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HELP with Behaviours That Challenge

Abstract

*When individuals with intellectual and developmental disabilities engage in behaviours that challenge, their potential for full community participation, integration and quality of life is greatly compromised. Embedded in the acronym HELP (**H**ealth, **E**nvironment & Supports, **L**ived Experience, **P**sychiatric Disorder), this article describes a biopsychosocial multi-perspective understanding of these behaviours. HELP is an approach that can be embraced comfortably by all stakeholders (including individuals with intellectual and developmental disabilities and their families), empowers problem solving and has implications for effective intervention.*

Behaviours that challenge (BTC), otherwise known as "challenging behaviours," (National Collaborating Centre for Mental Health [NCCMH], 2015) are observed in people with intellectual and developmental disabilities (IDD) (DSM-5; American Psychiatric Association, 2013). Epidemiological studies estimate that BTC are present in 5–15% of the population with IDD (NCCMH, 2015) and occur more frequently in those with greater severity of disability (Cooper, Smiley, Allan et al., 2009a; Cooper, Smiley, Jackson et al., 2009b). These behaviours may start early, have a relapsing and remitting course and can challenge services and care providers. As a consequence, individuals engaging in these behaviours are frequently the recipients of intrusive interventions including the over prescription of psychotropic medication, particularly antipsychotic medication, giving rise to serious side effects, increased medical morbidity and mortality (Alexander, Branford, & Devapriam, 2016; Sheehan et al., 2015). BTC lead to reduced quality of life both for individuals so engaged, and their care providers as well as frequently preventing full community integration.

Some BTC, while being a concern to care providers, are not apparently distressing to the individual (e.g., some repetitive behaviours, hoarding) and do not result in any harm to self, others or property destruction. These behaviours might more appropriately be referred to as antisocial (i.e., annoying, irritating and outside of the social norm; Bradley & Korossy, 2015). Whether to intervene in these antisocial behaviours should be given careful consideration because intervention may obstruct a vulnerable individual's right to self-expression.

BTC that result in harm to self, others, or destruction of the environment, can best be considered as communications of distress by individuals unable to communicate their distress in more conventional ways. This distress may arise as the consequence of body discomfort (e.g., medical condition), from situations in their environment (e.g., over-stimulating

surroundings giving rise to hyperarousal and meltdowns), from the interaction between personal, emotional and environmental circumstances (e.g., a task is too difficult or sadness about loss of a care provider), or it may signal psychiatric disorder. There may be multiple factors compounding the distress and confounding simplistic approaches to these behaviours. Attempts to treat without appreciating underlying cause can escalate the distress and exacerbate the situation to crisis proportions.

Systematic consideration of the personal and biopsychosocial complexities that give rise to expressions of underlying distress is paramount (Banks et al., 2007; Banks, Bush, & Other Contributors, 2016; Koritsas & Iacono, 2015). A robust diagnostic formulation embracing multidimensional circumstances, creates opportunities for collaborative problem solving, accurate diagnoses and person centred solutions (Holland, 2015; Jahoda, Willner, Pert, & MacMahon, 2013).

BTC have historically been referred to as "challenging" or "problem" behaviours or "behaviour problems," the latter sometimes even morphing into "behaviour disorders." All four descriptors create the impression that these behaviours are primarily a characteristic of the individual and consequently the focus of intervention is on trying to change the individual. "BTC" on the other hand implies an interaction between the individual and his/her environment and begs the question who is challenging whom (NCCMH, 2015). BTC is favoured by the present authors because (a) these behaviours arise in the context of an individual with unique needs in an environment that may not be optimally understanding or supportive of these needs (Banks et al., 2007; Banks et al., 2016) and (b) evaluations of both the individual, their physical-social environment and supports, are required for effective intervention and successful outcomes.

This article describes an effective, efficient (Goh, 2013) and sequential approach for understanding BTC. The HELP framework described here (Figure 1), provides a meaningful, intuitive and straightforward way to organize assessment, formulation and interventions across multiple domains of complexity. Essentially a biopsychosocial approach, HELP is unique in paying special attention to the emotional lives and needs of people with IDD (their "lived experience") and the contribution of unmet emotional needs to BTC (Bradley, Hollins, Korossy & Levitas, in press).

Tools associated with this HELP approach are also available online through the Developmental Disabilities Primary Care Initiative at Surrey Place Centre (2011). A recently published chapter provides more details, clinical tips and references to online resources (Bradley & Korossy, 2015) such as a booklet for care providers (Bradley & Caldwell, 2016). The Curriculum of Caring Agenda (http://machealth.ca/programs/curriculum_of_caring) embraces the HELP approach and self-advocates with IDD have given their voice to HELP through a musical adaption (https://vimeo.com/125914430) (Boyd, 2016).

HELP Framework and Approach for Understanding BTC

The HELP framework considers the aetiologies of BTC within four main conceptual themes: (1) **H**ealth; (2) **E**nvironments, supports and expectations; (3) **L**ived experience and emotional well-being; and (4) **P**sychiatric disorder (Figure 1). In the HELP approach these four areas are explored in sequential order so that those circumstances most frequently contributing to BTC are identified and addressed before assuming that any unusual or problematic behaviour must be of psychiatric origin.

These four themes are considered separately below. Suggestions for clinical practice (☺), and clinical vignettes (☺☺) are inserted at the end of each theme.

Case vignettes are in Appendix 3.

Health

Medical conditions can give rise to BTC (Appendix 1). In this context, the BTC are signals, or put another way, communications from the individual of physical discomfort or pain they are experiencing (Appendix 2). Individuals with IDD vary in their capacity to communicate to others that they are experiencing physical discomfort or are in pain (Boardman, Bernal, & Hollins, 2014). Even those who use words may

not spontaneously share their suffering with others unless specifically asked or prompted. However, care providers using effective communication strategies such as simple language, gestures and visuals (e.g., Books Beyond Words: Bradley & Hollins, 2013), enhance opportunities for individuals with IDD to alert care providers to their physical suffering; such detection paves the way for early intervention before pain-related behaviours escalate. For those individuals with limited or no language, care providers need to be attuned to small changes in facial expression or other body language that may signal that something is wrong (Caldwell, 2013; Leicestershire Partnership NHS Trust, 2013). Best practice guidelines in IDD recommend routine health screening (e.g., annual health checks) (Robertson, Hatton, Emerson, & Baines, 2014), and when BTC arise, review of physical status and examination (Sullivan et al., 2011).

