Medication Reduction Programs

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Background

Surveys of Psychotropic Medication Use

Surveys of psychotropic medication prescribed for people with an intellectual disability have been a common feature of publications almost since the introduction into clinical practice of antipsychotics and lithium in the 1950s. The initial focus of such surveys was those who lived in institutional care. A study by Lipman (1970) of 109 institutions in the USA demonstrated that 51% of residents were prescribed at least one psychotropic medication. Aman & Singh (1988) reviewed 35 such USA based surveys and concluded that typically 30–50% received a psychotropic medication of which antipsychotic prescribing was the main component. In addition, 25–45% received an antiepileptic. Many similar surveys followed from various parts of the USA and from other countries. Despite the closure of the institutions the widespread prescribing of psychotropic medications has continued and some places increased (Song et al., 2020). Recent surveys have identified that, although the prescribing of antipsychotics has remained stable, other psychotropic medication, such as antidepressants, benzodiazepines, antiepileptics and hypnotics, the use of multiple psychotropics for the same condition or behaviour and prescribing without a diagnosis of a mental health condition, have also become common (Glover et al., 2015).

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Dove et al. (2012) reviewed the prevalence and patterns of psychotropic medication in individuals with autism spectrum disorder (ASD). They examined 47 studies (data collection: 1976–2012), encompassing >300,000 individuals with ASD. The prevalence of psychotropic medication ranged from 2.7% to 80% (median [overall]: 45.7%; median [children]: 41.9%; median [adults]: 61.5%), with psychotropic polypharmacy occurring in 5.4–54% (median: 23.0%). Regarding medication classes, antipsychotics were most frequently used, followed by attention-deficit/hyperactivity disorder (ADHD) medications and antidepressants. They concluded that despite a lack of pharmacological treatment options for ASD core symptoms, the prevalence of psychotropic medication and polypharmacy in ASD patients was considerable.

With modern digital systems surveys of medication use have become easily accessible at either locally or nationally, but surveys on their own are of little value. At a very simplistic level these surveys fuelled the view that such prescribing was excessive and used as a form of social control while others argued that it was justified because of high levels of mental illness. Surveys have also been used as a form of quality control to demonstrate one institution or facility was demonstrating good or bad practice compared to another, however, the validity of such an approach is debatable. It is the interpretation of the surveys and the action that follows a survey that are important. These broadly fell into two main strands: attempts to understand the factors associated with the prescribing and a starting point for some process of review.

Factors Associated with the Prescribing of Psychotropic Medication

All sorts of factors associated with the prescribing have been reported. These include staffing ratios, particular behaviours, the type and size of dwelling, the presence of epilepsy or psychiatric diagnoses, and many others. Whether or not the prescribing was appropriate or not also became a subject of the surveys. Bates et al. (1986) cross tabulated psychiatric diagnoses for 242 institutionalised adolescents and adults with intellectual disability with their medication regimen and concluded that 45.4–60.9% were rated as appropriate and 39.1–54.6% were rated as inappropriate for the conditions diagnosed.

Two UK studies reported using general practice prescribing data from the Clinical Practice Research Datalink (CPRD) (Glover et al., 2015; Sheehan et al., 2015). Both studies examined the prescribing of medications acting on the central nervous system for people with intellectual disabilities or autism by general practitioners (GPs) in England. Although the primary enquiry of a study in 2015 by Public Health England (Glover et al., 2015) of 17,887 people with an intellectual disability and an additional 11,136 with autism living in England was of antipsychotics and anti-depressants a wider range of medications used for behaviour management in

this group of people were also included. The findings can be summarised as follows: (a) Rates of prescribing of antipsychotics and antidepressants were very high; (b) rose almost continuously with age; (c) there was a 40% overlap of the prescribing of antipsychotics and antidepressants; (d) prescribing rates were substantially higher than the rates of psychosis or affective disorders; and (e) simultaneous prescribing of medications from more than one category of psychotropic medication was common.

The study by Sheehan et al. (2015) using similar data focussed on new initiations of psychotropic medications and their indications and the trends in prescription use from 1999 until 2013. Prescriptions of antipsychotics declined by 4% (3–5%) per year between 1999 and 2013. New prescriptions of mood stabilisers also decreased significantly. However 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 sociodemographic factors and comorbidity.

Medication Review Programs

Although there are many surveys of the use of psychotropic medications by people with an intellectual disability there are fewer studies comparing the prescribing patterns before and after an active medication review programme. Most have focussed solely on antipsychotics and the literature is dominated by USA institutionally based programs.

The studies available relate almost entirely to people with an intellectual disability. With a significant overlap between autism and intellectual disabilities it is probable that many of the participants had both however there is no ability to know whether those with both suffered greater withdrawal problems, were more or less likely to manage without their psychotropic or were excluded from the studies. There are no accounts of medication review programmes for adults with autism who do not have intellectual disability.

The primary method used in reported USA studies was the establishment of a multidisciplinary review process. This followed the recommendation of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled persons (1977). Of the USA studies one showing the greatest change was a seven-year program using rigidly mandated guidelines. It demonstrated a reduction and maintenance of antipsychotic use from 41% of an institutional population to 12% (Findholt & Emmett, 1990). The study used a drug review committee with the specific remit to manage the use of psychotropic medication. The committee involved a team of psychologists, pharmacists, nurses and physicians. Although most such review committees operated within institutions Lepler et al. (1993) established a similar process with community-based facilities. This process led to a low psychotropic medication use of 17% and a reduction in dose for 75% of the individuals.

