribed for behaviour that challenge. Of 98 participants, 43 achieved complete discontinuation; at follow-up 7 had resumed use of antipsychotics. There were no significant differences in improvement of behavioural ratings between two discontinuation schedules. Higher baseline problem behaviour rating predicted higher odds of incomplete discontinuation.

Guidelines for the prescribing of psychotropic drugs for people with a learning disability

Concern about the overuse of psychotropic drugs prescribed for people with an intellectual disability has resulted in many guidelines. In 1995, a guideline for the use of psychotropic medication was developed in the USA following an international consensus conference on psychopharmacology. Its summary document proposed “The 10 dos – 4 don’ts principle” still remains very relevant to the current time (Reiss and Aman, 1998).

The ten dos include: treat any behaviour medication as a psychotropic medication; use within a coordinated care plan; base treatment on a diagnosis or specific hypothesis; obtain written consent; track efficacy by defining index behaviours; monitor side effects using rating instruments; monitor for tardive dyskinesia (NB. this could now be amended/add to by monitor for metabolic syndrome); review systematically and regularly; strive for lowest optimal effective dose; monitor use by peer or quality review.

The four don’ts include: don’t use psychotropic medications excessively, for convenience, or as a substitute for meaningful activity; avoid frequent medication and dose changes; avoid intraclass polypharmacy; minimise the use of long-term pm. orders (“pro re nata” or “as needed”), long-acting sedative/hypnotics, long-term hypnotics or anxiolytics, high antipsychotic doses and long-term anticholinergics.

In 2000, the American Journal on Mental Retardation published an expert consensus guideline for the treatment of psychiatric and behavioural problems in ID. It stated that a prescription for a psychotropic medication should be based on a psychiatric diagnosis or a specific behavioural–pharmacological hypothesis that results from a diagnostic and functional assessment. The medication should be given a trial of several weeks, use the same or lower

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Table II: Surveys of psychotropic drug use across different settings

<table>
<thead>
<tr>
<th>Psychotropic drug category</th>
<th>Percentage of patients receiving</th>
<th>Percentage of patients receiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotics</td>
<td>32</td>
<td>44</td>
</tr>
<tr>
<td>Anxiolytics</td>
<td>4.2</td>
<td>5</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>2.6</td>
<td>6</td>
</tr>
<tr>
<td>Hypnotics</td>
<td>11.1</td>
<td>5</td>
</tr>
<tr>
<td>Anticonvulsants (antiepileptics)</td>
<td>36</td>
<td>44</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>15.4</td>
<td>13</td>
</tr>
<tr>
<td>Lithium</td>
<td>1.6</td>
<td></td>
</tr>
</tbody>
</table>

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maintenance maximum doses as in general population and periodically consider gradual dose reduction. However the expert consensus group also advocated both start low and go slow – use lower initial doses and increase more slowly than in the general population and reduce doses at the same rate or slower both of these have been disputed.

In 2006, Deb et al. developed a quick reference guide “Using medication to manage behaviour problems among adults with learning disabilities”. This used both expert surveys and critical evaluation of available literature to achieve a consensus. Their guide, in addition to issues raised above, identified a wide range of other issues associated with the prescribing of psychotropics.

Deb then followed this up in 2009 with the collaboration: “International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities”. The key statements were that “The medication should be prescribed at the lowest possible dose and for the minimum duration, non-medication based management strategies and the withdrawal of medication should always be considered at regular intervals; if the improvement of the behaviours that challenge is unsatisfactory, an attempt should be made to revisit and re-evaluate the psychiatric formulation and the management plan”.

However, despite the numerous guidelines serious concerns were again raised about the overuse of antipsychotics and antidepressants by the report into the events at Winterbourne View a private treatment and assessment facility near Bristol UK.

People with autism

There are similar views and controversies about the use of psychotropic drugs for people (predominantly children) with autism. A US study of 2,853 children with Autistic Spectrum Disorder (Coury et al., 2012) showed:

- 763 (27 per cent) were taking psychotropics; 15 per cent were prescribed one, 7.4 per cent received two and 4.5 per cent received three or more.
- Among children aged 3 to 5 years, 11 per cent were taking psychotropics; among 6-to 11-year-old children, 46 per cent; and 66 per cent of adolescents aged 12 to 17 years.
- A parent report of comorbid diagnosis of attention-deficit/hyperactivity disorder, bipolar disorder, obsessive-compulsive disorder, depression, or anxiety was associated with a high rate of use, with 80 per cent receiving psychotropics.
- Only 15 per cent of children with no comorbid psychiatric disorder were taking psychotropics.
- Psychotropic drug use was also related to sleep and gastrointestinal problems.
- The prescription of psychotropics was highly related to comorbid psychiatric disorder. Other factors associated with use include medical comorbidities, race, ethnicity and older age.

