Introduction

Anti-psychotic medications (such as risperidone, olanzapine, and haloperidol) form an appropriate, and important, part of the treatment of the distressing symptoms that characterise and are associated with mental health conditions (such as bipolar disorder and schizophrenia), including those of adults with learning disabilities. However, anti-psychotic medication has also been used for people without any mental health diagnosis, to manage perceived ‘challenging’ and/or illegal behaviour. While this matter has been of long-standing concern in the UK, and in some other well-resourced countries (de Kuijper et al., 2010; McGillivray and McCabe, 2004; Matson and Neal, 2008), it has received much greater attention since the introduction of the government’s Transforming Care agenda (see Department of Health, 2012; Glover et al., 2014). Moreover, the focus has now extended beyond anti-psychotics to the use of other, so-called ‘psychotropic medication’ (see British National Formulary (BNF), Chapter 4, 2016) in the absence of (i) an appropriate mental health condition; or (ii) a neurological condition, such as epilepsy, for which anti-convulsant medication is the first-line treatment (NICE, 2016). The medications of interest include sedatives and anxiolytics (e.g., lorazepam), anti-depressants (e.g., citalopram, fluoxetine), and anti-convulsants (e.g., sodium valproate, carbamazepine) where these are used as mood stabilisers rather than to treat epilepsy.

In the UK, the recent concerns about the use of medication have had two major consequences. First, a range of practice guidelines have been developed, aimed primarily at General Practitioners (GPs) and psychiatrists (NICE guideline NG11, 2015; NICE Guideline NG54, 2016; NHS England, 2017; Royal College of Psychiatrists, 2016), focusing particularly on the use of psychotropic medication for the management of perceived behavioural problems. Importantly, the guidelines emphasise the importance of a multi-disciplinary approach to managing such behaviour, with medication being considered when (i) psychological or other interventions alone have not been effective, (ii) when treatment for co-morbid physical and/or mental health conditions is needed; and/or (iii) the risk to the service user or others is high. They also emphasise the importance of reviews (at 6 weeks, 3 months, and every 6 months thereafter, NHS England, 2017) of the benefits of continuing medication.

Secondly, our knowledge about patterns of prescribing of psychotropic medications to people with learning disabilities in the UK has improved considerably (e.g., Deb et al., 2015). Two recent studies (Glover and Williams, 2015; Sheehan et al., 2015), using General Practitioner (GP) records, are especially relevant. Both examined medication prescribing patterns for very large numbers of people with learning disabilities (N > 17,000 in England; Glover and Williams, 2015 and N > 33,000 across the UK; Sheehan et al., 2015). The data are complex: they rely on correct identification of people with learning disabilities; accurate recording of the rationale for prescribing and ages; the acknowledgment that some medications are prescribed for more than one reason; that some medicines may be being prescribed to prevent relapse; and so on. Nevertheless, there are two striking findings:

(i) people with learning disabilities are being prescribed psychotropic medication in the absence of a condition that would justify its use. Sheehan and his colleagues found that fewer than a third (29%, N=6,503) of those being prescribed anti-psychotic medication had a recorded mental health condition (including epilepsy)
for which such treatment would be appropriate. Similarly, with regard to anti-depressants, Glover and Williams (2015) suggested that this class of medications was being prescribed to far more individuals than had a recorded affective disorder;

(ii) psychotropic medication is being prescribed for the management of behavioural needs alone. For example, Sheehan et al. (2015) found that more than a third (35%) of people with recorded behavioural needs were prescribed anti-psychotic medication despite having no reported mental health or neurological condition for which such medicine would be appropriate. Indeed, among people with learning disabilities, taking into account the presence of a diagnosis relating to a neurodevelopmental, neurological or neurodegenerative condition (autism, epilepsy, or dementia), those with behavioural needs reported in their GP records were more than twice as likely as those without to be prescribed anti-psychotic medication.

