Senior Practitioner
Disability, mental health and medication: Implications for practice and policy

October 2010

Report by Dr Stuart Thomas, Kaisha Corkery-Lavender, Dr Michael Daffern, Dr Danny Sullivan and Dr Phyllis Lau

Supporting people to achieve dignity without restraints
Disability, mental health and medication: Implications for practice and policy

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Foreword

The role of the Senior Practitioner was established by the Disability Act 2006 (the Act) to protect the rights of people with a disability subject to restrictive interventions and compulsory treatment. Restrictive interventions are seclusion, mechanical and chemical restraints, as currently defined in the Act. People with a disability who are prescribed medication and people with dual disability (intellectual disability and mental illness) are a vulnerable group of people. Many of them are subject to restrictive interventions, particularly chemical restraint.

While many are receiving adequate and regular medical care, there are many health and medication matters we do not yet understand in relation to people with a disability who are subject psychotropic medication and those with dual disability in Victoria. The current assumption that it is sufficient to have a regular medication and/or psychiatric review with this group of people needs to be tested because there is an absence of an evidence-based practice guideline and standards for professionals working in this area, and a lack of in-depth expertise in the workforce to support such individuals. This study which asks whether there is a need for independent psychiatric reviews of medication prescribed for this group, was not conducted merely to test this assumption.

This study aims to provide a further understanding of the current practice being provided and add to the evidence for the need to improve practice. For some practitioners it affirms what they already know. The findings of this research also build on previous audits and other projects undertaken by the Office of the Senior Practitioner in the area of medication, mental health and people with a disability.

It is not surprising that a key theme emerging from the study and projects conducted to date indicate the need to establish partnerships with a range of stakeholders in order to improve practice and to achieve better outcomes for this vulnerable group. It is not solely the responsibility of one group of service providers or a group of professionals to address this issue.

A good starting point for this collaboration is the development of practice guidelines and standards on psychotropic medication for this group of people, and how and what a medication and mental health review should be for this group. The recommendations of this report are not intended to be an exhaustive list but a starting point for dialogue with various professionals supporting this group of people. As such I commend this report to you so that we may begin such a dialogue.

Finally, I thank the team of researchers led by Dr Stuart Thomas and the disability support providers who provided the necessary information for the researchers. I also thank the research reference panel for their insight, guidance, expertise and robust discussions in this project. In particular, I wish to thank the leadership of chief psychiatrist Dr Ruth Vine and her team, their collaboration and helpfulness are deeply appreciated not only for this project but for the day-to-day
assistance Disability Services has received in supporting people with dual disability, and those subject to psychotropic medication.

Thank you.

Jeffrey Chan, PhD
Senior Practitioner
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Executive summary

Background

• People with intellectual disability (ID) are at an increased risk of a co-occurring mental illness compared with the general population.

• Mental illness has proven particularly hard to detect in people with ID for a range of reasons, such as communication difficulties and a lack of guidelines surrounding the diagnosis and treatment of mental illness in this population.

• Mental illness can present itself in various ways; a common way is through behaviours of concern, such as aggression or self-harm.

• Medication has become increasingly common in the treatment of behaviours of concern among this population. Psychotropic medication is used to treat many kinds of mental illnesses in the general population; there is, however, no strong evidence of its efficacy to control behaviours of concern.

• There is a lack of formal guidelines and standards within Victoria designed to help medical practitioners in their evaluation and subsequent treatment of mental illness and behaviours of concern in people with ID.

Objectives

The Office of the Senior Practitioner (the office) commissioned the Centre for Forensic Behavioural Science (CFBS) to conduct an independent study on a random sample of 201 client case files. The primary objective was to investigate whether there is a need for an independent psychiatric review in this sample based on the clinical opinions of a psychiatrist and a pharmacist.

The key deliverables of the review were:

• a report detailing the characteristics of a sample of ID clients, their medication usage, and the proportion considered to require independent psychiatric review based on case file review data

• recommendations to inform GPs, psychiatrists and practice overall about mental health assessment, treatment and the need for independent psychiatric review

• recommendations for training and development of disability and mental health professionals including direct disability support professionals.

Results

• A large number of people were reported as being prescribed psychotropic medication, either regularly or when required on a pro re nata (prn) basis (98 per cent, 2 per cent unknown).

• Results indicated there were a large number of people reported to have a current or previous mental health diagnosis (43 per cent).

• The overwhelming majority of clients (n = 177, 88 per cent) were determined to be in need of independent psychiatric review according to consensus views of the psychiatrist and pharmacist, incorporating additional input from another independent psychiatrist.

Recommendations

• Improve integrated services for people with behaviours of concern and mental illness.

• Develop standardised guidelines to guide medical practitioners.

• Conduct ongoing regular medication reviews for people with ID on psychotropic medications.

• Consider establishing an interdisciplinary team to assist in assessing, managing and reviewing mental health and behaviours of concern in people with ID.

• Increase education about working with people with ID at all levels of care.
Key learnings

For psychiatrists
- Specialist training in ID should be included in the curriculum undertaken at Australian university.
- Standardised guidelines should be used when treating people with an ID and/or mental illness.

