

## 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)

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3 for which such treatment would be appropriate. Similarly, with regard to anti-  
4 depressants, Glover and Williams (2015) suggested that this class of medications  
5 was being prescribed to far more individuals than had a recorded affective  
6 disorder;

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8 (ii) psychotropic medication is being prescribed for the management of behavioural  
9 needs alone. For example, Sheehan *et al.* (2015) found that more than a third  
10 (35%) of people with recorded behavioural needs were prescribed anti-psychotic  
11 medication *despite* having no reported mental health or neurological condition for  
12 which such medicine would be appropriate. Indeed, among people with learning  
13 disabilities, taking into account the presence of a diagnosis relating to a  
14 neurodevelopmental, neurological or neurodegenerative condition (autism,  
15 epilepsy, or dementia), those with behavioural needs reported in their GP records  
16 were *more than twice* as likely as those without to be prescribed anti-psychotic  
17 medication.  
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21 At the least, these findings suggest poor clinical practice. In some cases, they raise concerns  
22 about the violation of the human rights of people with learning disabilities (for example, the  
23 prohibition of discrimination under Article 14 of the, *Human Rights Act 1998*; see Wadham *et*  
24 *al.*, 2007).  
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27 These two important studies of GP prescribing will have included, but will not have been  
28 limited to, individuals who are in contact with specialist community teams for adults with  
29 learning disabilities (CTLDs hereafter). It is rare for medication to be prescribed directly by  
30 CTLDs; instead, psychiatrists in these teams provide advice to GPs, normally in the form of a  
31 medical letter. The aim of the current study was to examine the use of anti-psychotic and  
32 other psychotropic medication by service users one year after their referral to a county-wide  
33 specialist community learning disabilities service for assessment, treatment and/or support  
34 for a mental health and/or behavioural need. In particular, we sought to investigate the extent  
35 to which the use of such medication was based on a recorded condition for which it would be  
36 appropriate.  
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## 40 **Methods**

### 41 **Ethics**

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

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

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

23 The data were collected by practitioner researchers who had previously worked (but with one  
24 exception) no longer worked in the service, and included:  
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- 27 1. The *British Picture Vocabulary Scale* – 3<sup>rd</sup> Ed. (BPVS-III, Dunn *et al.*, 2009). This is a  
28 brief measure of understanding of single words, covering a wide range of ability (from  
29 an age equivalent of 2 years 6 months to 16 y 11 m). It was used to provide a rough  
30 estimate of participants' intellectual functioning. Participants completed the measure  
31 as soon as possible after recruitment.  
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- 33 2. *Relevant 'diagnoses'*. Twelve months after recruitment, participants' records held by  
34 the relevant CTLD were used by the practitioner researchers to provide information  
35 about the presence or absence of mental health conditions or epilepsy ('diagnoses')  
36 for which advice about prescribing psychotropic medication might have been given.  
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- 38 3. The *Client Service Receipt Inventory* (CSRI, Beecham and Knapp, 2001; Strydom *et*  
39 *al.*, 2010) was developed for costing interventions. It was used here to collect data  
40 from paid or informal care-givers (and sometimes service users themselves, if they  
41 received only minimal support) about participants' psychotropic medications in the  
42 three months preceding follow-up, 12 months after recruitment. It was assumed that,  
43 by this time, any assessments and/or reviews of medication would have been  
44 completed by the CTLDs and that advice to GPs about changes in prescribing would  
45 have been provided by the relevant psychiatrist. As far as possible, we checked  
46 service users' CTLD records to find evidence of such advice. The reported  
47 medications were classified and the reported dosages checked. Chapter 4 of the  
48 British National Formulary (BNF; <https://www.bnf.org/products/bnf-online>), which  
49 provides the most up-to-date guidance for psychiatrists, pharmacists, GPs and others  
50 about psychotropic medication, was used.  
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## 55 **Results**

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

10 The 54 participants (28 men and 26 women) were overwhelmingly from white British  
11 backgrounds and ranged in age from 18-67 years (mean age: 39 years; s.d. 15). Fifteen  
12 people, all with what appeared to be severe learning disabilities, were unable to complete  
13 the measure of understanding of single words (BPVS). The median tested raw BPVS score  
14 of the remaining 39 was 104 (range: 4-165; age equivalent: 6 years 10 months; 95% CI: 6 y  
15 2 m to 7 y 5m), suggesting that the sample, though small, was diverse.  
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18 **Prescription of psychotropic medication 12 months after referral**

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20 ***What were the service users' assessed 'diagnoses'?***

21 All 54 participants met the necessary access criteria for specialist health services for people  
22 with learning disabilities. Seventeen participants had a current or past, (for three individuals)  
23 recorded diagnosis of a mental health condition, and a further seven had a diagnosis of  
24 epilepsy (two of whom had also been diagnosed with a mental health need). Together, these  
25 24 people comprised 44% of the sample. Psychotropic medication could have been  
26 appropriate for all of them. A further nine (17%) participants had a behavioural need on its  
27 own or in conjunction with another neurodevelopmental (autism and/or ADHD) or  
28 degenerative condition, while another six (11%) had a neurodevelopmental or degenerative  
29 condition only. The remaining 15 (28%) had learning disabilities but were not recorded as  
30 having any other condition for which psychotropic medication might be appropriate.  
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34 ***What psychotropic medications were recorded?***

