

## ADDRESSING BEHAVIOURS OF CONCERN: THE INTERPLAY OF HEALTH, COMMUNICATION LIMITATIONS, AND PSYCHO-SOCIAL FACTORS

Dr Chen Shiling

### ABSTRACT

**Persons with intellectual disability commonly present to healthcare professionals with behaviours of concern, which have a 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 needs to be implemented promptly and appropriately in a person-centred manner. The impact of these behaviours on caregivers cannot be overlooked and they must be supported and engaged actively throughout the process. Regular review and monitoring of the effectiveness as well as adverse effects of the interventions will need to be carried out. This article aims to outline an approach to the assessment and management of these behaviours.**

**Keywords: Intellectual disability, Behaviours, Health, Communication limitations, Ageing caregivers, Bio-psycho-social, Psychotropics**

**SFP2022; 48(6): 26-33**

### 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 in more recent times, “challenging behaviours” and “behaviours of concern”. Jeffrey Chan et al advocated the adoption of the latter 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).

There have been several definitions for BOC but one that is commonly quoted 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>2</sup> These BOC can include agitation, aggression, self-injurious behaviours, stereotypical behaviours, and/or behaviours directed towards objects.<sup>3</sup> 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>4-7</sup> One particular challenge clinicians encounter is the difficulty in differentiating a BOC unrelated to a psychiatric disorder from behaviours that are atypical presentations of a mental health disorder.<sup>8,9</sup> The diagnosis is also complicated by the prevalent use 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>10,11</sup> This occurs partially because the presentation of BOC is often determined by a number of complex factors, including organic conditions, psychiatric disorders, psycho-social and environmental influences, or a combination of all of these, making diagnoses challenging.<sup>12,13</sup> As a result, a comprehensive and thorough assessment of the possible causes of the BOC is a critical first step and may require input not only from various healthcare providers but also from both formal and informal caregivers. This is important as the impact of BOC is significant not only for the individuals but also for their caregivers and families.

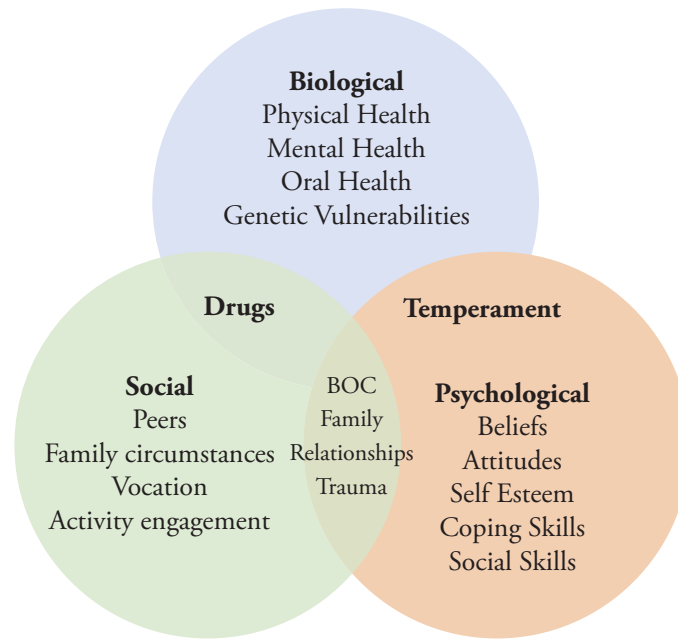
Therefore, it is crucial to obtain detailed histories from the caregivers and families, to ensure that their ability to cope with the behaviours can be assessed concurrently. It has been well reported that there are significantly higher levels of caregiver stress, reduced caregiver satisfaction, reduced self-efficacy, and increased institutionalisation risk when individuals have BOC.<sup>14,15</sup> Therefore, it is imperative that BOC be addressed in a timely manner so as to reduce caregiver stress and improve the quality of lives of persons with ID and their families. Consequently, the interventions required to address these BOCs also often need to be multidisciplinary and should cover medical, psychiatric, psychological, social, and environmental issues.

In this article, we will outline an approach to assessing BOC and highlight the health, communication, and psycho-social-environmental issues that may contribute to it.

---

DR CHEN SHILING

Founder, Happee Hearts Movement  
Head, Intellectual Disability Service, Tsao Foundation  
Physician, Geriatrics Medicine Dementia Team, Khoo Teck Puat Hospital



**Figure 1. BPS model**

Finally, we will briefly discuss the management principles including the usage of psychotropics.