☺ **Health** – Helpful tips:

(1) Consider "head to toe" health when reviewing physical status (so as to cover all aspects of the body);

(2) identify the cause (aetiology) of the IDD (e.g., a syndrome) as different IDD aetiologies have increased prevalences of different health issues that need attention throughout the lifespan (e.g., thyroid and celiac disease in Down syndrome);

(3) screen for these syndromes/aetiological associated medical conditions;

(4) identify and document each individual's unique response to pain (e.g., such as may occur when exposed to a circumstance generally considered to be painful) and document in case notes for future reference.
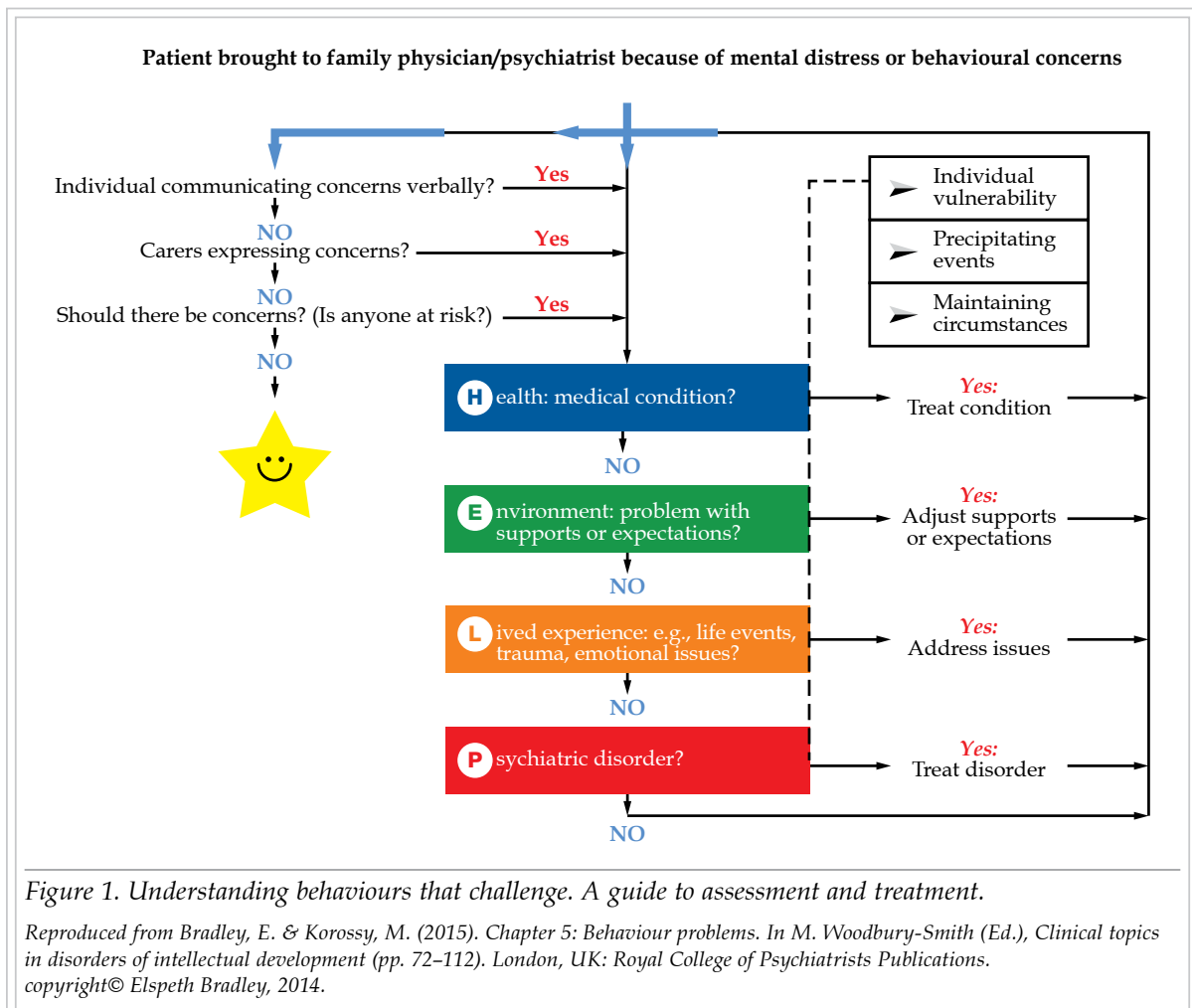

Figure 1. Understanding behaviours that challenge. A guide to assessment and treatment.

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☺☺ **Clinical vignettes:** Jane and Yvonne (see Appendix 3)

Environment, Supports and Expectations

Environment in this framework embraces family and social networks, as well as physical surroundings. Environment even includes the layout of places where people live, work and play and how they travel between these places (NCCMH, 2015). Supports and services can be broadly described as what is needed to enable full participation of all citizens in the communities in which they live (Ontario Ministry of Community and Social Services, 2016). For people with IDD, additional specific accommodations and adaptations may be needed to prevent secondary disabilities and handicap (World Health Organization, 1980) and to ensure opportunities for full inclusion.

Expectations can arise from within the individual or from care providers and systems of support. BTC may arise where there is mismatch between individual capacities, expectations, interests and preferences, supports available and care provider expectations. BTC arising from personal interest and preferences, while socially unacceptable, may not be distressing to the individual. On the other hand, mismatch between (a) the individual's unique developmental needs, skills, and capacities (b) supports and services provided or (c) care provider understanding and expectations, can result in some of the most severe BTC (e.g., screaming loudly, smearing faeces or aggression in response to a difficult request or to too many people being in close proximity).