Other medication review programmes have attempted to compare those that did not achieve any reduction, those that achieved partial reduction and those that discontinued the antipsychotic completely. The groups were often unmatched and the results difficult to interpret, however, many reported little or no difference in the characteristics of the outcome groups.

Medication review programmes have also been reported from outside of the USA. Jauernig and Hudson (1995) reported on a small programme located at an institution in Australia, in which 12% achieved total withdrawal and 86% some dose reduction. Branford (1996a, 1996b) reported on a study based in Leicestershire (UK) involving 123 people living in hospital and community settings in which 25% discontinued and 46% achieved a reduced dose. They also reported factors associated with successful withdrawal. A study from The Netherlands (de Kuijper et al., 2014) investigated the effects of controlled discontinuation of antipsychotics prescribed for behaviours that challenge. Of 98 participants, 43 achieved complete discontinuation.

Attempts to develop randomised controlled trials (RCT) of discontinuation or reduction of antipsychotics have found recruitment to be a major hurdle. A study first reported by Ahmed et al. in (2000) and with additional reporting by Smith et al. (2002) managed to recruit only 56 participants of which 36 underwent medication reduction and discontinuation. Their finding was that there was no difference between those that discontinued and those that achieved a greater than 50% reduction and controls. A further attempt at an RCT (McNamara et al., 2017) named Andrea LD reported on 22 participants randomised (intervention, $N = 11$; control, $N = 11$), 13 (59%) achieved progression through all four stages of reduction. Follow-up data at 6 and 9 months were obtained for 17 participants (intervention, $N = 10$; and control, $V = 7$; 77% of those randomised). There were no clinically important changes in participants' levels of aggression or challenging behaviour at the end of the study. Recruitment was challenging, which was largely a result of difficulty in identifying appropriate persons to consent and carer concerns regarding re-emergence of challenging behaviour. Reduced recruitment meant that the full trial became an exploratory pilot study. In addition to the findings from the now pilot, they also undertook an additional qualitative study. The Andrea LD team concluded that the difficulties in persuading people to take part was probably exacerbated by limited availability of alternative (i.e., behavioural) interventions to manage behaviour and therefore, focused support and alternative interventions are required. They recommended that further work focuses on support for practitioners, carers and patients in reducing antipsychotic medication.

Two very different systematic reviews of the effectiveness of the medication reviews have been published (Sheehan & Hassiotis, 2016; Nabhanizadeh et al., 2019). Sheehan and Hassiotis (2016) undertook a systematic review of programmes of reduction or discontinuation of antipsychotics for challenging behaviour in adults with intellectual disability. They included all studies published in peer review journals and all study designs. However, of the 45 studies identified for full text review only 21 met their criteria for inclusion. They excluded studies that had no individual outcomes, non-experimental observational studies and studies where most

individuals were taking antipsychotics for mental illnesses. All but six of the studies were based in institutional settings while the remainder were in community or mixed settings. They found ten studies that describe the outcome of reduction or discontinuation of antipsychotic medication as the proportion of the intervention group. Some were maintained on a lower dose or achieved medication discontinuation at follow-up (ranging from 3 months to over 10 years). The proportion of participants maintained on a reduced dose was between 19% and 83%, discontinuation of antipsychotics ranged from 4% to 74%. The proportion unsuccessful in attempts to reduce or discontinue antipsychotics was between 0% and 96%. Due to the study designs they were unable to obtain a summary measure of the successful reduction or discontinuation of antipsychotics.

A similar methodology was used by a team from The Netherlands (Nabhanizadeh et al., 2019), however, they focussed on studies that included the effect of medication reviews on identifying and/or reducing medication related problems in people with intellectual disabilities with no restriction of type of medication, age and level of intellectual disability. Literature databases were searched up to August 2017. Similar to Sheehan and Hassiotis (2016), they found that reviews differed in methodology, composition of the teams, institution types, study time and the nature of the input from various professionals. Six of the included studies reviewed all medications while two studies only reviewed psychotropics and antiepileptics. All studies were performed in multidisciplinary settings by a team that consisted of a pharmacist and medical staff or caregivers. Medication reviews, a combination of medication monitoring, patient education and patient follow-up were mostly undertaken by pharmacists. Four of the studies described how medication reviews were performed and which steps were involved. One study (Zaal et al., 2016) used the Systematic Tool to Reduce Inappropriate Prescribing (STRIP).

Several studies have also addressed factors associated with review programs. Sheehan and Hassiotis (2016) concluded that predictors of poor response could not be reliably identified and that the limitations of the data were such that they could not inform a population level approach to the issue. Nabhanizadeh et al. (2019) concluded there is insufficient evidence to determine whether the use of medication reviews significantly leads to a reduction of medication related problems and prescribing errors, however, there was a wide range of factors or approaches that could influence the outcome of a review programme. Some are reviewed below.