**CAUSES OF AND ASSESSMENT OF BEHAVIOURS OF CONCERN**

The primary objective of assessing BOC in persons with ID should be to not regard the behaviour as a problem but to strive to identify and address the underlying causes of or reasons for the behaviour. Health as defined by the World Health Organisation (WHO) is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.<sup>16</sup>

Putting this definition of health alongside the definition of BOC, it is clear that the presence of BOC impacts the quality of life of persons with ID negatively and does not signify positive health or well-being. 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 of this health issue and institute interventions and treatment accordingly.

Bearing this in mind, the biopsychosocial (BPS) framework commonly used in healthcare can be used to assess the BOC the person with ID is presenting with<sup>17</sup> (refer to **Figure 1** for the 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:

1. Biological
  - a. A physical health problem, e.g., constipation
  - b. A mental health problem, e.g., depression
  - c. An oral health problem, e.g., dental cavities

2. Psychological
  - a. Beliefs, attitudes, and values
  - b. Self-esteem and motivation
  - c. Coping and social skills
3. Social
  - a. Family dynamics
  - b. Social relationships
  - c. Work and recreational circumstances

It is important to highlight at this juncture that BOC in persons with ID are also closely intertwined with the cognitive and communication limitations encountered by these individuals.

All individuals with ID experience life in a distinct manner compared to the general population, and moreover, due to the heterogeneity of this population group, each individual also experiences life differently from another. For example, an individual with mild ID working in a supermarket and active in the community will experience life very differently from a person with severe ID who may be non-verbal and mostly homebound, but yet be able to engage meaningfully with his/her family and caregivers. The presentation of BOC in these two distinct groups will also naturally be different.

Using the BPS as a guide, and bearing in mind the cognitive and communication challenges faced by persons with ID, it is evident that BOC 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 and/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 circumstances worsen and a vicious cycle ensues. However, 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 long-time caregiver could present with frequent night awakening and/or restlessness. A person with mild ID might be able to express these emotions verbally to healthcare professionals but individuals with more severe ID might 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 manifestation misunderstood. Another example encountered fairly frequently would be in evaluating why an individual is resistive towards certain activities, such as performing specific tasks at an individual's sheltered workshop. This could be due to a multitude of reasons, including but not exclusive to boredom with or dislike of the task on hand or because he/she is not keen to sit near a particular participant.

As can be seen in the above examples, psychological issues are often closely related to social situations, and these should be examined hand-in-hand with psychological factors.

It is important to understand the individual's family circumstances and social networks, as well as the daily activities the individual partakes in his/her daily life. These could pertain to their routines at home, or that in their day centre or workplace. Complaints of wandering behaviour

could be a result of a reluctance to return to a negative home environment. Conversely, a refusal to let caregivers out of their sight could occur as a result of anxiety due to a fear of abandonment and loss. Particularly for persons with more severe disability, who are highly or fully dependent on their caregivers to be sensitive to and attend to their every need, the social and physical environment becomes critical. Simple things like inappropriate bath water temperature could lead to discomfort, or overstimulating or noisy environments could lead to distress for persons with ID with sensory processing disorders, and manifest as agitation and aggression.

A common point highlighted by all the examples above is that a thorough and holistic assessment with the aid of the BPS framework is an absolute prerequisite in managing any BOC.

As part of the assessment, clear documentation of the BOC is important and should include the following steps:

1. A list of the target BOC to be managed, which includes a precise description of the BOC
2. The frequency and severity of the BO C
3. An assessment of the possible causes (using the BPS framework) giving rise to the BOC
4. An evaluation of the triggers and outcomes of the BOC

A simple method of keeping track of point (4) would be to use the ABC recording method.<sup>18</sup> This is a simple way of collecting information about behaviours.

- **Antecedents (A):** what happened directly before the behaviour occurred
- **Behaviour (B):** the specific behaviour of interest
- **Consequences (C):** what happened directly after the behaviour occurred

It is important when using the ABC chart to focus on descriptions of ABC, rather than indicate any interpretations. Refer to Figure 2 below for an example of an ABC chart.

