

Challenging Behaviours: Best
Practices in Prevention, Assessment
and Intervention for People with an
Intellectual Disability, Physical
Disability or Autism Spectrum Disorder
English summary

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SUMMARY

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Introduction

People with an intellectual disability (ID), a physical disability (PD) or an autism spectrum disorder (ASD) are likely to manifest challenging behaviours. A challenging behaviour is defined as an action—or a set of actions—that is considered problematic because it departs from social, cultural or developmental norms. A challenging behaviour is harmful for the person or their social or physical environment and jeopardizes, actually or potentially, the physical or psychological integrity of the person, other persons or the environment, or compromises their freedom, integration or social ties [Tassé *et al.*, 2010].

Given the seriousness of the behavioural manifestations involved, challenging behaviours can have many negative consequences for those affected, including their quality of life and health. Moreover, the families of these individuals can also be impacted, as can the professionals who work with them.

Context of the request

In Québec, interventions for people with ID or ASD who present challenging behaviours are based on a clinical practice guideline entitled *Le service d'adaptation et de réadaptation auprès des personnes ayant des troubles graves du comportement* [Rehabilitation services for people with challenging behaviours], developed in 2010 by experts working with the Service québécois d'expertise en troubles graves du comportement (SQETGC) and published by the Fédération québécoise des centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement (FQCRDITED).

While this clinical practice guideline for challenging behaviours has the advantage of being operational and detailed, it is not, however, based on a systematic review of the scientific literature. It also focuses on individuals with ID or ASD but does not consider brain-damaged people being treated in the physical disability service program—individuals who are also likely to present challenging behaviour. In addition, a number of documents related to this practice have been published over the past 10 years by reputable scientific bodies, such as the National Institute for Care Excellence in the United Kingdom (NICE) and the *Haute Autorité de Santé (HAS)* in France—hence the relevance of reviewing the existing clinical practice guideline to ensure that practices are up to date. It is in this context that the SQETGC directors requested that INESSS produce a state-of-knowledge report to document best practices in prevention, assessment and intervention for people who have ID, PD or ASD and who present challenging behaviours.

Methodology

A systematic review of the scientific and grey literature was carried out in accordance with INESSS's production standards [2013]. A total of 52 documents were identified, including 18 from the grey literature on practices and 34 systematic reviews or meta-analyses. The methodological quality of the retained documents was determined using recognized assessment scales. Data from these publications were extracted, and the findings are presented as a narrative synthesis.

Findings

In general, the values and intervention principles encouraged in the documents consulted reflect the importance of establishing a close partnership with people with challenging behaviours and their families, and respecting their rights, including the right to be treated with dignity at all times and to receive support tailored to their needs and preferences. Involving people with challenging behaviours in decision-making, encouraging their independence, improving their quality of life and maintaining a respectful relationship of trust with them are also among the values and intervention principles put forward in the documents reviewed.

The practice-related documents concur that assessing risk and protective factors is a way to prevent the emergence of challenging behaviours later on. It is suggested that the individual's skills be assessed periodically in various areas (e.g., communication, social skills, self-determination, emotional management), as well as their overall state of health. Subsequent to these assessments, it is advisable, from an ecosystem perspective, to implement a set of preventive actions that reduce risk factors and strengthen protective elements, with respect not only to individual factors and the social context but also at the organizational level of the community setting and physical environment. The documents consulted stress the importance of providing the required physical care and appropriate support to help people develop their skills, achieve and maintain a good quality of life and facilitate their social participation. Finally, it is suggested that such a preventive approach be combined with organizational practices that support various settings to adequately meet the needs of individuals presenting challenging behaviours.

With regard to best assessment practices, the documents consulted emphasize that such assessments are used to inform care providers about several aspects of the presentation of challenging behaviours, including determination of its severity, understanding the functions of problematic behaviours or measuring the risks that such behaviours pose to the individual and to other people. Since challenging behaviours can have multiple causes, a comprehensive perspective should be considered during the assessment, with a focus on the needs—met and unmet—and on the preferences and life projects of the individuals. The practice-related documents recommend that an initial assessment be carried out by the care providers directly involved as soon as the problematic behaviours appear. This assessment should first delineate the behaviour, systematically measuring its frequency, duration, intensity and when it occurs. It should also be used to identify the elements contributing to the behaviour's onset (antecedent) and the responses provided after its occurrence (consequences). The documents further highlight the importance of

recognizing the expertise and contributions of family members to the assessment and of respecting how much involvement the person with challenging behaviours wants them to have. The assessment must also be carried out on an ongoing and flexible basis, bearing in mind that the factors contributing to challenging behaviours can vary over time.

The following eight key themes of best practices in intervention were identified in the documents consulted:

1. Psychosocial interventions;
2. Interventions focused on environmental adaptation;
3. Rewarding daytime activities;
4. Behavioural crisis interventions;
5. Post-crisis support;
6. Use of medication when required;
7. Control measures;
8. Behavioural support plans.

Despite the methodological limitations of the studies consulted, three types of psychosocial interventions appear to be generally effective in reducing problematic behaviours: interventions based on applied behavioural analysis; interventions based on the cognitive-behavioural approach; and interventions used in the Positive Behavior Support approach. These types of interventions are designed to increase replacement behaviours for challenging behaviours and reduce their frequency or severity. The systematic reviews consulted stress that the effectiveness of psychosocial interventions is strongly linked to the ability of various settings to customize their implementation strategies.

Other good practices for intervening with people presenting challenging behaviours were also identified in the literature consulted, including

- adapting the environment, when possible, to best meet the needs of people;
- implementing systematic interventions that encourage people to engage in rewarding daytime activities;
- developing individualized protocols for behaviour crisis interventions;
- providing post-crisis support not only to the people who manifest the challenging behaviours but also to those who witness them and to the staff responsible for intervening in such situations;
- making appropriate use of the medications intended to reduce or control challenging behaviours by first providing psychosocial interventions;
- using control measures only as a last resort, with a sustained focus on the safety of the individuals;

- using a behavioural support plan to coordinate interventions with family members and partners, and to ensure consistency and complementarity in the interventions available to people presenting challenging behaviours.

In terms of best practices related to service implementation, the literature consulted indicates the importance of establishing a provincial governance responsible for ensuring quality of practice, judicious use of allocated funds and accessibility of services. All of the documents consider training for staff working with individuals with challenging behaviours as one of the determining factors of service quality. It is therefore recommended that facility managers ensure that care providers are adequately prepared by providing them evidence-driven and practice-based training that is regularly updated. In addition, the literature reviewed emphasizes that individual or group supervision is an essential component of the support that should be available to staff.

Since interdisciplinary collaborative work is essential for intervention success, it is advisable to appoint a coordinator and maintain well-structured teams that have clear roles and responsibilities. Finally, it is also advisable to institute sectoral and cross-sector collaboration agreements to ensure access to primary and specialized health care, collaboration with the justice system, seamless service delivery in the community (education, recreation, transportation, employment) and access to a variety of respite and emergency support options for families and rewarding daytime activities for the individuals concerned.

Conclusion

Implementing the best practices documented in this state-of-knowledge report certainly represents a challenge for stakeholders working with people who present challenging behaviours. Although many of these best practices are already known and applied in Québec, additional efforts could be made to put them into place, since they are likely to improve the well-being and quality of life of the persons concerned and their families and, ultimately, to promote greater social inclusion.

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