At least, these findings suggest poor clinical practice. In some cases, they raise concerns about the violation of the human rights of people with learning disabilities (for example, the prohibition of discrimination under Article 14 of the, Human Rights Act 1998; see Wadham et al., 2007).

These two important studies of GP prescribing will have included, but will not have been limited to, individuals who are in contact with specialist community teams for adults with learning disabilities (CTLDs hereafter). It is rare for medication to be prescribed directly by CTLDs; instead, psychiatrists in these teams provide advice to GPs, normally in the form of a medical letter. The aim of the current study was to examine the use of anti-psychotic and other psychotropic medication by service users one year after their referral to a county-wide specialist community learning disabilities service for assessment, treatment and/or support for a mental health and/or behavioural need. In particular, we sought to investigate the extent to which the use of such medication was based on a recorded condition for which it would be appropriate.

Methods

Ethics
Ethical approval for this study was provided by NRES 12/EE/0372. Following the Mental Capacity Act (England and Wales) 2005 (MCA), there was a presumption that people with learning disabilities, as well as their care-givers, had the capacity to give or withhold consent to participation. For individuals who were assessed as lacking the relevant decision-making capacity, advice about their participation was sought from consultees (s. 30ff,MCA).

Context
This study was undertaken as part of a programme of research investigating the work of five locality-based CTLDs and, specifically, their work with adults with learning disabilities who possibly had additional mental health and/or behavioural needs. These CTLDs formed part of a county-wide service, based in the East of England and, between them, covered both urban and rural areas, some of which experienced significant deprivation. At the time of data collection, all the teams were multi-disciplinary and inter-agency, with: (1) NHS health care
provides in psychiatry, arts therapies (art and music), clinical psychology, learning disability
nursing, occupational therapy, and speech and language therapy; and (2) local authority
care managers (some of whom were qualified social workers) commissioning and monitoring
social care provision. Further details are provided in Clare et al. (2016).

Participants
There were two groups of participants. First, adults (aged 18 years or more) with learning
disabilities, recruited as soon as possible after being referred to, and accepted by, one or
another of the service’s five specialist community teams (CTLDs) for assessment, treatment
and/or support for a possible mental health and/or behavioural need. All were living in
community settings: on their own, with partners or family members, or with other people with
learning disabilities. There was considerable variation in the extent to which participating
service users received paid or informal social care support. The second group of participants
were care-givers (family members or paid support workers). Where possible, these
individuals were nominated by the participants with learning disabilities as people who knew
them well.

Measures and data collection
The data were collected by practitioner researchers who had previously worked (but with one
exception) no longer worked in the service, and included:

1. The British Picture Vocabulary Scale – 3rd Ed. (BPVS-III, Dunn et al., 2009). This is a
   brief measure of understanding of single words, covering a wide range of ability (from
   an age equivalent of 2 years 6 months to 16 y 11 m). It was used to provide a rough
   estimate of participants’ intellectual functioning. Participants completed the measure
   as soon as possible after recruitment.

2. Relevant ‘diagnoses’. Twelve months after recruitment, participants’ records held by
   the relevant CTLD were used by the practitioner researchers to provide information
   about the presence or absence of mental health conditions or epilepsy (‘diagnoses’) for
   which advice about prescribing psychotropic medication might have been given.

3. The Client Service Receipt Inventory (CSRI, Beecham and Knapp, 2001; Strydom et
   al., 2010) was developed for costing interventions. It was used here to collect data
   from paid or informal care-givers (and sometimes service users themselves, if they
   received only minimal support) about participants’ psychotropic medications in the
   three months preceding follow-up, 12 months after recruitment. It was assumed that,
   by this time, any assessments and/or reviews of medication would have been completed by the CTLDs and that advice to GPs about changes in prescribing would
   have been provided by the relevant psychiatrist. As far as possible, we checked
   service users’ CTLD records to find evidence of such advice. The reported
   medications were classified and the reported dosages checked. Chapter 4 of the
   British National Formulary (BNF; https://www.bnf.org/products/bnf-online), which
   provides the most up-to-date guidance for psychiatrists, pharmacists, GPs and others
   about psychotropic medication, was used.

