

HELP for behaviours that challenge in adults with intellectual and developmental disabilities

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Abstract

Objective To provide primary care physicians with an understanding of the causes of behaviours that challenge (BTC) in adults with intellectual and developmental disabilities (IDD), as presented in the 2018 Canadian consensus guidelines for primary care of adults with IDD; to offer a systematic approach to the assessment and treatment of such behaviours; and to link to tools to support these assessments.

Sources of information This review elaborates upon guidelines 26 to 29 in the mental health section of the 2018 Canadian consensus guidelines. Several of the authors participated in the development of these guidelines, which were based on literature searches and interdisciplinary input.

Main message Most adults with IDD are followed by primary care providers but they comprise a small proportion of primary care practices. Unique ways of communicating needs, diagnostic queries, and BTC are common in this population. This complexity can lead to missed diagnoses and inappropriate antipsychotic medication use with attendant risks. This article presents a systematic approach, HELP, to the assessment and treatment of factors of Health, Environment, Lived experience, and Psychiatric conditions that can lead to BTC and includes tools to support these assessments.

Conclusion A structured approach to the assessment and treatment of BTC in adults with IDD helps family physicians provide guideline-directed, individualized care to this population. This includes a systematic evaluation using the HELP

Editor's key points

- ▶ Adults with intellectual and developmental disabilities (IDD) are often not able to communicate their needs in conventional ways. Behaviours that challenge (BTC) are frequently a way in which patients with IDD communicate unmet needs. This review elaborates upon recommendations in the mental health section of the 2018 Canadian consensus guidelines for primary care of adults with IDD, suggests a systematic approach to the assessment and treatment of BTC, and identifies tools to support these assessments.
- ▶ To assess and manage BTC, determine the best way to engage and communicate with the patient and care providers. Complete a risk assessment. Evaluate the causes of the behaviours using the stepwise framework, HELP. Use available tools with caregivers and family, and take an interdisciplinary approach to understanding and treating the cause or causes of the behaviours.
- ▶ Be cautious regarding the use of psychotropic medications.

Points de repère du rédacteur

- ▶ Les adultes ayant des déficiences intellectuelles et développementales (DID) sont souvent incapables de communiquer leurs besoins de manière conventionnelle. Les comportements difficiles sont souvent une façon dont les personnes ayant des DID communiquent leurs besoins non comblés. Cette revue donne les détails des recommandations trouvées dans la section sur la santé mentale des Lignes directrices consensuelles canadiennes 2018 en matière de soins primaires aux adultes ayant une déficience développementale, propose une approche systématique d'évaluation et de traitement des comportements difficiles, et identifie les outils à l'appui de ces évaluations.
- ▶ Pour évaluer et prendre en charge les comportements difficiles, il faut déterminer la meilleure façon de mobiliser le patient et ses aidants, et de communiquer avec eux. Effectuer une évaluation du risque. Évaluer les causes des comportements à l'aide du cadre progressif HELP. Utiliser les outils disponibles auprès des soignants et de la famille, et adopter une approche interdisciplinaire pour comprendre et traiter la ou les causes des comportements.
- ▶ Être prudent quant à l'emploi d'agents psychotropes.

framework that takes place over multiple visits. A team of health professionals might be needed for optimal care, but these resources are not routinely available across Canada.

HELP pour les comportements difficiles chez les adultes ayant des déficiences intellectuelles et développementales

Résumé

Objectif Permettre aux médecins de première ligne de comprendre les causes des comportements difficiles chez les adultes ayant des déficiences intellectuelles et développementales (DID), comme le présentent les Lignes directrices consensuelles canadiennes 2018 en matière de soins primaires aux adultes ayant des DID; offrir une approche systématique d'évaluation et de traitement de ces comportements; et faire le lien avec les outils à l'appui de ces évaluations.

Sources d'information Cette revue donne les détails des recommandations 26 à 29 de la section sur la santé mentale des Lignes directrices consensuelles canadiennes 2018. Plusieurs des auteurs ont participé à l'élaboration de ces lignes directrices, lesquelles s'appuient sur des recherches dans les publications scientifiques et sur la contribution de membres de plusieurs disciplines.