Another study of 33,565 children with Autism Spectrum Disorder (Spencer et al.), 64 per cent had a filled prescription for at least 1 psychotropic, 35 per cent had evidence of psychotropic polypharmacy (≥2 classes) and 15 per cent used psychotropics from ≥3 classes concurrently. Among children with psychotropic polypharmacy, the median length of polypharmacy was 346 days. Older children, those who had a psychiatrist visit, and those with evidence of co-occurring conditions (seizures, attention-deficit disorders, anxiety, bipolar disorder, or depression) had higher odds of psychotropic use and/or polypharmacy.

The Winterbourne scandal and psychotropic drugs

The exposure of mistreatment of people with intellectual disability autism or both at Winterbourne View near Bristol shocked the UK. Although the Panorama programme primarily focussed on the abuse of residents the subsequent enquiry raised concerns about the use of psychotropic drugs and in particular antipsychotic drugs and antidepressants.
Quotation from the serious case review by Margaret Flynn:

7.31 We have heard deep concerns about over-use of antipsychotic and antidepressant medicines.
Health professionals caring for people with learning disabilities should assess and keep under review
the medicines requirements for each individual patient to determine the best course of action for that
patient, taking into account the views of the person wherever possible and their family and/or carer(s).
Services should have systems and policies in place to ensure that this is done safely and in a timely
manner and should carry out regular audits of medication prescribing and management, involving
pharmacists, doctors and nurses.

Studies of the use of psychotropic drugs post Winterbourne View

Following the publication in 2012 of Transforming Care: a national response to
Winterbourne View Hospital the Chief Pharmaceutical Officer for England commissioned
three pieces of work:

- investigate the prescribing for people with an intellectual disability, autism or both via the
general practice (GP) clinical practice research datalink (CPRD);
- commission the Care Quality Commission (CQC) to examine Second Opinion Authorised
Doctor (SOAD) data in relation to medicines agreed for those detained using the Mental Health
Act; and
- commission a collaborative improvement programme.

Also in addition to the above, a question about the use of antipsychotic drugs was included in an
intellectual disabilities hospital Census and a research programme was undertaken by the
Department of Psychiatry, University College of London.

The clinical practice research datalink (CPRD) study

The CPRD study examined the prescribing of drugs acting on the central nervous system to
people with intellectual disabilities or autism by general practitioners (GPs) in England.
The numbers of relevant patients identified (17,887 people with an intellectual disability and an
additional 11,136 with autism) suggested that the database covers about 7.8 per cent of the
English population. The study focussed on the use of drugs in four of the sections of chapter 4 of
the British National Formulary. Following the concerns of the Winterbourne enquiry
antipsychotics and antidepressants were included. However, following representations from
carer organisations and the literature that a wider range of drugs is used for behaviour
management in this group of people, the study included hypnotics, anxiolytics, the rest of the
section covering drugs used in psychoses and related disorders and antiepileptic drugs.
The findings can be summarised as follows:

- rates of prescribing of antipsychotics and antidepressants were very high;
- prescribing rates rose almost continuously with age;
- there was a 40 per cent overlap of the prescribing of antipsychotics and antidepressants; and
- prescribing rates were substantially higher than the rates of psychosis or affective disorders.

Simultaneous prescribing of drugs from more than one of the five BNF (sub)-sections was
common. Two in five adults (39.9 per cent) and 17.6 per cent of all children and young people
with an intellectual disability who were receiving any of the drugs were receiving drugs from two or
more groups. Corresponding proportions for people with autism but not intellectual disability
were 30.3 per cent for adults and 13.6 per cent for children and young people.

Second opinion authorised doctor (SOAD) data (CQC, 2016)

The CQC coordinates the provision of Second Opinion Appointed Doctors (SOADs), who visit
people detained under the Mental Health Act. They consider clinical records and opinion from
others, and decide whether medication to be prescribed for mental disorder is appropriate.
As part of this process, the CQC receives information about the type and dose of medication prescribed, together with the patient’s diagnosis. The key findings were:

- A total of 86 per cent of patients were prescribed at least one antipsychotic drug to be given on a regular basis. In total, 18 per cent were prescribed more than one antipsychotic drug to be given concurrently on a regular basis.
- A total of 24 per cent of patients were prescribed more than one different psychotropic drug to be given on a regular basis. When medication prescribed to be given “as required” is included, 57 per cent were prescribed more than one psychotropic drug; with 40 per cent prescribed five or more drugs.
- For more than a half of the prescriptions, the patient did not have a diagnosis of a disorder for which that drug was a recognised indication.

A collaborative improvement programme

NHS improvement invited expressions of interest from areas of England to get a deep understanding of current practices and test new ways of working. Their report categorised six key issues:

- the need to understand the pressures and reasons for prescribing;
- the importance of sharing up-to-date and comprehensive information;
- the significance of understanding the current medication processes;
- the value of integrated pathways of care;
- the importance of involving of people with ID, their families and carers; and
- the development of teams, skills and culture.