For general practitioners
- Training in supporting people with ID should be increased.
- People presenting with complex mental health and behaviours of concern should increasingly be referred forwards.

For disability support workers
- Their knowledge of available services should be increased.
- Training in detecting and monitoring mental health presentations and side effects of medication should be increased.
Background

Mental health and intellectual disability

The prevalence of intellectual disability (ID) in the Australian population has recently been estimated by the Australian Bureau of Statistics to be approximately 1 per cent.1 People with ID have a higher risk of co-occurring mental illness, such as depression and schizophrenia, in comparison with the general population, with studies estimating that 30–40 per cent of people with ID will experience a mental illness at some point in their lives.2,3,4 The exact prevalence of mental illness in people with ID varies depending on the research methodology. Some reasons behind the discrepancies in estimates include the difficulty of determining the presence of a mental illness within this population and the many different tools used to detect such illnesses.2,3 Prevalence studies have further produced results suggesting people with ID experience the same types of mental illness as that of the general population.4,5 Depression and anxiety are often cited as two of the most common diagnoses, which are reflected as being high-prevalence disorders in the general population.1,5,6

There are several theories about the relationship between mental health issues and people with ID.9 People with ID have been shown to experience more negative life events than the general population.9 Genetic origins of the disability can also be associated with certain types of mental health issues, as well as brain trauma, behavioural issues and factors related to their social environment.3,6

The impact of mental illness on a person with ID can be substantial, often affecting not only themselves but other residents within the house and carers working with them. Mental illness is particularly difficult to detect in people with ID, with most tools commonly used for screening relying predominantly on verbal feedback. For people with very little verbal communication ability this makes the process extremely difficult, thus assessments have to rely heavily on care workers’ opinions of the individuals’ mental state based on their collective observations and documentation in client case files. With a high turnover of care workers, lack of training in alternate communication methods and understaffing, these processes are often inconsistent. Furthermore it is often the case that behavioural, social and cognitive expressions of a mental illness can be overlooked or mistaken for symptoms of their disability.3,7,8

Behaviours of concern

For those who cannot communicate verbally, their primary outlet of communication is often behavioural; when their internal and external experiences are impacted by mental illness this time can be very frightening, lonely and confusing, often resulting in the person exhibiting problematic behaviours to communicate these issues.7,9 If it is unknown to carers and family that the person is experiencing an illness of any kind, then these behaviours are often interpreted purely as behaviours of concern and are thus treated solely as a behavioural outburst, leaving the actual underlying cause to be overlooked and therefore left untreated. The relationship between behaviours of concern and psychiatric conditions in people with ID is still undetermined. It is understood that people with a mental illness often display behaviours that are deemed to be problematic; however, it is disputed whether behaviours of concern are indicative of an underlying mental illness.10

Behaviours of concern are common among people with ID, with estimates ranging between 7 and 15 per cent.11,12 There are many presentations of such behaviours: self-injuries; verbal and physical assault; absconding; and inappropriate sexual conduct, all of which present a risk to the person displaying such behaviours as well as those around them and the community.10,13 There are many proposed explanations as...
to why an individual may display behaviours considered to be problematic: physical or mental discomfort, stress, environmental change, lack of understanding and communication difficulties.\textsuperscript{14,15} Despite the basic understanding of what may cause these behaviours and a magnitude of options for de-escalation and treatment of the source, the most common response is to use medication. Medication use within the ID population has become commonplace. With other options demanding significant time and resources, medication can commonly prove to be the choice for a quick fix to a potentially dangerous situation.\textsuperscript{16,17,18} The high level of co-occurring ID and mental illness, and the lack of understanding surrounding this issue, have contributed to high levels of medication use to control behaviours of concern, which may or may not be related to a mental illness.

**Psychotropic medication**

The assumption that psychotropic drug use within the ID population is too high is largely undisputed, with the ID population regarded as one of the highest medicated groups in society.\textsuperscript{19,20} Psychotropic medication is defined as any medication that alters the mental state of an individual, including cognitive functioning and mood. It is primarily used in the general population to treat mental illnesses such as schizophrenia and bipolar affective disorder. The use of these medications within the ID population, however, is not confined to their intended use. Psychiatrists and general practitioners (GPs) often prescribe psychotropic medication to the ID population as a means of controlling behaviours of concern. These particular medications are not licensed for this use, signifying that there is no evidence the consumption of these medications are in any way helping the individuals involved, and with no guarantee they will not worsen the problem. Despite the limited evidence into the effectiveness of psychotropic medication on behaviours of concern, studies have consistently illustrated the highest predictor of a prescription of this drug class is not mental illness but challenging behaviours.\textsuperscript{19,21,22,23}

Furthermore, people with ID are more likely than those in the general population to experience an array of physical and neurological health issues. These are more often than not managed with drug therapy; this, coupled with medication aimed at reducing behaviours of concern, can lead to polypharmacy (the prescription of two or more medications to an individual), having the potential to interact and exacerbate physical, mental, neurological and behavioural issues.\textsuperscript{18} In addition to not knowing how effective, if at all, medications are in controlling behaviours of concern, psychotropic medications have a range of potential side effects.\textsuperscript{9,24} These adverse reactions, which affect different people to different degrees, are normally explained and discussed with the patient before treatment commences. For people with ID, it is vitally important that they have as much understanding about the medication and potential adverse medication reactions as possible; where this is not achievable, a guardian or disability support professional should be well informed and receive appropriate supports to monitor potential adverse medication reactions.

