

Behaviour disorders in children with an intellectual disability

Stacey Ageranioti-Bélanger MD PhD¹, Suzanne Brunet MD¹, Guy D'Anjou MD¹, Geneviève Tellier MD²,
Johanne Boivin MD², Marie Gauthier MD¹

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Behaviour disorders are frequent in children with an intellectual disability, regardless of the underlying etiology. They are often disabling, and can create problems in everyday life and can mask, or reveal, an organic or psychiatric illness. Such behaviours are often chronic and more than one may be present in the same individual. This is further complicated by the fact that parents often do not seek help for the problem, perhaps believing that it is due to the child's disability and cannot be treated. The present review describes some general concepts dealing with the management of behaviour disorders commonly seen in children and youth with an intellectual disability, and gives a high level overview of behaviours commonly problematic in this patient population including sleep disturbances, agitated and aggressive behaviours, and self-injury behaviour. In general, while pharmacological treatment is possible, behavioural intervention is a more effective and better tolerated form of treatment.

Key Words: Aggression; Agitation; Intellectual disability; Mental retardation; Self-injury; Sleep disorders

The diagnosis of an intellectual disability (ID) relates to a heterogeneous group of individuals, approximately 3% of the population, whose intelligence quotient is <70. Behaviour disorders are frequent in children with an ID, can create problems in everyday life and can mask, or reveal an organic or psychiatric illness. It is crucial to adopt a multidisciplinary approach in treating these behaviours.

In the present review, we first describe some general concepts dealing with the management of behaviour disorders in children with an ID, and then provide an overview of, in our experience, the four most common of these disorders: sleep disturbances, agitation (as it relates to attention-deficit hyperactivity disorder [ADHD]), aggression and self-injury. The treatment of organic problems and psychiatric illnesses that may cause behaviour disorders is beyond the scope of the present article. The present article is based on a conventional and complete literature review, with many of the practical suggestions based on the experience of the authors (ie, group consensus).

GENERAL CONCEPTS

1. Assessment

The first step is to obtain an adequate medical history including onset of the behaviour disorder, evolution over time, extenuating or aggravating factors (eg, environmental stressors that could be impacting the child), functional impairment, a family history of psychiatric problems and the impact of the child's behavioural

Les troubles de comportement chez les enfants ayant une déficience intellectuelle

Les troubles de comportement sont fréquents chez les enfants ayant une déficience intellectuelle, quelle que soit leur étiologie sous-jacente. Ils sont souvent invalidants, peuvent créer des problèmes dans la vie quotidienne et masquer ou révéler une maladie organique ou psychiatrique. Ces comportements sont souvent chroniques et peuvent être multiples chez la même personne. Ils sont compliqués davantage par le fait que, souvent, les parents ne demandent pas d'aide, croyant peut-être qu'ils sont causés par la déficience de l'enfant et qu'ils ne peuvent pas être traités. La présente analyse décrit certains concepts généraux sur la prise en charge des troubles de comportement souvent observés chez les enfants et les adolescents ayant une déficience intellectuelle et donne un survol des troubles de comportement souvent problématiques au sein de cette population de patients, y compris les troubles du sommeil, les comportements agités et agressifs et l'automutilation. En général, le traitement pharmacologique est possible, mais l'intervention comportementale est plus efficace et mieux tolérée.

difficulties on other family members. It is also important to have information on the individual's level of functioning including cognitive, adaptive, social-functioning, levels of receptive understanding and expressive language (1). A thorough physical examination is required in all cases.

In cases where parents or tutors 'no longer recognize the child' and there are, for example, autonomic symptoms such as loss of appetite combined with a loss of weight or marked changes in sleep habits, a specific questionnaire dealing with psychiatric symptoms must be completed. A family history of depression, loss of interest in favourite activities, evidence of sadness and recent irritability should suggest the possibility of a depression. In investigating a possible anxiety problem, it is important not only to consider the family history, but also the avoidance of specific situations, difficulties with transitions, difficulties encountered in distancing oneself from attachment figures or the presence of adrenergic symptoms (eg, tachycardia, tremor) during a crisis. A bipolar illness must be considered in the presence of a family history or severe agitation cycles alternating with periods of apathy.