Legal and National Requirements

A 1989 USA wide review of practices of the use of psychotropic medication (Rinch et al., 1989) prescribed for people with intellectual disability showed that most USA states had rules and regulations for people in institutions. Some states had rules supported by court ordered guidelines for assessing tardive dyskinesia, restricting the use of anti-Parkinson medications and polypharmacy and implementing periodic medication interruptions. This requirement for these guidelines largely came from a

series of legal cases where considerable damages were awarded as compensation for causing the development of tardive dyskinesia, a syndrome of involuntary movements caused as a side effect of older antipsychotics. Several courts went further than just awarding damages by providing guidelines that could be used to mitigate damages.

The guidelines often included time-limiting prescriptions for psychotropics prescribed to manage behaviour and oversight by a multidisciplinary committee. These requirements alone were thought by Poindexter (1989) to explain the decline in use of antipsychotics from 32.1% of residents to 12.2% over a ten-year period. She recorded annually the use of all psychotropic medications in a stable cohort of 474 persons with an intellectual disability living in an institution in Arkansas USA.

Rinch et al. (1989) commented that few states had such requirements for those living in the community settings; however, two factors are likely to have changed the scope and impact of the legal rulings. The first is the closure of the large state institutions with most residential provision through community-based organisations or families and the second is the introduction of newer atypical antipsychotics with a reduced risk of tardive dyskinesia.

A different approach is under way in Australia through the use of restrictive practice legislation. Australian Government (2019) defined "chemical restraint means a restraint that is, or that involves, the use of medication or a chemical substance for the purpose of influencing a person's behaviour, other than medication prescribed for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition". However, the concern about the use of psychotropic medication as a chemical restraint has primarily been with the care of the older adult and it is early days to see how these impacts prescribing for people with intellectual disabilities or autism.

Further, international focus is provided by the World Health Organisation (WHO). Polypharmacy is one of the three categories mandated for action by the World Health Authority (WHO) third global patient safety challenge (*Medication Without Harm'* 2017). Through the '*Medication Without Harm'* challenge the WHO aims to "reduce severe avoidable medicine related harm globally by 50% in the next 5 years". Donaldson et al. (2017) highlighted the commitment of all health services to the challenge. This will be achieved by encouraging countries and key stakeholders to focus on early action priorities and developmental programmes to improve practice and health systems. In the UK a short life working group on reducing medication harm was established and reported in February 2018 (Department of Health and Social Care). Intellectual disabilities were highlighted by the working group.

Psychotropic Medication Scrutiny as a Part of Inspections

An alternative approach to legal requirements is to make psychotropic medication use a part of inspections and registration of service providers. In The Netherlands, the Dutch Health Care Inspectorate, which has extensive powers to investigate and

assess the quality of health services, prevention measures and medical products, receives reports on all restrictive and coercive interventions, including the use of involuntary medication. Part of the requirements since 2010 is for a mandatory medication review with a pharmacist. In the UK the Care Quality Commission a similar approach has been adopted with an expectation that the facility has a programme in place to minimise the use of psychotropic medications.

National Guidance

Concern about the inappropriate use of psychotropic medications prescribed for people with an intellectual disability has resulted in many guidelines. In the USA many of the initiatives to be more conservative with the prescribing of psychotropic medication were largely spurred on by the recommendations of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled persons (1990). 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 & Aman, 1998). The 10 dos included: '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/added to by monitor for metabolic syndrome): Review systematically and regularly: Strive for lowest optimal effective dose: Monitor use by peer or quality review. The 4 don'ts included: 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 prn. orders ('pro re nata' or 'as needed'), long-acting sedative/hypnotics, long-term hypnotics or anxiolytics, high antipsychotic doses and long-term anticholinergics (p. 67).

In 2000 the *American Journal on Mental Retardation* published an expert consensus guideline for the treatment of psychiatric and behavioural problems in intellectual disabilities (Rush & Frances, 2000). 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 maintenance maximum doses as in the 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*' (Deb et al., 2006).

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' (Deb et al., 2009).

Despite the numerous guidelines, however, serious concerns were 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 (South Gloucestershire Safeguarding Adults Board, 2012). The nation was scandalised by the expose by the television programme Panorama of systematic abuse of people with intellectual disability and autism. Following the television program, the UK Government requested the National Institute for Health and Care Excellence (NICE) to undertake a series of reviews of various aspects of practice in relation to intellectual disability and autism.

Prior to the scandal NICE in 2012 (NICE, 2012) had already issued guidance on autism: Autism-The management and support of children and young people on the autism spectrum (CG170). The key guidance in relation to psychotropics was:

- 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.
- 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
  - stop treatment if there is no indication of a clinically important response at 6 weeks.

In 2015 NICE issued '*Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*' NG11 (NICE, 2015).Their key guidance in relation to psychotropic medications was:

- 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

  - the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).
- Only offer antipsychotic medication in combination with psychological or other interventions.

In both CG170 and NG11 of the psychotropics only antipsychotics were considered to have any level of evidence sufficient to make a recommendation.

A Social Movement: STOMP

In July 2015 NHS England called together various stakeholders to discuss the findings from the various studies relating to the prescribing of psychotropic medication for people with an intellectual disability, autism or both and agree a way forward. It was clear that producing yet more guidance would not change the approach to prescribing psychotropic medications. For the five years prior to this a similar concern about the overuse of antipsychotics 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% (Health and Social Care Information Centre, 2012) in people with dementia.

