

## THE RELATIONSHIP BETWEEN BEHAVIOURS OF CONCERN AND HEALTH: WHAT CAN PRIMARY CARE PHYSICIANS DO?

Dr Chen Shiling

### ABSTRACT

Persons with intellectual disability commonly present to healthcare professionals with behaviours of concern, which has significant impact on their quality of life, as well as that of their caregivers. These behaviours often result from a combination of complex factors, which includes physical and mental health conditions, psycho-emotional issues, and social-environmental difficulties, all of which are made more challenging by their inherent cognitive and communication difficulties. A comprehensive assessment is essential and the objective will be to determine the underlying reason(s) for the behaviour. Depending on the underlying cause(s) ascertained, pharmacological and/or non-pharmacological treatment will have to be implemented promptly and appropriately in a person-centred manner. It is elucidation of the underlying cause(s) and the various contributing factors that may pose significant challenges for primary care physicians due to limited time, resources, and training. This article aims to propose a practical approach to assessing and managing behaviours in the primary care setting.

**Keywords:** Intellectual disability, Behaviours, Health, Communication limitations, caregivers, Bio-psycho-social, General practitioners, primary care physicians

SFP2024; 50(8): 12-17

### INTRODUCTION

Persons with intellectual disability (ID) commonly present with behavioural issues, and various terms have been used to describe these behaviours. These include “problem behaviours”, “difficult behaviours”, and “challenging behaviours”. In place of these terms, Jeffrey Chan et al (2012) advocated the adoption of the phrase “behaviours of concern” to describe these behavioural issues in order to reduce the perception that these behaviours are inherent as problems or challenges in persons with ID, but rather to emphasise the importance of responding to these behaviours with understanding and support.<sup>1</sup> For the purposes of this article, we will therefore refer to these behavioural issues as “behaviours of concern” (BOC).

---

DR CHEN SHILING

Founder and Executive Director, Happee Hearts Movement  
Physician, Khoo Teck Puat Hospital

Though widely recognised as being common, the exact prevalence of BOC in persons with ID has been difficult to estimate accurately due to inconsistent definitions and study methodology over the years, with studies reporting rates ranging from 5.7 percent to 17 percent.<sup>2-5</sup> One particular challenge clinicians encounter is in differentiating a BOC from a mental health condition, especially as both can co-exist in the same individual.<sup>6,7</sup> The diagnosis is also complicated by the prevalent usage of psychotropics in managing BOC, with 14-30 percent of persons with ID presenting with BOC reported to be receiving these medications even in the absence of a diagnosed psychiatric disorder.<sup>8,9</sup> This occurs partially because the presentation of BOC is influenced by a number of complex factors, including organic conditions, psychiatric disorders, psychosocial and environmental determinants, or a combination of all of these, making diagnoses challenging.<sup>10-12</sup>

Primary care physicians are the first line of care in the community and are often the first point of contact for patients. Therefore, it is likely that families and caregivers will first consult their primary care doctors when their charge(s) with ID present with BOC. It is also possible that an existing patient with ID under the care of the said primary care physician may present with a change in behaviour from a previous baseline and require a more in-depth assessment.

In this article, the author aims to suggest a practical approach to assessing BOC in relation to health, in order to implement appropriate treatment in the primary care setting. In the following section, let us first look at the definitions of Health and BOC, and describe their relationship.

### THE RELATIONSHIP BETWEEN BEHAVIOURS OF CONCERN AND HEALTH

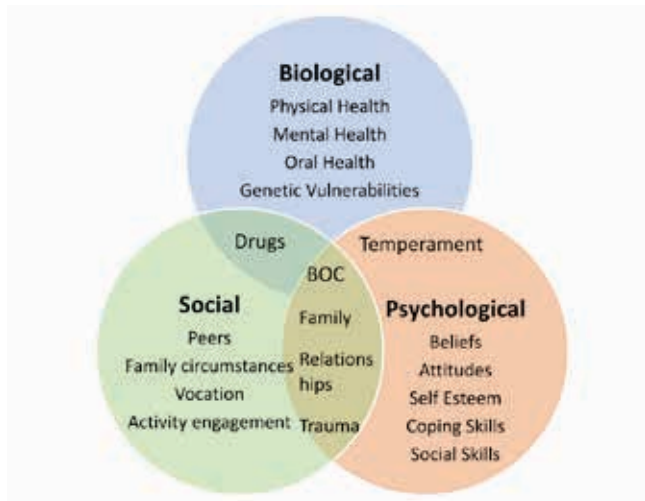
There have been several definitions for BOC, but one that is commonly referred to describes BOC as “Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities”.<sup>13</sup> These BOC can include agitation, aggression, self-injurious behaviours, stereotypical behaviours, and/or behaviours directed to objects.<sup>14</sup> Similarly, there have been multiple definitions of health through the centuries, but one that is commonly recognised today is that of the World Health Organisation (WHO), which regards Health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>15</sup>