Side effects of psychotropic medication treatment can actually increase the behaviours of concern they are trying to control.\textsuperscript{9,19} If people with ID cannot express themselves verbally, they may ‘act out’ in order to try to communicate distress, or more simply may act upon their side effects, for example, breaking into a locked fridge and eating its entire contents because a side effect of the medication may be constant hunger. Or someone experiencing restlessness and/or irritation due to their medication may be seen pacing and not following instructions to sit still. Other side effects include, but
are not limited to, insomnia, drowsiness, excessive thirst, weight gain, swallowing difficulties, social withdrawal, muscle spasms and lack of coordination. Furthermore the misinterpretation of these behaviours often leads to increases in medication dosages, thus perpetuating the cycle.

Guidelines

The Victorian Disability Act 2006 defines chemical restraint as any medication primarily used to control behaviour, and which is not being used to treat an underlying physical or mental illness, or a physical condition. Psychotropic medication, such as antipsychotics (otherwise known as major tranquilisers) used in the treatment of psychosis, are widely used as chemical restraints.

Despite the lack of concordance surrounding mental illness within the ID population and the high levels of psychotropic medication use, there is an absence of guidelines within Victoria outlining diagnosis and treatment of mental illness and behaviours of concern within this population. Victoria does have legislation surrounding the mandatory reporting of chemical restraint (e.g. psychotropic medication use within the ID population when it is used as chemical restraint on the Restrictive Intervention Data System or ‘RIDS’). There are, however, no guidelines regarding the minimum length of time between medication reviews for people receiving restrictive interventions. Furthermore, in contrast with some other countries and states, there is no specialist training available in Victoria for GPs or psychiatrists in the ID field. In the United Kingdom (UK) all psychiatrists receive clinical training in intellectual disabilities (referred to as learning disability in the UK), with an option to specialise in the field. This option for specialisation is arguably needed within Victoria.

The UK guidelines have recently been adapted by the World Psychiatric Association, and are recommended as the foremost international guidelines to follow when diagnosing and treating people with ID and co-occurring mental illness, or behaviours of concern. The guidelines provide a comprehensive outline for the medical profession to use when treating people with ID. They include information about how to identify mental illness and classify behaviours of concern, recommending certain diagnostic tools, such as the Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities (DC-LD). The guidelines also provide recommendations about follow-up and review of medication effectiveness. With the maximum length allowed between reviews set at 12 months, preceded by an initial follow-up set at around 3–4 months. This allows for any concerns of patient or care workers to be discussed, as well as the practitioner checking on the wellbeing of the client and asking appropriate questions to ascertain the effectiveness of the medication. While a minimum should be established there obviously needs to be a degree of variation in review processes contingent on severity/complexity of the presenting behaviour(s) of concern and conditions of the person.

An overwhelming theme in the UK guidelines is the emphasis on the need to keep medication levels to a minimum, with the goal always being to remove medication from the person’s treatment plan as soon as possible, especially when the medications are being used primarily for behavioural control.
Aims of the study

The aims of the study were to:

- estimate the prevalence of mental illness in a random Victorian sample of people with ID
- assess the use of psychotropic medication within the same sample, taking into consideration previously diagnosed mental illness, physical disabilities and behavioural problems
- determine the need for independent psychiatric review (IPR) within the same sample as a result of high rates of psychotropic medication use
- illustrate the need for prescribing guidelines regarding the treatment of mental illness in people with ID.
Method

Literature review
An extensive literature review that searched key journals in the field was conducted. The following keywords and their related terms were used: ‘intellectual disability’, ‘mental ill health’, ‘co-morbid diagnosis’, ‘institution vs community settings’, ‘medication’ and ‘psychotropic drugs’. The initial target journals were: The Journal of Intellectual Disability Research, World Psychiatry, Journal of Psychopharmacology, Journal of Applied Research in Intellectual Disabilities, Research in Developmental Disabilities, The British Journal of Psychiatry, Australian and New Zealand Journal of Psychiatry, American Journal of Mental Retardation, Psychological Medicine, and the British Journal of Learning Disabilities. The researchers then used a simple snowballing technique whereby reference lists from related articles sourced were reviewed and then additional relevant articles sought and read. Articles older than 10 years were excluded due to previous comprehensive reviews of that period.

Ethics
Ethics approval was sought and obtained from the Monash University Human Ethics Research Committee. Assessing personal data with the express consent of the participants followed strict ethical guidelines. The client files were never taken out of the Office of the Senior Practitioner. Information that was extracted was de-identified and secured in a locked cabinet in a secure building.