Message principal La plupart des adultes ayant des DID sont suivis en soins de première ligne, mais ils représentent une petite proportion de ces pratiques. Les façons uniques de communiquer leurs besoins, les demandes liées au diagnostic et les comportements difficiles sont courants dans cette population. Cette complexité pourrait donner lieu à des diagnostics erronés et à l'emploi inapproprié d'antipsychotiques, sans parler des risques que cela comporte. Cet article présente l'approche systématique HELP d'évaluation et du traitement des facteurs santé, environnement, expérience vécue et affections psychiatriques pouvant entraîner les comportements difficiles, et inclut les outils à l'appui de ces évaluations.

Conclusion Une approche structurée d'évaluation et de traitement des comportements difficiles chez les adultes ayant des DID aide les médecins de famille à dispenser à cette population des soins individualisés et fondés sur les lignes directrices. Cela inclut une évaluation systématique à l'aide du cadre HELP, qui s'étale sur plusieurs visites. Une équipe de professionnels de la santé pourrait être nécessaire pour dispenser des soins optimaux, mais de telles ressources ne sont pas toujours accessibles dans les différentes régions canadiennes.

Adults with intellectual and developmental disabilities (IDD) are often not able to communicate their needs. Behaviours that challenge (BTC) are frequently a way in which patients with IDD communicate unmet needs. This review elaborates upon both background information and guidelines 26 to 29 in the mental health section of the 2018 Canadian consensus guidelines for primary care of adults with IDD,¹ suggests a systematic approach to the assessment and treatment of BTC, and identifies tools to support these assessments.

Case description

Ella is a 19-year-old woman with fragile X syndrome, moderate intellectual disability, and epilepsy. She is brought in by group home staff to be seen as a walk-in patient in a family medicine clinic owing to aggressive behaviour toward her roommates and home staff. This behaviour resulted in her being expelled from her work-training program. On one occasion, the police were called to the group home. During this clinic visit, the staff member of Ella's group home accompanying her asks for her medications to be reassessed because her prescribed medications are "not controlling her behaviour." Her current medications are as follows: 600 mg of controlled-release carbamazepine twice daily, recently increased 6 weeks ago owing to increased seizures; 500 mg of naproxen twice daily as needed for dysmenorrhea; 34 g of polyethylene glycol 3350 twice daily as needed for constipation; an oral contraceptive, recently started; 2 mg of lorazepam every morning and 4 mg at bedtime, started 2 months ago at a walk-in clinic for insomnia; and 5 mg of olanzapine at bedtime, started in the emergency department 1 week ago when Ella was brought in by police owing to aggression.

A common response from many health care providers is to feel overwhelmed by the complexity of Ella's diagnoses and the difficulties in communicating with her. It is important to realize, however, that the goal in such cases is not to focus on Ella's behaviours per se, but to identify and treat the underlying cause of the behaviours of concern. This case highlights important principles in the assessment and treatment of BTC.

- What is Ella communicating through her behaviour about her needs?
- Does her behaviour pose a risk to herself, others, or her environment, or does it limit her inclusion?
- What should be the primary care provider's approach to caregivers' concerns about Ella's behaviour?

Sources of information

A librarian experienced in IDD health research conducted searches spanning the years 2010 to 2017 in PubMed, MEDLINE, Scopus, PsycINFO, the Cochrane Database of Systematic Reviews, and the National Institute for

Health and Care Excellence resources, starting with the following terms pertinent to this topic: *intellectual disability, intellectual developmental disorder, developmental disabilities, and learning disabilities or difficulties*, combined with *problem behavior or behavior problems, challenging behavior, aggression, self-injurious behavior, mental disorder, behavior disorder, and treatment or management*. Similar and related terms were used to search book catalogs such as the National Library of Medicine. In addition, all IDD journals were reviewed for content not captured in the above searches, and professional, academic, and government sites were scrutinized for IDD-related guidelines, reports, and policy statements.

