~ Medication Review Guide for GPs ~

A guide for GPs on the use of psychoactive medications for adults with intellectual disability who present with behaviours of concern

Centre for Developmental Disability Health Victoria

2015

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Introduction:

This resource has been designed to guide and assist General Practitioners (GPs) and Disability Support Personnel (DSP)* when reviewing the medication regimen for a person with an intellectual disability who has been identified as having behaviours of concern** and for whom antipsychotic medication is being considered or already prescribed.

The first part of the Guide provides information for GPs, the second part for DSP. Both are included in the one document as understanding each other's role and expertise facilitates successful collaboration.

** People paid to support people with disability in those life tasks they find difficult come from a range of backgrounds, and have widely differing degrees and types of education and training for the role. Various terms are used to describe this workforce, including Support staff, Disability Support Workers, Disability Support Professionals and Disability Support Personnel. We have chosen to use Disability Support Personnel (DSP) in this publication as we feel this describes their work and acknowledges the range of experience and expertise they bring to their role.*

***Behaviours of Concern is the terminology currently used in Victoria and elsewhere for "those behaviours that are severe and frequent enough to put the person's safety, or that of others, at risk and that may lead to use of restrictive practices (Emerson & Einfeld, 2011). This is synonymous with the term Challenging Behaviours.*

A letter to General Practitioners:

Dear Doctor,

This Guide to Medication Review of Psychoactive Medication has been developed to support medical practitioners who often have the difficult job of determining if it is appropriate to use medication for the treatment of 'behaviours of concern' (also known as 'challenging behaviours') in people with intellectual disability. Disability legislation in Victoria requires justification for and monitoring of medications that restrict behaviour (chemical restraint), and was developed in response to the past lack of accountability and overuse of these medications in this population.

The Centre for Developmental Disability Health Victoria (CDDHV) has developed this resource to facilitate the decision making process, by ensuring that the medical practitioner has the necessary information. We have included a range of forms and other resources to assist you to work with your patients with disabilities and the family members and disability staff who support them.

If in your opinion the diagnosis for which the medication has been given is clear, then record the diagnosis and the rationale behind it. However, when the diagnosis is either uncertain or unknown, this resource will step you through the decision making process.

This Guide has been developed in consultation with General Practitioners and Psychiatrists who have worked in the field for many years. I hope you find it helpful in the care of your patients with intellectual disability.

Yours sincerely,

Assoc. Professor Bob Davis PhD, MB, BS, FRACGP, DRACOG, GDEB.
Director of Clinical Services,
Centre for Developmental Disability Health Victoria.

Table of Contents

KEY POINTS

- People with intellectual disabilities who have difficulty using language to communicate may express their symptoms, feelings and experiences through changes in their behaviour.

- If this behaviour is of concern to the person or to those who provide support to them in their daily life, whether family members or paid support staff, then they may present to their GP for assessment and management of the behaviour. Such a behavior may be termed a ***'behaviour of concern'*** or ***'challenging behaviour'.***

- A change in behaviour may reflect underlying physical or mental ill-health. Behaviour change may also be a response to the physical, sensory or social environment and/or changes in life circumstances.

- The assessment process is, in general terms, the same as for anyone else presenting to the GP with complex or non-specific symptoms. It relies on a comprehensive history and examination, formulation of a provisional diagnosis and management plan. Regular review is then essential to monitor the response and identify adverse reactions. If the response is not as expected then reassessment is required.

- It is important that this process of assessment, management and review is adequately documented in both the medical practitioner's records and in the person's file held by the patient and those supporting him/her.

- The Assessment and Management Framework on the following page provides a structure for working through the process, highlighting some of the particular considerations important when working with someone with an intellectual disability.

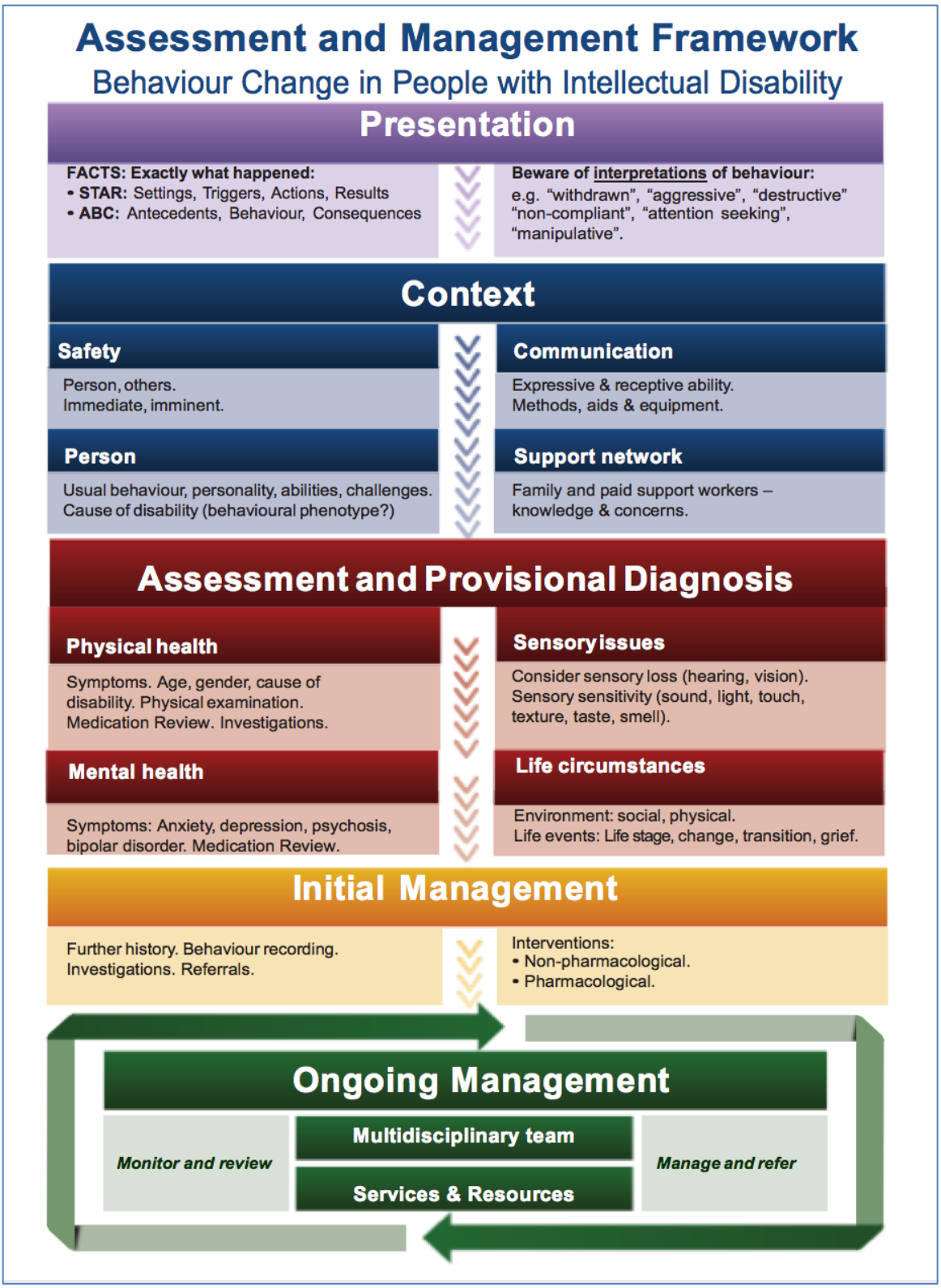
- Medication Review is a key part of an assessment of physical and mental health in someone with intellectual disability presenting with behaviours of concern.