Source database
The Restrictive Intervention Data System (RIDS) is an online database administered by the Office of the Senior Practitioner. It records all reported instances of mechanical and/or chemical restraints (including seclusion) used on an individual with ID. For the purpose of this study the focus was on chemical restraint only. This includes any chemical substance given to an individual for the sole purpose of behavioural control, including pro re nata (prn) (as needed) medication.

Participants
The sample consisted of 201 participants who were randomly selected from the RIDS database. All participants were aged 18 years or over and were residing in supported community living accommodation. The study specifically excluded individuals who were currently residing in congregate care because this group was the subject of a separate review.

Procedure
Client files for the 201 participants were requested from case managers around Victoria. All relevant data was extracted and de-identified using a data collection tool specifically designed for the study. The de-identified information was then sent to a consultant psychiatrist and a pharmacist to independently assess the need for independent psychiatric review for each client file. To further increase validity of the results, a random 10 per cent of the files were sent to an independent consultant psychiatrist for assessment.

Analysis
Data were collected and entered into an SPSS database. The sample was characterised using simple descriptive statistics, with statistical comparisons carried out using chi-squared tests of association.
Results

Source database

At the time of the study the RIDS database held information on 1,317 individuals. Their ages ranged from five to 85 years. There were a total of 431 females and 886 males in the database, with 751 people living in metropolitan regions and 566 in rural regions. The random sample obtained from this database was representative of the overall population recorded to have received a restrictive intervention, with the exception of geographic regions. There was a significant ($\chi^2 = 5.685, p = 0.017$) overrepresentation of individuals from rural areas in the random sample sourced for the study.

Primary outcomes

The reviewers received the data for the 201 clients and independently assessed the data determining the need for IPR (see Figure 1, page 12).

Psychiatrist’s review

The psychiatrist identified 172 (85.5 per cent) cases in need of IPR. Five broad reasons were identified by the reviewing psychiatrist as to why an individual would be considered in need of an IPR.

The most common reason cited was ‘potential for adverse effects’, and was listed 134 (66.7 per cent) times. See Table 2 on page 12 for further details.

Pharmacist’s review

The pharmacist identified 173 (86.1 per cent) cases in need of IPR across 13 reason categories. The most common reason cited for need of review was ‘potential drug interactions including additive side effects’, which was listed 112 (55.7 per cent) times. For a full breakdown of reasons stated, see Table 2.

Table 1: Characteristics of the sample

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 201</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>140</td>
<td>70%</td>
</tr>
<tr>
<td>Female</td>
<td>60</td>
<td>30%</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>94</td>
<td>47%</td>
</tr>
<tr>
<td>Rural</td>
<td>102</td>
<td>51%</td>
</tr>
<tr>
<td>Severity of ID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>40</td>
<td>20%</td>
</tr>
<tr>
<td>Moderate</td>
<td>74</td>
<td>37%</td>
</tr>
<tr>
<td>Severe</td>
<td>29</td>
<td>14%</td>
</tr>
<tr>
<td>Profound</td>
<td>3</td>
<td>1%</td>
</tr>
<tr>
<td>Mental illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>86</td>
<td>43%</td>
</tr>
<tr>
<td>No</td>
<td>109</td>
<td>54%</td>
</tr>
<tr>
<td>Psychotropic medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>198</td>
<td>99%</td>
</tr>
<tr>
<td>No/missing</td>
<td>2</td>
<td>1%</td>
</tr>
<tr>
<td>Prescriber</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>106</td>
<td>53%</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>35</td>
<td>17%</td>
</tr>
<tr>
<td>GP and psychiatrist</td>
<td>45</td>
<td>22%</td>
</tr>
<tr>
<td>GP and neurologist</td>
<td>7</td>
<td>3%</td>
</tr>
<tr>
<td>Behaviours of concern</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>167</td>
<td>823%</td>
</tr>
<tr>
<td>No</td>
<td>33</td>
<td>16%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male and female</td>
<td>Range</td>
<td>Mean</td>
</tr>
<tr>
<td></td>
<td>18–85</td>
<td>42.48</td>
</tr>
</tbody>
</table>

Differences in frequencies reflect the relative completeness of data available. Percentages reported to nearest whole number.
Office of the Senior Practitioner: Including people with behaviours of concern in the social inclusion agenda