**ABC Chart**

**Name:** \_\_\_\_\_

Date	Time	Antecedent	Behaviour	Consequence
		What specific activity or event occurred before the behaviour?	What specifically did the person do or say?	What happened after or as a result of the behaviour?
XX	XX	Not getting food he wanted	Head banging against the wall	Giving him the food he wants

**Figure 2. ABC Chart**

Encouraging caregivers to note down the behaviours in the ABC chart can help tremendously in uncovering the reasons for the behaviours. A clear pattern may emerge, for example, demonstrating that the BOC occur predominantly during meal times, which will give further clues with regards to the possible causes.

However, 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 and the people around him/her, as well as on his/her environment.

In the next section, some potential health issues that may occur in persons with ID and present with BOC, as well as some pitfalls in making diagnoses, will be shared.

### HEALTH CONDITIONS

In addition to being mindful of the presence of health conditions common to the general population, it will also be important for healthcare professionals to bear in mind that certain groups of individuals with ID have the propensity to develop specific health conditions, and to keep a lookout for them when assessing BOC.<sup>19</sup> Refer to **Table 1** for some of these examples:

Syndrome	Common Health conditions
Down Syndrome	Thyroid disease, early onset dementia, obesity, obstructive sleep apnoea, oral health issues, visual impairment, eczema
Tuberous sclerosis	Seizures, benign tumours in various organs, e.g., eye, heart, lung, kidney
Angelman Syndrome	Seizures, sleep issues
Cornelia de Lange syndrome	Cardiac defects, increased risk of respiratory infections, hearing problems
Williams syndrome	Chronic ear infections, hearing loss, hypothyroidism, diabetes mellitus
Lowe syndrome	Visual impairment, kidney abnormalities, seizures, increased risk of fractures, degenerative bone disease

**Table 1. Common health conditions in individuals with specific syndromes.**

Other than these specific health conditions, it is also well recognised that there are certain behavioural phenotypes associated with specific syndromes. These refer to observable characteristics that occur more often in individuals with specific genetic syndromes than in individuals without that

syndrome.<sup>20,21</sup> It will also be helpful for healthcare providers to be aware of these. Refer to **Table 2** for some of these examples.

Syndrome	Behavioural Phenotype
Down Syndrome	Positive in mood, distractable
Fragile X	Gaze avoidance, hand biting, tics
Tuberous sclerosis	Obsessive-compulsive behaviour, repetitive behaviours, nonverbal and autistic behaviours
Angelman Syndrome	Head-banging, hand biting, picking at skin, sores, nails, pulling off fingernails and toenails, explosive outbursts tantrums, destructive and aggressive behaviour, excitability, arm hugging/hand squeezing, reduced sensitivity to heat/pain
Prader Willi	Hyperphagia, hyperactivity
Lesch-Nyhan Syndrome	Self-injurious behaviour
Cornelia de Lange Syndrome	Self-injurious behaviour particularly directed to the hands
Williams Syndrome	Reduced fear of strangers and excessive friendless towards other

**Table 2. Behavioural phenotypes in individuals with specific syndromes.**

These specific health conditions and behaviour phenotypes are important to note for healthcare professionals, but clinicians must first and foremost remember that not all individuals with specific syndromes show all the possible health conditions or behaviour phenotypes.<sup>21</sup> These merely serve as a guide. Another common pitfall is that of “diagnostic overshadowing”, which refers to the phenomenon in which behavioural or emotional difficulties seen in people with ID are attributed to the ID itself.<sup>22</sup> An example would be the caregiver of an adult with Down Syndrome complaining that he/she is requiring more prompting in doing his/her activities, and the healthcare professional consulted viewing this as part of his/her ID when this might be the initial presentation of early onset Alzheimer’s disease dementia or a frontal lobe tumour impairing motivation.

Other associated phenomena seen in persons with ID that can make it more challenging during assessments include “psychosocial masking”, which refers to an individual’s limited social experiences impacting on their ability to give a clear history of their symptoms or “baseline exaggeration”, which refers to how increasing severity or intensity of

symptoms could be viewed as part of the individual's inherent challenges with adaptive functioning.<sup>23</sup> Healthcare professionals need to be aware of these potential pitfalls and be intentionally mindful and reflective in practice when assessing persons with ID. Many of these phenomena affect how persons with ID communicate their symptoms and emotions to the people around them, and this brings us to the next section, which will highlight some of the communication challenges they face.