2013 intellectual disabilities hospital Census

The publication of a census from the Health and Social Care Information Centre has further raised concerns about the use of psychotropics. Survey responses were received from 104 provider organisations on behalf of 3,250 people with an intellectual disability, autism or both who met the inclusion criteria for the 2013 intellectual disabilities census. Over two-thirds (68.3 per cent or 2,220) had been given an antipsychotic leading up to census day.

Independent research undertaken by department of psychiatry university college London

Sheehan et al. studied the data from 571 general practices contributing data to The Health Improvement Network clinical database. This involved 33,016 adults (58 per cent male) with an intellectual disability who contributed 211,793 person years’ data.

Their primary conclusions were similar to the CPRD study that:

- the proportion of people with intellectual disability who have been treated with psychotropic drugs far exceeds the proportion with recorded mental illness;
- antipsychotics are often prescribed to people without recorded severe mental illness but who have a record of challenging behaviour;
- the findings suggest that changes are needed in the prescribing of psychotropics for people with intellectual disability;
- more evidence is needed of the efficacy and safety of psychotropic drugs in this group, particularly when they are used for challenging behaviour; and
- the rate of new antipsychotic prescribing was significantly higher in people with challenging behaviour, autism and dementia and in those of older age, after control for other socio-demographic factors and comorbidity.
National institute for health and care excellence (NICE) guidance

In addition to the research undertaken on the prescribing of psychotropic drugs the National Institute for Health and Care Excellence was commissioned to undertake a number of reviews of various aspects of practice in relation to intellectual disability.

Prior to the Transforming Care programme NICE had issued guidance: Autism – The management and support of children and young people on the autism spectrum (CG170). Key guidance relating to psychotropic drug prescribing from NICE guidance CG170 Autism – The management and support of children and young people on the autism spectrum was as follows:

1. Consider antipsychotic medication for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour.

2. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist who should:
   - identify the target behaviour;
   - decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact;
   - review the effectiveness and any side effects of the medication after 3–4 weeks; and
   - stop treatment if there is no indication of a clinically important response at 6 weeks.

Key guidance relating to psychotropic drug prescribing from NICE guidance NG11 “Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges” was as follows:

1. Consider antipsychotic medication to manage behaviour that challenges only if:
   - psychological or other interventions alone do not produce change within an agreed time or;
   - treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or; and
   - the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

2. Only offer antipsychotic medication in combination with psychological or other interventions.

In 2015, NICE issued “Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges” NG11. Key guidance relating to psychotropic drug prescribing from NICE guidance NG54 “Mental health problems in people with intellectual disabilities: prevention, assessment and management” was as follows:

1. For pharmacological interventions for mental health problems in people with intellectual disabilities, refer to the NICE guidelines on specific mental health problems and take into account the principles for delivering pharmacological interventions.

2. For people with intellectual disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms:
   - consider reducing or discontinuing long-term prescriptions of antipsychotic drugs;
   - review the person’s condition after reducing or discontinuing a prescription;
   - consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems; and
   - annually document the reasons for continuing the prescription if it is not reduced or discontinued.

In both CG170 and NG11 of the psychotropic drugs only antipsychotic drugs were considered to have any level of evidence sufficient to make a recommendation.
In addition to considering the role of psychotropic drugs for the management of challenging behaviours and for autism in NICE guideline (NG54) Mental health problems in people with learning disabilities: prevention, assessment and management it addressed the issue of mental health problems.

The interpretation of challenging behaviours displayed by people with intellectual disabilities autism or both as manifestations of mental illnesses lies at the heart of views about whether the use of psychotropic drugs is appropriate or not. It is a widely held belief that people with an intellectual disability have significantly higher rates of mental illnesses and such illnesses often prove refractory to treatment with psychotropic drugs. However, so many of the studies to support such a stance had categorised challenging behaviours as mental illnesses. Despite such methodological problems NG54 made two key recommendations.

The “call to action” and the birth of STOMP

In July 2015, NHS England called together various stakeholders to discuss the findings from the various studies reported above and agree a way forward. It was clear that producing yet more guidance would not change the approach to prescribing psychotropic drugs for people with an intellectual disability, autism or both. For five years prior to this a similar concern about the overuse of antipsychotic drugs in dementia had been addressed using a novel approach of a “Call to Action”. The “Call to Action” resulted in an increase in reviews of antipsychotic prescribing and a reduction in the inappropriate prescribing of this form of medication by 51.8 per cent Health and Social Care Information Centre (HSCIC) (2012) in people with dementia.

NHS England agreed to adopt a similar “Call to Action” methodology for the ID population called “Stopping over medication of people with an intellectual disability, autism or both (STOMP)”. The progress with STOMP is reported in a companion paper in this journal (Branford et al., 2018).

References


Further reading


NICE guidance Autism (2012), “The management and support of children and young people on the autism spectrum (CG170)”.


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