Putting the definition of health alongside the definition of BOC, we can presume that the presence of BOC signifies suboptimal physical, mental, and social well-being, and

impacts the quality of life of persons with ID negatively. Consequently, if BOC are regarded as signs that the health status of the individual is not optimal, it is reasonable that the role of healthcare providers will be to ascertain the underlying cause and institute interventions and treatment accordingly.

Bearing this in mind, the biopsychosocial (BPS) framework commonly used in healthcare can be used to contextualise and assess BOC that individuals with ID may present with.<sup>16</sup> See **Figure 1** for the BPS model.

**Figure 1. BPS model**



Using the BPS model, and placing the BOC right in the centre of the diagram, we can see that there could be a number of interrelated reasons for a BOC. These would include:

**Biological**

- A physical health problem, e.g., Constipation
- A mental health problem, e.g., Depression
- An oral health problem, e.g., Dental caries

**Psychological**

- Beliefs, attitudes, and values
- Self-esteem and motivation
- Coping and social skills

**Social**

- Family dynamics
- Social relationships
- Work, vocational, and recreational circumstances

It is important to highlight at this juncture that BOC in persons with ID are closely intertwined with the cognitive and communication limitations encountered by these individuals. It is a direct result of these lifelong challenges and consequent distinct life experiences, that individuals with ID may not be able to make sense of and communicate experiences that indicate bio-psycho-social problems, unlike individuals in the general population. Using the BPS as a guide, and bearing in mind these difficulties, it is evident

that BOCs are often multifactorial in their causes. For example, a person with ID who is non-verbal but able to vocalise may shout repeatedly when experiencing physical discomfort or pain. This pain could stem from constipation, reflux, a toothache, or even from disturbing hallucinations. Although initially predominantly related to physical or mental health problems, the inability of the individual to express this pain or discomfort adequately to caregivers and healthcare professionals could lead to increased anxiety and distress, which could consequently increase the intensity and persistence of the shouting. The frustration and helplessness experienced by the caregivers due to their inability to understand the cause of the shouting could result in even higher levels of stress and escalating anxiety on their part, which would inadvertently lead to reduced caregiver capacity, which in turn could translate to poorer care and increased discomfort, resulting in even more agitation in the individual affected. This is a vicious cycle.

The above example illustrates how biological causes can present with a BOC, and the importance of evaluating for and treating these before the condition and circumstance worsens and a vicious cycle ensues. Once biological causes are ruled out, the next step will be to ask if the BOC being assessed is related to psychological causes.

For example, an individual suffering from grief and confusion from losing a beloved caregiver could present with frequent night awakening and/or restlessness. A person with mild ID may be able to express these emotions verbally to healthcare professionals but individuals with moderate to severe ID may neither be able to process these feelings nor express them in a manner that others understand. As a result, these emotions could be very easily overlooked, and the resulting behaviour misunderstood.

As can be seen in the above example, psychological issues are often closely related to social situations, and these should be examined hand-in-hand. It is important to understand the individual's family circumstance and social networks, as well as the daily activities the individual partakes in his/her daily life. These could pertain to his/her routines at home, in the day centre, or workplace. All these factors play a part in contributing to the BOC and will need to be targeted in the management plan. In the next section, we will look at a suggested approach to assessing BOC with these factors in mind, for clinicians in the primary care setting.

**A PRACTICAL APPROACH TO ASSESSING BOC**

Once we consider the presence of BOC to be a symptom of suboptimal health and well-being, the next step will be to diagnose the root cause. For all clinicians, the natural follow-on steps will be history-taking and physical examination, before coming up with a provisional diagnosis and giving a trial of treatment. The author proposes that this is the same approach clinicians can take in assessing a BOC, with a few added considerations.