  For more information see: **Medical Assessment and Management of Behaviours of Concern in People with Intellectual Disability**

  http://cddh-online.monash.org

Assessment and Management Framework for Behaviours of Concern in People with Intellectual Disability

This Guide for GPs is designed to be used in conjunction with the eLearning Resource for GPs: ***Medical Assessment and Management of Behaviours of Concern in People with Intellectual Disability*** available at **http://cddh-online.monash.org**



Medication Selection, Monitoring and Review: Key Contributors

- Medication review is a key part of an assessment of physical and mental health in someone with intellectual disability presenting with challenging behaviour.

Many people can usefully contribute including:

- The person with disability and/or their advocate
- Family members
- Disability personnel supporting the person at home, education, recreation, work
- Medical practitioners: General Practitioner and Specialists involved
- Pharmacist
- Community/Practice Nurse.

Roles and Responsibilities of the Medical Practitioner and Disability Personnel

	General Practitioner (GP)	Disability Support Personnel (DSP)
Assessment	Establish who are the key stakeholders in the life of the person. Work in collaboration with the person and those who support him/her in the provision of health care. Review information provided by the person, their family and the DSP. Undertake a comprehensive medical & psychiatric assessment including past medication history. Includes family history – may need to contact family members. Formulate provisional & differential diagnoses. Decide on an appropriate intervention. Evaluate risk and benefit of this intervention. Prescribe if indicated. Discuss the anticipated benefit and potential adverse effects of medication with the patient, family and DSP as appropriate. Inform them of side effects they should monitor and what to do if they detect these. Arrange review to monitor efficacy. Consider requesting staff chart behaviour to provide more objective information when reviewed. Note: consider initial behaviour recording to establish baseline before intervention. Ensure support staff are clear about any change in management/medication. Provide patient and DSP with written summary of outcome of assessment and the management plan decided upon.	Make a long appointment for medical assessment if there is concern about a change in behaviour. Complete forms within the Medication Review (DSP: 1,2,3,4 – see pages 33,35,36,38) Accompany the person with disability to the medical practitioner and encourage and support the person to communicate directly with the doctor to the extent possible. Provide the GP with further information about the person from the file and from personal knowledge as required. Bring relevant documentation and reports: health files; behaviour charts; outcomes/reports from previous medical, psychiatric, behaviour and communication assessments; current medication/ treatment sheets. Record outcome of consultation with assistance of GP. Document if chemical restraint prescribed. Observe and record response (include behaviour charting) to intervention, including medication, and take these to regular GP review appointments.
Investigations, referrals	Select investigations and referrals as indicated. Provide specific information to Disability Staff re how to arrange these. Review results and respond appropriately. Review patient regularly.	Assist in obtaining further documentation as requested by the medical practitioner. Arrange investigations as ordered by GP. Make a GP appointment to review results.
Formulation	Make provisional diagnosis.	The diagnosis may not be clear and so

	General Practitioner (GP)	Disability Support Personnel (DSP)
	There is often an element of uncertainty and so a trial of an intervention may be indicated. Close monitoring and regular review of response to intervention are required to confirm or disprove diagnosis. Documentation is important for future reference.	close monitoring of response to intervention are required to confirm or disprove diagnosis. Regular review by the medical practitioner is required.
Use of Medication	Decide whether any medications meet the definition of chemical restraint (see page 13). Document: If medication is treating an underlying psychiatric condition, such as anxiety, depression, psychosis, bipolar disorder, then it is not chemical restraint. If however the medication is specifically targeting the behaviour without a diagnosis then it is being used as a chemical restraint. Provide disability staff with information about medication – indications, potential side effects. Refer to: www.betterhealth.vic.gov.au Provide behaviour chart and mark commencement of medication. Consider establishing a baseline before commencing the medication so you can measure response. Review regularly to monitor response to medication (i.e. Is behaviour changing?). If response is not as expected, then reassess diagnosis and re-evaluate medication choice.	If medications are considered to be chemical restraint, request documentation from the medical practitioner to meet the legal reporting requirements for chemical restraint. Report use of chemical restraint if required. Carefully document response to medication. Arrange regular appointments for GP to monitor response and take charts and other documentation to those appointments. Ensure that the person's health history, and past assessments from relevant professionals remain in the patient's current file, and are available to supporting staff and health professionals. Such information should not be archived.
Ongoing management	Annual Health Assessment including medication review. Rationalise the use of all medications and prescribe/de-prescribe as indicated. Review regularly to monitor medication for efficacy and adverse effects (i.e. Is behaviour changing? Behaviour charts are very helpful in documenting changes noticed by disability personnel). If response is not as expected, then re-evaluate medication choice and/or reassess diagnosis.	Yearly Annual Health Assessment, including medication review. Inform the doctor of significant social and environmental changes in the person's life. Report any known health issues within the person's family. Behaviour charts can be used to document response to medication and other interventions.

Administrative and Reporting Requirements

Note: The terms Medication Chart and Treatment Sheet in this context are synonymous and used to describe the list of medication that someone is taking.

	Medical Practitioner	Pharmacist	Disability Support Personnel
Medication chart /Treatment Sheet & Webster pack	• Prescribe medication and update patient file, - including indication for medication. • Write up medication chart.	• Dispense medication in Webster pack based on current medication chart/ prescriptions. • Check current medication chart is consistent with dispensed medication. • Educate staff in administration procedure.	• Bring the person's health records, including the medication chart, to all doctor's appointments. • Ensure documentation of any medication changes are recorded on medication chart. • Ensure current medication chart is presented to pharmacist. • Maintain current medication chart within the person's health file.
Reporting requirements	• Sign medication record on medication chart. • Refer if clinically indicated. • Document psychiatric diagnosis and evidence for diagnosis in patient file.		• Report chemical restraint to Authorised Program Officer. • Record if psychiatric diagnosis has been made and by whom.

PART 1: General Practitioner

Health and behaviour

When a person's behaviour changes, consider underlying disorders of physical and/or mental health or changes in the person's physical, social or sensory environment.

When a change in behaviour is related to physical or mental ill-health, then addressing the underlying cause is the most effective way to address the change in behaviour. **Effective management depends on accurate diagnosis.**

When an **underlying psychiatric disorder** is thought to be the cause for a change in behaviour, psychoactive medication may be indicated.

When **no medical/psychiatric cause** of the behaviour change is identified **and** the behaviour is putting the person and/or others at **significant physical risk**, then the use of **psychoactive medication** may be indicated for a period of time. The use of medication in this way is **Chemical Restraint**. The exception to this is when sedating or anxiolytic medication is used to enable medical or dental investigations or treatment.

Effect of changes in the physical and social environment

Even subtle changes in a person's physical and interpersonal environment can have an enormous impact on the behaviour of a person with intellectual disability and/or autism. Changes at home, in day activities, in friends, in support staff can all impact on behaviour. Likewise changes in this environment can be powerful mechanisms to positively impact on behaviour.

Victorian Legislative Definition of Chemical Restraint

Under Victorian legislation (Disability Act, 2006, S.3.1), chemical restraint is :

'the use, for the primary purpose of the behavioural control of a person with a disability, of a chemical substance to control or subdue the person but does not include the use of a drug prescribed by a registered medical practitioner (a doctor or psychiatrist) for the treatment, or to enable the treatment, of a mental illness or a physical illness or physical condition'.

The legislation states that restraint or seclusion can be used **only** in order to **prevent the person with the disability:**

- ***Causing physical harm to themselves***
- ***Causing physical harm to any other person***
- ***Destroying property such that they risk harm to themselves or others.***

Chemical restraint should be **assessed against other available options** and only used if it is the **least restrictive** to the person in the circumstances.

Reporting Requirements: Chemical restraint

In Victoria, the use of medications that meet the legislative definition of chemical restraint must be reported to the Office of the Professional Practice (Disability), Department of Health and Human Services.