In 2013 Manchester University (UK) published a report *Mobilising and organising for large scale change in healthcare "The Right Prescription"*: A call to action on the use of antipsychotic drugs for people with dementia (Boyd et al., 2013). It was felt that the issue of overmedication of people with an intellectual disability, autism or both met the criteria and was an appropriate methodology to use. The Manchester University team identified a number of factors that could assist in ensuring a good outcome from a call to action that were used as a template for the England programme. These included:

- There needs to be a clear, intolerable, situation, which galvanises people towards taking action.
- Resources are maximised through intensive preparatory work to align with performance levers and to identify role models and high level support.
- Flexibility is provided to allow the approach to evolve in response to the context.
- Strategy is utilised to enhance receptiveness of the organisation and resources available.
- Relationships are developed which cross organisational/professional/hierarchical boundaries.
- Reflection on the process is built in and becomes an iterative occurrence.
- Alignment is secured with organisational and performance drivers.
- Respected role models are identified.
- Coaching support forms one of the leadership behaviours.
- Social media can be utilised to enable additional access to resources and support.

- A baseline of data is provided.
- Metrics are identified at an early stage.
- Participants are drawn from a variety of organisations, dependent on the goals of the work. In addition, that the participants involved are supplemented by those from additional organisations, professions, etc. through a process of iterative reflection

The program to stop the overmedication of people with an intellectual disability, autism or both (STOMP) was launched on June 1st 2016 together with the Minister for Care for the UK government. The STOMP Intellectual Disabilities, Autism or both pledge was signed at a summit in London by the Royal Colleges of Nursing, Psychiatrists and GPs, the Royal Pharmaceutical Society, the British Psychological Society, NHS England and The Minister for Care. In England a very large number of people and organisations are involved with the care of people with an intellectual disability, autism or both. There are the people themselves; direct carers (both paid and unpaid); professionals, such as psychiatrists and nurses; organisations that fund and oversee the provision of care; organisations that provide support and advice to professionals, carers, families and others; organisations that advocate on behalf of the people; statutory organisations that oversee standards of care; and many others. Over the subsequent 2 years the aim of the STOMP team was to support and encourage organisations and individuals from a wide range of settings to pledge to do something about overmedication. There was no attempt to control or focus the initiatives that were many and varied. Some initiatives included: (a) The Royal College of General Practitioners (RCGP) undertook a launch of STOMP accompanied by the launch of a guidance document for GPs developed by NHS England in collaboration with a wide range of other organisations (NHS England, 2016a, 2016b). The guidance was aimed at GPs but was equally applicable to other professional groups. (https://www.england.nhs.uk/wp-content/uploads/2016/06/stopping-over-medication.pdf). (b) The Royal College of Psychiatrists issued guidance for psychiatrists called 'Psychotropic Drug Prescribing for People with Intellectual Disabilities, mental health problems and/or behaviours that challenge' (2016). (c) The Centre for Pharmacy Postgraduate Education (CPPE, 2017) developed a number of educational programmes for all pharmacists. (d) The Voluntary Organisations Disability Group (VODG) (2017) a national charity that represents leading not-for-profit organisations, NHS England and sector stakeholders took the lead and developed the STOMP pledge for social care. The resources (https://www.vodg.org.uk/campaigns/stompcampaign/) offered include a self-assessment template, access to the STOMP logo, advice on preparing to visit the doctor and other audit tools. (e) The Challenging Behaviour Foundation (CBF) (2018), a charity for people with severe learning disabilities whose behaviour challenges, was commissioned to develop a set of online and hard copy resources for families. The resources were based on a consultation that CBF carried out with over 100 families to find out about their experiences of medication and what would be helpful to them. These resources gave families helpful advice at each step of the journey, from the possible introduction to withdrawal from psychotropic medication. The resource is published on the CBF website. (http://medication.challengingbehaviour.org.uk/). (f) A large independent provider of care programmes for people with an intellectual

disability, autism or both (CMG, 2017) developed a best practice guide and launched it in the UK parliament. (g) A musical performance piece was developed by Inclusive pop group Mixit, following research with many families and people with an intellectual disability. The piece is based on someone's real life experience of overmedication of their daughter, and gets across all of the STOMP core messages in a fun but powerful way. This piece was commissioned by NHS England to be used around the country with professionals, providers, families and people with an intellectual disability. This has proven to be a powerful reminder for all regarding the need to prioritise this work as the people performing genuinely understand what the campaign means. Mixit have performed at many health and professional conferences

In addition to the many organisations is the complexity of the prescribing of the medication. In England most prescribing is undertaken by general practitioners (GPs). Initiation of prescribing is mostly undertaken by specialists who refer the person back to the GP when the situation or illness is stabilised. Alternatively, the specialist makes recommendations and the treatment is prescribed solely by the GP on the recommendation of a specialist. It is common for a person with an intellectual disability, autism or both to receive advice about their care from more than one specialist and although the overall prescribing is undertaken by GPs. To bring about a review or change to the prescription requires a degree of collaboration and commitment from a number of medical and other healthcare professionals.

In the two years following the launch of STOMP over 500 organisations pledged to undertake some initiative to reduce overmedication of people with an intellectual disability, autism or both. A fuller account of the programme was provided by Branford et al. (2019a, 2019b). The strategy involved people from every facet of the care of the individual with intellectual disabilities, autism or both so that change would happen.

The question was—did all this activity make any difference- did it actually result in a large-scale reduction in the use of psychotropic medication? A number of surveys demonstrated that STOMP was very effective at raising awareness of the issue of overmedication within the intellectual disability and autism arenas, however, had it changed prescribing?