In most circumstances, a suspected psychiatric etiology would require evaluation and management by a child psychiatrist. The prevalence rate of psychiatric disturbances, in the population of children with an ID, is 20% to 35%, that is, three to five times higher than that for the general population. It is important to rule out the possibility of a psychiatric disturbance when the patient shows behavioural symptoms of recent onset, experiences

¹Department of Pediatrics, CHU Sainte-Justine; ²Department of Psychiatry CHU Sainte-Justine, Montreal, Quebec

Correspondence: Dr Stacey Belanger, CHU Sainte-Justine, 2e Etage, Bloc 1, Local 2123, 3175 ch Cote-Sainte-Catherine, Montreal, Quebec H3T 1C5.

Telephone: 514-345-4931 ext 7727, e-mail stacey_ageranioti_belanger@hotmail.com

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exacerbation of baseline behavioural symptoms or does not respond to a well conducted behavioural approach (Table 1). In general, the psychiatric symptomatology does not vary greatly from one living environment to another, is accompanied by autonomic symptoms (eg, significant decrease or increase in appetite), includes acute psychomotor agitation or apathy, and does not respond to a behavioural approach.

The main organic causes that might explain a behaviour disorder must be considered. For example, obstructive apneas could explain a sleep disorder, while physical or sexual abuse or chronic pain (eg, toothache, constipation) may be manifested by aggressive behaviour. A chronological link may exist between the onset of the behaviour disorder and the use of medication (eg, benzodiazepine resulting in a disinhibition).

2. Treatment

The first step usually requires working closely with educators and caregivers involved with the care of the child, to adopt a behavioural approach or to make changes to the environment (Table 2). When the use of a behavioural approach alone does not suffice, a pharmacological approach may be indicated. While patients with an ID respond to psychotropic medications, the response is often inferior when compared with the population without an ID and side effects are more frequent. Medication must be introduced slowly, and its effectiveness monitored closely (ie, start low, go slow). Nonoptimal dosing or not allowing sufficient time to observe the effects after a change in medication are among the more frequent causes of failure of psychotropic drugs. If no underlying psychiatric illness has been identified, medication will be prescribed based on the patient's symptoms (eg, agitation, aggressiveness), and should be administered in close collaboration with educators and families. Unfortunately, due to a lack of resources for this population, pharmacological intervention is increasingly used.

SLEEP DISORDERS

The prevalence rate of sleep disorders in the paediatric population is 20% to 30%, and may increase to 80% in children with an ID, regardless of their age (2). A detailed review of the subject can be found elsewhere (3-5). Research evidence indicates that sleep problems exist when sleep behaviour causes a problem for the child, his family or both (4). Whether the child or the family is affected, managing sleep disorders in a patient with an ID is of utmost importance. Sleep deprivation in humans can have negative side effects including decreased alertness, mood changes (eg, irritability, fatigue) and cognitive changes (eg, short-term memory alteration) (4).

1. Etiology

The most common type of sleep disorders in this population are behavioural (eg, night-waking, night-settling, early waking). Causal factors include a potentially different sleep physiology as a result of perturbation of the neural structures that regulate sleep (6). Associations have been reported between the occurrence of sleep problems in children with an ID and impaired cognitive, social and communication skills that may hinder the learning of appropriate child behaviour, including sleep behaviour (7).

A psychiatric illness, or underlying medical conditions such as epilepsy (6), obstructive apneas during sleep (3) and gastroesophageal reflux disease (8), may greatly affect the sleep behaviour of children with an ID. Environmental factors (eg, sleep routine) and certain characteristics pertaining to the family (eg, family dynamics, maternal depression, attachment difficulties) are also important contributing factors.

TABLE 1
Basic principles concerning the search for a psychiatric diagnosis in children with an intellectual disability

- Avoid relating all findings to an intellectual disability.
- Do not forget that medication may alleviate symptoms (eg, aggression) while leaving the etiology of the psychiatric condition undiagnosed.
- Avoid minimizing psychiatric symptoms, but also avoid the excessive search for psychiatric symptoms.