- The chemical restraint must be included in a **Behaviour Support Plan**, which is approved by an Authorised Program Officer (APO) from the relevant disability organisation and reviewed regularly.
- Staff supporting the person with disability **must report** the use of chemical restraint to the APO monthly. The APO then reports to the Senior Practitioner, Office of Professional Practice through the Restrictive Interventions Data System (RIDS).

Summary of templates for General Practitioners

1. Determine safety and risk

- Patient information — **DSP: Template 1 (p.33)**
- Safety and risk assessment — **DSP: Template 2 (p. 35)**
- Description of behaviour — **DSP: Template 3 (p.36)**
- Consider behaviour chart — **GP: Template 4 (p.21)**

2. Identify underlying medical and psychiatric conditions

- Medical, psychiatric and medication history — **DSP: Template 4 (p.38)**
- Underlying medical cause for behaviours — **GP: Template 1 (p.18)**
- Underlying autism spectrum disorder — **GP: Template 2 (p.19)**
- Underlying psychiatric disorder — **GP: Template 3 (p.20)**

3. Consider possible contribution of cause of disability to behavior disability (Behavioural Phenotype) — **GP: Template 5 (p. 27)**

4. Consider information and concerns of all key people

- Key Contributors — **See p. 9**

5. Review current medications

- Medication information: Compare Treatment Sheet with doctor's own records — **DSP: Template 4 (p.38)**

6. Review information from Disability Support Personnel and request further information as required.

- Request for information from Disability Support Personnel — **GP: Template 6 (p.28)**

7. Review behaviour charts — **GP: Template 4 (p.21)**

- Compare baseline with response to intervention (s)

8. When using medication as a Chemical Restraint

- Document rationale for medication & provide copy to DSP — **GP: Template 7 (p.29)**
- Review medication regularly — **GP: Template 7 (p.29)**

Use of medication to address behaviours of concern

➢ For people with a psychiatric diagnosis

For people with a psychiatric diagnosis, management of the illness in people with intellectual disability is based on the same principles as used for the general population, including the use, choice and dose of medication.

➢ For people without a psychiatric diagnosis

For people displaying behaviours of concern who do not have a psychiatric diagnosis, consider:

❖ ***Does the behaviour put the person or others at significant immediate physical risk?***

➢ **If YES** → *Have potential underlying/contributing causes (physical ill-health, mental ill health, social, sensory and /or physical environmental changes) been identified and addressed?*

→ *Have behavioural specialists (e.g. disability services) been involved in assessment and formulation of management recommendations?*

→ *Is there a non-pharmacological intervention that may be appropriate?*

❖ ***Does the person have an autism spectrum disorder (whether previously diagnosed or not)?***

➢ **If YES** → *Has attention been paid to providing them with:*
- *A consistent, predictable environment?*
- *Appropriate communication and planning tools (e.g. visual timetables)?*

Note: Older people with an Autism Spectrum Disorder (ASD) and an intellectual disability may not have been identified as having an ASD as children as the criteria were much narrower then. Adults often benefit from seeing a psychologist specialising in working with people with autism.

❖ ***Is chemical restraint indicated in order to protect the person concerned and/or others while other strategies (communication, environmental, behavioural) are put into place?***

If the above have been considered, and the behaviours continue to put the person or others at significant physical risk, then using medication as a chemical restraint may be considered **for a limited and defined period of time** while other strategies are put into place.

When prescribing medication, the following **principles** should be applied:
- Effective treatment depends on **accurate diagnosis**
- **Document** indication and anticipated time frame for its use
- Use the medication **best suited** to the patient and with the **least side effects.** Note: Newer antipsychotic medications have more metabolic and less movement effects, the older antipsychotics have less metabolic but more movement effects.
- Use the **minimum effective dose** (start low and go slow)
- **Document** efficacy and adverse effects
- **Review** regularly (at least every 3 months) both for efficacy, to detect adverse effects and review the need for the medication.

Flowchart: *Is the medication I am prescribing chemical restraint?*

Is this patient presenting with behaviours of concern (challenging behaviour) that presents a significant threat to the person or others?

YES ↓

NO
→ **No medication indicated for behaviour.**

Have I excluded:

- **Underlying disorders of physical health?**
- **Medical/Psychiatric conditions associated with the disability?**
- **Deterioration of vision or hearing?**
- **Changes in the person's physical, social, sensory environment?**

YES ↓

NO
→ **Investigate above issues.**

Have you diagnosed a psychiatric illness for which the use of psychoactive (including antipsychotic) medication is indicated?

YES ↓

Treat with medication indicated by diagnosis and ensure the symptoms, diagnosis and response to treatment are documented.

NO ↓

Has the patient been seen by a specialist Behaviour Assessment Team? If so, are the strategies they recommended being applied?

YES ↓

NO
→ **Refer for assessment and management**

Do you consider antipsychotic or other psychoactive medication is indicated for the immediate safety of the patient or others?

YES ↓

If prescribed, medication would be used as chemical restraint.
→ **Complete documentation (including indication, time frame of medication and date of review) for the disability support personnel as per legal requirements of Office of the Professional Practice, DHHS.**

TEMPLATES: General Practitioners

GP: Template 1: Identifying underlying medical conditions

General Questions	Examples of further prompts
What? *Description - what happens precisely – how does the person's behaviour change?* *Triggers? What happens immediately prior to and after the behaviour?* *Reinforcers? What happens immediately after the behaviour?*	▪ Precise description of what happened including time course and severity ▪ Where was the person? Who were they with? What were they or others doing at the time? ▪ What happened after the behaviour? What did the person do? Others do? ▪ Was the behaviour always present but not at the current severity? ▪ Has there been a sudden change of behaviour?
When? *Does the behaviour occur more often at any particular time of the day?*	▪ Relationship to meals? Position? Sleep? Any particular activity? Any particular time of day/week/year? Does it happen more in a particular place or with a particular person? ▪ When does it always occur? ▪ When does it never occur?
Why? *Does any activity or event make the behaviour more likely?*	▪ Are there any known triggers to the behaviour? Person, place, activity?
History? *What is the long-term history of the behaviour?*	▪ Has this ever happened before? ▪ Is there an association with the onset and certain physical/mental distress/ illness/life event?
Medical/psychiatric disorders *known to be more common in people with the disability that could explain the behaviour?* *(Therapeutic Guidelines Ltd, 2012)*	Is the behaviour associated with the cause of the intellectual disability? Ask about medical problems known to be associated. e.g. People with Down syndrome are more likely to develop: Hypothyroidism, loss of vision/hearing, arthritis, dementia. People with cerebral palsy are more likely to develop: reflux oesophagitis, constipation, muscle spasm, epilepsy.
Consider ***Common Medical Problems***	Behavioural changes associated with dental pain, reflux and indigestion, constipation, depression etc.
Consider "Masquerades" *that could present as behaviour change.* *(Murtagh & Rosenblatt, 2011)*	**D**epression, **D**iabetes mellitus, **D**rugs (side effects of medication), **A**naemia, **T**hyroid disease, **S**pinal dysfunction, **U**rinary Tract Infections.

GP: Template 2: Could this person have an autism spectrum disorder?

(this may or may not have been previously identified/diagnosed)

Autism/ Autism Spectrum Disorder	• Does the person have more difficulty with social relating, social communication or social understanding than would be explained by their degree of intellectual disability? • Does the person engage in ritualistic or repetitive behaviours or marked repetition of speech (echolalia)? • Does the person have an unusual degree of difficulty coping with change in their social, sensory or physical environment? • Does the person demonstrate unusual sensitivity to particular sensory experiences such as light, sound, smell, touch and taste? Does the person seek to avoid these or does he/she seek them out? • Does the person have surprising abilities and skills that are beyond what one would expect from their degree of disability?

If autism is suspected then assessment by an experienced psychologist experienced in working with people with autism spectrum disorders will be required to make the diagnosis and assist with strategies to assist the person and those who work and live with him/her.