## History-Taking

The medical interview is a key task performed by doctors. In the evaluation of BOC, this step is even more critical. In history-taking to gather information regarding the BOC, additional information will be required in a few key areas. These include:

- A precise description of the BOC, e.g., John is agitated and shouts repeatedly on some nights of the week.
- Information surrounding the BOC. This includes in particular the antecedent, which refers to what happens before the BOC, and the consequence, which refers to what happens after the BOC, e.g., John usually starts getting agitated and shouting a short while after dinner. When these episodes occur, he will sleep poorly the whole night and his appetite will be poor the next day.
- Information surrounding the psychosocial circumstances, especially pertaining to any recent changes or transitions. The impact of changes in psychosocial and environmental situations on individuals with ID cannot be overstated. A change of routine in the day centre or a change in caregiver can be sufficient to affect the individual's overall health and wellbeing. People with ID rely on their caregivers for their daily needs to varying degrees depending on their level of severity. The consequence of this is that their overall wellbeing is largely determined by the people around them. For example, if a caregiver is taken ill and admitted to the hospital, and this is not explained to the person with ID in a manner that he understands, the individual could become anxious, refuse food, or have poor sleep.
- Information regarding the patient's communication ability. Is this individual able to communicate verbally in full sentences or in two- to three-word phrases? Or is he non-verbal and can only vocalise? What words does he commonly use and what do they mean to him? This history will need to be gathered from someone who knows him well, likely a family member or care staff. This will determine the extent of information the patient can comprehend, and how much of his needs he can express to his caregivers and healthcare professionals. The more limited his communication ability, the higher the likelihood that the BOC may be an avenue through which the individual is expressing his needs, wishes, and desires.<sup>17,18</sup>

In the above example, if the BOC is occurring in an individual with moderately severe levels of ID who communicates through a few single words and gestures, the hypothesis could be that he may have constipation and is experiencing discomfort after a meal. This results in poor sleep and also reduced oral intake the next day.

## Physical Examination with Some Communication Caveats

After developing a hypothesis, the next step will be examining the patient specifically to elucidate physical signs. One difference between examining an individual with ID and someone in the general population is that there may be a significant communication gap between the clinician and patient. Whether the patient is verbal with limited vocabulary or uses gestures predominantly will determine how the clinician carries out the examination. The less the individual is able to express their needs, the more attentive the clinician will have to be to non-verbal cues such as facial expressions, vocalisations, or body language. It is also important to be aware that the patient's usage of common terms like "pain" might not be accurate or consistent, and might not hold the meaning understood by the clinician. For example, an individual with moderate ID may associate the word "pain" with blood-taking, and when asked if there is pain, he might say "no" even if he has discomfort in his abdomen. Therefore, all verbal and non-verbal communication have to be interpreted alongside the clinical picture.

An additional point to note about examining individuals with ID is that they could be more fearful or anxious compared to someone in the general population, as they might not understand what the clinician is doing, and some could also have had prior negative healthcare experiences.<sup>19</sup> It is therefore of utmost importance for the clinician to demonstrate patience and allow the individual time to adjust and cooperate with the examination.

### Investigations and Interventions

For individuals with ID, carrying out investigations may not always be straightforward. Patients may be unwilling to cooperate with blood-taking or radiological investigations out of fear. Therefore, clinicians will have to make a clinical judgement on how essential these investigations are and may opt to give a trial of treatment rather than pursue these further. The interventions will also have to take into consideration what is acceptable to the patient. In the above example, it could be difficult for the patient to tolerate or allow suppositories, in which case the laxatives will have to be orally administered. Furthermore, the caregivers of adults with ID are commonly their ageing parents, who will be the ones ensuring their compliance to interventions. Therefore, time must be taken to explain the management plan clearly to these elderly carers, who will need to have the resources and capacity to carry out these interventions. For example, an adult with ID who attends a day centre may have difficulty taking medications three times a day, or his elderly mother who has visual impairment may not be able to accurately measure the dosage of certain medications. These limitations will have to be taken into consideration.