TABLE 2
Clinical approach to a behaviour disorder in a child with an intellectual disability

1. Properly identify the behaviour disorder in the history.
2. Consider an organic cause to explain the behaviour disorder.
3. Find a possible chronological link between the symptoms and the use of medication.
4. Consider a psychiatric illness that can explain the behaviour disorder.
5. Propose the following steps for treatment:
 - a. Usually start with a behavioural approach or modify the environment.
 - b. Behavioural approach alone does not suffice and ADHD symptoms are present: treat ADHD.
 - c. Behavioural approach alone does not suffice and no indicators for an underlying psychiatric illness or ADHD exist: use pharmacological approach based on symptoms.
 - d. Initial assessment indicates a psychiatric illness: refer to a child psychiatrist. If the physician is comfortable with his/her assessment, he /she may start the treatment.

ADHD Attention-deficit hyperactivity disorder

2. Assessment

A detailed assessment including a daily log where parents record information is necessary (9). A standardized questionnaire may also be useful. The Children's Sleep Habits Questionnaire (CSHQ) (10) covers the most common complaints in sleep problems in children.

3. Treatment

a. General approach: Proper sleep hygiene is an important first step for treating sleep disorders in children with an ID. For example, having a bedtime routine and sleep scheduling with consistent bedtimes and morning waketimes that allow for sufficient sleep duration, will ensure a restful sleep (5, 11) and may also modify a child's or a parent's behaviour, which may be contributing to the sleep difficulties.

Sleep and behaviour may deteriorate when children with an ID are away from home in an environment where the bed, surroundings, voices, noises and odours are unfamiliar. They may easily become over-stimulated by television, excessive noise or a temperature change (12) that can interfere with the sleep-onset latency, reduce the amount of sleep or cause early-morning awakening. For this reason, it is important to plan before-sleep routines and activities that have a calming effect on young children such as rhythmic movements and soothing music (13).

b. Behaviour modification: Based on clinical experience, behavioural interventions are useful in treating sleep problems in children with an ID, especially night-settling, night-waking and co-sleeping problems. A step-by-step approach is usually advised. Parents often require the help of a health professional to devise appropriate behavioural modification approaches for their child (14).

The use of systematic-ignoring and graduated systematic-ignoring (15) are considered efficacious treatments. Other behavioural interventions (eg, scheduled awakenings, faded bedtime and positive routines), which are useful in treating sleep problems in healthy children (4) are promising, but require further evaluation in children with an ID (14).

c. Pharmacological treatment: Over-the-counter or nonprescription medications or products are often used, but other than melatonin, these have not been studied in randomized controlled trials in the treatment of children suffering from sleep disorders. Studies have shown that melatonin, alone or in combination with behaviour management programs, may be useful to treat children who have difficulty staying asleep and who wake up too early in the morning (2,16). The physiology, adverse effects and drug interactions of melatonin were reviewed by Phillips and Appleton in 2004 (16), but the long-term effects are unknown (3).

There are few data supporting the use in children of medications commonly used to treat sleep disorders in adults such as selective or nonselective benzodiazepine receptor agonists, sedating antidepressants, anticonvulsants and alpha-2 agonist antihypertensives.

AGITATION

1. General approach

Agitation refers to a spectrum of behaviours, during which an individual is restless and hyperactive, that lead to disruptive, uncooperative and even belligerent behaviour. If the agitation is 'excessive', it is important to rule out an organic or environmental cause that could trigger, or aggravate, this symptom. Moreover, the child with an ID, who is agitated or inattentive, may exhibit these behaviours because of academic and/or social expectations that are not appropriate for his/her developmental age. Despite the diagnostic difficulties involved with children with an ID (17), some patients do manifest ADHD or ADHD-like symptoms.

2. Intellectual disability and ADHD

The prevalence rate of ADHD in the general population is 5%, (18) and between 9% to 16% in the paediatric population with an ID (19). The long-term impact of ADHD is significant in children with an ID, and can result in anxiety, aggression and social ostracism problems, especially in adolescents (20). Detailed reviews of the topic of ADHD and ID are available (19).

