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Assessment, Intervention, and Training Needs of Service Providers for Children with Intellectual Disabilities or Autism Spectrum Disorders and Concurrent Problem Behaviours

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Abstract

This study documented the perceived needs of therapists, specialists, and managers who work with children with intellectual disabilities (ID) and/or autism spectrum disorders (ASD) and concurrent problem behaviours (PBs). Seventy-five respondents from specialized PB and early childhood programs within eight public rehabilitation centres were surveyed. They were asked to describe current practices and perceived needs in terms of assessment, intervention, and training with respect to the target population. Overall, the perceptions of staff were consistent with the results of previous studies examining families' perspectives. Salient themes include the need for specialized assessments for PBs in young children, collaboration between multiple service providers and families, and additional staff training in child development and interventions for PBs. These findings underscore the importance of offering diversified services adapted to the needs of children with PBs, their families, and their service providers.

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Cover Page Footnote

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Abstract

This study documented the perceived needs of therapists, specialists, and managers who work with children with intellectual disabilities (ID) and/or autism spectrum disorders (ASD) and concurrent problem behaviours (PBs). Seventy-five respondents from specialized PB and early childhood programs within eight public rehabilitation centres were surveyed. They were asked to describe current practices and perceived needs in terms of assessment, intervention, and training with respect to the target population. Overall, the perceptions of staff were consistent with the results of previous studies examining families' perspectives. Salient themes include the need for specialized assessments for PBs in young children, collaboration between multiple service providers and families, and additional staff training in child development and interventions for PBs. These findings underscore the importance of offering diversified services adapted to the needs of children with PBs, their families, and their service providers.

Despite the practical and methodological challenges posed by the study of problem behaviours (PBs) among children with intellectual disabilities (ID) and/or autism spectrum disorders (ASD), studies to date have demonstrated a higher prevalence of PBs among this group than in their typically developing peers (Baker, Blacher, Crnic, & Edelbrock, 2002; Matson, Gonzalez, Wilkins, & Rivet, 2008). Reported comorbidity rates vary considerably, ranging from 13% to 94%, with a general consensus for approximately 60% (Gurney, McPheeters, & Davis, 2006; Icasiano, Hewson, Machet, Cooper, & Marshall, 2004; Jang, Dixon, Tarbox, & Granpeesheh, 2011; Matson, Wilkins, & Macken, 2009).

Children who display PBs experience numerous negative consequences as a result of these behaviours. For instance, they are more likely to be excluded from childcare, school, leisure activities, and other types of social environments (Machalicek, O'Reilly, Beretvas, Sigafoos, & Lancioni, 2007; McGill, Papachristoforou, & Cooper, 2006; Rojahn, Aman, Matson, & Mayville, 2003; Wodehouse & McGill, 2009). Children with ID and/or ASD who also display PBs¹ present more complex clinical profiles and may respond differently to these services (Machalicek et al., 2007; Plant & Sanders, 2007). Unfortunately, this is also the case for the families of these children. Their PBs contribute to higher levels of parental stress and major adaptation difficulties as well as a decreased quality of family life (Hastings & Brown, 2002a; Lecavalier, Leone, & Wiltz, 2006). The needs and perceptions of families of children with PBs have been investigated. Overall, these studies have revealed that families are dissatisfied with specialized services, that their children with PBs are often excluded from specialized services due to their behaviour, and that these services are often only provided as punctual interventions during a time of crisis, without long-term planning (Knox, 2000; McGill et al., 2006; Wodehouse & McGill, 2009).

Moreover, PBs also present difficulties for the institutions that serve children with ID/ASD, for instance in determining the parameters of interventions to be delivered (type, intensity, duration, site, etc.), in training staff, and in coordinating the activities of an increased number of service providers (Hastings & Brown, 2002b; McGill et al., 2006; Mitchell & Hastings, 2001; Rivard, Dionne, Morin, & Gagnon, 2013; Tassé, Sabourin, Garcin, & Lecavalier, 2010; Wodehouse & McGill, 2009). Therapists working with individuals who engage in PBs suffer from increased stress levels, have an increased number of workplace accidents, and report having more negative experiences at work (Hastings, 2005; Hastings & Brown, 2002b; Lambrechts, Kuppens, & Maes, 2009; Mitchell & Hastings, 2001; Tassé et al., 2010). Although several studies have examined the needs and perceptions of families of children with ID/ASD and PBs, there is comparatively limited information available on service providers' experience. The challenges faced by those who work in public agencies that serve persons with ID/ASD have received little attention, particularly in regard to assessment, intervention, and training. Documenting and integrating this information with families' perspectives could lead to specific recommendations to improve the quality and effectiveness of services. With this goal in mind, the present study sought to determine the needs of staff who work

¹ For ease of reading, young children with ID and/or ASD who display PBs are henceforth referred to as "children with ID/ASD and PBs."

in public rehabilitation centres with respect to the assessment of young children with ID/ASD and PBs, intervention strategies, and the types of training needed to effectively assess and intervene with this population.