GP: Template 3: Underlying psychiatric disorder

Mental illness	Further Prompts
Depression	Is there a history of social withdrawal (eg not wanting to leave bedroom or house)? What did s/he enjoy doing? Is there a lack of enjoyment in previously preferred activities? Has there been evidence of depressed mood (e.g. less smiling/joking, crying)? Does the person wake at night or have difficulty getting to sleep? Is there history of weight loss and weight gain?
Bipolar Disorder	Are there days/weeks of hyperactivity with markedly decreased sleep, driven behaviour, disinhibition, absconding, euphoria (e.g. laughing for no apparent reason)? Are there days/weeks of lowered mood and activity, loss of interest in previously enjoyed activities, social withdrawal? Is there a history of cycles of these behaviours that occur repeatedly?
Anxiety Disorder	Does the person become agitated and distressed in certain environments or by particular objects and people? How does the person cope with changes in routine?
Psychosis	Are there any signs of hallucinations or delusions? Auditory hallucinations may lead to people speaking to themselves (as a new behaviour). Visual hallucinations may lead to people appearing to be frightened of something no-one else can see. Delusions of grandeur are relative, and someone with an intellectual disability may express these by believing they are the house supervisor, the boss, bus driver, or that they have been speaking to God or Jesus. Paranoid delusions may be demonstrated through apparent fear or targeting of a person or environment for no apparent reason.

GP: Template 4: Behaviour recording/charting

Charting behaviour over time provides data on which decisions about management can be made, and the efficacy of medication and other interventions monitored, in the same way seizure charts inform the monitoring and management of epilepsy.

The data provides more objective information than subjective impressions, and this is particularly important when information is provided by Disability Support Personnel who work in teams where staff work shifts and staff turnover can be high.

The decision about what behaviour is to be charted, and how it is to be classified, requires careful discussion between the GP who needs information to guide management, and the support staff who will be charting the behaviour.

In someone with **bipolar disorder,** for example, careful descriptions of behaviour characteristic of different mood states enable charting the persons cycling mood. It is important to use descriptions of the behaviour to be charted, rather than diagnostic terms (manic, depressed etc), as the latter may mean very different things to different people.

Characteristic behavioural clusters may be detected by, for instance, charting behaviour, sleep and weight. Episodes of mania may, for instance, be manifest in days/weeks of loud and disruptive behaviours in association with decreased sleep and weight and depression as days/weeks of irritability and withdrawal in association with daytime sleep and increasing weight.

- **Mood in someone in whom bipolar disorder has been identified or is suspected could be described as:**

1: Hyperactive, sleeping less than 4 hours a night, loud shouting & singing, laughing.
2: Difficulty concentrating, disturbed sleep, loud, giggling to self, labile mood.
3: Focuses well when doing puzzles and iPad games, sleeps 6-8 hours at night.
4: Irritable, less interested in usual preferred activities, withdrawn, occasional crying.
5: Wants to be left alone, stays in bed/at home, not wanting to go to usual activities, quiet.

- **Frequency could be categorised as:**
  1. 20+ times a day/month/year
  2. 10-20 times a day/month/year
  3. 5-10 times a day/month/year
  4. 1-5 times a day/month/year
  5. 0 times a day/month/year

- **Severity could be categorised as:**
  0. No behaviour of concern
  1. Behaviour easily redirected
  2. Behaviour hard to redirect
  3. Behaviour that cannot be redirected
  4. Major incident

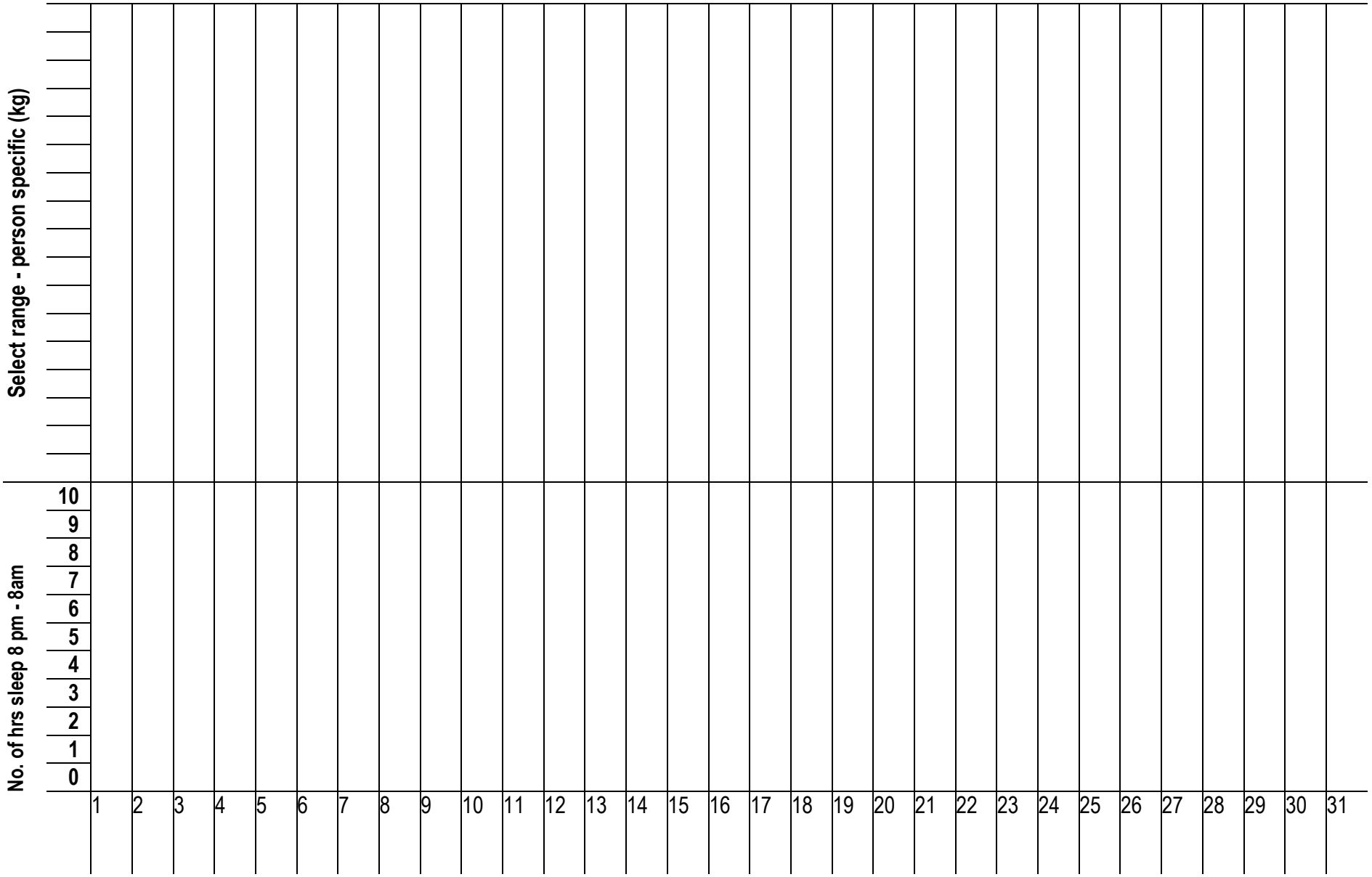
Examples of Behavioural Charts: Pages 23-26