If a child with an ID is diagnosed as having ADHD or ADHD-like symptoms, it is important to assess its impact on the child and the family. If a nonpharmacological approach does not solve the problem, a pharmacological treatment may be indicated, particularly when associated with the presence of functional impairment, peer rejection and parental burnout.

3. Pharmacological treatment

Methylphenidate (MPH) has been the most extensively studied medication used in children with an ID and ADHD, with 20 double-blind, placebo-controlled studies conducted through 2006 (19). Response rates vary between 45% to 66% in the population with an ID, versus 77% in the population without an ID (19), with benefits including decreased impulsivity, inattention and hyperactivity, in both classroom and leisure activities.

Unfortunately, children and adolescents with an ID and comorbid ADHD treated with MPH are more at risk than the general population for developing tics and social isolation associated with apathy. Appetite loss, mood disorders and transitional psychotic symptoms are also reported (19).

There are no recent studies in patients with ID investigating the use of other psychostimulant or nonstimulant medications. The usual recommendation is to try two different stimulants before considering other options, such as atomoxetine (19). Alpha agonists, such as clonidine and guanfacine, are also used.

AGGRESSION

There are different types of aggression: a) toward others (eg, hitting, biting, kicking); b) destructive/disruptive behaviours (eg, breaking windows, screaming, etc); and c) toward self (eg, self-injurious behaviour including biting, self-hitting, head banging) (see below). The first two types of aggression can be further subdivided into planned and reactive aggression. In planned aggression, as in conduct disorder, the subject is calm and plans his aggression. In contrast, reactive aggression is a reaction to a situation or an environment.

Children with an ID manifest aggressive behaviour more often than children with average intelligence. In this population, planned aggressive behaviours are quite rare. The etiology of aggression includes a number of medical, neurological, psychiatric and environmental factors; therefore, assessment and treatment must be multifaceted. Common triggers for reactive aggressive behaviour are pain or an inability to comprehend a minor event. A psychiatric problem may increase or induce aggressive behaviours. From the onset, the assessment of an aggressive child must include detecting a psychiatric disorder. For a review of the evidence regarding this topic, the reader may consult the Expert Consensus Guidelines for the Treatment of Psychiatric and Behavioural Problems in Mental Retardation (21).

1. Assessment

Assessment of symptoms of aggression in a patient with an ID is conducted in a manner similar to that used for the general population. The Aberrant Behaviour Checklist, a screening assessment tool for identifying psychopathology in children and adolescents with mental retardation, may also be useful (22). The questionnaire must be adapted to the patient's cognitive development to detect a physical or psychiatric cause.

If aggressive behaviour is not of recent onset, one should assess the circumstances that cause aggressive behaviours. For example, if these behaviours are observed before performing an academic task, then perhaps academic expectations are too high.

If aggressive behaviour is of recent onset, a physical cause (eg, a tooth infection) must be ruled out first.

2. Treatment

a. Behaviour modification: Planned aggression responds best to an educational approach with clear limits within a consequence-based structure (ie, withdrawal of privileges). Reactive aggression tends to respond best to a modified behavioural approach. First, the crises, their intensity and the contributing factors are investigated. Changing the settings that trigger the aggression, teaching an alternative, acceptable, behaviour to serve the same communicative function, and consistently rewarding the new, desired behaviour are advised. Furthermore, it is important to determine which changes to the environment will improve the situation and to warn the patient about impending changes to his/her environment.

b. Pharmacological treatment: Only if the behavioural approach does not solve the problem should a pharmacological approach be considered.

If there is no specific diagnosis, treatment will target the symptoms (eg, selective serotonin reuptake inhibitors for anxiety and neuroleptics for psychotic symptoms).

According to the Expert Consensus Guidelines for the Treatment of Psychiatric and Behavioural Problems in Mental Retardation, prolonged use of benzodiazepines and anticholinergics, long half-life hypnotics or high doses of antipsychotic medications should be avoided (21).