As health workers, we tend to evaluate environments and supports from our own perspectives of what we find to be desirable and comfortable. However there are now numerous reports from people with IDD and especially from those with autism, alerting us to the reality that their sensory and perceptual experiences may be different and what is attractive to me may actually be quite "toxic" to another. In addition, the intensity of pleasure or discomfort may, for some, be related to the degree of control they have over the circumstance. For example, Temple Grandin, an adult with autism describes as a child:

"When people hugged me, I stiffened and pulled away to avoid the all-engulfing tidal wave of stimulation. The stiffening up and flinching was like a wild animal pulling away" http://www.autism.com/advocacy_grandin. Yet Temple also describes herself as seeking deep pressure stimulation: "It was an approach-avoid situation." As a child she reports she "used to like to get under the sofa cushions and have my sister sit on them." As an older person she developed a "Squeeze Machine," a device to provide comforting pressure to large areas of the body (Grandin & Scariano, 1986, pp. 86-99). Attention to the uniqueness of each person with IDD (person-centred approach) and full partnership with that person in decisions that involve them, is critical to effective intervention for BTC (Beadle-Brown, Hutchinson, & Whelton, 2012; Mansell, Beadle-Brown, & Bigby, 2013).

Individual profile of needs. Individual developmental needs, skills and capacities can be identified through assessment of: cognitive and adaptive skills, emotional needs, attachment patterns, self-regulation capacities, communication, sensory sensitivities, motor skills and difficulties, and observed behaviour. Interprofessional participation that may be needed for comprehensive assessment (Daalemen, 2016; Kerr et al., 2014) is listed in Appendix 4. Ensuring a good match between individual developmental profiles and accommodations and supports needed, will prevent undue mental and emotional stress, mood dysregulation, anxiety and panic; the outside manifestations of these personal negative experiences can be BTC.

A functional behavioural assessment, usually conducted by a behaviour therapist, aims to determine what the outcome is for the individual when engaging in BTC – for example, does it result in getting needed attention ("attention-seeking"), or some other desirable outcome ("tangibles") or result in being able to exit a situation that is intolerable for them ("escape")? This assessment provides an *in vivo* evaluation of what is happening in the individual's actual environment during times when BTC are present and can identify triggers to occurrences of these behaviours. Identifying triggers offers opportunities for targeted interventions. Understanding the link between these triggers (stressors) and individual responses alerts care providers to individual needs that might other-

wise be overlooked and if not attended to lead to more serious psychiatric disorder (Bradley, Hollins, Korossy & Levitas, in press)

Person-centred environments and supports. These can be considered at the Individual, Program, and Service system levels (Appendix 5) (Beadle-Brown et al., 2012; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008; Mansell et al., 2013). Emotional distress arising from mismatches between individual needs and supports available can either be internalized (e.g., anxiety, mood dysregulation, adjustment problems) or externalized (e.g., BTC).

☻ **Environment, supports and expectations** – **Helpful tips**:

(1) Map out with individual and care providers a detailed "day in the life of" the individual from waking in the morning to going to bed at night to identify daily patterns, adaptive skills and needed supports;

(2) "Shadow" the individual for a half day to experience some aspects of their daily reality, circumstances they encounter and their responses to these (invaluable direct access to the individual's physical and social support environment and their unique responses to these).

☻☻ **Clinical vignettes**: John and Guthrie (see Appendix 3)

Lived Experience and Emotional Well-Being

Emotional distress may give rise to BTC. Many individuals with IDD have difficulty expressing in words their inner world and emotional experiences; and some may be completely unable to do so. Opportunities to share life's daily frustrations, as well as joys in work, recreational and social networks, with chosen like-minded peers are not so available in supported living circumstances. Because of these communication differences there may be mistaken assumptions that those with IDD do not have an emotional life and their feelings and concerns are consequently ignored or dismissed (Gilmore & Cuskelly, 2014; Hubert & Hollins, 2010; Sinason, 1992). However it is clear from self-advocate accounts (MacMahon et al., 2015)

and from clinicians working therapeutically with individuals with disabilities, that mental well-being is experienced in the feelings of the body (as well as expressed in words) and is impacted profoundly by relationships, perception of self and empowerment in the outside world, irrespective of cognitive abilities. For those with IDD for whom these feelings and concerns about day to day circumstances and relationships have become intolerable, psychological therapies, including the range of talking therapies, with appropriate adaptations for communication styles, are of benefit (Beail et al., 2016; Campbell, Robertson, & Jahoda, 2014). Through body language such as breathing rhythms, motor patterns and non-word vocalizations, even individuals with no language can be observed to engage in meaningful reciprocal emotional responses to others and clearly experience emotional relief when the communicating partner takes the time to learn from them their unique non-verbal body language (Caldwell, 2013; Schuengel, Oosterman, & Sterkenburg, 2009; Sterkenburg, 2008). Validating painful emotional experiences, whether rooted in the present or the past, is a powerful therapeutic intervention for BTC arising from these distressing experiences (e.g., Eye Movement Desensitization Reprocessing (EMDR) treatment for trauma (Mevissen, Lievegoed, Seubert, & De Jongh, 2012); Intensive Interaction (Caldwell, 2013); and Individual Therapy for Attachment and Behaviour (ITAB) (Porges, 2003; Schuengel et al., 2009; Sterkenburg, 2008).