## Monitoring and Review

In prescribing medications to persons with ID, it is important to be aware that in addition to atypical presentations, they might also have atypical responses to treatment.<sup>20</sup> Moreover, due to their communication difficulties, they might not be able to express discomfort from side effects they might potentially experience. Therefore, it is often prudent to institute individual interventions one at a time, so as to be able to monitor the effect of the said intervention specifically and in isolation. Monitoring will also require close follow-up of their behaviours to review if there is any change from the existing baseline to suggest side effects or discomfort. It is also important to ensure a review date, so the clinician can review if the BOC has resolved. This is critical as the hypothesis for the BOC, even if accurate, could be addressing only one factor that is contributing to it. For example, the BOC of shouting could be related to constipation, but there could also be an added element of anxiety. Only in reviewing the individual after a suitable time period will the clinician be able to look for distinct improvements and changes, enabling them to address other factors as well.

The author proposes that taking these usual examination steps with the above added considerations will allow the clinician to come to a provisional diagnosis with regards to the presenting BOC. Understandably, this process does not come without challenges, and the next section will briefly highlight a few of the difficulties faced by primary care physicians.

## **CHALLENGES IN ASSESSING BOC**

### **Limited Knowledge and Experience**

A number of studies have been conducted amongst general practitioners to review their attitudes and confidence in seeing patients with ID. A few common findings have included doctors reporting communication difficulties with patients, facing challenges in assessments and examination, having a lack of training and experience, and an inadequate knowledge of services and resources available.<sup>21-23</sup> All of these pose difficulties for the clinician in assessing persons with ID for common health conditions, especially when they present with BOC. However, an encouraging finding is that many general practitioners also showed a willingness to be involved in further training and valued the need for increased education in skillsets to attend to persons with ID.<sup>21</sup>

### **Limited Resources**

In addition to the lack of skills and expertise, many general practitioners have also indicated that they face significant limitations in the resources they have on hand to support the patients with ID they see. Common problems they face include consultation time constraints and patients' subsequent poor compliance with management plans.<sup>21</sup> Some suggestions to overcome these have included increasing

the duration of time set aside for these consultations. Some general practitioners have also shared that support teams in the community will be useful but this will need to be implemented in a sensitive manner that considers the work processes of the clinicians. Whilst collaborative and liaison work is important, the doctors generally do not feel that they have sufficient time to engage sufficiently with these community teams.<sup>24</sup>

### **Multifaceted Nature of BOC**

The multifaceted nature of BOC and the need to consider the biopsychosocial factors is not always a straightforward process. Encouraging caregivers to note down the behaviours in an ABC (Antecedent, Behaviour, Consequence) chart can help tremendously in uncovering the reasons for the behaviours.<sup>25</sup> However, in order for caregivers to do this, they will need to be educated and supported, so that this does not add to their caregiving stress. Additional networks and support systems will therefore need to be activated and work hand-in-hand with the clinicians in helping these families. Thereafter, the interventions that may need to be implemented could cross the biological, psychosocial, and environmental aspects, which will require significant levels of interdisciplinary work, coordination, and integration. These might pose difficulties to many clinicians in the primary care setting.

With the above challenges in mind, it is important for primary care physicians to know when to seek additional professional help for their patients. In the following section, the circumstances in which the clinician might need specialist help will be highlighted.

## **REFERRAL TO SPECIALIST TEAMS**

After a comprehensive assessment, if there is an obvious cause for the BOC, this should be managed appropriately and promptly, with regular monitoring of the interventions.

One reason for referral to a specialist team will be if the clinician has delineated the likely causes and contributing factors to the BOC, and perhaps even instituted initial treatment, but assesses that the management requires the interventions of a multidisciplinary team. For example, after treating an individual's constipation and anxiety, if it is clear that other psychological and communication strategies as well as caregiver empowerment is critical, it will be important for the clinician to make a referral to a specialist team that has access to these resources.

Also, one important point to highlight at this juncture is that it is not always possible to find a cause for every BOC. If indeed a cause cannot be found after all effort has been made to consider the various possibilities, including allowing a period of observation, and actively consulting formal and informal caregivers, then the strategy employed should be to minimise the impact of the behaviour on the individual, the people around him/her, and also his/her environment.

In these situations, non-pharmacological management

should be considered and employed first. These management strategies should aim to address the psycho-social or environmental issues faced by the individuals that might be contributing to the BOC. This could include behaviour strategies, counselling, or making adjustments to the social and physical environment.