35 Twelve months after referral, it appeared that 41 (76%) of the 54 participants were using  
36 regular psychotropic medications, of whom about a quarter (24%, n=10) were also taking  
37 PRN medication. One additional person was using PRN medication on its own. Table 1  
38 shows the number of participants using each medication, categorised according to Ch. 4 of  
39 the British National Formulary, 2016.  
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**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)**

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

<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**

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

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

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3 in a county-wide service comprising five locality-based specialist community teams (CTLDs).  
4 The aim was to document participants' recorded use of psychotropic medication, that is,  
5 medication that affects a person's mental functioning through action on the Central Nervous  
6 System, twelve months after they had been accepted by the study for assessment, treatment  
7 and/or support for a putative or diagnosed mental health and/or behavioural need.  
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10 The available data indicated that more than three-quarters (77%, n=42) of the sample of 54  
11 participants, were using regular and/or as required (PRN) psychotropic medication. Of these,  
12 just over a half (57%, n=24) had recorded mental health or neurological conditions that  
13 would, in principle, have justified the use of these kinds of medication and, indeed, could  
14 have been life-saving. In contrast with the findings of Glover and Williams (2015), no regular  
15 or as required medication was being used above its recommended dose.  
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18 The overall findings were consistent with those of the two previous, very large, studies  
19 (Glover and Williams, 2015; Sheehan *et al.*, 2015). There was a discrepancy between the  
20 number of participants using psychotropic medication and the presence of a recorded mental  
21 health condition or epilepsy. There were 18 participants (33% of the whole sample) who  
22 were reported as using one or more psychotropic medications, either regularly and/or as  
23 required (PRN), in the apparent absence of any condition that would have justified its/their  
24 use. There was, therefore, evidence that psychotropic medication was 'overused' (Sheehan  
25 *et al.*, 2015, p. 1).  
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28 The study reported here had a number of limitations: the sample was small, and we make no  
29 claim that it was representative even of the service users seen by the five CTLDs in the  
30 learning disability service. There were particular difficulties in recruiting men and women who  
31 needed permission from a consultee (a family member) to participate but were not living with  
32 their families; many paid support workers were reluctant to take on this role. For service  
33 users with mild learning disabilities, often with very limited support, there were other  
34 difficulties: in a few cases, we were reliant on self-reports although, where possible, the  
35 practitioner researchers asked to see the participants' medication. In contrast with the two  
36 large studies (Glover and Williams, 2015; Sheehan *et al.*, 2015), we had no access to  
37 primary care records so we did not know the extent to which advice about changes in  
38 medication had been given to GPs following psychiatric reviews, or accepted by them.  
39 Strikingly, nor was it even possible to locate all the relevant information as we were unable to  
40 find many of the psychiatrists' letters to primary care services. It is unlikely that these letters  
41 were not written. Moreover, at least some of them may have contained information about  
42 additional conditions relevant to those participants apparently using psychotropic medication  
43 without an appropriate justification. These problems in locating medical letters were  
44 indicative of the challenges that made it difficult, even for practitioner researchers who had  
45 worked, or were working, in the teams, to reconstruct the 'story' of the responses to referrals.  
46 While perhaps exacerbated by staff vacancies around the time of the study, so that relevant  
47 documents were not always filed, there were systemic barriers to formal knowledge  
48 exchange. These included different information technology (IT) systems for psychiatry vs  
49 other NHS health care practitioners; online systems for local authority care managers and  
50 psychiatrists vs. paper for other NHS team members; separate physical locations for  
51 different members of the same team (see Farrington *et al.*, 2015). Instead, as Farrington and  
52 his colleagues noted, there was a reliance on informal solutions ('corridor conversations')  
53 that appeared arbitrary and were unsustainable. The clinical governance, IT and other issues  
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3 that compromise formal knowledge exchange in this (and, anecdotally, other) specialist  
4 community services for people with learning disabilities need urgently to be resolved so that  
5 relevant documents are available for review by team members and by others concerned with  
6 service users' well-being.  
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9 The study raised other issues. As the NICE guidelines emphasise (e.g., NICE, 2015, 2016),  
10 there is no alternative to a multi-disciplinary approach to mental health and/or behavioural  
11 needs. Data collection for this study was carried out before these guidelines were available  
12 and practice in this service has since changed. It is still worth, however, asking why  
13 psychiatrists might still provide advice about using psychotropic medication apparently in the  
14 absence of a diagnosed condition for which it would be appropriate. Any *perceived* 'crisis' in  
15 a community setting is known to have significant adverse impacts on the service user  
16 involved, any victims, and on their family and paid care-givers; it may also raise safeguarding  