Daily stress. Managing stress in optimizing physical and mental well-being has become a most crucial part of 21st century living with its rapidity of change and the daily need to absorb an exponentially increasing amount of information. When the body is threatened with more than it can handle, it essentially "crashes" and moves from cognitive and communication strategies when solving problems into triggering a primal biological survival system – the autonomic nervous system (ANS) which offers, and prepares, the body for three immediate solutions: Fight (aggression), Flight (fleeing), Freeze (cessation of movement). These instinctive responses are experienced as emotion dysregulation (Dvir, Ford, Hill, & Frazier, 2014; Raju, Corrigan, Davidson & Johnson, 2012; Loos & Loos Miller, 2004; Porges, 2003; Porges, 2007). Some BTC (e.g., aggression to self and

others, running, screaming and "noncompliance") are also signs of this triggering into ANS activity. The role of everyday stress, from the perspective of the individual with IDD, must be considered in any evaluation of BTC. Successful psychological and behavioural interventions and supports increase the capacity of the individual to tolerate negative emotions (in ASD positive emotions can also be difficult to manage) so as not to trigger into these distressing and disruptive states. (See Allen et al., 2015; Beail et al., 2016; Gore et al., 2013; Matson et al., 2011).

Vulnerability and lifetime stress. As a group, individuals with IDD live much more stressful lives than their same age peers. They experience greater exposure to negative life events and traumatic experiences (e.g., physical, sexual, emotional abuse, bullying, stigma, exclusion, hate crimes) (Llewellyn, Vaughan, & Emerson, 2015). Some IDD aetiologies may confer specific risk for such adversity and traumatic experiences (e.g., autism and sensory hypersensitivities). Individuals with IDD are at risk of developing insecure attachment patterns and consequent difficulties in affect regulation. (Schuengel et al., 2009; Schuengel, de Schipper, Sterkenburg, & Kef, 2013). They are also more vulnerable to the impact of stress in part because they use less effective coping strategies. Some mitigating circumstances such as confidants and social networks are less available. Social isolation is recognized, as are the need for supports in developing friendships, activities and relationships (Gilmore & Cuskelly, 2014). Some BTC (e.g., aggression), are associated with these past adversities and poor social supports and may be better understood in terms of post-traumatic stress conditions and associated characteristic symptoms of re-experiencing, avoidance and hyperarousal (Hubert & Hollins, 2010; Tomasulo & Razza, 2007).

Much can be done to promote resilience and reduce exposure to negative life events – at the (a) Individual, (b) Program and (c) Service system levels of support as well as (d) taking care to include perspectives from individuals with IDD. For example in (a) individual therapies successfully employed to enhance affect regulation include counselling, anger management, positive behaviour support, cognitive behavioural, dialectical, dynamic and trauma informed therapies and mindfulness practices (Beail et al., 2016; Mallinckrodt, 2000); in (b) "toxic" environments can be avoided by attention to unique individual needs such as sensory hypo- and hyper-sensitivities, structure and consistency in environments and skilled staff support; in (c) the impact of predictable psychosocial crises, such as those involving transitions (Levitas & Gilson, 2001) can be minimized or prevented with adequate planning and preparation; in (d) "Nothing about us without us" and "Being with rather than doing to" may be helpful reminders that disability confers a different experience and therefore different perspectives on daily existence; involving people with IDD in their care and in service development is necessary to understand and integrate these perspectives. Such efforts can be anticipated to reduce BTC.

☺ Lived experience – Helpful tips:

(1) Identify and document chronologically the individual's birth to old age life event experiences: identify traumas generally known to cause distress (e.g., loss and bereavement, abuse (physical, sexual, emotional, bullying, neglect), early separation) as well as those events that may be personally distressing to the individual with IDD but which may go unrecognized by care providers unless specifically looked for (e.g., transition transitions and sensory sensitivities in ASD, humiliation or shame associated with performance, teasing and exclusion)

(2) Identify specific vulnerabilities (e.g., ASD, attachment issues)

(3) Assist individuals develop resilience in response to stress (e.g., opportunities to learn coping strategies; affect management and de-escalation strategies; access to anger management training, as well as group and individual opportunities to explore emotional concerns)

(4) Consider, as required, staff training in: Attachment, Trauma, Developmental-focused support (e.g., Circle of Security http://circleofsecurity.net/for-parents/animations/) (Hoffman, Cooper, & Powell, 2016); Emotional regulation (Raju et al., 2012); Low arousal approaches (Woodcock & Page, 2010); ASD friendly environments (Bradley

& Caldwell, 2013); Intensive Interaction (Caldwell, 2013)

(5) Provide support for staff e.g., self care, mindfulness practices (Singh et al., 2009).

☺☻ **Case vignette:** Jack (see Appendix 3)

Psychiatric Disorder

People with IDD are often referred for psychiatric evaluation because of BTC. Psychiatric misdiagnosis are made by clinicians unacquainted with the lives of people with IDD and the many ways in which medical conditions, inappropriate environments, supports and expectations, and subsequent physical and emotional distress, can mimic psychiatric disorder (Bradley, Hollins Korossy & Levitas, in press). Additional complexities in understanding BTC arise when physical and mental health conditions and especially those that are cyclical or episodic (e.g., mood disorders, allergies, constipation) occur together; likewise several psychiatric disorders can co-exist (e.g., ADHD and mood disorder), other developmental disorders may be present (e.g., ASD) and life events may follow a predictable event pattern (e.g., anniversaries, holidays). Systematic psychiatric evaluation of these potential co-existing circumstances is crucial (Appendix 6).

Mood, anxiety, adjustment, trauma and stressor-related disorders are under-diagnosed in IDD (Fletcher, Loschen, Stavrakaki, & First, 2007) and psychotic-like presentations may be diagnosed as psychotic disorders (Emerson & Einfeld, 2011). Aggression is a symptom which has different causes in individuals with IDD (Bradley & Hollins, 2010, Table 18.2; Bradley & Lofchy, 2005, Table 1). Aggression (to self, others or the environment) is a common reason for Emergency Room visits by adults with IDD: in one study aggression represented greater than 40% of presentations, followed by suicidal behaviour or ideation at 26% (Lunsky et al., 2012; Tint & Lunsky, 2015). At these times antipsychotic medication may be initiated to manage risk in the acute situation. Unfortunately in the absence of subsequent review as to the underlying cause of these aggressive behaviours this medication is often continued despite being considered poor practice (Alexander et al., 2016). In Ontario

21.1% of adults with IDD are on antipsychotic medication in the absence of a psychiatric diagnosis (Lunsky, Klein-Geltink, & Yates, 2013). Conclusions from a UK primary care data base of 33,000 adults, six selected secondary care sites and second opinion Care Quality Commission-appointed doctors, related to 945 reports, provide robust evidence of widespread inappropriate use of psychotropic medication in people with IDD (Alexander et al., 2016); these findings have resulted in a "Call for Action" to improve this practice (NHS England, 2015; Sheehan et al., 2015).