Main message

While most adults with IDD are followed by primary care providers, they comprise a small proportion of primary care practice populations.^{2,3} In addition, there is evidence that these providers feel ill-prepared to provide guideline-based care.⁴ This is particularly relevant when considering BTC. A UK study demonstrated that 36% of primary care patients with IDD were assessed for BTC over a 15-year period.⁵

In Ontario, adults with IDD are seen in emergency department settings about twice as often as their general-population counterparts.⁶ In one study, aggressive behaviour was the reason for more than 40% of these visits.⁷ In addition, the most commonly prescribed medications in this population are psychotropic medications.⁸ In spite of a lack of evidence supporting their efficacy and ongoing concern about harm, antipsychotics continue to be frequently prescribed in treating aggression without a diagnosis of psychotic disorder.^{5,9} A better understanding of BTC in people with IDD and an organized approach to addressing their needs are clearly needed.

What are BTC? Behaviours that challenge are any actions by individuals that are harmful or dangerous to themselves, others, or the environment, or that limit opportunities for inclusion, participation, and integration in their local communities. Some individuals with IDD, up to one-third of whom might have coexisting autism, might not have verbal or conventional nonverbal ways to express day-to-day needs, difficulties, or feelings such as happiness or distress. Instead, caregivers are left to make inferences from nonverbal vocalizations, body language, and any unusual behaviour as to what these might be communicating. Are these BTC, for example, an expression of pain, a desire for a preferred activity, avoidance of a noisy environment, or resulting from stressful life events? In people with autism, sensory hypersensitivities and hyposensitivities are extremely common and can trigger BTC; these sensory sensitivities often go unrecognized and should be routinely explored for in adults with IDD and autism, presenting with BTC.

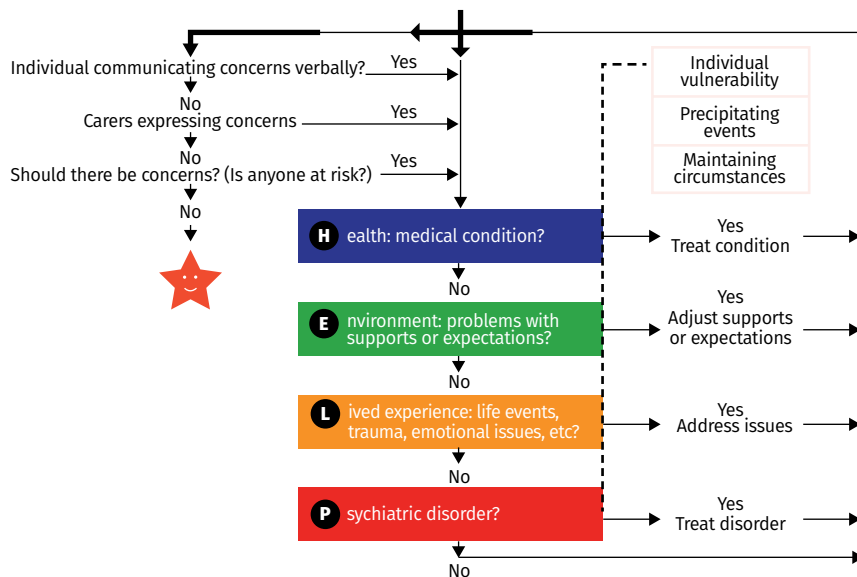
It should be noted that the original term *BTC* was “behaviours that challenge services,” thus referencing the co-constructed nature of this problem behaviour. In other words, BTC occur when the health, developmental, and personal needs of the individual with IDD might not be fully understood, where necessary supports are not available, where expectations might be inappropriate, and where needed environmental accommodations are not made. It follows that an assessment of both the individual and the environment is necessary in understanding what might be contributing to BTC. In the absence of direct reports from the patient, the primary care provider is reliant on observations of family and of paid caregivers and on finding other ways to engage with the patient (eg, using visuals, gestures, and body language). Understanding the communication skills of the patient, whether presymbolic, symbolic, or verbal,¹⁰ will enhance direct doctor-patient interaction. Establishing with caregivers robust data collection, along with visually presented and timely summaries, will enhance patient assessment as well as provide indirect information about the patient’s supports.

What is it about BTC that challenge the health care provider? Interprofessional teams with skill sets that meet the needs of this population are highly beneficial but are not available to many primary care providers. The evaluation of BTC in adults with IDD requires primary care providers to adapt their practices. Engaging both the individual and their families and caregivers takes much longer than a usual doctor-patient appointment, with assessments often requiring longer appointment times and multiple visits. Supporting caregivers in their observations of patient behaviour and collection of data often requires encouragement, perseverance, and commitment to repeated assessments using the HELP (Health, Environment, Lived experience, and Psychiatric conditions) tool.