## COMMUNICATION LIMITATIONS

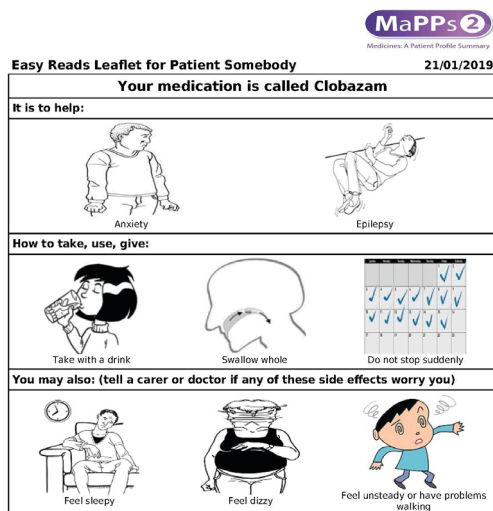
Communication is an essential life skill, and in the general population, occurs through the five key modalities of listening, watching, speaking, reading, and writing. However, persons with ID face difficulties with all these different aspects of communication and these challenges have been well recognised as contributing significantly to many of the BOC they present with.<sup>24-28</sup> Between milder to more severe levels of ID is a spectrum of communication profiles. Those with mild ID are likely to communicate with speech, but their ability to understand abstract concepts, their use of vocabulary, and their ability to read and write may be limited. Individuals with moderate ID often also communicate verbally, but these may be in the form of short phrases or single words, which may go hand-in-hand with other forms of communication methods such as using sign language. Those with severe to profound ID may not be able to communicate using speech at all and may rely on their caregivers to interpret their body language, vocalisations, or facial expressions. Moreover, it is common for persons with ID, in particular those with more severe levels of ID, to have sensory impairments such as visual and hearing impairment, which will understandably pose further communication difficulties.<sup>29,30</sup>

With all these barriers to the usual methods of communication, it is evident that persons with ID will have to find alternative methods to communicate their needs and their wants. Behaviours therefore often becomes a mode that is employed. Simply put, behaviours can often be used

as a means of communication. For example, a person who is nonverbal and has no other means to communicate may scream and hit out when they are in pain or in distress because they have no other way of conveying their pain to the people around them. Similarly, he/she may also use behaviour such as pushing or spitting to communicate his/her likes or dislikes with regards to other people or food, simply because they have no other means to communicate.

The critical role communication plays in BOC is supported by a number of studies that report BOC being more common in those with more severe ID, as the increasing difficulties with communication add additional challenges and complexities to expression of needs, wishes, and desires.<sup>31,32</sup> When a BOC is used as a form of communication, the principle underpinning the management of such a behaviour will be to replace the functional but inappropriate behaviour with one that is more appropriate. This could involve using an alternative method of communication, such as using pictures or teaching the person with ID to express their frustration in a different manner.

In addition to having difficulties expressing themselves, an important point that cannot be overemphasised about communication is that it is a two-way process. The difficulties persons with ID face with communication also make it harder for the individuals to understand information that is conveyed to them, which may consequently lead to inappropriate responses presenting as a BOC.<sup>33</sup> In order to reduce the possibilities of such BOC in persons with ID, it is important that information is communicated clearly to them in a manner they comprehend, and all attempts must be made to get their consent or assent. For example, when performing venepuncture or even checking the blood pressure for a person with ID, it is important that the intent and steps are explained clearly to them, so that their cooperation and agreement can be sought. Resources such as pictures, videos, and easy-read formats can be used to help in the explanation. Easy-read materials refer to the presentation of text in an accessible, clear, and easy to understand format.<sup>34</sup> Refer to **Figure 3** for an example of an easy-read material.



**Figure 3. Easy-read leaflet  
Source: MaPPs Easy Reads**

Overall, it is key that attempts be made by healthcare professionals to understand the communication profiles of the individuals with ID who present to them. Effort must also be undertaken to convey information to them in a manner that they understand. All of these will need to be carried out in a supportive environment, which brings us to the next section.