Public Health England (Mehta & Glover, 2019) undertook to develop a methodology to assess the impact of STOMP on GP prescribing using a GP database. For adults with intellectual disabilities, some changes in prescribing trends were seen following the launch of STOMP in the intended direction; however, it was not possible to say whether or not these were the result of the program. It is still early days yet to see whether this approach has a significant and long-term impact or whether it is a component that needs to be combined with other approaches.

Mental Health and Autism Diagnoses as an Exclusion

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 psychotropics is appropriate or not. The presence of

a mental health diagnosis in combination with intellectual disabilities, autism or both is also a key factor in whether the individual will be included in a medication review programme. It is widely believed that people with an intellectual disability, autism or both have significantly higher rates of mental illnesses and such illnesses often prove refractory to treatment (Cooper et al., 2007).

In addition to considering the role of psychotropics for the management of challenging behaviours and for autism, in 2016 NICE addressed the issue of mental health problems; however, many of the studies on mental health had categorised challenging behaviours as mental illnesses. Despite this methodological problem, NICE (2016) made two key recommendations which were: (a) "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"; and (b) "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 annually document the reasons for continuing the prescription if it is not reduced or discontinued". The inconclusive nature of this guidance and concern about the validity of so many of the diagnoses accumulated by people with an intellectual disability, autism or both provides an added dimension of complexity to any prospective review programme. If any person with any mental health diagnosis (including autism) is to be excluded then large numbers of people who may be receiving unnecessary and inappropriate medication will continue to do so without justification.

Financial Incentives

Some healthcare systems provide financial incentives to organisations or individuals to encourage a particular health gain or activity. In the UK an example is the Coverage, Quality, and Impact Network (CQUIN) (NHS England 2020) developed by the Commissioning for Quality and Innovation. The CQUIN is a framework within the NHS that supports improvements in the quality of services and the creation of new, improved patterns of care. Choice about which incentives to adopt can be optional. General practices can also be incentivised to undertake additional initiatives through the General Medical Services contract Quality and Outcomes Framework (NHS England/BMA 2019) and, under another scheme, NHS organisations can bid to gain the time of a pharmacist specifically trained to undertake reviews. In the UK this system of financial incentives was widely adopted to encourage care home review of antipsychotics prescribed to manage behavioural problems in dementia. This activity both preceded and was in addition to the Dementia Alliance (2011) "call to action" programme. Although such financial incentives

achieve an increase in reviews and changes to prescribing practice it is unclear whether the change is maintained when the financial incentive ends or the specialist reviewer is withdrawn. Also, if the reviewer is not clearly embedded in the core activity of the organisation it is possible that the reviews will be ignored. For example, Zaal et al. (2016) undertook a medication review pilot study using STRIP in adults with intellectual disability. In total, 127 medication-related problems were detected, mainly potentially inappropriate or unnecessary medications; however, after six months, only 15.7% of the interventions were implemented. Their conclusion was that although medication review using STRIP seems feasible in adults with an intellectual disability and identified medication-related problems, the implementation rate of suggested interventions was low. They recommended that to improve the implementation rate, the treating physician should be involved in the review process. A similar project was undertaken in the Manchester area of the UK (Buckley, 2017). A specialist pharmacist was employed to visit GP practices and identify from their prescribing systems people with an intellectual disability who were on inappropriate psychotropics and provide the general practitioners with guidance on withdrawal; however, again, few of the reductions took place.

Financial incentives are a fundamental part of many national healthcare systems. Whether such incentives are the key to ensuring a greater uptake of systematic reviews of psychotropic medications remains unclear; however, the competition from other medical specialities demanding equally pressing healthcare improvements is intense. Regrettably, it seems to need a scandal to move intellectual disabilities and autism to the front of the queue.

Multidisciplinary Team Reviews

Most of the medication review programs included in the systematic reviews by Sheehan and Hassiotis (2016) and Nabhanizadeh et al. (2019) indicated that the interdisciplinary or multidisciplinary team was the body that undertook the reviews and oversaw the programme. The importance of the composition of the team is unclear. For many of the programmes a trained clinical pharmacist maintained the records and undertook the reviews. The other members included physicians, nurses, neurologists, psychiatrists, psychologists and caregivers. What is unclear is whether a largely medical approach involving pharmacists, nurses and physicians was more successful than a broader team involving psychologists, educationalists, managers of various descriptions, advocates, and other lay members.

Following the publication of the WHO (2017) global safety challenge the reduction of polypharmacy in the care of the older adult has become a focus for many studies. The term ”deprescribing” has become widely adopted. Reeve et al. (2014) undertook a review of the deprescribing process in older adult care and identified 5 key elements which were: “Obtaining a complete medication history, identifying medicines that are potentially inappropriate, evaluating the possibility of reducing or discontinuing the medicines, Implementing a plan for reducing or discontinuing

the medicines, ongoing monitoring documentation and support". Gupta and Cahill (2016), focussing on deprescribing in mental health, extended these elements. They felt the extra elements reflected a need to have a greater focus on making the process a therapeutic alliance and listening to the patient's experience of and attitudes toward the medication. They included the following three additional steps: "assessing the timing and context exploring the patient's experience, attitudes and meaning around medication setting a framework for the deprescribing intervention". Although there is no similar work to identify the elements necessary for a successful medication review within intellectual disability or autism it is likely that the added dimension of exploring the experience of those caring for the person and involving them in the process would be an additional key element.