Results
Relevant data were available for 54 individuals from the 322 relevant referrals made to the
CTLDs. Initially, consent (or favourable advice from a consultee) was given by 80 service
users; 189 did not respond; 53 were excluded because they did not consent (or their
consultee’s advice regarding participation was unfavourable). Twelve months later, three of the participants had died; another six had withdrawn; and 17 people were either uncontactable (e.g., they had moved to a different county) or it was not possible to obtain valid data (e.g., neither the care-giver nor the service user was able to provide information).

**Service user characteristics at referral**

The 54 participants (28 men and 26 women) were overwhelmingly from white British backgrounds and ranged in age from 18-67 years (mean age: 39 years; s.d. 15). Fifteen people, all with what appeared to be severe learning disabilities, were unable to complete the measure of understanding of single words (BPVS). The median tested raw BPVS score of the remaining 39 was 104 (range: 4-165; age equivalent: 6 years 10 months; 95% CI: 6 y 2 m to 7 y 5m), suggesting that the sample, though small, was diverse.

**Prescription of psychotropic medication 12 months after referral**

**What were the service users’ assessed ‘diagnoses’?**

All 54 participants met the necessary access criteria for specialist health services for people with learning disabilities. Seventeen participants had a current or past, (for three individuals) recorded diagnosis of a mental health condition, and a further seven had a diagnosis of epilepsy (two of whom had also been diagnosed with a mental health need). Together, these 24 people comprised 44% of the sample. Psychotropic medication could have been appropriate for all of them. A further nine (17%) participants had a behavioural need on its own or in conjunction with another neurodevelopmental (autism and/or ADHD) or degenerative condition, while another six (11%) had a neurodevelopmental or degenerative condition only. The remaining 15 (28%) had learning disabilities but were not recorded as having any other condition for which psychotropic medication might be appropriate.

**What psychotropic medications were recorded?**

Twelve months after referral, it appeared that 41 (76%) of the 54 participants were using regular psychotropic medications, of whom about a quarter (24%, n=10) were also taking PRN medication. One additional person was using PRN medication on its own. Table 1 shows the number of participants using each medication, categorised according to Ch. 4 of the British National Formulary, 2016.
Table 1: The use of different psychotropic medications (categories from Chapter 4, British National Formulary, 2016) by participants (numbers in brackets indicate the number of participants using each medication)

<table>
<thead>
<tr>
<th>BNF categorisation</th>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4.1 All hypnotics and anxiolytics</strong></td>
<td></td>
</tr>
<tr>
<td>4.1.1 Hypnotics</td>
<td>Melatonin (2)</td>
</tr>
<tr>
<td>4.1.2 Anxiolytics</td>
<td>Lorazepam (4)&lt;sup&gt;1&lt;/sup&gt;, Diazepam (1)&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>4.2 All antipsychotics</strong></td>
<td></td>
</tr>
<tr>
<td>4.2.1 Antipsychotic Drugs</td>
<td>Sulpiride (1), Chlorpromazine Hydrochloride (1)</td>
</tr>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; Generation</td>
<td>Aripiprazole (2), Quetiapine (2) Olanzapine, (3), Risperidone (8)</td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; Generation</td>
<td>Haloperidol (1) Lithium carbonate (2)</td>
</tr>
<tr>
<td>4.2.2 Antipsychotic depot injections</td>
<td></td>
</tr>
<tr>
<td>4.2.3 Drugs used for mania and hypomania</td>
<td></td>
</tr>
<tr>
<td><strong>4.3 All antidepressants</strong></td>
<td></td>
</tr>
<tr>
<td>4.3.1 Tricyclic and related antidepressant drugs</td>
<td>Amitriptyline (1)</td>
</tr>
<tr>
<td>4.3.3 Selective serotonin reuptake inhibitors</td>
<td>Sertraline (9), Citalopram (8), Fluoxetine (6)</td>
</tr>
<tr>
<td>4.3.4 Other antidepressant drugs</td>
<td>Mirtazapine (2), Venlafaxine (1),</td>
</tr>
<tr>
<td><strong>4.8 All antiepileptic drugs</strong></td>
<td></td>
</tr>
<tr>
<td>4.8.1 Control of the epilepsies</td>
<td>Sodium valproate(3), Levetiracetam (3),</td>
</tr>
<tr>
<td>4.8.2 Drugs used in status epilepticus</td>
<td>Topiramate (3), Carbamazepine (2), Epilim chrono (2), Phenobarbital (1), Phenytoin (1), Lamotrigine (4)</td>
</tr>
<tr>
<td></td>
<td>Clobazam (1) Zonisamide (1), Clonazepam (1), Buccal midazolam (2), Lorazepam (2)&lt;sup&gt;2&lt;/sup&gt;, Diazepam (1)&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>1</sup> Both medications were only to be used as required (PRN) rather than regularly; <sup>2</sup> Where these ‘as required’ medications were given to people with a diagnosis of epilepsy, it was assumed that they were being used to treat status epilepticus (as recommended by NICE, 2016).