## PSYCHO-SOCIAL-ENVIRONMENTAL FACTORS

Research on the social networks of the general population suggests that those who have friends and diverse networks tend to have better outcomes for their health, mental health, and well-being.<sup>35,36</sup> Studies however show that persons with ID have smaller social networks and less interpersonal relationships compared to people who do not have ID. Furthermore, it is interesting to note that when asked, persons with ID state that support staff make up 43 percent of their social networks, fellow centre participants with ID made up 25 percent, family members 14 percent, and others 11 percent.<sup>37,38</sup>

This tells us that the composition of their social networks are distinct from that of the general population, and also the critical roles that support staff and families play in the lives of persons with ID. This becomes even more pertinent as persons with ID and their caregivers age, resulting in caregivers passing on before their adult child. When that happens, the persons with ID inevitably start relying even more heavily on support staff. This, however, is a precarious situation, as support staff may regularly change, which will be significant and disruptive for persons with ID due to their already small social networks. The important roles family and support staff play in providing emotional support and in engaging the individuals in activities can be expected to lead to BOC if there are disruptions in these important relationships.<sup>39</sup>

The number of social relationships persons with ID have has also been shown to relate to their level of ID, with more severely disabled individuals having smaller networks.<sup>40,41</sup> This makes the situation even more challenging, as persons with more severe levels of ID are already known to have higher risk of BOC and greater care needs, as well as their caregivers having higher levels of stress.<sup>31,32</sup> Moreover, with fewer interpersonal relationships and a higher risk of their social network breaking down, it makes them even more susceptible to suffering the ill effects of psycho-emotional-social losses. These may manifest as new BOC or worsening of existing behaviours. In essence, the families of persons with ID are crucial in providing physical, emotional, and social support to them.<sup>42,43</sup>

However, the impact of lifelong caregiving on the health, social, and financial well-being of caregivers of persons with ID cannot be overemphasised.<sup>44</sup> As roles and responsibilities change over the course of life, 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>45</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 may express this by pushing him away or even hitting him. His father could then end up more frustrated and even more insistent, which worsens the tension and stress. A vicious cycle could ensue with increased resistive behaviour and agitation, and ultimately, result in institutionalisation.

As the above example illustrates, it is therefore of vital importance to institute the appropriate interventions for BOC as soon as possible in order to break the vicious cycle. The next section will give a brief outline on the approach to management.

## PHARMACOLOGICAL AND NON-PHARMACOLOGICAL MANAGEMENT OF BEHAVIOURS

After a comprehensive assessment, if there is an obvious physical or psychiatric cause for the BOC, this should be managed appropriately and promptly, with regular monitoring of the interventions, any potential adverse effects, and the effectiveness of the treatment plan.

However, if no distinct or treatable physical or psychiatric disorder is found, then 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. For example, if the behaviour is potentially emerging out of boredom, attempts to engage the person more meaningfully will be required. If the assessment suggests that there is an environmental issue that may be contributing to the BOC, for example, excessively warm or cold temperatures in their activity centre, adjustments should be made if practical as far as possible. After interventions have been implemented, a period of observation needs to ensue, to monitor and review the effectiveness of these non-pharmacological treatments, as they often take time. Attempts to address psycho-emotional needs of persons with intellectual disability through counselling where appropriate should also be

actively carried out.

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 based management. 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. It is important to remember that the lack of adequate caregiver support for the use of non-pharmacological management should not be the only reason for using medication, although in practice this may happen due to high and severe levels of caregiver stress, leading to imminent care breakdown. Under such circumstances, the patient needs to be reviewed closely and medication should be used for as short a period as possible. 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.

Listed below are some of the situations under which the clinicians may consider using medication<sup>46,47</sup>:

- To treat an underlying mental health disorder
- Failure of non-pharmacological interventions
- Significant risk/evidence of harm/distress to self, others, or property
- To calm the person to enable implementation of non-pharmacological interventions
- Risk of care or placement breakdown

When used, medications should always be prescribed at the lowest possible dose and for the shortest possible duration. The reduction or withdrawal of medication and additional implementation of non-pharmacological strategies should always be considered at regular intervals.

The effectiveness and possible adverse effects of all the interventions should be monitored at regular intervals, which will include collecting subjective and objective information from the persons with ID themselves, their family members, formal and informal caregivers, and from members of the medical team caring for the patient. Physical examination and relevant investigations such as blood investigations and electrocardiograms should also be performed when necessary.

Overall, the choice and decision as to which pharmacological and/or non-pharmacological interventions should be implemented and prioritised will depend on each individual and family's unique circumstances. Ultimately, the approach needs to be person-centred, which refers to a "process of continual listening, and learning; focused on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends."<sup>48</sup> The person-centred approach demands that the person with ID be placed right in the centre of any plan, and to consider first and foremost his/her values, priorities, and wishes.