Sometimes, after giving a sufficient duration of trial of non-pharmacological management, medication may be needed either on its own or as an adjunct to non-pharmacological strategies.<sup>26,27</sup> The usage of medications in these circumstances may be viewed as an interim strategy, sometimes to allow time for the non-pharmacological interventions to work. This may happen in practice when there are high and severe levels of caregiver stress, leading to imminent care breakdown. Under such circumstances, the patient needs to be reviewed closely and medications titrated carefully. Other resources such as respite care may also need to be organised to support the caregiver and the family in coping with the high behavioural care needs of the person with ID. In these situations, a specialist team will need to be engaged and involved.

## **THE CRUCIAL ROLE OF THE CAREGIVERS**

As can be seen in the above section, the role of the caregivers in addressing BOC in individuals with ID is critical. The impact of lifelong caregiving on the health, social, and financial well-being of caregivers of persons with ID cannot be overemphasised.<sup>28</sup> As roles and responsibilities change over the life course, many parents of persons with ID eventually face dual or even triple responsibilities of caregiving. They care not only for their adult child with ID, but also for their own ageing parents, and/or ailing spouse. This is termed “compound caregiving”.<sup>29</sup> With increasing life expectancy in both the person with ID and his/her caregiver, the ageing caregiver ends up having to care for his/her adult ID child who is also starting to develop his/her health issues as they age. This is an extremely challenging situation.

Consider this example: An adult with moderate ID in his 40s who was previously able to manage his basic activities of daily living himself, but now suffers from declining mobility and recurrent falls, will start requiring more physical care from his father. However, his ageing father would be struggling with his own deteriorating health, and may have difficulties providing increased physical care for his adult son. Assisting his son during bath times or during transfers could be challenging, resulting in further near falls during these episodes. Due to the fear, anxiety, and uncertainty that relate around these care episodes, the individual with ID could become resistive to his father’s attempts to care-give, and might express this by pushing him away or even hitting him. His father would then end up more frustrated and even more insistent, which would worsen the tension and stress. A vicious cycle would ensue with increased resistive behaviour and agitation, and even result in institutionalisation.

As the above example illustrates, it is therefore of vital importance to institute appropriate interventions not only for the adult with ID, but also to address the health and social needs of his caregiver. The caregivers in these situations need to be seen not only as individuals with their own needs, but also in their caregiving role. Committed in their caregiving role, many caregivers may neglect their own issues, to the detriment of the overall outcome.

Overall, the decision as to which pharmacological and/or non-pharmacological interventions should be implemented and prioritised will depend on each individual’s and family’s unique circumstances. Lifelong caregiving is already beset with numerous health, psycho-emotional, and financial challenges; what more when family relationships and quality of life are impacted and threatened by stressful and sometimes disruptive BOCs. As such, the needs of the caregivers need to be addressed and catered to, so as to support and sustain them in their caregiving role. Studies have shown that meaning and fulfilment can be derived from caregiving and can even bring about better mental health outcomes, positive wellbeing, and greater life satisfaction in the caregivers themselves.<sup>30</sup> Therefore, with proper support, the relationships and mutual interdependence between the person with ID and his/her caregiver can be enhanced.<sup>31</sup>

## **CONCLUSION**

Persons with ID commonly present to healthcare professionals with BOC, which often result from a combination of complex factors. These include physical and mental health conditions, and psycho-emotional and social-environmental difficulties, and are made more challenging by their inherent cognitive and communication difficulties.

Health as defined by the World Health Organization (WHO) is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Bearing this in mind, the presence of BOC can be regarded as a sign that the person with ID does not have optimum health and wellbeing, and the BPS framework can be used by healthcare professionals to guide the comprehensive assessment of BOC in persons with ID. The natural steps taken by clinicians in assessing patients include history-taking and physical examination prior to coming up with a provisional diagnosis and giving a trial of treatment. The same approach can be undertaken in assessing a BOC, with a few added considerations, including atypical presentations, the communication profiles of the individuals, and the psycho-emotional and social circumstances.

Depending on the underlying cause(s) ascertained, pharmacological and/or non-pharmacological treatment will have to be implemented promptly and appropriately. As BOC not only have a significant impact on the quality of life of the individuals with ID, but also on the lives of their caregivers, it is essential to engage and support caregivers actively from the onset. Their wellbeing relates directly to their caregiving capacity, and consequently also

contributes significantly to determining the outcomes of the interventions implemented.

Ultimately, if healthcare professionals can successfully identify the underlying causes of BOC and address the issues appropriately and in a timely manner, this will improve the quality of life of many individuals with ID as well as that of their families.