What is the primary care approach to BTC? In keeping with the 2018 Canadian consensus guideline for adults with IDD, BTC are best assessed within the Patient’s Medical Home model.¹¹ This is a central hub where patients and their families feel most comfortable—a place where they feel listened to and respected as active participants in both decision making and the provision of their ongoing care.¹² The ideal Patient’s Medical Home for adults with IDD is an interprofessional clinic that includes expertise in medicine, occupational therapy (OT), behaviour analysis (BA), speech-language therapy, and nursing. As many physicians practise outside this model, consideration should be given to how available staff such as nurses, physician assistants, or social workers can support assessments. In this setting, the HELP framework guides the assessment (**Figure 1**).¹³

Figure 1. Diagnostic framework for behaviours that challenge

Patient brought to family physician or psychiatrist because of mental distress or behavioural concerns



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Assessment of health. The first step is a risk assessment¹⁴ to determine if the patient’s behaviour poses harm to the patient or others so as to determine urgency and where best to conduct the assessment (Table 1).¹³⁻²¹ Next, determine if a physical health diagnosis or side effect of a medication is responsible. A complete history of the presenting behaviour taken with the patient and caregiver, using appropriate engagement and communication strategies,¹⁰ should include characteristics of the behaviour, such as frequency, intensity or disruption, duration, location, and description of usual pain behaviour. Then, complete a medication review, including recent changes and side effects, and a review of body systems, including changes in sleep, appetite, and physical and social activity. This is followed by a physical examination focusing on the more common causes of BTC in this population (Figure 2).¹³ Syndrome-specific Health Watch Tables are recommended (eg, autism and fragile X syndrome [Table 1]).^{18,19}

Provide caregivers with tools such as stool, menses, and sleep charts to gather information on health and behaviour (Table 1).²¹ Having this information at a glance allows the physician to rule out these common causes of BTC. An Antecedent-Behaviour-Consequence (ABC) chart can also be used (Table 1).¹⁵

Revisiting the case: visits 1 and 2

You use the HELP framework to evaluate Ella’s new aggressive behaviour and check the Health Watch

Table for a summary of common disorders in children and adults with fragile X syndrome.¹⁹

Visit 1: assessment of physical health. You discover that Ella is relatively new to the group home and, while she communicates verbally, she understands better when visual cues are provided. A risk assessment is performed and staff members believe that they currently can keep Ella and the other residents safe in the short term. After taking a thorough history of the behaviour, you ask Ella if you can examine her and visually demonstrate how this is done. On thorough physical examination, you find that her vital signs are normal and that Ella has otitis media on the right side. You start treatment and ask to see Ella back within a week for 30 minutes.

Before her second visit, the registered nurse speaks to her mother and finds that there is no reported past or present history of abuse or previous psychiatric diagnoses. Her mother relates that Ella is disappointed not to be living independently like her siblings. Her mother also worries about Ella’s new difficulty with sleep, about her obsessive cleaning rituals before going to bed, and that she does not have enough support in her new home.

Visit 2: complete medication review. The registered nurse sees Ella first and finds that her behaviour has partially improved, and she reviews the medication history. On examination, you find her otitis media