With these in mind, the interventions are then formulated to facilitate the achievement of these goals and aspirations, if appropriate.

Not only is the person-centred approach crucial, caregiver and family support are critical and cannot be overemphasised. Lifelong caregiving is already beset with numerous health, psycho-emotional, and financial challenges, what more when family relationships and quality of life is impacted and threatened by stressful and sometimes disruptive BOC. As such, the needs of the caregivers must 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 and positive wellbeing, as well as greater life satisfaction in the caregivers themselves.<sup>49</sup> Therefore, with proper support, the relationships and mutual interdependence between the person with ID and his/her caregiver can be enhanced, with persons with ID providing caregiving and companionship in turn to their ageing parents.<sup>50</sup>

This person-centred and family-centric approach strives not only to focus centrally on the needs of the individuals and their caregivers but also requires that the management plan be communicated clearly to the person with ID, their families, and all other relevant professionals involved in his/her care. This helps to ensure that all parties are aligned and in agreement with the goals that have been set. It will also allow for timely feedback in monitoring for adverse effects and efficacy.

Once a management plan has been initiated, a clear timeline for review should be set. If the improvement of the BOC is unsatisfactory at the point of review, an attempt should be made to re-assess and review the diagnosis and management plan. At any point along the way, if there are concerns or if challenges with the diagnosis and/or management persist, a referral to a psychiatrist should be considered.

## 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, as well as 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 Organisation (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 health and wellbeing are not at their optimum for the person with ID, and the BPS framework can be used by healthcare professionals to guide the comprehensive assessment of BOC in persons with ID. Specific health conditions, the communication

profiles of the individuals, and the psycho-emotional and social circumstances surrounding the individual and his/her family need to be considered carefully.

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, taking into consideration the individual's wishes and needs. 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. Interventions for the individual with ID therefore cannot be carried out in isolation without the close support of his/her families.

The overall management plan must be communicated clearly to the person with ID, his/her family, and all other relevant professionals involved in his/her care. Regular monitoring and review of the effectiveness of the interventions will need to be carried out, with reassessments and adjustments of management conducted in a timely manner.

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

## REFERENCES

1. 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
2. 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.
3. Soni S. *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*. Edited by N. Bouras and G. Holt. (Pp. 424;£ 48.00; ISBN 0-521-60825-2.) Cambridge University Press: Cambridge, UK. 2007. *Psychological Medicine*. 2008 Feb;38(2):303-4.
4. Qureshi H, Alborz A. Epidemiology of challenging behaviour. *Mental Handicap Research*. 1992 Jul;5(2):130-145.
5. Kiernan C, Reeves D, Hatton C, Alborz A, Emerson E, Mason H, Swarbrick R, Mason L. The HARC challenging behaviour project. Report; 1997.
6. Emerson E, Kiernan C, Alborz A, Reeves D, Mason H, Swarbrick R, et al. The prevalence of challenging behaviors: a total population study. *Res Dev Disabil*. 2001 Jan-Feb;22(1):77-93. doi: 10.1016/S0891-4222(00)00061-5. PMID: 11263632.
7. Lowe K, Allen D, Jones E, Brophy S, Moore K, James W. 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.

## 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 biopsychosocial (BPS) framework can be used to assess the BOC the person with ID is presenting with, and the ABC recording method can be used to collect information about the BOC.**
- **Specific health conditions and behavioural phenotypes can occur in persons with ID with certain syndromes. However, healthcare professionals need to be mindful of pitfalls in diagnosis, in particular “diagnostic overshadowing”, which refers to the phenomenon in which behavioural or emotional difficulties seen in people with ID are attributed to the ID itself.**
- **Persons with ID face difficulties with communication and it is imperative for healthcare professionals to seek to find ways to communicate with them in a manner that they can understand.**
- **Persons with ID have smaller social networks and are largely dependent on their families and support staff. Particularly with increasing longevity, this leads to increasing challenges for ageing caregivers and their adult children with ID.**
- **Overall, the choice and decision on which pharmacological and/or non-pharmacological interventions should be implemented will depend on each individual and family's unique circumstances. The approach needs to be person-centred and family centric, with caregivers actively engaged throughout the entire process.**