Knowledge and Participation in Decision Making

One of the dangers of prescribing psychotropic medications for people with intellectual disability, autism or both is that with time all those involved in providing the day to day care of the individual become disempowered and feel unable to take action to stop the medication. In a study by Singh et al. (1996) of four USA State facilities many of the nurses and other professionals felt they has little influence over decisions to initiate or discontinue medications and parents almost no influence. Over 80% of staff felt that training was inadequate and 96% desired some continuing education.

Once the care of the individual has been referred from the specialist or crisis team back to the general practitioners and community pharmacist, they may also feel that as if the original recommendation came from a specialist it cannot be challenged or that the specialist is only accessible to deal with crises. Many specialist teams have long waiting lists for referrals and limited access to experienced clinical pharmacists. It sometimes appears that the whole system is geared toward dealing with crises and short interventions and adding medications and general practitioners may feel they do not have the skills and training or the time to take on a long-term commitment to reduce medication prescribed in a crisis.

There have been a number of studies looking at factors associated with a preparedness to deprescribe medications in the care of the older adult (Anderson et al., 2014). Their key finding was that the decision to stop a medication by an individual is influenced by multiple competing barriers and enablers. Knowledge of these will aid in the development of a deprescribing process, particularly in approaching the topic of cessation and what process should be used. Anderson et al. (2014) undertook a qualitative evaluation of 21 studies that explored primary care physicians' perspectives on managing older, community-based adults. Barriers and enablers to minimising inappropriate prescribing emerged within four analytical themes: (1) problem awareness; (2) inertia secondary to lower perceived value proposition for

ceasing versus continuing; (3) self-efficacy in regard to personal ability to alter prescribing; and (4) feasibility of altering prescribing in routine care environments given external constraints. factors. The first three themes were intrinsic to the prescriber (e.g., beliefs, attitudes, knowledge, skills, behaviour) and the fourth was extrinsic (e.g., patient, work setting, health system and cultural). A study from The Netherlands focussed on discontinuation of medications of people with an intellectual disability (de Kuijper & Hoekstra, 2017). They investigated physicians' reasons not to discontinue long-term, off-label antipsychotics. Of the 3299 clients of six large service providers, 977 took one or more antipsychotic medications. Physicians were willing to discontinue their prescriptions in 51% of cases, varying from 22% to 87% per service provider. The variables ”a living situation with care and support” and ”challenging behaviour” were associated with a higher chance of discontinuation. The main reasons for decisions not to discontinue were concerns for symptoms of restlessness, the presence of an autism spectrum disorder, previously unsuccessful attempts to discontinue and objections against discontinuation by legal representatives.

Behaviour and Other Monitoring Tools

Some of the guidelines mandated in the USA for institutions for people with an intellectual disability have involved the regular monitoring of behaviour and side effects, particularly tardive dyskinesia. A wide range of monitoring systems were devised together with validated rating scales. The *Dyskinesia Identification System: Condensed User Scale* (Sprague et al., 1989) rating scale for tardive dyskinesia and the *Aberrant Behaviour Checklist*) (Aman & Singh, 1986) were the most widely reported; however, a major criticism of many of the institutional studies was the lack of objective measures of behaviour during the process of medication change (Sheehan & Hassiotis, 2016).

Availability of Alternatives

Any programme that solely encourages the removal of psychotropic medications without plans to deal with the problem behaviour is likely to be unsuccessful; however, what remains unclear from many of the accounts of medication review programmes is what strategies were adopted to prevent the likelihood of a deterioration or when it occurred what actions could be taken to prevent the re-instatement of the medication. Two strategies have emerged: (1) The prescribing of an alternative psychotropic rather than an antipsychotic; and (2) Training in or availability of alternative non-pharmacological programmes to manage the behavioural problem.

Alternative Psychotropics

Luchins et al. (1993) identified the use of alternative psychotropic medications as the most significant variable in reducing the use of antipsychotics in a 75-bed facility in Illinois, USA. They recorded the change to the prescribing of antipsychotics over a five-year period. For those with a diagnosis of psychosis the dose of antipsychotic increased over the five-year period for those who received an alternative psychotropic medication the dose of antipsychotic decreased. Whereas no individual was receiving an alternative psychotropic at the beginning of the period, 41 did receive alternate psychotropic medications at the end including lithium (26), carbamazepine (9), buspirone (9) and propranolol (2).

To what extent the replacement of antipsychotics with alternative psychotropic medications has occurred in other programs is often unclear. Large database surveys (Glover et al., 2015; Mehta & Glover, 2019) have shown a significant increase in the use of antidepressants, antiepileptics and benzodiazepines both regularly prescribed and on an 'as required' basis and prescribing multiple psychotropic medication becoming a feature. This also adds to the complexity of medication review programmes.

Alternative Non-Medication Approaches

It is unclear from most of the accounts of medication review and reduction programs whether other non-medication strategies were put in place to manage problem behaviours prior to the commencement of the programme or upon the emergence of such problem behaviours during the program. Fielding et al. (1980) reported that prior to their medication reduction program a psychologist who specialised in behavioural analysis had developed and supervised programmes for each individual but that these were put on hold during the period of medication withdrawal. Findholt and Emmett (1990) described the composition of their interdisciplinary team as such that it could act as a crisis intervention team if problems occurred. It is interesting to note that over the seven-year period not only did they achieve a reduction in the use of antipsychotics (41–12%), they also reduced antidepressant use (14–2%) and anxiolytic use (13–3%) at the same time.