Challenges Associated with the Definition and Assessment of PBs in Young Children with ID/ASD

One of the main challenges associated with the study of PBs in early childhood is the lack of consensus regarding the terms and definitions used to describe these behaviours (Farmer & Aman, 2011; Morin & Méthot, 2003; Rivard, Dionne, & Morin, 2012; Rivard et al., 2013; Tassé et al., 2010). For example, these have been labelled conduct problems (Dandreux & Frick, 2009), challenging behaviours (e.g., Hastings & Brown, 2002b; Lambrechts et al., 2009), behavioural problems (e.g., Lecavalier et al., 2006; Tassé et al., 2010), and aberrant behaviours (Rojahn et al., 2003) to reflect different the operational definitions. This has led to disagreements with respect to study design and, in turn, a lack of continuity and comparability across research projects. The definition of PBs adopted in the present study is used by institutions serving individuals with ID and ASD in Québec, Canada. The authors defined a PB as:

[an] action or set of actions deemed problematic because it deviates from social, cultural or developmental norms and is prejudicial to the person or the person's social or physical environment.... [It] is deemed severe if it actually or potentially jeopardizes the physical or psychological integrity of the person, another person, or the environment, or jeopardizes the person's freedom, social integration, or social ties. (Tassé et al., 2010, p. 68)

A second challenge related to the study of PBs in early childhood is the scarcity of appropriate assessments. The few measures that are presently available often do not support the evaluation of the breadth and severity of children's PBs or do not provide norms for specific age groups and diagnoses (Farmer & Aman, 2010; Mahan & Matson, 2011; Matson, Gonzalez, & Rivet, 2008). Language presents an additional obstacle to the availability of assessments. For instance, there are no French measures for PBs that provide norms for children under the age of 6 with ID/ASD. Tests normed among typically developing children require adjustments prior to use with children with ID/ASD, as PBs may manifest differently among individuals with developmental or intellectual disabilities (Aman, Tassé, Rojahn, & Hammer, 1996). What might be labelled a PB in children without ID/ASD may be difficult to distinguish from the symptomatology of ID/ASD (e.g., repetitive, stereotyped behaviours) or manifestations of sensory problems or physical discomfort (Bakken et al., 2010; Barnhill, 2008). Therefore, the content validity and factorial structure of test items must be verified among children with ID/ASD (Farmer & Aman, 2010). However, a few recently developed measures directly address PBs in young children with ASD and show great promise. Notably, the Baby and Infant Screen for Children with Autism Traits (BISCUIT; Matson, Fodstad, Mahan, & Rojahn, 2010) assesses PBs in children with ASD aged 17 to 37 months. The Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1996) is a version of the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983) adapted for persons with intellectual and developmental disabilities aged between 4 and 18 years. A version of the DBC was recently developed for use

among children with ID, including those with ASD, under 4 years of age (DBC-Under 4, Gray et al., 2012). Our group is presently developing French norms for the use of this checklist among children with ASD under the age of 7.

Families' Perception of Services

As mentioned in the introduction, several studies have documented how the families of children who engage in PBs perceive the services they receive. A study by Warfield & Hauser-Cram (1996) involving 44 mothers of 5-year-old children with ID revealed a relationship between the presence of PBs and difficulties in finding general or specialized child-care services suited to their child's situation. These mothers reported that their children received services at home rather than in an integrated environment such as daycare. In general, their satisfaction with services was low. The authors of this study highlighted the importance of specialized training in PBs within the agencies providing these services.

Wodehouse & McGill (2009) surveyed 13 mothers whose children, aged between 7 and 17 years (mean: 9.9 years), presented ID and PBs. They investigated their perception of services provided to their family. These mothers reported difficulties in accessing information, collaborating with professionals, and obtaining respite care. With respect to specialized services, the mothers mentioned the inefficiency of the intervention strategies used, a lack of expertise regarding PBs and autism among professionals, and a lack of communication regarding the services provided to their children. They also reported that their children were more likely to be excluded from general and specialized services due to their PBs.

Another study conducted among 66 families of young people (ages 3–19, mean: 12.3 years) with ID and PBs investigated their perceptions regarding the supports and treatments provided by service agencies and professionals (McGill et al., 2006). They reported receiving little psychological support and observing that professionals lacked expertise about autism and about the causes and management of PBs. Many (61%) found that the supports provided were ineffective in meeting their family's needs. Two-thirds of the families received respite care, but 36% of these said their children had been excluded from this service due to their PBs, which were found to be more serious than those of non-excluded children.

The need for further studies of PBs among children with ID/ASD is evident in the present scarcity of assessments adapted to this population and in families' overall perception of services. Data available from the point of view of service providers is limited. Yet understanding the challenges faced by agencies that provide services to children with PBs is crucial for the development of instruments and intervention programs that are better suited to needs of these young children and their families.