SELF-INJURY

Self-injury behaviour (SIB) has been defined as a response that produces physical injury to the individual's own body. In children, it is most commonly reported in association with an ID (reported at rates ranging from 7% to 22%) (23), a pervasive developmental disorder, or a genetic syndrome, such as Lesch Nyhan, Cornelia de Lange, Fragile X, Prader-Willi or Tourette syndrome. Approximately 10% of the general population of two-year-olds engage in SIB, such as head banging as part of a tantrum, as part of normal development. As the child ages and develops language communication these behaviours decrease. In children with an ID a similar trend in their development is seen, but it is slower. A review of this topic is provided by Berkson et al (23).

The onset of SIB is often abrupt and violent. Self-injury is performed on any part of the body, but most often occurs on the head, neck and hands (24). In children with an ID, SIB consists of repetitive and stereotyped acts performed for no specific reason (23). It may pose significant health risks, such as permanent scars or damage to the eye (eg, cataract, perforation or retinal detachment) (24). SIB begins in childhood with an increase in incidence into the teenage years (25). Once established, SIB is difficult to treat (25). It may decrease with age; when this is observed, it corresponds to a better management of the child's impulsivity.

1. Etiology

SIB is both determined genetically and acquired. It is due to a complex interaction between neurobiological and environmental variables (26), and is often a means of communication for patients with poor social skills (27), or for those living in an environment with little or no social interaction. Pain insensitivity has been hypothesized to be a contributor to SIB, but according to Breau et al (28), children with severe cognitive impairments who display SIB do not show reduced reaction to pain. Another hypothesis suggests that individuals with SIB have low endogenous opioid levels and that SIB provokes opioid release, which may function as a reinforcer (28).

2. Clinical approach

The first step in assessing SIB is to observe the patient, preferably in his or her environment. The presence of painful conditions that may be difficult to diagnose should be considered; for example, sinusitis, dental abscess, otitis media, gastrointestinal reflux, urinary tract infection, bone fracture, or migraines could lead to the new onset or an increased rate of SIB (27). Certain medical conditions, although not causing pain in the area concerned by SIB, may cause irritability or discomfort and exacerbate SIB (eg, constipation) (27). If no underlying medical condition is apparent, it is important to identify the environmental determinants of the subject's specific response to a stimulus and the functions the aggression serves for them in that setting, so as to develop a behavioural approach for this type of behaviour. These determinants may vary from one patient to another and may also vary for the same SIB. Once the assessment is completed, behavioural therapies are usually used, followed by pharmacological agents if necessary.

a. Behaviour modification

A personalized approach is recommended. The first choice of behavioural interventions is the selection of reinforcement and extinction-based strategies.

b. Pharmacological treatment

Direct effects: The success rate of pharmacological agents varies. Risperidone or olanzapine may decrease aggression and SIB in children with ID (29,30). Some patients respond to anticonvulsants

such as topiramate or valproic acid (31). Fluoxetine and trazodone have also been used (32). However, the majority of studies on pharmacological treatment of SIB have been performed in adults or in children with autistic spectrum disorders (33).

Indirect effects: Certain medications may indirectly cause other behavioural changes, such as sleep disorders or mood changes that will interfere with behaviour modification. However, sedation caused by other medications may be effective in the management of SIB.

c. Restraints

The use of restraints (ie, mechanical devices fitted to limit movement or reduce injury) is often considered for severe cases of SIB. However, not only do they prevent children from participating in certain activities, but they could also be detrimental to their development. For legal and ethical reasons, this method of intervention must be used with caution.

Behavioural problems are a common occurrence in children with an ID, and often have a harmful effect on the functioning of the child and the child's family. In the present article, we reviewed the literature to highlight common behaviour issues in children with an ID. Based on this knowledge, practical information is offered to be integrated into routine clinical practice. The current management of behaviour disorders in children and youth with an ID focuses on symptomatic treatment using behaviour modification before pharmacological intervention. It is clear that further research is required to help identify best practices for behaviour disorders in children and youth with an ID. Parents and professionals need to be educated about the importance of prevention and the optimal management of such disorders.

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