Figure 1: Number in need of review

Table 2: Reasons for review

<table>
<thead>
<tr>
<th>Psychiatrist's criteria</th>
<th># of times cited</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polypharmacy</td>
<td>60</td>
<td>29.9</td>
</tr>
<tr>
<td>Outside PBS scheme</td>
<td>26</td>
<td>12.9</td>
</tr>
<tr>
<td>Unorthodox prescribing for drug conditions</td>
<td>116</td>
<td>57.7</td>
</tr>
<tr>
<td>Potential for adverse effects</td>
<td>134</td>
<td>66.7</td>
</tr>
<tr>
<td>No psych diagnosis but medication is prescribed</td>
<td>90</td>
<td>44.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pharmacist's criteria</th>
<th># of times cited</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polypharmacy</td>
<td>13</td>
<td>6.5</td>
</tr>
<tr>
<td>Potential for adverse effects</td>
<td>35</td>
<td>17.4</td>
</tr>
<tr>
<td>Potential drug interactions including additive side effects</td>
<td>112</td>
<td>55.7</td>
</tr>
<tr>
<td>Drug contraindicated in patient</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Side effects likely to exacerbate problem behaviours</td>
<td>50</td>
<td>24.9</td>
</tr>
<tr>
<td>Potential for overdose</td>
<td>43</td>
<td>21.4</td>
</tr>
<tr>
<td>Therapeutic drug monitoring required</td>
<td>60</td>
<td>29.9</td>
</tr>
<tr>
<td>Additional drug(s) may be required</td>
<td>13</td>
<td>6.5</td>
</tr>
<tr>
<td>Medication error – duplication</td>
<td>17</td>
<td>8.5</td>
</tr>
<tr>
<td>Reason for use should be reviewed</td>
<td>27</td>
<td>13.4</td>
</tr>
<tr>
<td>Suspect side effects</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Review concurrent use of more than one drug in the same drug class</td>
<td>45</td>
<td>22.4</td>
</tr>
<tr>
<td>Dose requires review</td>
<td>98</td>
<td>48.8</td>
</tr>
</tbody>
</table>
Examples of cases in need of independent psychiatric review (IPR)

Polypharmacy
Definition: prescription and administration of 5 ≥ regular medications and/or > 12 doses/day at one time to an individual.
Example: A 49-year-old male with a moderate to severe level of ID. Has epilepsy with no other physical or mental health issues noted. He is on 15 regular medications daily, with no less than 20 doses throughout the day. He is not only prescribed multiple antiepileptic drugs and laxatives, but there are several potential drug interactions between the antiepileptic drugs, the psychotropics, metformin (drug to help control sugar levels in type 2 diabetes) and the benzodiazepines (minor tranquilisers).

Outside of PBS scheme
Definition: medication prescribed for mental health disorder; however, the drug is not licensed for this indication by the PBS or is prescribed in excessive doses.
Example: A 25-year-old male with a moderate level of ID and autism. Is prescribed haloperidol daily; this prescription is outside of the PBS licensing. The only medication approved for use in autism is risperidone.

Unorthodox prescribing
Definition: the psychotropic medication prescribed is not indicated for the diagnosed mental disorder.
Example: A 52-year-old female with a moderate level of ID, diagnosed with depression. She is prescribed chlorpromazine (antipsychotic) on a daily basis. There is no indication for the need for this medication because it is not approved for use in depression.

No psychiatric diagnosis but medication prescribed
Definition: no indication for the prescription of psychotropic medication.
Example: A 43-year-old male with an unknown level of ID and Down syndrome. Is prescribed olanzapine (antipsychotic) on a daily basis; there is no indication within his file of a mental illness of any kind, therefore the prescription of olanzapine is not indicated.

Potential for adverse effects
Definition: psychotropic medication prescribed may exacerbate diagnosed mental condition.
Example 1: A 38-year-old male with a moderate level of ID. He has grand mal epilepsy and no recorded mental illness. He is prescribed high doses of an antipsychotic (olanzapine) on a daily basis; however, there is no indication in his file why this is the case and has the potential to greatly exacerbate his epilepsy (also falls under: unorthodox prescribing).

Example 2: A 58-year-old man with a moderate level of ID, with no recorded mental illness. Is profoundly deaf and has an atonic colon (lack of normal muscle tone in the colon causing chronic constipation). He is prescribed haloperidol (antipsychotic) daily, which has the potential common side effect of constipation. Therefore the psychotropic prescribed in this instance may exacerbate the diagnosed medical condition. There is no indication why he is prescribed an antipsychotic (additionally falling under the category no psychiatric diagnosis but medication prescribed).

Adverse side effects likely to exacerbate behaviours of concern
Definition: side effects of psychotropic medication have the potential to negatively impact on the person’s behaviour.
Example: A 47-year-old male with a severe level of ID. Has no recorded mental health issues, has epilepsy and diabetes. The client is on a number of antiepileptic drugs, which have potential drug interactions with the psychotropics (metformin and benzodiazepines) he is also routinely prescribed. Furthermore risperidone is contraindicated in diabetes, potentially increasing blood-glucose levels in diabetic patients. In addition, antiepileptic drugs are known to cause changes in mood and behaviour, which may explain some of his behaviours of concern; there is no note of this in his file (also falls under polypharmacy).

Potential for overdose

Definition: excessive doses of one or more medications, or potentially lethal combinations of medications.

Example 1: A 43-year-old male with autism and a moderate level of ID. Has no recorded mental or physical health issue. The client is prescribed olanzapine (antipsychotic) in excessive doses – three times the normal maintenance dose. Furthermore the client is additionally prescribed chlorpromazine (antipsychotic), which potentially interacts with olanzapine; the concurrent prescriptions of these two drugs should be reviewed and noted in the history.

