The Royal Children's Hospital Melbourne

Transition Support Service

Managing young people with an intellectual disability and/or autism spectrum disorder

A resource for GPs

About this resource

This information has been developed for general practitioners who care for young people with an Intellectual Disability (ID) and/or Autism Spectrum Disorder (ASD), and can also be found at https://melbourne.healthpathways.org.au/.

Remuneration — useful MBS billing codes

These MBS items provide opportunities to provide longer consultation times for patients with ASD and/or ID.

	Code	Frequency	Amount	Explanation
ID	701	12 Months	$60.30	Brief <30 for health assessment
	703	12 Months	$140.10	Standard 30–45 minutes for health assessment
	705	12 Months	$193.35	Long 45–60 minutes for health assessment
	707	12 Months	$273.10	Prolonged 60+ minutes for health assessment
	10990	When concenssion card holder bulk billed	$7.50	Bulk billing incentive item for Commonwealth concession cardholder or a child under 16 years of age
	723	12 Months * If GP considers qualification for chronic disease	$116.15	Team care arrangements (3 practitioners)
	735–758	No more than 5 in 12 months	$50.90–$197.70	Multi-disciplinary case conference — fee depends on duration and whether organising or participating
ASD	721	12 Months — GPMP* If GP considers qualification for chronic disease	$146.55	GP management plan for chronic disease management
	732	Up to every 3 months	$116.15	Review of GPMP or TCA
	723	12 Months — TCA * If GP considers qualification for chronic disease	$116.15	Team care arrangements (3 practitioners)
	735–758	No more than 5 in 12 months	$50.90–$197.70	Multi-disciplinary case conference — fee depends on duration and whether organising or participating
Mental health	2700	12 Months	$72.85	At least 20–40 minutes
	2701	12 Months	$107.25	At least 40 minutes
	2715	12 Months	$92.50	At least 20–40 minutes — where mental health training has been undertaken
	2717	12 Months	$136.25	At least 40 minutes — where mental health training has been undertaken
	2712	Up to twice in 12 months	$72.85	Review of mental health treatment plan

Rebates current as at November 2019. To search MBS online go to: www.health.gov.au/mbs/search

Key issues and considerations

Behaviour

Patients with an ID and/or ASD commonly experience high levels of anxiety, mood disturbance, impulsive behaviours and explosive outbursts, particularly in situations they find stressful. It can be challenging to establish and underlying medical or psychiatric diagnosis and assess the response both to non-pharmacological approaches and to medication. It is also more difficult to identify medication side effects in patients with cognitive and communication difficulties.

A few tips:

- Is there a change in the patient's normal pattern of behaviour?
- Does this change in behaviour relate to:
  - a change in physical or mental health (e.g pain, anxiety)?
  - a change in the person's social or sensory environment (e.g. moving classroom)?
  - a change in their life circumstances (e.g. loss of a family member, transitions between year levels at school, changing schools, moving house)?
- Is behaviour support included in the patient's NDIS plan, if applicable?

Medication and other management considerations

When the patient with an ID and/or ASD, and their family, is going through a particularly challenging time, it may be tempting to add, or increase the dose of, medication. This is, however, often of limited benefit and creates further risks to the patient.

First line approaches therefore include:

- Optimising behavioural strategies
- Identifying and managing environmental triggers e.g. focusing on activities the patient finds pleasurable and calming

Allied Health practitioners such as psychologists, occupational therapists and speech pathologists may assist in addressing particular issues.

Appointments

Challenges may relate to the sensory or social environment of a busy waiting room:

A few tips:

- Try scheduling these patients at the beginning or end of a session to minimise waiting times
- Offer an alternative quiet space to wait in the clinic if possible
- Provide the option of providing carer-only or phone consultations where appropriate

Anxiety

Anxiety is very common in children and adolescents and young adults with an ID and/or ASD.

- Identify triggers for anxiety and ameliorate them wherever possible through modification of the physical, social and sensory environment
- Discuss with the patient or carer strategies which may be helpful
- A professional to assist with teaching social skills which could be applied at home, school or other environments, can be helpful (e.g. Occupational Therapy)

Medications

If the anxiety or depression is severe enough to warrant medication, SSRIs are the drugs of choice.

- If SSRIs are needed, prescribe **in conjunction with other supports** (e.g. psychological input, social skills training and behavioural support)
- Commence with a **low dosage and increase slowly** until a therapeutic dose is reached. The time limited trial of medication should be carefully monitored to evaluate the efficacy and any side effects
- Observe behaviour to determine effectiveness and identify side effects, particularly if patients are not able to communicate verbally
- If the medication appears to have had no benefit after a few months, or if it comes unacceptable side affects, it should be ceased and another SSRI trialled

Emotional dysregulation, recurrent meltdowns or mood problems

As a general principle, non-pharmacological approaches for behaviour management should be the first step. However, consider medication for the following indications:

- To help manage risk to themselves or others
- To enable the person to participate in family, school and community life
- To improve the quality of life for the patient and family

The choice of medication will be dictated by the presenting symptoms, underlying diagnosis, potential side effects and past responses.