Although there are no studies that set out specifically to test whether the implementation and training of an alternative such as positive behavioural support can enable psychotropic medication reduction the two are linked in the STOMP review clinic in Sunderland in the North East of England (Branford et al., 2019b) where there is a collaboration between a prescribing pharmacist and the Positive Behavioural Support (PBS) (2015) Team. Staff are supported by the PBS team if problems develop, and trained to collect behavioral data. A functional assessment of behaviours is undertaken and a behavioural support plan developed. For the medication deprescribing plan the PBS team refers to a prescribing pharmacist who works

with the person taking medication, their staff and family members to deprescribe the psychotropic (mostly antipsychotics). The process is fully supported by the PBS team and behavioural data was used to guide prescribing decisions. The view of staff, family and the person was regularly obtained to guide decisions. No targets or timescales were set when the work was initiated. To date, a majority of the people referred to the clinic have come off their medication altogether and others are undergoing a reduction programme.

Withdrawal Regimens

There are a number of approaches to withdrawing psychotropic medications including: (1) just stopping, (2) tapering according to a predetermined schedule, (3) substituting an alternative medication that is easier to reduce, and (4) gradual reduction according to the needs and opinion of the patient or carers. Sheehan and Hassiotis (2016) in their systematic review of antipsychotic review programmes could not recommend any specific approach to withdrawal of psychotropic medication. Although some studies used pre-designed schedules, others provided for the reduction to go at a pace that was variable according to the situation. The advantage of a more rapid reduction is that it is achieved in a relatively short period but the disadvantage is that it risks withdrawal problems. A slow reduction may lose the enthusiasm of the participants and fail to reach a conclusion.

A bimodal approach was adopted by Fielding (1980) using fifty-day assessment periods. For the first 20 days the medication of 192 participants remained the same but with behavioural monitoring. For the following 30 days the individual received no psychotropic medication and if the score of problem behaviours from the behaviour monitoring doubled the medication was restarted. At the end of the first 50-day period only 108 individuals were receiving psychotropic medications. A number of months later the process was repeated resulting in 83 patients remaining on medication. Sixty-eight of the remaining 83 were then entered into a new program of gradual dose reductions and all but eight achieved permanent dose reductions.

Many guidelines and algorithms are available. For example, the deprescribing tools provided by the Australian New South Wales programme (http://www.nswtag.org.au/deprescribing-tools/) included the following psychotropic medicines: (1) benzodiazepines and hypnotics, (2) antipsychotics for treatment of behavioural and psychological symptoms of dementia; (3) selective serotonin reuptake inhibitors and serotonin noradrenaline reuptake inhibitors and (4) tricyclic antidepressants. These guidelines were developed in the context of older adult care rather than care for individuals with intellectual disabilities or autism or both. Thus, although these guidelines are useful aids the rate of withdrawal should always be directly informed by the direct carers or, if possible, by the patient themselves. If the rate of dose reduction is considered to be too rapid there should always be the flexibility to change it or even to go back a couple of steps. For some people this will make the process very extended tying up much prescriber time. With the advent of multiple

psychotropic medication prescribing there is also the issue of which medication to withdraw first. Again, there is little or no empirically-based guidance. Do you remove the medications that appear to have no benefit first or focus on an area of concern first and hope the rest get removed later? If the focus is to remove problematic medication rather than unnecessary medication the STRIP rating scale developed by Zaal et al. (2016) has been developed to assist.

Deprescribing in care of the older person is far more developed with an ever-increasing number of scales, tools, algorithms, risk scores and guidelines (Reeve et al., 2013, 2014). Scott et al. (2017) identified four types of tools to assist deprescribing: (1) Screening tools or criteria that help identify medications more likely than not to be inappropriate for a given set of circumstances. These include the Beers' (2012) criteria, and the STOPP tool (Gallagher et al., 2008). (2) Risk scales which estimate the global anticholinergic and sedative burden of all the medication being used by individual patients. These include the Drug Burden index and *Anticholinergic Risk Scale*. (3) Risk scores or clinical prediction rules which estimate the risk of adverse drug events in individual patients; and (4) Deprescribing guidelines directed at particular medications (or classes) which identify clinical scenarios where a particular medication is likely to be inappropriate and how to safely wean or discontinue it. It is unclear how useful these are in the context of people with intellectual disabilities, autism or both.

Withdrawal Problems and Relapse

There is a confusing terminology associated with withdrawal problems. Classically medications such as opioids and benzodiazepines are regarded as addictive in that the person suffers a degree of craving when they stop the medicine and that the withdrawal is associated with a range of symptoms that they did not experience before. It was many years before there was general agreement of a benzodiazepine withdrawal syndrome because it was widely thought that the symptoms suffered were just a return of pre-existing anxiety or insomnia.