The pattern of psychotropic medication use of the participants appeared unexceptional: none of those with a mental health condition (such as a bipolar disorder) and/or epilepsy was receiving medication that, when checked against the British National Formulary (BNF, 2016), could be considered inappropriate. The reported dosages of each medication were also checked against the BNF recommendations: not a single one was recorded as being used at
higher than the recommended dose. Polypharmacy (prescribing more than one medication to treat co-existing conditions) was most evident among those with a diagnosis of epilepsy. Where service users were taking more than one medication in the same class, it was not possible to ascertain whether this was long-term or was a snapshot of a process of change.

What medications were being used by those with no recorded mental health or neurological condition?

The use of psychotropic medications has been of most concern when prescribed in the absence of an appropriate mental health need or neurological condition such as epilepsy. For this reason, we examined their use by the 30 participants with no additional current or past diagnosis: that is, only those with an additional developmental (autism, ADHD) or degenerative (dementia) condition on its own; or only a behavioural need with or without an additional developmental or degenerative condition. Table 2 shows the data.

Table 2. Psychotropic medications recorded by participants with no current or past additional conditions, an additional developmental or degenerative condition only, or a behavioural need with or without an additional developmental condition

<table>
<thead>
<tr>
<th>Additional conditions</th>
<th>No. of participants</th>
<th>No. with recorded psychotropic medications</th>
<th>No. of different psychotropic medications</th>
<th>No. with recorded regular psychotropic medication</th>
<th>No. with recorded as required (PRN) psychotropic medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>None current or past</td>
<td>15</td>
<td>8</td>
<td>1-2</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Autism/ADHD/dementia only</td>
<td>6</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Behavioural need (with or without autism/ADHD/dementia) only</td>
<td>9</td>
<td>6</td>
<td>1-3</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

More than half (53%, n= 8) of the fifteen participants with no recorded additional diagnosis, apart from a learning disability, were reported to be using regular psychotropic medication (mainly anti-depressants). Two-thirds of those with an additional developmental or degenerative condition (67%) or behavioural need (67%) also seemed to be receiving psychotropic medication. Only participants with an additional behavioural need were using as required medication.

Discussion

In order to complement recent studies using very large samples of adults selected from a large database of GP records (Sheehan et al., 2015) or because they were entitled to annual health checks by GPs (Glover and Williams, 2015), we carried out a small descriptive study.
in a county-wide service comprising five locality-based specialist community teams (CTLDs). The aim was to document participants’ recorded use of psychotropic medication, that is, medication that affects a person’s mental functioning through action on the Central Nervous System, twelve months after they had been accepted by the study for assessment, treatment and/or support for a putative or diagnosed mental health and/or behavioural need.