When the above areas of concern (the H, E and L of HELP) are adequately assessed, psychotic presentations and aggression are often better understood in terms of mood dysregulation, anxiety, adjustment problems in response to acute and chronic stressors or trauma (Bilderbeck, Saunders, Price, & Goodwin, 2014; Bradley et al., in press; Marwaha, Broome, Bebbington, Kuipers, & Freeman, 2014). With appropriate intervention for these specific conditions the apparently "psychotic" symptoms and behaviours resolve (Dossetor, 2007; O'Dwyer, 2000; Van Schalkwyk, Peluso, Qayyum, McPartland, & Volkmar, 2015).

Hyperarousal (especially in ASD) triggered by "toxic" environments can also give rise to aggression – or running and freezing behaviours as part of the Autonomic Nervous System Fight-Flight-Freeze responses. Attending to this arousal and these toxic environments is usually therapeutic.

Sometimes BTC are truly a manifestation of psychiatric disorder or emotional distress so severe that it has triggered psychiatric illness. Careful evaluation is needed to differentiate between behaviours communicating severe mental distress associated with psychiatric disorder, from those underpinned by H, E and L issues (outlined above), as treatment is different. Several different parallel medical and psychological treatments may be required to target different aetiological circumstances (e.g., mood disorder requires ongoing treatment whereas allergies can be treated as these occur).

The mental state examination (MSE) is a clinical interview conducted by psychiatrists to understand presenting problems and diagnose psychi-

atric disorders (Levitas, Hurley & Pary, 2001). Patients without cognitive and communicative disabilities are usually able to share their inner thoughts, emotions, experiences ("symptoms") and observations by the examining psychiatrist (or described by others) of their behaviours ("signs") assist in determining whether these markers meet diagnostic criteria for psychiatric disorder(s). Respect, warmth and empathy usually enhance the dialogue between clinician and patient, optimize identification of important symptoms and signs, and increase psychiatric diagnostic accuracy. This standard MSE has to be adapted to the communicative, cognitive and emotional capacities of the patient with IDD (Boardman et al., 2014; Bradley & Lofchy, 2005; Deb, Matthews, Holt, & Bouras, 2001). Such adaptations include careful consideration as to where the interview is conducted (familiar place or unfamiliar clinic?), the length of the interview (as needed for patient comfort or according to a pre-determined outpatient standard?) and who might accompany the patient (who knows the patient best – e.g., family member, day staff, night staff?). It is always worth reflecting how the MSE may be experienced by the individual with IDD – from their perspective (Ng, Jarvinen, & Bellugi, 2014) and what their desired outcome of this meeting is. For example, questions the individual does not understand and particularly those with embedded meaning (e.g., the "do you hear voices") may be reminders to them of painful failure experiences at school and they reply "yes" to avoid exposing a lack of understanding. On the other hand the individual may reply "yes" because they want to please the doctor or they see this as a way to keep engaged with the empathic clinician who is helping.

It could be argued that focusing on the therapeutic rapport is the most important component of the MSE working with people with IDD; the need for any urgent specific information can usually be obtained from a care provider who knows them well. If therapeutic rapport is developed from the outset, there is opportunity in later meetings to develop more reliable strategies to determine whether crucial symptoms (from a diagnostic perspective) such as voices, are present, as well as a more accurate description of the nature of these voices. For individuals with severe communication disabilities (e.g., IDD and ASD) focusing on emotional engagement through non-verbal cues

and body language is likely to be the only way the psychiatrist is going to gain accurate access to their current affective status; such access has substantial implications not only for diagnostic accuracy but also for determining what may be contributing to the behaviours of concern (see case # 6 Nada).

☺ Psychiatric disorder – Helpful tips:

(1) Review of Sections H., E., L., and implementation of needed interventions will diminish BTC unless these behaviours are associated with psychiatric disorder.

(2) Any remaining BTC can be reviewed: (a) to determine if these represent a significant change from baseline (usual) behaviours and (b) if changes meet criteria for diagnosable psychiatric disorder (Appendix 6).

(3) "Management" of BTC (actions taken to ensure immediate safety of everyone – these may involve sedating medication) is different from "treatment" of BTC (actions taken to eliminate or treat the underlying cause). Treatment with psychotropic medication is only indicated when psychiatric disorder has been diagnosed. Medication to manage BTC should be short term (while underlying cause and appropriate treatment is being sought).

(4) Review previous diagnoses – are they still valid after HELP review?

(5) Review psychotropic medications (Bradley, Behavioural and Mental Health Working Group, & Developmental Disabilities Primary Care Initiative Co-editors, 2011a), when and why prescribed, by whom, side effects, whether and how each medication has made a difference (if any) to behaviours for which they were prescribed (target behaviours) (Alexander et al., 2016).