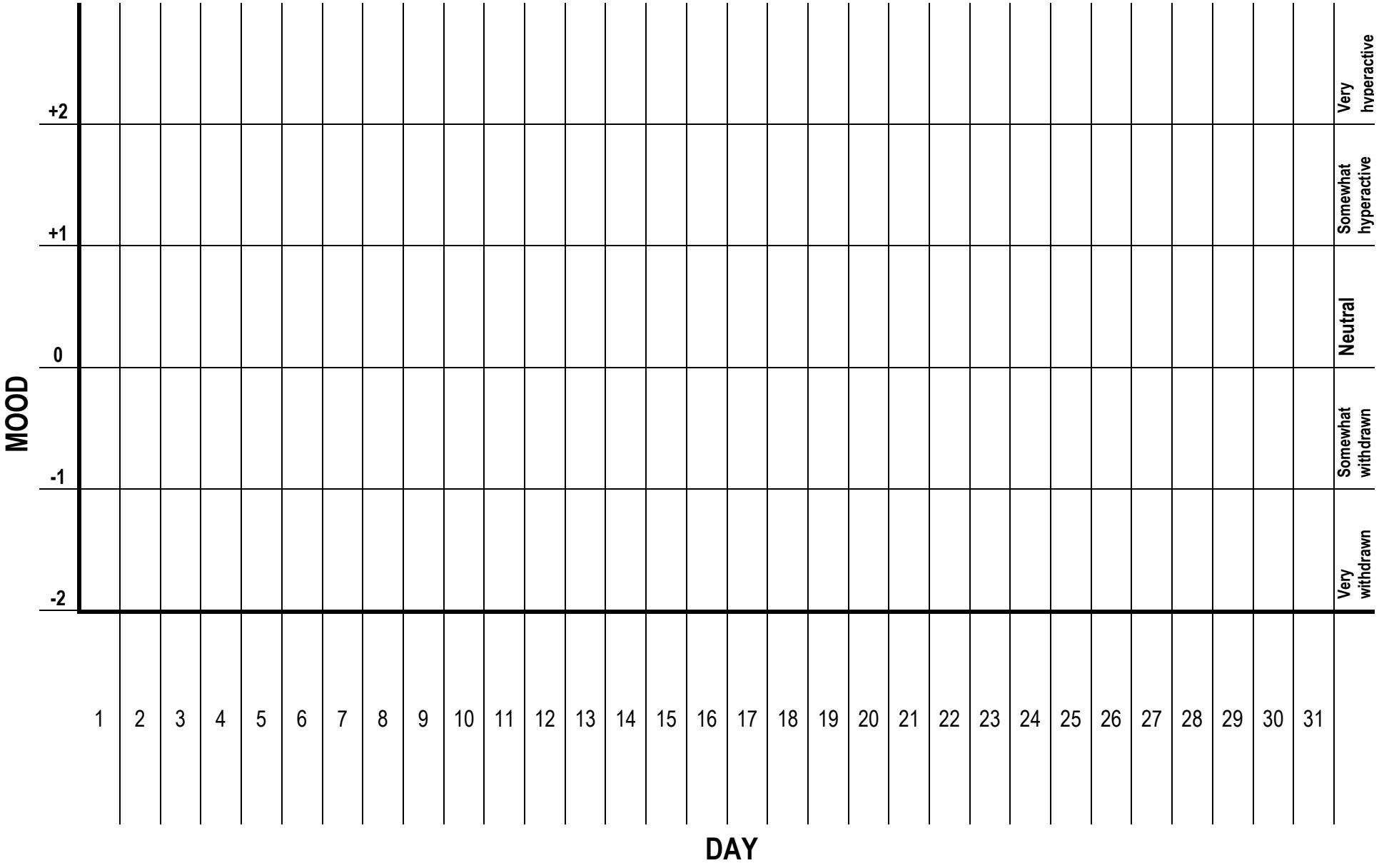
- ***Weight and sleep***
- ***Mood***
- ***Specific behaviours***
- ***An example***

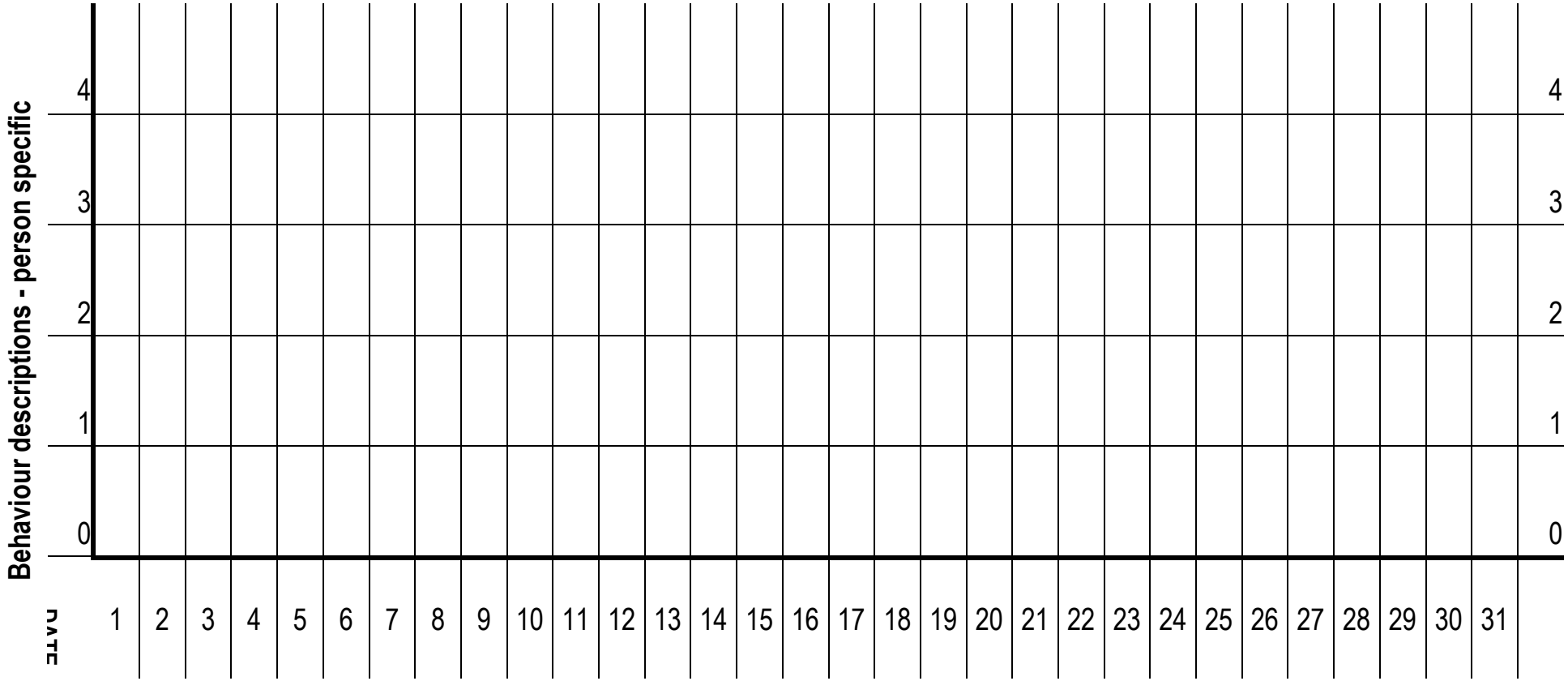
Name: _____

WEIGHT AND SLEEP CHART

MONTH _____







BEHAVIOUR BEING CHARTED IS:

0 = No Behaviour

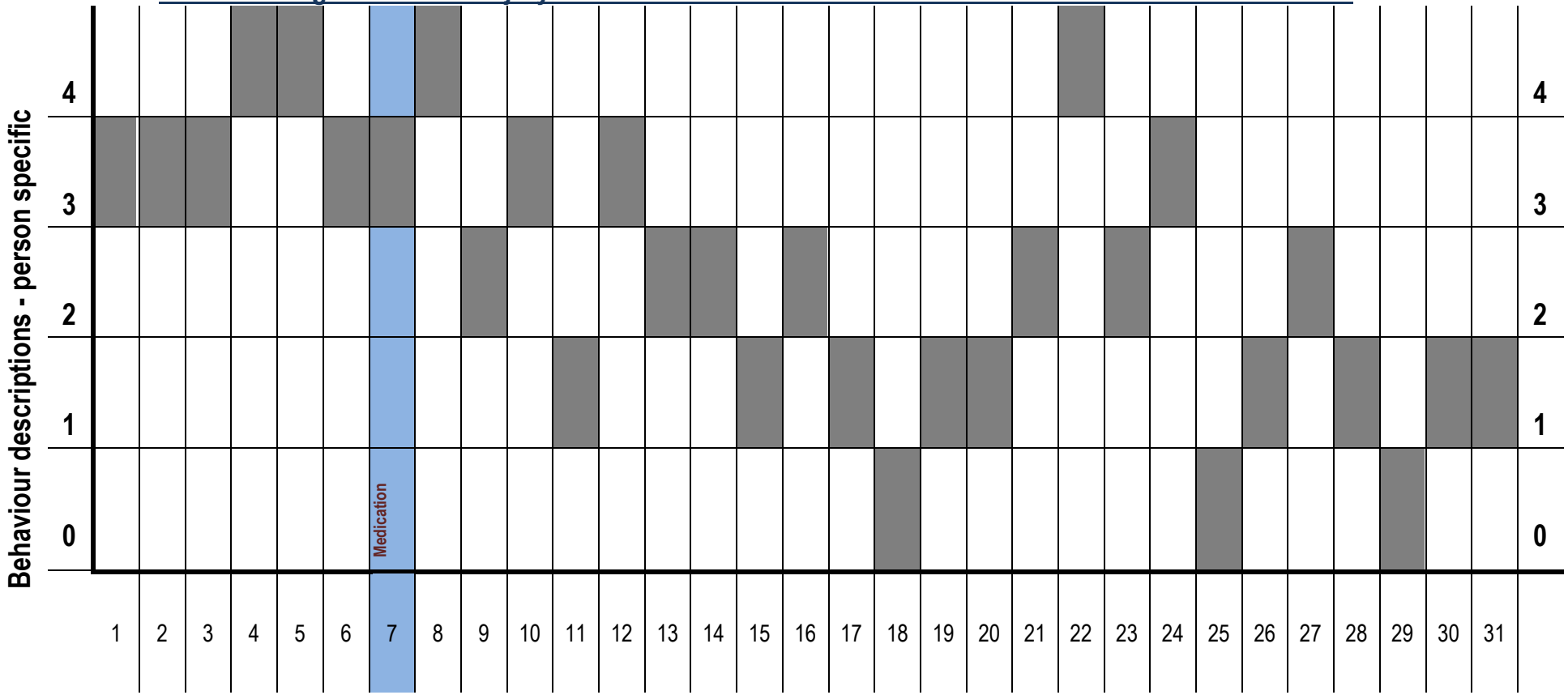
1 = Behaviour easily redirected

2 = Behaviour: hard to redirect

3 = Behaviour: cannot redirect

4 = Behaviour: major incident (e.g. injury to self or others or significant property damage)

EXAMPLE: Agitation & self injury decreased after medication commenced. Still occasional outbursts.



BEHAVIOUR BEING CHARTED IS: Agitated behaviour including self-injury, aggression and loud vocalisation

0 = No behaviour of concern. 1 = Behaviour - easily redirected 2 = Behaviour- hard to redirect

3 = Behaviour - unable to redirect. 4 = Behaviour - major incident (e.g. injury to self or others)

GP: Template 5: Behavioural Phenotypes: Aetiology of disability and behaviour

Type of Disability	Behavioural phenotype: examples of behaviours associated with particular genetic conditions
Fragile X	Social anxiety, eye gaze aversion, hand stereotypies, hypersensitivity to sensory stimuli, perseverative speech
Prader-Willi	Hyperphagia, temper tantrums, impulsiveness, self-injurious behaviour, non-compliance, repetitive speech, inactivity, skin picking, Psychosis in maternal disomy variant
Cornelia de Lange	Self-injurious behaviour, aggression
Rett Syndrome	Stereotypic hand movements such as hand-wringing or hands in mouth
Williams syndrome	Indiscriminate friendliness, short attention span, hyperacusis, anxiety
Smith-Magenis syndrome	Self-hugging, putting objects into orifices, self-injury
Velo-Cardio- Facial (Di George) Syndrome	Increase risk of paranoia, mood swings, psychosis, bipolar mood disorder, aggression
Down Syndrome	Obsessive behaviours, non-compliance
Lesch-Nyhan syndrome	Extreme self-mutilation
Tuberous Sclerosis	Impulsiveness, sudden outbursts of agitated behaviour, aggression, self-injurious behaviour

Websites for further information about behavioural phenotypes

- Online Mendelian Inheritance of Man: www.omim.org
  Excellent resource for health conditions and behaviours associated with the aetiologies of intellectual disability.

- Fragile X syndrome: www.fragilex.org.au/
- Prader-Willi syndrome: www.pws.org.au/
- Cornelia de Lange syndrome: www.cdlsaus.org/?page=home
- Rett Syndrome: www.rettsyndrome.org/
- Tuberous Sclerosis: www.tsalliance.org/
- Williams syndrome: www.williams-syndrome.org/
- Smith-Magenis syndrome: www.smithmagenis.org/start.htm.
- Lesch-Nyhan syndrome: www.ninds.nih.gov/disorders/lesch_nyhan/lesch_nyhan.htm
- Autism spectrum disorder: www.amaze.org.au
- Down Syndrome: www.down-syndrome.org/reviews/2069/
- Velocardiofacial Syndrome: www.genome.gov/25521139

GP: Template 6: Request for further information from Disability Support Personnel

- Name of patient:
- Name of support personnel accompanying patient today:
- Length of time the support person has worked with the person
- Date of next Appointment
- There **has** / **has not** been a change of medication for this patient

Disability support personnel –

Please bring the following observations /reports to the <u>next</u> appointment:

- **Documentation recording/charting of behavioural changes**
- **Documentation of medication side-effects**

  (*GP: Provide a list of most likely side effects and how these may be demonstrated e.g. nausea – reluctance to eat; effects of antipsychotic medications – weight gain, food seeking behaviours, movement disorders.)*
- **Documentation recording changes in the person's environment**

  (e.g. changes in people, place, activities, sensory)
- **Results** of any non-medical interventions
- **Other** (please specify)

<u>Other existing documentation that may be relevant</u>

Reports/ documents that may be provided by disability support personnel to the medical practitioner:

- Copies of all comprehensive assessments made by qualified professionals:
  - Functional Behavioural Assessment, Behaviour Support Plan
  - Speech pathology communication assessment report
  - Behaviour charts
  - Sleep charts
- Copies of previous medical reports
- Copies of psychiatric reports
- Client Treatment Sheet (all changes to medication need to be documented)

Disability support personnel can also check with family and previous disability support personnel for archived and additional material.

GP: Template 7: Documentation for use of Chemical Restraint

Note: This can be printed and given to staff for reporting requirements

Patient Name:

Date of Birth:

Date of Medication Review:

Details of medication for this patient:

Reason for prescribing medication:

Reason medications are considered a least restrictive option:

Anticipated time of next medication review:

Medical Practitioner's signature:

Date:

Other resources for GPs

- **eTG complete**

Since 2012 eTG complete has included *Management Guidelines: Developmental Disability, Version 3, 2012* as a separate pdf file. This eBook contains information designed to inform, guide and support their care of their patients with intellectual and associated developmental disabilities across the age spectrum, from birth to old age.
www.tg.org.au

- **Centre for Developmental Disability Health Victoria**

The CDDHV is funded by the Dept of Health and Human Services to improve the health care for and health outcomes of people with intellectual and associated developmental disabilities. The CDDHV engages in a range of clinical, research, education and resource development activities to support mainstream health practitioners in their care of their patients with intellectual and associated developmental disabilities.
www.cddh.monash.org

- **Victorian Office of Professional Practice**

The Office of Professional Practice lies within the Department of Health and Human Services and drives best practice to deliver positive outcomes for people who access human services. The Office works in partnership with professionals and organisations to maximise people's quality of life, promote people's development and safeguard their rights.