The available data indicated that more than three-quarters (77%, n=42) of the sample of 54 participants, were using regular and/or as required (PRN) psychotropic medication. Of these, just over a half (57%, n=24) had recorded mental health or neurological conditions that would, in principle, have justified the use of these kinds of medication and, indeed, could have been life-saving. In contrast with the findings of Glover and Williams (2015), no regular or as required medication was being used above its recommended dose.

The overall findings were consistent with those of the two previous, very large, studies (Glover and Williams, 2015; Sheehan et al., 2015). There was a discrepancy between the number of participants using psychotropic medication and the presence of a recorded mental health condition or epilepsy. There were 18 participants (33% of the whole sample) who were reported as using one or more psychotropic medications, either regularly and/or as required (PRN), in the apparent absence of any condition that would have justified its/their use. There was, therefore, evidence that psychotropic medication was ‘overused’ (Sheehan et al., 2015, p. 1).

The study reported here had a number of limitations: the sample was small, and we make no claim that it was representative even of the service users seen by the five CTLDs in the learning disability service. There were particular difficulties in recruiting men and women who needed permission from a consultee (a family member) to participate but were not living with their families; many paid support workers were reluctant to take on this role. For service users with mild learning disabilities, often with very limited support, there were other difficulties: in a few cases, we were reliant on self-reports although, where possible, the practitioner researchers asked to see the participants’ medication. In contrast with the two large studies (Glover and Williams, 2015; Sheehan et al., 2015), we had no access to primary care records so we did not know the extent to which advice about changes in medication had been given to GPs following psychiatric reviews, or accepted by them.

Strikingly, nor was it even possible to locate all the relevant information as we were unable to find many of the psychiatrists’ letters to primary care services. It is unlikely that these letters were not written. Moreover, at least some of them may have contained information about additional conditions relevant to those participants apparently using psychotropic medication without an appropriate justification. These problems in locating medical letters were indicative of the challenges that made it difficult, even for practitioner researchers who had worked, or were working, in the teams, to reconstruct the ‘story’ of the responses to referrals. While perhaps exacerbated by staff vacancies around the time of the study, so that relevant documents were not always filed, there were systemic barriers to formal knowledge exchange. These included different information technology (IT) systems for psychiatry vs other NHS health care practitioners; online systems for local authority care managers and psychiatrists vs. paper for other NHS team members; separate physical locations for different members of the same team (see Farrington et al., 2015). Instead, as Farrington and his colleagues noted, there was a reliance on informal solutions (‘corridor conversations’) that appeared arbitrary and were unsustainable. The clinical governance, IT and other issues
that compromise formal knowledge exchange in this (and, anecdotally, other) specialist
community services for people with learning disabilities need urgently to be resolved so that
relevant documents are available for review by team members and by others concerned with
service users’ well-being.

The study raised other issues. As the NICE guidelines emphasise (e.g., NICE, 2015, 2016),
there is no alternative to a multi-disciplinary approach to mental health and/or behavioural
needs. Data collection for this study was carried out before these guidelines were available
and practice in this service has since changed. It is still worth, however, asking why
psychiatrists might still provide advice about using psychotropic medication apparently in the
absence of a diagnosed condition for which it would be appropriate. Any perceived ‘crisis’ in a
community setting is known to have significant adverse impacts on the service user
involved, any victims, and on their family and paid care-givers; it may also raise safeguarding
concerns. ‘Crisis’ referrals to psychiatrists often demand a rapid response, but the
immediately available options may be very limited and none may clearly be in a service
user’s best interests: admission to a (not always local) in-patient service; increased use of
physical restraint and/or calling the police though the person him or herself cannot
meaningfully be involved in the criminal justice system; or advising the prescription of
medication, particularly short-term ‘as required’ sedative medication, until the situation can
be discussed with other members of the CTLD.