## REFERENCES

- Chan J, Arnold S, Webber L, Riches V, Parmenter T, Stancliffe R. Is it time to drop the term 'challenging behaviour'? *Learning Disability Practice*. 2012 May 31;15(5):36-38. doi:10.7748/ldp2012.06.15.5.36.c9131
- Qureshi H, Alborz A. Epidemiology of challenging behaviour. *Mental Handicap Research*. 1992 July;5(2):130-145. https://doi.org/10.1111/j.1468-3148.1992.tb00041.x
- Kiernan C, Reeves D, Hatton C, et al. The HARC challenging behaviour project. Report; 1997.
- Emerson E, Kiernan C, Alborz A, et al. The prevalence of challenging behaviours: a total population study. *Res Dev Disabil*. 2001 Jan-Feb;22(1):77-93. doi: 10.1016/s0891-4222(00)00061-5. PMID: 11263632.
- Lowe K, Allen D, Jones E, et al. Challenging behaviours: prevalence and topographies. *J Intellect Disabil Res*. 2007 Aug;51(Pt 8):625-36. doi: 10.1111/j.1365-2788.2006.00948.x. PMID: 17598876.
- Sturmey P, Burcham KJ, Perkins TS. The Reiss Screen for Maladaptive Behaviour: its reliability and internal consistencies. *J Intellect Disabil Res*. 1995 Jun;39 ( Pt 3):191-5. doi: 10.1111/j.1365-2788.1995.tb00500.x. PMID: 7640488.
- Moss S, Emerson E, Kiernan C, Turner S, Hatton C, Alborz A. Psychiatric symptoms in adults with learning disability and challenging behaviour. *Br J Psychiatry*. 2000 Nov;177:452-6. doi: 10.1192/bjp.177.5.452. PMID: 11060000.
- Clarke DJ, Kelley S, Thinn K, Corbett JA. Psychotropic drugs and mental retardation: I. Disabilities and the prescription of drugs for behaviour and for epilepsy in three residential settings. *J Ment Defic Res*. 1990 Oct;34 ( Pt 5):385-95. doi: 10.1111/j.1365-2788.1990.tb01549.x. PMID: 2266549.
- Deb S, Fraser W. The use of psychotropic medication in people with learning disability: towards rational prescribing. *Human Psychopharmacology: Clinical and Experimental*. 1994 Jul;9(4):259-72.
- de Winter CF, Jansen AA, Evenhuis HM. Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. *J Intellect Disabil Res*. 2011 Jul;55(7):675-98. doi: 10.1111/j.1365-2788.2011.01390.x. Epub 2011 Mar 3. PMID: 21366751.
- Bowring DL, Totsika V, Hastings RP, Toogood S, Griffith GM. Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. *Br J Clin Psychol*. 2017 Mar;56(1):16-32. doi: 10.1111/bjc.12118. Epub 2016 Nov 23. PMID: 27878840.
- McIntyre LL, Blacher J, Baker BL. Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *J Intellect Disabil Res*. 2002 Mar;46(Pt 3):239-49. doi: 10.1046/j.1365-2788.2002.00371.x. PMID: 11896809.
- Emerson E, Bromley J. The form and function of challenging behaviours. *J Intellect Disabil Res*. 1995 Oct;39 ( Pt 5):388-98. doi: 10.1111/j.1365-2788.1995.tb00543.x. PMID: 8555715.
- Soni S. *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*. Edited by N. Bouras and G. Holt. Cambridge University Press: Cambridge, UK. 2007. *Psychological Medicine*. 2008 Feb;38(2):303-4.
- Jadad AR, O'Grady L. How should health be defined? *BMJ*. 2008 Dec 10;337:a2900. doi: 10.1136/bmj.a2900. PMID: 19073663.
- Engel GL. The clinical application of the biopsychosocial model. In *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 1981 Jan 1 (Vol. 6, No. 2, pp. 101-124). Oxford University Press.
- Patel P, Goldberg D, Moss S. Psychiatric morbidity in older people with moderate and severe learning disability: II: the prevalence study. *Br J Psychiatry*. 1993 Oct;163:481-91. doi: 10.1192/bjp.163.4.481. PMID: 8252287.
- Emerson E. *Challenging behaviour: Analysis and intervention in people with severe intellectual disabilities*. Cambridge University Press; 2001 May 28.
- Iacono T, Bigby C, Unsworth C, Douglas J, Fitzpatrick P. A systematic review of hospital experiences of people with intellectual disability. *BMC Health Serv Res*. 2014 Oct 25;14:505. doi: 10.1186/s12913-014-0505-5. PMID: 25344333; PMCID: PMC4210514.