Table 3: Discrepancies between reviewers (primary outcome)

<table>
<thead>
<tr>
<th>Pharmacist and pharmacist cross-tabulation</th>
<th>Psychiatrist review</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Total</td>
</tr>
<tr>
<td>Psychiatrist review</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>149</td>
<td>22</td>
<td>171</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>4</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>173</td>
<td>26</td>
<td>199</td>
</tr>
</tbody>
</table>

= Agreed

= Disagreed

Table 4: Discrepancies between reviewers (secondary outcome)

<table>
<thead>
<tr>
<th>Psychiatrist and pharmacist cross-tabulation</th>
<th>Pharmacist review</th>
<th></th>
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</thead>
<tbody>
<tr>
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<td>Yes</td>
<td>No</td>
<td>Total</td>
</tr>
<tr>
<td>Psychiatrist review</td>
<td></td>
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</tr>
<tr>
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<td>178</td>
</tr>
<tr>
<td>No</td>
<td>18</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>Total</td>
<td>195</td>
<td>4</td>
<td>199</td>
</tr>
</tbody>
</table>

= Agreed

= Disagreed
Example 2: A 31-year-old male with an unknown level of ID and autistic tendencies. Has an anxiety disorder. Is prescribed quetiapine prn; there was, however, no time interval specified or maximum daily dose for this prn. All prn drugs, especially psychotropics, should have a maximum daily dose and time intervals.

Discrepancies between reviewers
There was some level of discrepancy between the two reviewers, as illustrated in Table 3. The two reviewers agreed that 149 (75 per cent) individuals were in need of IPR, and that four (2 per cent) were not in need of IPR. They disagreed in 46 (23 per cent) cases, with the psychiatrist stating 22 cases were in need of independent review and the pharmacist disagreeing, stating that 24 of those cases were in need of review.

Secondary outcomes
Following a discussion between the psychiatrist and pharmacist regarding the discrepancies identified in specific cases, the two reviewers further enhanced their agreement on the perceived need for IPR. The psychiatrist identified an additional seven cases in which it was agreed there was a need for review and the pharmacist identified an extra 21 cases. This bought the agreed level of need for IPR between to the two experts up to 177 (88.9 per cent) out of 199 cases, and the level of agreement between the two reviewers increasing to 180 (90.5 per cent) cases.

Independent reviewer
To enhance validity an independent reviewer (a psychiatrist with expertise in working with people with ID) was asked to complete reviews on a random 10 per cent sample of the 201 case files. Based on the available information provided to the independent reviewer it was determined all 20 cases assessed were in need of IPR. There was a level of disagreement between the independent reviewer and the pharmacist and psychiatrist. The pharmacist disagreed with the independent reviewer in two out of the 20 cases, and the psychiatrist disagreed in five out of the 20 cases.

Interactions
There were no significant interactions found when the psychiatrist’s opinion on need for independent review was analysed against the prescriber (GP or psychiatrist), the presence of a mental illness and the severity of ID (mild, moderate, severe, profound). Furthermore there were no significant differences found for the pharmacist when these variables were compared with need for IPR.
Discussion

The study investigated the level of mental illness and psychotropic medication use in a random sample of 201 adults with ID in supported community living. Additionally, the number of cases in need of an IPR was investigated, based on available case notes and the expert opinions of a psychiatrist and a pharmacist, and another independent psychiatrist.

As reflected in previous literature, there was a high incidence of mental illness recorded within the sample. Furthermore the study findings reiterated the high levels of psychotropic medication use in people with ID (98 per cent), which previous studies had illustrated.\(^{18,23}\)

Results of the current study illustrate an overwhelming number of people were determined to be in need of an IPR. Initially the reviewers independently rated the need for review based on a set of predetermined criteria. The psychiatrist rated a total of 172 (85.6 per cent) cases needing review; the pharmacist identified 173 (86.1 per cent) cases. There was, however, some level of discrepancy between the two, with the reviewers agreeing on 153 out of the 201 cases (77 per cent). Following the initial review the two experts had the opportunity to discuss their disagreement on certain cases. Subsequently the pharmacist increased the need for review by 21 cases and the psychiatrist increased need for review by seven cases. Collectively it was concluded there was a total of 177 (89 per cent) people in need of IPR.

What is noteworthy in this process are the main reasons behind the increase in consensus. Following discussion between the psychiatrist and the pharmacist, the pharmacist agreed that the increased cases needing review were all attributable to the person receiving psychotropic medication in the absence a psychiatric diagnosis. The increase in the psychiatrist’s agreement for a need for review was related to medication issues, such as medication interactions or potential for overdose. It is not altogether surprising that the pharmacist would be more sensitive to issues of polypharmacy and potential adverse reactions due to the interaction of multiple medications based on their training. Furthermore, it is not surprising that a psychiatrist would be more sensitive to mental health issues and the appropriate medication for a specific mental illness. This finding illustrates the usefulness of an interdisciplinary approach when prescribing and reviewing psychotropic medication for people with ID.

The complexity of the cases reviewed, in addition to the levels of disagreement between the experts, opens a discussion as to what constitutes an IPR. Following an evaluation of the results and discussion between reviewers, researchers and service providers it was agreed there were three main areas involved in review:

- quality of prescribing
- diagnosis
- medication-based problem behaviour.