‘Crisis’ demands to ‘do something’ are not unique to psychiatry among medical disciplines,
and perhaps reflect more general expectations regarding the prescription of medication. An
analogy may be drawn with the complex dynamics underlying the (over-) prescribing of
antibiotics (Fleming-Dutra et al., 2016) and the increasing, and very serious, risks of
resistance (NICE, 2017). Despite the well-known risks, patients continue to seek
prescriptions for antibiotics when they are not clinically justified, and GPs continue to
respond. It has been argued that medical practitioners face particularly intense pressures
when there are uncertainties about the diagnosis and a ‘wait and see’ approach may have
very adverse consequences for the patient and their care-givers (for example, otitis media in
children, Moro et al., 2009) and/or may lead to litigation (see Woon and Fisher, 2016). For
people with learning disabilities, for whom the reliable diagnosis of mental health conditions
remains problematic (Buckles et al., 2013), the prescription of psychotropic medication may
appear to be the least risky strategy. Some support for this account comes from Wastell et
al. (2016): in an exploration of the reasons provided by psychologists, nurses, and
psychiatrists for prescribing psychotropic medication for behavioural needs, tensions were
identified between good clinical practice (safe, evidence-based and ethical), risk, and
contextual factors (such as conditions in a service user’s social care provision). These
studies highlight the importance, once individuals are taking psychotropic, including anti-
psychotic, medication of carrying out reviews, including multi-disciplinary reviews (NICE
guidelines, 2015, 2016) to ensure that any medicines are of benefit.

The discrepancies between the prescription of psychotropic, including anti-psychotic,
medication and the presence of diagnosed conditions for which such medication would be
appropriate have now been convincing documented; there remains, however, much more
for CTLDs to do. First, as noted, there is a need to develop knowledge exchange systems
that reflect and promote the multi-disciplinary and inter-agency collaboration that is a feature
of community learning disability services. Secondly, clinical decision-making of all kinds
depends on the collection of reliable and valid data. Relevant data collection is most likely to take place when it makes limited demands on care-givers, reflects their input and so can be ‘owned’ by them, and provides rapid or even immediate feedback. Investment in apps, such as Lincus (www.innovationagencyexchange.org.uk) and their development to provide more sophisticated information is required. Data collection also becomes much more feasible where CTLDs have established working relationships with social care providers (including families) in the relevant geographical locality. In addition, such relationships enable team members to understand not only the immediate environment in which referrals for assessment, treatment and support of service users’ mental health and/or behavioural needs take place but also the broader local context (for example, the availability of suitable staffing, opportunities for social inclusion for service users). The pressure upon CTLDs to adopt outpatient clinic models to save resources is, we believe, short-sighted and highly regrettable, in part because it is more likely to lead to a requirement for crisis management and the perpetuation of inappropriate prescribing.

Thirdly, more complex formulations of service users’ needs are required to guide decision-making about medication and other interventions and establish person-centred outcomes. Increasingly, such formulations should include neurobiological as well as other relevant information, and should be produced by CTLDs as a team, rather than by different disciplines, in collaboration with families and other care-givers (and with service users, as far as possible) and other involved NHS, LA and third sector agencies. The production of such integrated formulations is a key part of establishing working relationships between CTLDs, service users and those who care for or about them. The complexity of this task should not be underestimated; but that does not mean the effort should not be made.

There are now many studies that indicate that psychotropic medication is prescribed to manage the perceived behavioural needs of people with learning disabilities in the absence of a clear justification such as a relevant mental health or neurological condition. We argue that prescription of these medications may be a marker of the difficulties that CTLDs often experience in providing comprehensive intervention and management plans that include psychotropic medication when it is justified, underpinned by detailed assessments and integrated formulations. Investment in developments that promote multi-disciplinary and inter-agency working is needed to promote ‘good practice’ by CTLDs in responding to referrals for mental health and/or behavioural needs.

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References


Royal College of Psychiatrists (2016), Psychotropic Drug Prescribing for People with Intellectual Disability, Mental Health Problems and/or Behaviours that Challenge: Practice guidelines [FR/ID/09], Royal College of Psychiatrists, London.