(6) If medication is being tried for behaviours rather than for a psychiatric disorder, is the medication trial following robust practices (Bradley, Behavioural and Mental Health Working Group, & Developmental Disabilities Primary Care Initiative Co-editors, 2011b)

☺☺ Case vignette: Nada (see Appendix 3)

Discussion

The HELP approach with its catchy mnemonic, assists in robust evaluation of BTC, provides the basis for a comprehensive diagnostic evaluation and promotes multi perspective understanding, interventions and delivery of targeted treatments. HELP embraces a biopsychosocial and person- centered approach accepted as good practice in addressing these behaviours (NCCMH, 2015). The approach is unique in integrating the lived experience of people with IDD (the "L" of HELP) into the biopsychosocial perspective. HELP also addresses complexities that arise in BTC (e.g., the same behaviour, even in the same person, can have different causes; in contrast the same cause may give rise to different BTC; added to this the severity of the behaviour may not reflect the severity of the underlying cause). Caregivers, such as frontline staff, are often the first to observe emerging BTC and are in a key position to begin the process of problem solving surrounding their causal basis and their resolution. It is crucial to consider every behaviour that challenges, and each episode of occurrence, within a comprehensive framework that is meaningful to all stakeholders, including the individual with IDD, and one which stakeholders can readily implement.

Other ways in which HELP may be utilized with good outcomes include:

- Review of poor response to previous interventions and treatments
- Review of previous psychiatric diagnoses that have responded poorly to evidence-based practice for that disorder:
  - Is the psychiatric diagnosis accurate and the poor response to treatment because of unaddressed issues in the other domains (the H, E and L)?
  - When these other domains are addressed adequately do the symptoms and behaviours that gave rise to this diagnosis also remit?
- Medication reviews and management. For example a positive or negative response to a new medication or dose change may be due to other things going on in the person's life rather than attributable to the medication change.

- HELP provides "the scaffolding" to permit the implementation of medication good practice guidelines for adults with IDD (Bhaumik et al., 2015). Staff may be understandably fearful of changes in medications prescribed in the past for frightening and dangerous behaviours. With a collaborative multi perspective approach that identifies alternative, less intrusive intervention options, frontline staff are likely to be more willing to support reductions in these medications.

Systematically addressing, within a collaborative framework, medical, environmental, support, emotional and psychiatric issues that arise in the lives of people with IDD, will greatly improve their quality of life and diminish behaviours of concern. In this context, current practices of overuse of harmful psychotropic medication to manage BTC should become unnecessary (Alexander et al., 2016 p. 16).

Key Messages From This Article

People with disabilities. HELP is a way for all of us to understand when your behaviours are communicating distress and what can be done to help you feel better.

Professionals. HELP provides a biopsychosocial, multi perspective understanding of individuals with IDD who are engaging in BTC; this approach works to promote their health and well-being.

Policymakers. BTC prevent access by people with IDD to a range of health-promoting services available to the general population. HELP flags service system issues that may be contributing to these behaviours and illuminates opportunities for prevention.

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APPENDIX 1: Physical and Medical Conditions
That May Cause Discomfort or Pain (Appendix 2)
and May Be the Cause of, or Associated with, BTC

Consider discomfort/pain related to:

- Occasional common ailments (e.g., cough, colds, flu, headaches)

- Allergies (e.g., rash, itch)

- Sensory discomforts (e.g., new clothes, shoes)

- Otitis (ear infections); hearing impairment; sound hypersensitivity

- Visual problems (e.g., cataracts, light sensitivity)

- Mouth and teeth (e.g., cavity, abscess, gum disease, teeth grinding; drooling; swallowing problems)

- Gastrointestinal (e.g., dysphagia; GERD; H. pylori-related dyspepsia; gallstones; lower GI problems (Crohn's disease, ulcerative colitis, irritable bowel syndrome); constipation and hemorrhoids

- Menstrual cycle phases – dysmenorrhea/ premenstrual syndrome; peri-menopause/ menopause (may start earlier)

- Urinary tract infections; urinary incontinence

- Endocrine and autoimmune conditions (e.g., diabetes, thyroid)

- Musculoskeletal (e.g., related to physical condition such as cerebral palsy, spasticity, arthritis, fractures, myalgias, osteoporosis, degenerative disc disease)

- Neurological (e.g., epilepsy; headaches); acquired brain injury; dementia

- Dermatology (e.g., rashes, abrasions, infections, burns)

- Sleep problems (e.g., sleep apnea)

- Medication side effects, changes in medication

- Medical conditions associated with genetic syndromes (e.g., seizures and tuberous sclerosis)

- Syndrome-related BTC (e.g., self-injurious behaviours in Cornelia de Lange or Lesch-Nyhan syndromes)

- Respiratory (e.g., pneumonia, asthma, aspiration)

- Cardiovascular (e.g., congenital heart condition, vascular disease)

- Infectious (e.g., Tuberculosis (TB), Lyme disease, scabies, pin worms)

- Other (e.g., check family history for medical conditions and screen for these conditions)

APPENDIX 2: Pain and BTC

Pain may not be recognized if it presents atypically and is manifested as BTC; in people with IDD both verbal and non-verbal (gestures or body language) expression of pain may be compromised. Despite formidable difficulties in assessing pain in some people with IDD, there is no evidence that they suffer any less from a noxious experience; proposed "elevated thresholds" may be an artifact of extreme motor impairment (e.g., Rett syndrome). Pain may be a setting event for BTC resulting in greater frequency and intensity (Bradley & Korossy, 2015). There is evidence that pain may not be effectively recognized or managed (Beacroft & Dodd, 2011), that mistaken staff beliefs may be influencing care of residents who experience pain and that use of structured communication aids and additional training may be helpful (Beacroft & Dodd, 2011; Rose, 2011). Tools such as *DisDat* can guide care providers to systematically explore the possible cause of distress or pain (Regnard, Matthews, Gibson, & Learning Disability and Palliative Care Team at Northgate Hospital in Northumberland, UK, 2008)

APPENDIX 3: ☺☺ Case Vignettes
Under Corresponding HELP Sections

Ⓗealth

Jane: During adolescence, following a very stressful time transitioning from middle to high school, Jane started to engage in sudden episodes of frenzied agitation, hyperactivity and screaming, accompanied by pinching herself causing bruising. These behaviours were recognized as occasions of heightened intense anxiety triggered by too many people talking and too much activity going on around her. Systematically monitoring these behaviours, it was observed that Jane would trigger more easily when bothered by her seasonal allergies, monthly menses and occasions of constipation. Providing more proactive management of each of these medical conditions diminished these episodes.