These categories are not universally independent of one another, however, do suggest different approaches and varying levels of commitment from service providers. Quality of prescribing was by far the most common reason listed by each reviewer in determining the need for IPR. The pharmacist cited this reason 95 per cent of the time and the psychiatrist stated it in 81 per cent of cases determining need for review. This included categories such as polypharmacy, over prescribing, dangerous drug combinations, serious side effects and prescribing outside the PBS scheme. While poor documentation in the person’s medical records may artificially increase the reported number of cases identified as being in need of review, it also illustrates a potentially major
issue in the quality of drug prescriptions this population is receiving. Input at the prescribing stage from a pharmacist could help resolve this issue. A pharmacist’s expert knowledge of medication combinations and interactions could help reduce some of the quality-of-prescribing issues.

Furthermore side effects of medications should be monitored more closely and there ought to be regular medication reviews to ensure the person with ID is receiving the appropriate dose, combination and type of medication. A guide has recently been developed in the UK to support the successful review of medication, and could be used to help reduce some of the above issues. The guide has specific sections aimed at the GP, the client and the house supervisor/support workers attending the medication review. It outlines the responsibilities of each participant in the process.\textsuperscript{34}

The second category to emerge within the results was a diagnostic-driven review; this category was cited by the pharmacist in 24.4 per cent of cases, and by the psychiatrist in 21 per cent of cases. This was defined as the need for review based on the need for a mental health investigation, preferably conducted by a psychiatrist experienced in working with people with ID. The study found that that 43 per cent of the sample were classified as having received a mental health diagnosis at some point in their lives, illustrating high prevalence of mental illness and the need for services to support this group within the community. Many of the identified mental health issues were not formal diagnoses but suggested reasons why a person may be behaving a certain way. This was often coupled with medication to treat the suspected issue without any record of a formal investigation into their mental health.

There are a number of guidelines available pertaining to the assessment and subsequent treatment of mental illness in people with ID. For example, the European Association for Mental Health in Mental Retardation (EMHMR) has recently published a guide for assessing and treating mental illness in people with ID, developed using expert opinions and current knowledge in the area. These guidelines outline the necessary steps a medical practitioner should take to ensure they come to the most accurate diagnosis possible, allowing for better treatment options (including medication choices).\textsuperscript{35} Guides like these are widely accepted and used throughout the UK. Furthermore World Psychiatry recently endorsed the use of diagnostic manuals DC-LD and DM-ID as best practice for identifying mental illness in people with ID, stating that other manuals such as the DSM-IV and ICD-10 are not as sensitive or accurate when working with this particular population.\textsuperscript{35,36,37,38}

The final theme to emerge within the results was medicating based on problem behaviour. Previous studies have shown that high levels of psychotropic drug use has been linked to behaviours of concern.\textsuperscript{23,24} The current results support this notion: 98 per cent of the sample were recorded as receiving psychotropic medication, with less than half of the sample having a recorded mental illness diagnosis, suggesting that over half of people receiving a prescription for psychotropic medication are doing so for the purpose of behavioural management. There are several issues surrounding medication as a means to control behaviours of concern, and a limited evidence base supporting the use of psychotropic medication for the purpose of behavioural control.

Furthermore these medications are often sedative and may result in reduced cognitive or adaptive functioning.\textsuperscript{18,39} There are guidelines concerning the treatment of behavioural issues with references to medication use, which have been endorsed by the Royal College of Psychiatrists and are
widely accepted as best practice in the UK. This guide provides step-by-step suggestions as to what a practitioner needs to do prior to prescribing medication. Some of the steps involved are the appropriate assessment of mental health as well as the implementation of a behavioural intervention. The guide emphasises the need for medication to be a last resort in the treatment of behaviour problems and that, if decided upon, it should be given at the minimum dose for the shortest period of time possible. Additionally the guide recommends regular medication reviews, with the main aim to decrease the amount of medication a person is receiving.15 Furthermore the Australian Psychological Society have recently developed guidelines outlining the most effective behavioural interventions for treating behaviours of concern in people with ID. The guide has been collaboratively produced by a group of experts, with the aim of reducing the need for restrictive interventions and better handling behaviours of concern.40

There are a few limitations within the methodology of the current study. Due to the nature of the data used, there was a certain level of inconsistency in the details available. The data was not originally collected for the purposes of the study. Therefore, there were numerous cases with missing data, incomprehensible writing, incomplete medication charts and incomplete case notes. Thus the level of need for review as determined through this approach may have been over or indeed underestimated due to the inconsistencies in case files and on RIDS.

The usefulness of an interdisciplinary approach was illustrated by the increase in the number requiring review following consultation between the two independent experts. An interdisciplinary approach allows for more options regarding assessment and treatment. With a team of experts from different disciplines there are more likely to have fewer margins for error, such as medication duplication or the oversight of side effects.