The Office brings together the Office of Principal Practitioner (child protection and youth justice) and the Office of the Senior Practitioner (Disability). This integration has strengthened the department's commitment to working in collaboration with our service partners to deliver holistic services for clients with complex needs. The Senior Practitioner (Disability) has powers under the Disability Act 2006 for ensuring that the rights of persons who are subject to restrictive interventions and compulsory treatment are protected and that appropriate standards in relation to these practices are complied with.
http://www.dhs.vic.gov.au/about-the-department/our-organisation/organisational-structure/our-groups/office-of-professional-practice/practice-resources-opp/practice-resources-disability/chemical-restraint-what-disability-support-workers-need-to-know

- **Office of the Public Advocate**

The **Office of the Public Advocate** provides a range of services and can become involved in advocacy and guardianship matters or when people with a disability are exploited, neglected or abused. The Office of the Public Advocate can be contacted directly to give advice on individual situations 1300 309 337
www.publicadvocate.vic.gov.au

PART 2: Actions for Disability Support Personnel

Reminder for Disability Support Personnel:

- Ensure the medical practitioner is given a full and accurate medical history
- It is essential that the support worker attending the consultation knows the person well, and has done so over a long period of time.
- The same support staff should attend all appointments when possible.
- Contact previous disability support personnel and family members for additional information.

1. Introduction

This resource is designed to guide and assist General Practitioners (GPs) and Disability Support Personnel (DSP) in a medication review for someone with an intellectual disability who is on medication for behaviours of concern (challenging behaviours).

The first part of the Guide provides information for GPs, the second part for DSP. Both are included as understanding each other's role facilitates collaboration.

People with intellectual disability may present with a behaviour that reflects underlying physical or mental ill-health, or changes in their environment or life circumstances.

The Guide for GPs is designed to be used in conjunction with the eLearning modules for GPs: ***Medical Assessment and Management of Behaviours of Concern in People with Intellectual Disability*** available at http://cddh-online.monash.org.

Disability support personnel may wish to alert GPs to this online resource.

2. Victorian Legislative Definition of Chemical Restraint

Under Victorian legislation (Disability Act, 2006, S.3.1), chemical restraint is:

'the use, for the primary purpose of the behavioural control of a person with a disability, of a chemical substance to control or subdue the person but does not include the use of a drug prescribed by a registered medical practitioner (a doctor or psychiatrist) for the treatment, or to enable the treatment, of a mental illness or a physical illness or physical condition'.

The legislation states that restraint or seclusion can be used **only** in order to **prevent the person with the disability:**

- ***Causing physical harm to themselves***
- ***Causing physical harm to any other person***
- ***Destroying property such that they risk harm to themselves or others.***

Chemical restraint should be **assessed against other options** and only used if it is the **least restrictive** to the person in the circumstances.

Reporting Requirements: Chemical restraint

The use of medications that meet the legislative definition of chemical restraint must be reported to the Office of the Professional Practice (Disability), Department of Health and Human Services.

- The Chemical Restraint must be included in a **Behaviour Support Plan**, which is approved by an Authorised Program Officer (APO) from the relevant disability organisation and reviewed regularly.
- Staff supporting the person with disability **must report** the use of Chemical Restraint to the APO monthly. The APO then reports to the Office of the Senior Practitioner through the Restrictive Interventions Data System (RIDS).

3. Behavioural Phenotypes

Certain causes of disability are associated with a greater likelihood of the person having certain characteristic behaviours. For example a missing piece on Chromosome 15 causes Prader-Willi Syndrome, and Prader-Willi syndrome is associated with excessive eating and the risk of life threatening consequences if diet is not carefully managed.

Knowing the cause of someone's disability therefore can both explain some behaviours and inform the person, those supporting him/her and the GP about certain health risks that need to be monitored.

It is important to remember that **not everyone** with a known genetic difference shows **all** the behaviours associated with that condition.

See page 27 for more details about Behavioural Phenotypes.

4. Further information and Resources

See page 30.

Templates for Disability Support Personnel

DSP: Template 1: Patient information to take to GP.

Please answer each question in this review. If you do not know the answer, please write "don't know". Do not leave any questions unanswered.

This review is being conducted for:

Name_____

Date of Birth_____/_____/_____

Next of Kin:

Medical Guardian/person responsible:

Cultural and language background_____

Gender ☐ Male ◯ ☐ Female

Does the person live in supported accommodation ☐ Yes ☐ NO

If so, what organisation provides the support staff?

Day activities:

Monday

Tuesday

Wednesday

Thursday

Friday

Interests and abilities:

What are the person's interests / favourite activities/ abilities?

What disabilities does the person have? (please circle):

Physical Intellectual Autism spectrum Hearing impairment

Vision impairment

Communication

What can the person understand (receptive communication)?

How does the person express himself/herself?

With words Sign Communication device

Body language and gesture Through his/her behaviour

Does the person use a communication aid or device? If so, what is the device?
Please make sure the person brings their communication tools to the consultation with the GP.

How does the person express their wants/needs and feelings?

How would the support worker know this person was in pain?

Mobility

Independent

Needs mobility aid for long distances (specify aid required)

Uses mobility aid for short distances (specify aid required)

Personal care

Independent Needs some assistance (specify tasks)

Needs full assistance

Support network:

Family:

Name of key worker/disability support personnel working with the person

Name of person completing this form, their role and how long they have worked with the person

Name of people and services collaborating, or who were consulted, in completing this form

DSP: Template 2: Safety and Risk Assessment

Persons name:

Name of Disability Support Personnel working with the person

.....

Name of person completing this form, their role and how long they have worked with the person

.....

Name of people and services collaborating, or who were consulted, in completing this form

.....

.....

Please answer each question in this checklist. If you do not know the answer, please write "don't know". Do not leave any questions unanswered.

Safety: List any known safety issues for the person with a disability:

At home _____

In the community_____

In the education/workplace_____

While travelling_____

List issues for:

People living with the person with a disability:

_____

People working with the person with a disability:

_____

Other people in the community:

_____

DSP: Template 3: Description of the behavior of concern

Behaviour: *Precise description*	
Duration *Minutes, hours, days*	
Frequency *Times per day/week/month/year*	
Duration *When did the behaviour first occur?* *How long has the person engaged in this kind of behaviour?* *Days/weeks/months/years*	
Settings *Where is the person when he/she is engaging in the behaviour?* *Are there any settings in which the behaviours always/never occur?*	
People involved *Who is present when s/he engages in the behaviour?* *What are those people doing?*	
Triggers *Suspected, likely or known*	
Steps to stop behaviour *What steps are taken to stop the behaviour during an episode? How successful are they?*	
What follows the behaviour? *What happens immediately after the behaviour has stopped?*	

Severity *Injuries to person? To others? Property damage? What have been the worst injuries and / or damage to property arising from the person's behaviour?*	
Key people *Do all those who know the person well agree with the description of the behaviour?* *If not, how long have they known the person and what is their role?*	
Advocate *Is an advocate needed? If so, why?*	
Additional information *Any other information or thoughts about the behaviours?*	

Example: Behaviour: Evan shouts at staff and co-residents;

Frequency	2-3 times every day
Setting	Worse when returns to house from the day program
(Likely) Triggers	Feeling anxious or frustrated when rings his mother and she does not answer, when unexpected events occur, when has to wait for anticipated event.
Duration:	Several hours
Severity	Disturbs co-residents Neighbours complaining
Consequence:	Very disruptive and upsetting for fellow residents and staff. Misses out on regular programs.