17 concerns. 'Crisis' referrals to psychiatrists often demand a rapid response, but the  
18 immediately available options may be very limited and none may clearly be in a service  
19 user's best interests: admission to a (not always local) in-patient service; increased use of  
20 physical restraint and/or calling the police though the person him or herself cannot  
21 meaningfully be involved in the criminal justice system; or advising the prescription of  
22 medication, particularly short-term 'as required' sedative medication, until the situation can  
23 be discussed with other members of the CTLD.  
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27 'Crisis' demands to 'do something' are not unique to psychiatry among medical disciplines,  
28 and perhaps reflect more general expectations regarding the prescription of medication. An  
29 analogy may be drawn with the complex dynamics underlying the (over-) prescribing of  
30 antibiotics (Fleming-Dutra *et al.*, 2016) and the increasing, and very serious, risks of  
31 resistance (NICE, 2017). Despite the well-known risks, patients continue to seek  
32 prescriptions for antibiotics when they are not clinically justified, and GPs continue to  
33 respond. It has been argued that medical practitioners face particularly intense pressures  
34 when there are uncertainties about the diagnosis and a 'wait and see' approach may have  
35 very adverse consequences for the patient and their care-givers (for example, otitis media in  
36 children, Moro *et al.*, 2009) and/or may lead to litigation (see Woon and Fisher, 2016). For  
37 people with learning disabilities, for whom the reliable diagnosis of mental health conditions  
38 remains problematic (Buckles *et al.*, 2013), the prescription of psychotropic medication may  
39 *appear* to be the least risky strategy. Some support for this account comes from Wastell *et*  
40 *al.* (2016): in an exploration of the reasons provided by psychologists, nurses, and  
41 psychiatrists for prescribing psychotropic medication for behavioural needs, tensions were  
42 identified between good clinical practice (safe, evidence-based and ethical), risk, and  
43 contextual factors (such as conditions in a service user's social care provision). These  
44 studies highlight the importance, once individuals are taking psychotropic, including anti-  
45 psychotic, medication of carrying out reviews, including multi-disciplinary reviews (NICE  
46 guidelines, 2015, 2016) to ensure that any medicines are of benefit.  
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53 The discrepancies between the prescription of psychotropic, including anti-psychotic,  
54 medication and the presence of diagnosed conditions for which such medication would be  
55 appropriate have now been convincingly documented; there remains, however, much more  
56 for CTLDs to do. First, as noted, there is a need to develop knowledge exchange systems  
57 that reflect and promote the multi-disciplinary and inter-agency collaboration that is a feature  
58 of community learning disability services. Secondly, clinical decision-making of all kinds  
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3 depends on the collection of reliable and valid data. Relevant data collection is most likely to  
4 take place when it makes limited demands on care-givers, reflects their input and so can be  
5 'owned' by them, and provides rapid or even immediate feedback. Investment in apps, such  
6 as Lincus ([www.innovationagencyexchange.org.uk](http://www.innovationagencyexchange.org.uk)) and their development to provide more  
7 sophisticated information is required. Data collection also becomes much more feasible  
8 where CTLDs have established working relationships with social care providers (including  
9 families) in the relevant geographical locality. In addition, such relationships enable team  
10 members to understand not only the immediate environment in which referrals for  
11 assessment, treatment and support of service users' mental health and/or behavioural needs  
12 take place but also the broader local context (for example, the availability of suitable staffing,  
13 opportunities for social inclusion for service users). The pressure upon CTLDs to adopt out-  
14 patient clinic models to save resources is, we believe, short-sighted and highly regrettable, in  
15 part because it is more likely to lead to a requirement for crisis management and the  
16 perpetuation of inappropriate prescribing.  
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21 Thirdly, more complex formulations of service users' needs are required to guide decision-  
22 making about medication and other interventions and establish person-centred outcomes.  
23 Increasingly, such formulations should include neurobiological as well as other relevant  
24 information, and should be produced by CTLDs as a team, rather than by different  
25 disciplines, in collaboration with families and other care-givers (and with service users, as far  
26 as possible) and other involved NHS, LA and third sector agencies. The production of such  
27 integrated formulations is a key part of establishing working relationships between CTLDs,  
28 service users and those who care for or about them. The complexity of this task should not  
29 be underestimated; but that does not mean the effort should not be made.  
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34 There are now many studies that indicate that psychotropic medication is prescribed to  
35 manage the perceived behavioural needs of people with learning disabilities in the absence  
36 of a clear justification such as a relevant mental health or neurological condition. We argue  
37 that prescription of these medications may be a marker of the difficulties that CTLDs often  
38 experience in providing comprehensive intervention and management plans that include  
39 psychotropic medication when it is justified, underpinned by detailed assessments and  
40 integrated formulations. Investment in developments that promote multi-disciplinary and  
41 inter-agency working is needed to promote 'good practice' by CTLDs in responding to  
42 referrals for mental health and/or behavioural needs.  
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