In conclusion the current study supported the notions that mental illness is prevalent in the ID population and there is a high level of psychotropic medication use to treat behaviours of concern. Furthermore the study highlighted the need for additional knowledge and attention to be paid in the area of prescribing, identification of mental illness and treatment of behavioural problems within this population. There is a call for implementation of existing guidelines to help manage some of these areas.

Specific recommendations are outlined on the following page.
Recommendations

• The current study is a starting point in the investigation into the need for ongoing independent reviews. The next step should be to conduct a number of clinically IPRs by expert clinicians in the ID field.

• Alternative options to medication, such as psychological/behavioural interventions need to be highlighted as a first point of call for managing behaviours of concern, either implementing these at a service level or through consultation with a specialist.

• When an individual presents with possible mental illness, refer accordingly for an investigative assessment with an expert.

• There is a need for ongoing regular reviews when a person is prescribed any form of medication aimed at controlling behaviours of concern. Added to this there is a need for strict timelines for these reviews, to ensure the person is monitored for adverse side effects and the effectiveness of the prescribed medication.

• An interdisciplinary team should be involved in treating mental illness and behaviours of concern in people with ID. A psychiatrist is expertly trained in detecting psychiatric illnesses and a pharmacist is expertly trained in medication interactions and effects, allowing the person being treated to receive the best care available.

• A major finding in this study was the great variability in available client information, with the majority of client files missing data or being largely illegible. This suggests the need for a more standardised reporting format and process in case files. This would also serve to improve information sharing requirements with GPs and specialists.

• There is a clear need for increased training at all levels of care: direct disability support professionals, GPs, psychologists and psychiatrists.
  – Disability support professionals need to be trained and supported in implementing behavioural support interventions as recommended from the behaviour intervention support team, the psychiatrist, psychologist, occupational therapist and/or other relevant professionals.
  – GPs need additional knowledge in the benefits of positive behaviour support, and thus refer the person on appropriately.
  – Psychiatrists need training in detecting and treating mental illness specific to the ID population.

• Behaviour Intervention Support Teams needs to heighten their profile and let GPs and disability support workers know what they offer, and work in partnership with them.

• Specialist input at the start of a medication regime may be needed if there is any cause for concern regarding multiple prescriptions, prescribing for the purposes of behavioural control and/or in the presence of an identified or suspected mental illness.
Key learnings

For psychiatrists

- Additional training specific to mental illness and ID is required, coupled with the need for ongoing professional development in this area.
- It would be ideal if specialist training was included in the original curriculum undertaken at university in Australia; ideally this would allow for a specialist group of psychiatrists trained in ID and mental health.
- Standardised guidelines surrounding the prescribing of psychotropic medication for people with ID should be developed and adopted.
- Mandatory guide for detecting and treating mental illness in people with ID.

For general practitioners

- There is a need for increased knowledge of the available supporting professional disciplines such as behaviour support intervention team, psychiatrists, pharmacists and occupational therapists.
- There is a need for extended consultation times for people with ID. Making these the first appointments of the day will prevent delays.
- The benefits of conducting appointments close together has also been suggested, allowing any additional information about the client that wasn’t readily available to be provided in the follow-up consultation, as well as the opportunity for any concerns of the person, service provider or carer to be raised.
- Use a key disability support professional or the person most familiar with the needs of the person with ID and their presenting conditions rather than ad hoc use of a proxy staff member when attending a consultation.
- There is a need to emphasise the benefits of consulting a pharmacist when prescribing to this population because patients are often prescribed more than one medication at a time; a consulting a pharmacist can help to avoid polypharmacy and potentially serious side effects.
- Ideally there would be specialist training available for GPs specifically relating to treating people with ID.
- A specialist group of clinicians to support GPs working with people with ID should be created.

For disability service providers

- A key disability support professional accompanying the person with ID to any appointment must have a good understanding of the person’s needs within their daily lives. They should have a fairly strong relationship with the person with ID as well as a good basic knowledge of their history.
- A checklist of all information that needs to be bought to an appointment should be developed, whether it is an initial appointment or a review. This should include:
  - lists of every medication the person is on, with dosage, frequency and administration intervals
  - any previous diagnoses and assessments.

There is a document entitled the Residential services practice manual (currently in its second edition, 2009). The use of this document is mandatory for departmental workers only and briefly outlines some of the policies surrounding a medical appointment that a disability service provider has to ensure it occurs. Find it online at <www.dhs.vic.gov.au/disability>.51
• Given the above, there is a real need for a more accessible, shorter and less confronting checklist.

• The capacity of disability support professionals to implement psychological interventions and provide additional training where appropriate should be assessed.

• Recruiting disability support professionals who have the values, skills and experience to work with people with ID and co-occurring mental illness should be improved.

Existing recommended guidelines

• Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability (2001).37


• A protocol to guide a collaborative medication review for adults with behaviours of concern (2008).34


• A package of six DVDs called Health and disability: Partnerships in action – A teaching and learning resource in disability health and inter-professional education has been produced by Monash University and the Centre for Developmental Disability Health Victoria. The package aims to educate health professionals on various issues in health care relating to people with ID. More information can be found at <www.cddh.monash.org/partnerships-in-action>.
References