Yvonne: A 30-year-old woman, registered blind with presymbolic language skills (no speech) engaged in serve head banging causing bruising and discolouration around her eyes. Thinking this cyclic behaviour might reflect mood disorder, her sleep wake hours were monitored over several months. Her sleep pattern was found to follow a phase shift pattern so that every 8–10 weeks Yvonne would switch from sleeping mostly at night to sleeping mostly during the day. However in keeping with her group home routine she would be encouraged to get up during the day even when her inclination was to sleep; it was at these times the self-injury would occur. Melatonin was prescribed to regulate her sleep wake cycle and her self-injury stopped. Yvonne's visual impairment had prevented light activating those parts of the brain that regulate sleep (e.g., hypothalamus and pineal gland) (Lockley, Arendt, & Skene, 2007).

Ⓔnvironment, Supports and Expectations

John: An adult with presymbolic communication skills is observed to head bang when people become too noisy. When this occurs, care providers are reminded of John's autism, associated noise hypersensitivity and the necessity to ensure that others do not become too noisy or if this is not possible, assist John in removing himself. They are also working with John to encourage him to wear noise muting headphones; if these work for him he may be able to remain in the room with peers, despite the noise they are making.

Guthrie: 39 years. old, has mild ID and lives in a group home. He can engage in a two way conversation and describe his daily activities. He quickly gets anxious with certain events (e.g., disappointment that a prearranged meeting does not take place). Guthrie, who has fragile X syndrome, is of above average height and build. When upset, he appears frightening to those who do not know him. He has been picked up by the police on several occasions after being reported as displaying disruptive behaviour (shouting, threatening movements with sticks) in public places (e.g., after a friend did not show up).

Guthrie was assessed by the Multi-Discipline Team (MDT). Guthrie and care providers, working with the MDT Behaviour Therapist identified situations that caused him anxiety (fragile X syndrome is associated with anxiety). Changes in Guthrie as he escalated to full anxiety were identified. Staff taught him how to recognize these changes and agreed upon support strategies at each stage of his escalating behaviour (e.g., redirection, find a quiet place, count to ten). As staff became familiar with these behaviours and strategies, Guthrie learned to recognize his own feelings at these times and, with support, was soon able to initiate appropriate action (e.g., remove himself, rehearsed anxiety management strategies, relaxation exercises). Psychological and communication assessments indicated that Guthrie's strengths were in non-verbal understanding (e.g., visual) compared to verbal, even though he appeared to use words with great panache. Care providers were helped to recognize that in supporting Guthrie they needed to provide visual cues and check out his understanding in a sensitive way, even though he would insist he understood. A trial of beta blockers was prescribed to reduce his sympathetic (autonomic nervous system) drive and feelings of anxiety. Guthrie provided feedback through the use of visuals and staff monitoring target behaviours, to determine whether this medication reduced his reactivity to environmental triggers. The team supporting Guthrie liaised with the local community police unit to share ways to

support Guthrie should he get into difficulties in the community. Ongoing staff training, especially when there were staff changes, was crucial to the maintenance of this support for Guthrie.

Lived Experience and Emotional Well-Being

Jack: A 32 year old gentleman with autism spectrum disorder and moderate IDD, reported hearing voices to his case worker. When seen in the ER he described hearing voices on and off over a long time. These voices he reported told him to hurt himself or others and although he had not acted upon this he was very concerned "I keep telling them to stop … and they follow me outside." As he spoke about his voices he became tearful, distressed and fearful, but denied they were currently present. He said the voices only occurred when at his work. He reported they started there several years previously after witnessing an altercation between two workers. Work was described as being stressful for Jack and staff said he would make up stories involving strange people and persisted in getting 1-1 staff attention. As a child Jack had witnessed violence between his parents, his father left and Jack was currently living with his mother and brother. On one occasion when Jack was describing his voices he suddenly interrupted with a memory of his brother collapsing in a restaurant. Jack started to relive distress that he was not allowed to go with his brother in the ambulance to the hospital.

Following medical, psychological, occupational therapy and psychiatric assessments it became clear that Jack's voices occurred when he was anxious and particularly when his anxiety was evoked by witnessing and hearing altercations between people around him and being confused as to whether he was the reason for their altercation. Essentially triggers in the present took him back to feelings he experienced as a child growing up in his family. The people he was speaking about to staff while at work, were identified as TV personalities and cartoon characters he had focused on to help him manage escalating anxiety in the work place especially when he was unable to garner the 1-1 support he desperately needed at these times. Jack was referred for trauma therapy and has responded well to affect regulation support with an EMDR-trained therapist and changes to his work environment to better accommodate his

autism needs – clear expectations, consistency, quieter work space.

As with so many people with IDD what appears to be maladaptive and BTC are in fact their best attempts to manage with the resources they have available to them to deal with a present that has triggered unresolved issues from the past. Careful attention to the specifics of how individuals attempt to manage such past triggered distress may be key to assisting then with more adaptive strategies (e.g., Jack already had a repertoire of favourite cartoons and responded to staff working with him to select characters from these favourite movies to support better affect regulation).

Psychiatric Disorder

Nada: Care providers expressed concerns that Nada, a 54 year old adult with Down syndrome, had in recent months become more withdrawn. Usually a very talkative social person she was now saying little and no longer initiated any social interactions. She was having difficulties understanding verbal directions and showing less interest in usual activities. Care providers wondered if Nada was depressed; they also endorsed some items on a brief dementia screen. A visiting therapist observed Nada sitting alone at the lunch table (her peers had finished and left); she showed no response to peer or staff approaches and did not reply to their questions or requests. At times she made episodic repetitive deep inhalations and with subsequent exhalations made a sighing sound. The therapist engaged with Nada's noisy breathing in and out patterns using an Intensive Interaction approach (Caldwell, 2013). Within a few seconds Nada was looking directly at the therapist and engaging with her "in a conversation" of loud inhalations breaths and exhalation sighs. Within a few minutes Nada and the therapist had extended the conversation to involve their fingers, palms and arms. Nada began to initiate different movements and the therapist followed in the conversation. She smiled and laughed out loud; she was emotionally engaged with the therapist. Through this exchange the therapist determined that Nada was not demonstrating depressed mood. She was showing capacity to both initiate and sustain a conversation – a conversation in body language rather than using words.