- Deutsch SI, Burket JA. Psychotropic medication use for adults and older adults with intellectual disability; selective review, recommendations and future directions. *Prog Neuropsychopharmacol Biol Psychiatry*. 2021 Jan 10;104:110017. doi: 10.1016/j.pnpbp.2020.110017. Epub 2020 Jun 13. PMID: 32544599.
- Lennox NG, Diggins JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. *J Intellect Disabil Res*. 1997 Oct;41 ( Pt 5):380-90. doi: 10.1111/j.1365-2788.1997.tb00725.x. PMID: 9373818.
- Phillips A, Morrison J, Davis RW. General practitioners' educational needs in intellectual disability health. *J Intellect Disabil Res*. 2004 Feb;48(Pt 2):142-9. doi: 10.1111/j.1365-2788.2004.00503.x. PMID: 14723656.
- Ziviani J, Lennox N, Allison H, Lyons M, Del Mar C. Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *J Intellect Disabil Res*. 2004 Sep;29(3), 211-225. DOI:10.1080/13668250412331285163.
- Bond L, Kerr M, Dunstan F, Thapar A. Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *J Intellect Disabil Res*. 1997 Oct;41 ( Pt 5):391-400. doi: 10.1111/j.1365-2788.1997.tb00726.x. PMID: 9373819.
- Freeman R, Matthews K, Griggs P, Quick S. Functional behavioral assessment.
- Deb S, Kwok H, Bertelli M, et al. International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. *World Psychiatry*. 2009 Oct;8(3):181-6. doi: 10.1002/j.2051-5545.2009.tb00248.x. PMID: 19812757; PMCID: PMC2758582.
- Matson JL, Neal D. Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. *Res Dev Disabil*. 2009 May-Jun;30(3):572-86. doi: 10.1016/j.ridd.2008.08.007. Epub 2008 Oct 8. PMID: 18845418.
- Taggart L, Truesdale-Kennedy M, Ryan A, McConkey R. Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *J Intellect Disabil*. 2012 Sep;16(3):217-34. doi: 10.1177/1744629512456465. PMID: 22890999.
- Perkins EA, Haley WE. Compound caregiving: when lifelong caregivers undertake additional caregiving roles. *Rehabil Psychol*. 2010 Nov;55(4):409-17. doi: 10.1037/a0021521. PMID: 21171800.
- Grossman BR, Webb CE. Family support in late life: A review of the literature on aging, disability, and family caregiving. *Journal of Family Social Work*. 2016 Aug 7;19(4):348-95.
- Heller T, Factor A. Family support and intergenerational caregiving: Report from the State of the Science in Aging with Developmental Disabilities Conference. *Disabil Health J*. 2008 Jul;1(3):131-5. doi: 10.1016/j.dhjo.2008.04.004. PMID: 21122721.

### LEARNING POINTS

- **Persons with ID commonly present with behavioural issues, and various terms have been used to describe these behaviours. These include “problem behaviours”, “difficult behaviours”, “challenging behaviours”, and “behaviours of concern” (BOC).**
  - **BOC can be defined as “Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities”.**
  - **The primary objective of assessing BOC in persons with ID is to strive to identify and address the underlying causes of or reasons for the behaviour.**
  - **The World Health Organisation (WHO) defines Health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.**
  - **Putting the definition of health alongside the definition of BOC, we can presume that the presence of BOC signifies suboptimal physical, mental, and social well-being, and impacts the quality of life of persons with ID negatively. The biopsychosocial (BPS) framework can be used to assess the BOC the person with ID is presenting with.**
  - **The usual steps clinicians undertake in assessing patients can be employed in assessing BOC, with a few added considerations, including atypical presentations, the communication profiles of the individuals, and the psycho-emotional and social circumstances surrounding them.**
  - **Overall, the decision as to which pharmacological and/or non-pharmacological interventions should be implemented will depend on each individual’s and family’s unique circumstances. The approach needs to be person-centred and family-centric, with caregivers actively engaged throughout the entire process.**
-