The description informs an understanding of Evan's behaviour, which, in turn, indicates effective interventions. In this case, Evan becomes distressed when life does not go the way he expects. His distress communicates his need for predictability and consistency in his life and the examples inform potential interventions. For example: Setting up pre-arranged times when he calls his mother; avoiding unexpected events to the extent possible and having visual communication tools/a social story to help him cope when unexpected events do occur; and the use of a visual timetable and/or calendar to assist him better understand and manage anticipation of upcoming events.

DSP: Template 4: Past medical, psychiatry and medication history

Current conditions:

CURRENT Medical condition	When was diagnosis made?	By whom was diagnosis made?	Treatment Intervention

CURRENT Psychiatric condition	When was diagnosis made?	By whom was diagnosis made?	Treatment Intervention

Past medical conditions:

PAST Medical conditions and Surgical procedures	Year	Medical practitioners of health service involved (if known)	Treatment Intervention

Past psychiatric conditions:

Psychiatric condition PAST	Year	Medical practitioners or health service involved (if known)	Medication	Effect of medication / positive & negative. Why was it ceased?

Medication

Note: Ensure you also have a copy of the person's current treatment sheet and take to consultation.

Current medication and dosage	Why was medication prescribed?	How long has the person been on the medication?	Response Reaction to medication

References

Brylewski, J., & Duggan, L. (2004). Antipsychotic medication for challenging behaviour in people with learning disability. *The Cochrane Database of Systematic Reviews*, 2004(3), 1–24. Centre for Developmental Disability Studies. (2006). Health care in people with intellectual disability. Sydney: NSW Department of Health.

Cooper, S. A., Smiley, E., Allan, L. M., Jackson, A., Finlayson, J., Mantry, D., & Morrison, J. (2009). Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. *Journal of Intellectual Disability Research*, 53(3), 200–216. doi: 10.1111/j.1365-2788.2008.01060.x

Cooper, S. A., Smiley, E., Finlayson, J., Jackson, A., Allan, L., Williamson, A.,…Morrison, J. (2007). The Prevalence, Incidence, and Factors Predictive of Mental Ill-Health in Adults with Profound Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20(6), 493–501. doi:10.1111/j.1468-3148.2007.00401.x

Cooper, S. A., Smiley, E., Jackson, A., Finlayson, J., Allan, L., Mantry, D., & Morrison, J. (2009). Adults with intellectual disabilities: prevalence, incidence, and remission of aggressive behaviour and related factors. *Journal of Intellectual Disabilities Research*, 53, 217–232.

Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190(1), 27–35. doi: 10.1192/bjp.bp.106.022483

de Leon J, Greenlee B, Barber J, Sabaawi M, Singh NN. (2009). Practical guidelines for the use of new generation antipsychotic drugs (except clozapine) in adult individuals with intellectual disabilities. *Research in Developmental Disabilities*, 30, 613–669.

de Winter, C. F., Jansen, A. A. C., & Evenhuis, H. M. (2011). Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. *Journal of Intellectual Disability Research*, 55(7), 675–698. doi: 10.1111/j.1365-2788.2011.01390.x

Deb, S., Salvador-Carulla, L., Barnhill, J., Torr, J., Bradley, E., Kwok, H.,… Bouras, N. (2010). *Problem Behaviours in adults with intellectual disabilities: An international guide for using medication*. The World Psychiatric Association (WPA): Section Psychiatry of Intellectual Disability (SPID).

Deb, S., & Unwin, G. L. (2006). *Guide to using psychotropic medication to manage behaviour problems among adults with intellectual disability.* University of Birmingham.
Department of Health. (2011). Victorian Population Health Survey 2009. Melbourne.

Department of Developmental Disability Neuropsychiatry (2014). *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers.* Department of Developmental Disability Neuropsychiatry. Prepared by Julian Trollor and Andrea Ching, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Medicine, University of New South Wales. http://3dn.unsw.edu.au/the-guide

Emerson, E., & Einfeld, S. L. (2011). *Challenging behaviour* 3rd Ed. Cambridge: Cambridge University Press.

Griffith, G. M., Hutchinson, L., & Hastings, R. P. (2013). “I’m not a patient, I’m a person”: The Experiences of Individuals With Intellectual Disabilities and Challenging Behavior—A Thematic Synthesis of Qualitative Studies. *Clinical Psychology: Science and Practice*, 20(4), 469–488. doi: 10.1111/cpsp.12053

Griffiths, H., Halder, N., & Chaudhry, N. (2012). Antipsychotic prescribing in people with intellectual disabilities: a clinical audit. *Advances in Mental Health and Intellectual Disabilities*, 6(4), 215–222. doi: http://dx.doi.org/10.1108/20441281211236661

Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F. M., & Purdie, D. M. (2004). ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. *Health Promotion International*, 19(2), 167–175. doi: 10.1093/heapro/dah204

McDonald, R., Forster, S., Carling-Jenkins, R., Tracy, J., Torr, J., & Davis, R. (2012). *Social inclusion for people with developmental disability in Victoria: Final report.* Melbourne: Department of Human Services.

McDonald, R., Tracy, J., Henderson, D., Raab, T., Hall, K., & Inglis, K. (2014). *Primary health needs of people with intellectual disability in the Frankston-Mornington Peninsula catchment: Final report.* Melbourne: FMPML.

McKenzie, K. (2011). Providing services in the United Kingdom to people with an intellectual disability who present behavior which challenges: A review of the literature. *Research in Developmental Disabilities*, 32(2), 395–403. doi: http://dx.doi. org/10.1016/j.ridd.2010.12.001

Murtagh, J., Rosenblatt, J. (2011). *Murtagh’s General Practice*. McGraw-Hill, Australia.

Myrbakk, E., & von Tetzchner, S. (2008). Psychiatric disorders and behavior problems in people with intellectual disability. *Research in Developmental Disabilities*, 29(4), 316–332. doi: http://dx.doi.org/10.1016/j.ridd.2007.06.002

Royal Australian & New Zealand College of Psychiatrists. (2013). Intellectual disability: Prescribing psychotropic medication for patients with an intellectual disability. Retrieved December 16, 2014, from https://http://www.ranzcp.org/Publications/Elearning.aspx

Therapeutic Guidelines Limited. (2012). *Management guidelines: Developmental disability Version 3.* Melbourne: Therapeutic Guidelines Limited. Also available on eTG complete [internet].

Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunsky Y, McMillan S. (2011): Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician*. 2011 May; 57(5):541-53.

Thomas, S., Corkery-Lavender, K., Daffer, n. M., Sullivan, D., & Lau, P. (2010). *Disability, mental health and medication: Implications for Policy and Practice.* Melbourne: Monash University.

Tsiouris, J. A., Kim, S. Y., Brown, W. T., Pettinger, J., & Cohen, I. L. (2013). Prevalence of psychotropic drug use in adults with intellectual disability: Positive and negative findings from a large scale study. *Journal of Autism and Developmental Disorders*, 43(3), 719–731. doi: 10.1007/s10803-012-1617-6

Unwin, G. L., & Deb, S. (2010). The use of medication to manage behaviour problems in adults with an intellectual disability: A national guideline. Advances in Mental Health and Intellectual Disabilities, 4(3), 4–11. doi: 10.5042/amhid.2010.0538

Victoria State Government. (2006). Victorian Disability Act 2006 No.23/2006. from http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/0B82C05270E27961CA25717000216104/$FILE/06-023a.pdf

Webb, J., & Stanton, M. (2009). Working with primary care practices to improve service delivery for people with learning disabilities – a pilot study. *British Journal of Learning Disabilities*, 37(3), 221–227. doi: 10.1111/j.1468-3156.2009.00555.x

Webber, L. S., McVilly, K. R., & Chan, J. (2011). Restrictive interventions for people with a disability exhibiting challenging behaviours: Analysis of a population database. *Journal of Applied Research in Intellectual Disabilities*, 24(6), 495–507. doi: 10.1111/j.1468 3148.2011.00635.x