Table 1. Links to tools for the assessment of BTC in adults with IDD

| TOOLS FOR ASSESSMENT OF BTC | WEBSITE OR LOCATION |
|--|---|
| Adapted CBT tools: manual, guide for carers, information, resources, and worksheets | www.ucl.ac.uk/psychiatry/cbt |
| Antecedent-Behaviour-Consequence chart ¹⁵ | surreyplace.ca/ddprimarycare/tools/mental-health/guide-to-understanding-behaviour-abc/ |
| Auditing psychotropic medications ¹⁶ | surreyplace.ca/ddprimarycare/tools/mental-health/auditing-psychotropic-medication-therapy/ |
| Environment and supports checklist ¹⁷ | surreyplace.ca/ddprimarycare/tools/mental-health/guide-to-understanding-behaviour-abc/ |
| Health Watch Tables for specific syndromes | surreyplace.ca/ddprimarycare/health-watch-tables/ |
| Health Watch Table—autism spectrum disorder ¹⁸ | surreyplace.ca/ddprimarycare/health-watch-tables/autism-spectrum-disorder (includes links to autism spectrum disorder screening tools) |
| Health Watch Table—fragile X syndrome ¹⁹ | surreyplace.ca/ddprimarycare/health-watch-tables/fragile-x-syndrome |
| Life events checklists | surreyplace.ca/ddprimarycare/tools/mental-health/guide-to-understanding-behaviour-abc/ Predictable crises (Levitas and Gilson, ²⁰ Table 1): http://media.wix.com/ugd//e11630_3dfd0afd30344475d98cbffa253f6c92.pdf |
| Modified IDD mental health screening tools | Glasgow screening tool for depression and anxiety: www.derbyshirehealthcareft.nhs.uk/EasySiteWeb/GatewayLink.aspx?allid=7840 Glasgow screening tool for psychosis (page 106): http://theses.gla.ac.uk/7597/1/2016MuirDClinPsy.pdf Screening tool for ADHD: www.divacenter.eu/Content/VertalingPDFs/DIVA_5_ID_English_Form.pdf Glasgow Risk Screen: http://mypsych.nhsggc.org.uk/media/2024/the-glasgow-risk-screen.pdf National Task Group Early Detection Screen for Dementia (translated into multiple languages): http://aadmd.org/ntg/screening |
| Physical causes of BTC | Outlined in Figure 2 ¹³ |
| Risk assessment tool ¹⁴ | surreyplace.ca/ddprimarycare/tools/mental-health/risk-assessment-tool-for-adults-with-dd/ |
| Sleep, stool, menses charts ²¹ | surreyplace.ca/ddprimarycare/tools/physical-health/monitoring-charts/ |
| Books Beyond Words: resources include those for use by health care providers; topics include abuse (cost and free) | https://booksbeyondwords.co.uk/#/supporters/ |

ADHD—attention deficit hyperactivity disorder, BTC—behaviours that challenge, CBT—cognitive-behavioural therapy, IDD—intellectual and developmental disabilities.

has resolved. As Ella has no psychiatric diagnosis, you wonder if the olanzapine was started to control behaviour that might have been partially due to the otitis media. You decide to taper and discontinue her olanzapine, as well as her lorazepam, starting with the morning dose, and order bloodwork (carbamazepine and thyroid-stimulating hormone levels, presence of *Helicobacter pylori*, and complete blood count and chemistry). You ask staff members to complete and bring charts tracking her menses, sleep, and stool, as well as the ABC chart. You arrange for a third appointment (30 minutes).

Assessment of environment and supports. Behaviours that challenge sometimes occur because environments do not meet the developmental needs of the adult with IDD. Caregiver and environmental supports can be insufficient or overly restrictive for the person's needs. It is

important to facilitate “enabling environments” to meet unique developmental needs; often, doing so can diminish or eliminate BTC (**Figure 3**).^{17,22} Creating an enabling environment can best be done using the expertise of specialists in OT and BA to review the context of the BTC and conduct a comprehensive functional assessment, and a speech-language pathologist to assess and improve functional communication. Ensure access to available provincial or territorial and federal funding sources, as well as resources and community supports.

Lived experience, life events, and emotional distress. Adults with IDD are more likely to experience adversity, abuse, trauma, and negative life experiences than adults without IDD are.²³ There is good evidence that those who experience abuse show consistent patterns in the nature and timing of BTC.²⁴ Their disability might have contributed to attachment issues resulting in