It was subsequently found that Nada's hearing aids had been wrongly reassembled after her last checkup (which coincided with the changes in her behaviour); as a result Nada was not able to make out verbal communication. The therapist bypassed the need to use words and instead engaged with Nada in a body language conversation which Nada very much enjoyed and in which she fully participated.

APPENDIX 4: Examples of Interprofessional Participation Important for Assessment of BTC
(Lindsay & Hoghton, 2016; Bradley, Goody, & McMillan, 2009)

- Audiology

- Behaviour therapy

- Communication speech-language therapy

- Medical

- Family medicine

- Clinical genetics

- Pediatrics

- Neurology – Psychiatry

- Nursing

- Occupational therapy

- Other therapies – for example, music, drama, movement and dance, dietetics, counselling, pets

- Pharmacology

- Physiotherapy

- Psychology

- Service coordination and social work

APPENDIX 5: Elements of (a) Individual (b) Program (c) Service System Level Supports (d) Embracing the Perspectives of Clients, Families and Other Stakeholders

(a) Individual needs include attention to:

- The crucial role of communication. Finding ways that individuals, despite severity of disability, can communicate their needs whether through words or non-verbal means (Boardman et al., 2014) as well as feel emotionally connected, even in the absence of words (e.g., meaningful conversations with care providers using body language [Caldwell, 2013]). The General Medical Council, UK (General Medical Council, 2016) provides guidance on communicating with patients with IDD (includes videos on BTC)

- Physical environment e.g., appropriate adaptations for hearing, visual and motor impairments, attention to sensory hyper- and hypo-sensitivities, autism friendly; availability of a Snoezelen room; regular opportunities for exercise (Ogg-Groenendaal, Hermans, & Claessens, 2014) and physical activities

- Individualized programming with consistency of approach and coordination across environments (Banks et al., 2016)

- Psychological supports (Beail & Faculties for Intellectual Disabilities of the Royal College of Psychiatrists and the Division of Clinical Psychology, British Psychological Society, 2016)

- "Do no harm" approach to pharmacological interventions

(b) Program supports include awareness and understanding of:

- The importance of staff training about IDD, communication, disability-friendly environments and crises prevention (Bradley & Caldwell, 2013)

- The impact of positive and negative attitudes and emotions on client (and care provider) wellbeing

- Emerging practices (e.g., staff training in positive behaviour and low arousal approaches, acceptance based interventions, mindfulness practices)

- The difference between management of BTC and treatment of underlying causes of these BTC (see also page 108)

(c) Service system considerations:

- Many BTC can be prevented by a HELP approach with access to appropriate services for necessary assessments and interventions. BTC are more prevalent in services that are crises reactive i.e., no preventive planning and little access to specialized supports.

- Advocacy for the appropriate service(s) is an effective intervention for BTC

- Implementing the appropriate service(s) and addressing unmet needs, is effective treatment with good outcomes

- BTC may be a flag for service system failures. Identifying the latter offers opportunity to avoid inappropriate pre-scription of psychotropic medication in response to these behaviours

(d) Perspectives of clients, families and other stakeholders

- Inside-out and Outside-in perspectives (Bradley, Caldwell, & Korossy, 2015; Elbard, 2015)

- Perspectives from individuals with Down syndrome, their siblings and par-ents (Skotko, Levine, & Goldstein, 2011a; 2011b; 2011c)

- Curriculum of Caring (Boyd, 2015) "Voices of experience": Video clips of individuals with IDD, caregivers and health staff sharing their perspectives and wisdom.

APPENDIX 6: Determining Whether There is an Episode of Psychiatric Illness and Diagnosing Psychiatric Disorder

(1) Seek information from a care provider who knows the individual well currently and has known them in the past before the present behaviour concerns

(2) Elicit details about BTC such as when, where, frequency, antecedents, behaviours, consequences (Drummond, 2011).

(3) Identify when the individual's behaviour was last at their best – i.e., before the onset of behaviour concerns; find an "anchor" time (e.g., birthday, public holiday)

(4) Explore their daily pattern, skills and behaviours before this anchor time. Inquiry about the individual's daily life from getting up in the morning to going to bed at night will elicit important information about each individual's unique baseline against which to measure any change

(5) Compare symptoms and behaviours before concerns (4 above) with current concerns (2 above) and determine whether there has been a significant change (e.g., lasting at least one week, such as: loss of interest in play or work; self-care; social engagement, initiative, need for change in supervision or place-ment) (Bradley & Bolton, 2006). A significant change represents "an episode of illness."

(6) If there has been an episode of illness can this be subtyped? – (i.e., do the symptoms and behaviours meet criteria for a DSM or ICD mental health disorder?)

☹ **Note:** Even though it may not be possible to subtype the episode of illness (because of difficulty in getting an account of the patient's experience), this does not negate the presence of significant psychiatric dis-turbance (episode of illness) which has to be addressed

(7) Can an event be identified that may have triggered this episode of illness (e.g., loss, transition)?

(8) Are there other non-episodic symptoms and behaviours that meet DSM or ICD criteria (non-episodic disorder)? Identifying such "background" disorders is important to cor-rectly interpret the origin of current behav-iours (e.g., is concern about hyperactivity due to an increase in ADHD [background disorder] or due to an episode of mania [episodic disorder]).

(9) Several episodic and non-episodic psychiat-ric disorders may also co-exist. Determine which psychiatric disorders, if any, need to be the focus of immediate attention.