There is a similar debate underway with the selective serotonin reuptake inhibitors where difficulties in withdrawing the medication are frequently experienced (Davies & Read, 2019). Recently, Horowitz and Taylor (2019) disputed the current guidelines recommending short tapers between 2 and 4 weeks, down to therapeutic minimum doses, or half-minimum doses, before complete cessation. They maintained that these tapers show minimal benefits over abrupt discontinuation, and are often not tolerated by patients. They maintained that tapers over a period of months and down to doses much lower than minimum therapeutic doses have shown greater success in reducing withdrawal symptoms.

Of the various psychotropics prescribed for people with an intellectual disability and autism the withdrawal effects of the antipsychotics have been the most widely studied. Withdrawal of most of the older antipsychotics increased the risk of the emergence of tardive dyskinesia and other dyskinetic movements and for those with

antimuscarinic side-effects the emergence of short-term cholinergic symptoms during the first week after dose reduction. There have been little or no studies of the withdrawal effects of the antidepressants with this population and most of the studies of withdrawal of valproate and the other antiepileptics have been in the context of epilepsy.

Finally, there is the issue of relapse. Does the withdrawal of the psychotropic precipitate relapse? Many withdrawal problems are associated with the various psychotropic medications commonly prescribed for people with an intellectual disability, autism or both. Some problem behavior may worsen in the short- or long-term with the reduction of the psychotropic medication. Part of the development of a deprescribing plan is an understanding of these problem behavior and experiences and whether the person, carers and family have strategies in place to manage them. Alternatively, other problem behaviours may improve simply because being a part of a study that requires numerous assessments inadvertently increases the attention given to the person. For example, the carers may reduce the demands on the person during a medication withdrawal leading to the conclusion that the withdrawal was successful only for the problems to re-emerge when demands are placed on them again. Yoo et al. (2003) in a single case study on an individual participating in a clinical trial of risperidone postulated that environmental variables can determine the effects of pharmacotherapy

Table 1 identifies the withdrawal problems associated with the various psychotropic medications. There is no reason to believe that those with intellectual disabilities or autism will suffer withdrawal problems to a greater or lesser extent than the general public, however it presents differently.

Table 1 Withdrawal problems associated with psychotropic medications

Psychotropic medication being withdrawn	Reported Presentations	Guidance if occurring
All Antipsychotics	Dopaminergic syndrome Withdrawal dyskinesia, akathisia, dystonia, tardive dyskinesia	Slow rate of withdrawal
Chlorpromazine, clozapine, olanzapine, quetiapine	Cholinergic syndrome Nausea, vomiting, headache, restlessness, anxiety, insomnia, fatigue, malaise, myalgia, diaphoresis, rhinitis, paraesthesia, loose bowels	Generally occur within first week or two of dose reduction. No specific recommendations
Clozapine	Rebound psychosis Psychosis above pre-treatment levels, illusions, hallucinations, catatonia	Represcribe clozapine
Antimuscarinics used to manage extrapyramidal side effects of older antipsychotics	Cholinergic syndrome Nausea, vomiting, headache, restlessness, anxiety, insomnia, fatigue, malaise, myalgia, diaphoresis, rhinitis, paraesthesia, loose bowels	Withdraw slowly May take up to 3 months to withdraw successfully

(continued)

Table 1 (continued)

Psychotropic medication being withdrawn	Reported Presentations	Guidance if occurring
Benzodiazepines	Benzodiazepine withdrawal syndrome: Abdominal cramps, agoraphobia, increased anxiety, physical symptoms of anxiety (muscle tension, tight chest, palpitations, fast heartbeat, sweating, trembling or shaking) blurred vision, depression, difficulty sleeping, dizziness, face and neck pain, headaches, inability to concentrate, increased sensitivity to light, noise, touch and smell, loss of interest in sex, loss of appetite, nausea, nightmares, panic attacks, restlessness, sore eyes sore tongue and metallic taste, tinnitus tingling in the hands and feet, unsteady legs, vomiting, weight loss. Severe withdrawal symptoms can include: Burning sensations in the skin, confusion, depression (severe), depersonalisation (feeling detached from your surroundings), derealisation (feeling out of touch with reality), hallucinations, memory loss, muscle twitching, paranoia and delusions, seizures.	British National Formulary (n.d.) recommends transfer to diazepam and slowly withdraw
Hypnotics	Insomnia, anxiety, euphoria irritability, tremor, inner restlessness, speech difficulties, abdominal pain, hypertension, tonic-clonic seizures, and confusion/ disorientation/delirium	Slow taper and introduce sleep hygiene
Tricyclic antidepressants	Anxiety, fast or irregular heartbeat, flu-like symptoms, insomnia, low blood pressure, problems with movement, restlessness, spontaneous orgasm strange dreams	Slow withdrawal
Selective Serotonin Reuptake Inhibitors and related antidepressants	Dizziness or vertigo, electric shock sensations in head, flu-like symptoms, problems with movement, sensory disturbance (such as smelling something that isn't there), stomach cramps, strange dreams, tinnitus	Most sources suggest that withdrawal effects are short lived however recent concerns suggest much slower withdrawal
Melatonin	None reported	
Methylphenidate	Fatigue and disturbed sleep patterns are common signs of methylphenidate withdrawal. Users undergoing detoxification also report cravings for methylphenidate. Some users develop depression after halting methylphenidate use.	Treat sleep disturbance with short term hypnotic
Lithium	Unclear if a specific withdrawal syndrome but concerns about withdrawal precipitating relapse	Slow withdrawal

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