Figure 2. Health conditions causing behaviours that challenge



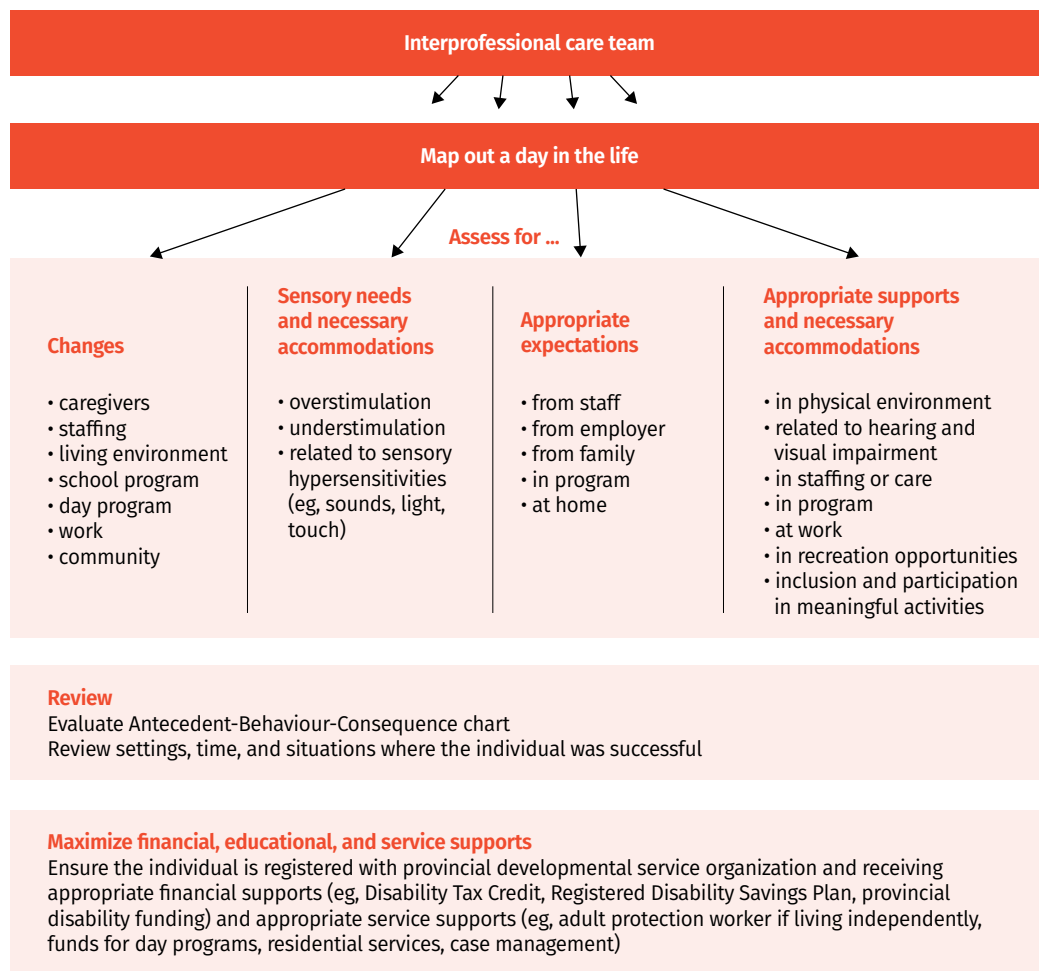
Adapted from Bradley and Korossy.¹³

difficulty with self-regulation, a low threshold of tolerance, and unpredictable emotional responses. Because of their disabilities, they have more challenges in daily living and independence, which results in increased anxiety and emotional distress. All these factors have a negative effect on mental health and can lead to the development of anxiety, panic, depressed mood, and symptoms of posttraumatic stress disorder with or without psychotic features (eg, hearing voices and dissociating or reliving

the experience). It is essential to screen for these negative life experiences and abuse, both past and present, as well as to be alert to missed developmental milestones that can trigger BTC.¹⁷ Throughout this assessment, a trauma-informed approach to care is necessary.

Revisiting the case: visit 3

Visit 3: complete review of environment and life events. Caregivers have noticed less frequent

Figure 3. Assessment of environments and supports

Adapted from Bradley and the Behavioural and Mental Health Working Group of the Developmental Disabilities Primary Care Initiative.¹⁷

aggressive behaviour from Ella since the elimination of olanzapine and lorazepam. The OT specialist, nurse, and physician review the menses, stool, sleep, and ABC charts and, as a result, determine that Ella's sleep is delayed at night owing to her ritual behaviour and because she is disrupted by the noises her roommate makes. Caregivers have requested that Ella be moved to another room or use earplugs, and you write a letter to support this action. Results of her *H pylori* titre are positive and you initiate treatment for this.