For patients with difficulty communicating, monitoring for side effects of medication is very important. Carers should be alerted for the signs they should be looking for, and what to do if they notice a change. Each class of medication has its own side effect profile, so each needs to be considered separately. The three most common classes of medications used in people exhibiting behavioural outbursts are:

1. SSRIs (where mood or anxiety are clearly established as reasons for the behavioural outbursts).

   Side effects may include: nausea, dry mouth, insomnia, agitation, dizziness, sexual problems (e.g. difficulty reaching orgasm).

2. Mood stabilisers such as Epilim or Tegretol (where there are clear signs that sustained mood lability across days or weeks drives the disruptive behaviours).

   Side effects may include: Nausea, rash, changes in appetite and weight, bleeding and tender gums, irregular menstrual periods, headache.

3. Antipsychotics (usually used to decrease or regulate arousal which is commonly seen in these patients).

   Side-effects need to be carefully monitored and may include: weight gain, drowsiness, slowed thinking, and excessive sedation that needs to be carefully monitored. Extrapyramidal side effects, dyskinesia, and breast swelling/galactorrhoea may occur.

Considerations for patients on antipsychotics

- Is there excessive sedation?
- Have you or the carer noticed differences with movement, gait or posture?
- Check weight and examine the cardiovascular system

- Have there been any extrapyramidal side effects including tremor, dystonia, akathisia, tardive dyskinesia etc.?
- Have they had an ECG to check QT interval?
- Does the patient need blood monitoring including prolactin, LFTs and FBE?

Attention Deficit Hyperactivity Disorder (ADHD)

Even though patients with high functioning autism can focus very well on tasks in which they are interested, many have difficulties with both executive function and disinhibition which are the hallmarks of ADHD. ADHD symptoms may also be a feature of the phenotype of patients with more severe intellectual disability and ASD and lead to poor educational or skills development, impulsive and disruptive behaviours.

Trialling medication may be warranted. The best medication to treat ADHD symptoms are stimulants. There are two main groups:

1. Methylphenidate e.g. Ritalin/Concerta.
2. Dexamphetamine e.g. Dexamphetamine/Vyvanse.

   The other group of ADHD medications is the non-stimulants such as Atomoxetine (Strattera) and Guanfacine (Intuniv). (Atomoxetine and Intuniv are on an authority streamlined item on PBS).

An authority script will be obtained, and doses will be adjusted by either the paediatrician or psychiatrist. If there are side-effects such as reduced appetite, significant weight loss (check weight and height at each visit), headaches, lethargy, sleep issues or mood related issues this needs to be discussed with the patient, parent and the paediatrician or psychiatrist, and the doses adjusted accordingly.

Social and educational issues

If these issues are identified early, the school and psychologist should be engaged in supporting the young person.

- Are their current interests forming the basis of educational and psychological intervention?
- Is there access to additional support within the classroom e.g. educational support officer?
- Is support provided for social skills development and social integration at school and in the community (e.g. occupational therapy)?
- Is there pathway to further training, work or a day placement?

Respite

Particularly for patients with a severe ID and/or ASD or high-functioning patients with mental health issues, respite or short term accommodation, can be an important consideration.

Funding for short term accommodation (respite) can be included in the NDIS plan:

- Are the family linked in with community supports and NDIS?
- Is there a plan to support ongoing social, personal care and independent living skills?
- Monitor weight

Medication considerations

If medication is required for patients with an ID and/or ASD, consider:

- **Diagnosis:** effective treatment depends on accurate diagnosis
- **Safety:** lowest effective dose of least toxic alternative
- **The least restrictive option:** medication that minimises the impact on function, independence, and participation
- **Formulation:** for example, those who have difficulty swallowing tablets/capsules, liquids, chewable/crushable tablets or granules may be preferable. Consultation with a pharmacist can be helpful in discussing available formulations for related medications
- **Start low, go slow:** start at a low dose and increase slowly to a therapeutic dose
- **Monitoring:** inform family/carers about anticipated effect, and likely side effects and what to do if they occur
- **Review:** review regularly to monitor for effectiveness and side effects

Aetiology

The patient's underlying aetiology may inform you about health vulnerabilities e.g. reflux in patients with cerebral palsy or Cornelia de Lange syndrome, depression in patients with Down syndrome, anxiety in patients with Fragile X syndrome.

Co-existing conditions

Epilepsy

Many people with an ID and/or ASD are on medications for epilepsy. Both the choice of medication and the formulation are important for efficacy and compliance. For example, if they are unable to swallow tablets/capsules, the chewable/crushable 100 mg Epilim tablets may be helpful.

Dental issues

Dental problems can be difficult to detect in patients with an ID and/or ASD especially in those with severe disabilities. Patients may have oral sensitivity and discussion with the dentist about the importance of oral hygiene, and the best ways of achieving optimal oral health is important. Patients on saliva control medication need to be checked carefully for dental problems and should be referred to a specialist dentist.

Transition Support Service
The Royal Children's Hospital Melbourne
50 Flemington Road Parkville
Victoria 3052 Australia
Transition.support@rch.org.au
www.rch.org.au/transition

190501