Psychiatric disorders. Once physical health, environment issues, and life events have been assessed and treatment initiated, consider a psychiatric diagnosis. However, it is important to remember that apparent hallucinations or delusions, rather than being

pathological, might reflect developmentally appropriate behaviour, like imaginary friends or self-talk, or might be associated with past trauma. Owing to the high rate of comorbidity in IDD, individuals with IDD should be screened for autism (see the Health Watch Table for autism¹⁸). Relevant to Ella's case, 30% of people with fragile X syndrome have autism (see the Health Watch Table for fragile X syndrome¹⁹). The most frequent psychiatric concerns in people with IDD presenting with agitation, anxiety, or changes in mood, however, are likely adjustment disorders. They are commonly associated with transitions, unresolved issues in the environment, and past or current trauma.²⁵ In general, psychotic disorders tend to be overdiagnosed and mood and anxiety disorders underdiagnosed. The HELP framework is also relevant for evaluating behavioural changes in

those individuals with a genetic syndrome known to be associated with a specific behavioural phenotype. In Ella's case, fragile X syndrome is associated with aggressive behaviour, mood instability, and anxiety in adulthood. It would be important to know Ella's baseline behaviour and mood before the present exacerbation (see the guide to understanding behavioural problems and emotional concerns, page 75).¹⁷

Use of antipsychotics: In most cases, do not prescribe antipsychotic medication for BTC without a firm diagnosis of psychosis, preferably by a psychiatrist experienced in treating people with IDD. An exception can be made for individuals in a behavioural crisis. While evaluation to identify the underlying cause or causes of the BTC continues, such medications can be prescribed for interim management; however, they should be reassessed within 72 hours. If there is evidence that the BTC are underpinned by a psychiatric disorder, then a trial of diagnosis-specific medication targeting the key symptom cluster (eg, anxiety, mood) might be indicated. Identify clear target behaviour and symptoms, and review with the patient and caregiver on a regular basis.^{26,27} It is important to "start low and go slow" and watch for paradoxical responses, which are more common in adults with IDD.²⁸ At a minimum, psychotropic medication review should occur at 3-month intervals using the appropriate tool (Table 1).¹⁶ Success of a medication trial is associated with several factors including confidence in the medication and patient and care provider confidence in the doctor.²⁹

Ongoing HELP diagnostic review is repeated as necessary to identify and address causes of BTC (Figure 1).¹³

Revisiting the case: visit 4

Visit 4: refer to assess for psychiatric disorder. Ella's behaviour has almost completely resolved, her sleep has improved, she is no longer taking psychotropic medications, and she appears content. You consult a psychiatrist familiar with adults with IDD regarding her ritualized evening cleaning and learn that the behaviour might be associated with fragile X syndrome sensory processing and integration problems rather than obsessive-compulsive disorder. The psychiatrist recommends OT and BA input to evaluate sensory sensitivities, establish coping strategies, and develop behaviour support plans for caregivers. Your follow-up plan includes a visit to discuss sensitive issues like menstrual periods, sexuality, and genetic counseling, and another visit to review the fragile X syndrome Health Watch Table.¹⁹ You ask Ella if she will make a return visit. She agrees with a nod and a smile.

Conclusion

Behaviours that challenge are frequently a way in which patients with IDD communicate their unmet needs. Our understanding of and response to these

communications requires a collaborative approach involving the patient and the patient's team. The HELP framework is a simple, easy-to-remember, systematic review of the broad causes of behaviour: Health problems (including medications), Environments and supports, Lived experiences, and Psychiatric conditions. In most cases, assessment of a psychiatric diagnosis is best pursued once issues in the other areas have been addressed. Using the appropriate health provider and caregiver tools will also enhance successful intervention for BTC. When a clear psychiatric diagnosis exists, treatment with psychotropic medications might be indicated, along with other diagnosis-specific treatments such as psychological therapies. Antipsychotic medication is sometimes used to manage BTC in an acute crisis. In this context, the patient response should be reevaluated in 72 hours, as efforts to identify the causes of the BTC continue so that appropriate treatment can be initiated. The interprofessional team is essential to successful, comprehensive intervention for BTC. Family physicians will need to advocate on their patients' behalf to help access those disciplines that are a necessary part of their equitable health care. 🌿

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Contributors

All authors contributed to the literature review and interpretation, and to preparing the manuscript for submission.

Competing interests

None declared

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