Public ID/ASD Services in Québec

In the province of Québec, public institutions called rehabilitation centres provide specialized developmental and rehabilitation services to persons with ID/ASD of all ages living within their catchment area. These services are organized into several programs

targeting clients' needs according to their age and clinical diagnosis. Of particular interest to the present study are the centres' early childhood programs for children with ID/ASD and its programs for individuals with PBs. These two programs were initially structured as though they served mutually exclusive populations: either young children, presumed not to have PBs, or older children, adolescents, and adults with PBs. For instance, in order to determine their specific needs, children enrolled in early childhood services are assessed in terms of their intellectual functioning, their adaptive behaviours, and the severity of their autism symptoms but are not screened for PBs. At the time of the study, rehabilitation centres assessed these three domains using the Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III; Wechsler, 2002), Adaptive Behavior Assessment System-II (ABAS-II; Harrison & Oakland, 2003), and Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Rothen Renner, 1988), respectively. One impetus for the present study was the realization that many young children referred to rehabilitation centres present PBs which may pose significant obstacles to the effectiveness of interventions and yet there are no formal evaluations or strategies in place to better serve this population.

Rehabilitation centres' early childhood programs include a range of specialized services for children aged 6 or under that are adapted to the child's diagnosis of ID and/or ASD. The implementation of these programs varies somewhat across centres. Children with ASD, or with both ID and ASD, typically receive early behavioural intervention (EBI) services. These interventions are grounded in applied behaviour analysis and based on a curriculum (e.g., Maurice, Green, & Luce, 1996). The child and therapist meet 5 days a week, for a total of approximately 20 hours per week, most often in a separate room at the child's daycare facility. Sessions consist primarily of discrete trial teaching emphasizing preschool tasks and abilities (for a detailed description of current practices in Québec, see Rivard et al., 2013). In contrast, the specialized PB programs are available to individuals of all ages whose PBs require more intensive or diversified services compared to individuals who have ID/ASD without PBs. Although this program does not exclude young children, the lack of systematic screening for, and formal acknowledgement of, PBs in this age group entails that these services are typically accessed at a later age (Rivard et al., 2013). For instance, a child's PBs may only be identified after weeks or months of receiving EBI from the early childhood program. These behaviours are typically addressed once the child is no longer being served by this program (i.e., he or she now receives services for children over 6) and begins to experience integration difficulties at preschool or school. The specialized PB programs adopt a functional behaviour assessment and intervention model (FBA; see Griffiths, Gardner, & Nugent, 1998) focused on identifying and addressing the factors that elicit and maintain PBs. These programs require the involvement of a larger and more diverse body of specialists. Rehabilitation centres typically form multidisciplinary teams who meet every 2 weeks to adapt a client's intervention plan according to FBA. In most centres, these teams consist of a psychologist, a psychoeducator, a nurse, a manager, and a therapist but may also include a speech-language pathologist or an occupational therapist.

Objectives

The general objective of the present study was to develop a portrait of the assessment, intervention, and training needs of rehabilitation centre staff members who provide services to young children with ID/ASD and PBs. The three research questions stemming from this objective were (a) which assessment tools are used for PBs in young children and which do staff feel are needed?, (b) which types of interventions do children with PBs receive in these centres and which needs do staff identify in this area?, and (c) which kinds of training had staff received to assist this population and in which areas did they feel more training was needed?

Method

This research project was evaluated and approved by the Joint Research Ethics Board of Québec's Rehabilitation Centres. Data collection consisted of a mail-in survey conducted among the staff of eight rehabilitation centres using a questionnaire developed specifically for the purposes of this study.

Participants

Seventy-five staff members from eight rehabilitation centres in the province of Québec participated in this study. Table 1 presents several characteristics of these participants. All were French speakers and conducted their day-to-day professional activities in French. Almost half (46.7%) of these participants were therapists who provided direct services to children and their families and had, at minimum, a post-secondary degree in specialized education. These therapists typically delivered EBI or other interventions for young children in daycare settings. Approximately 40% of respondents were specialists who had at least a master's degree and belonged to a professional corporation. These psychologists, psychoeducators, occupational therapists, and speech-language pathologists were responsible for assessing clients, devising individualized intervention plans in consultation with families, and supervising therapists' implementation of these plans. The remaining group (13.3%) consisted of managers. These were team leaders who notably made decisions regarding staff training, resource allocation, and the assignment of clients to specialized programs and specific therapists on the basis of specialists' assessments. Regarding the ID/ASD programs of interest, 68% of participants worked in the early childhood programs and the remaining 32% worked in the specialized PB programs.

Measures

The questionnaire used for data collection was developed based on the scientific literature regarding the assessment, intervention, training, and integration challenges reported by the families of children with ID/ASD and PBs. Ten researchers and rehabilitation centre staff members provided input on the preliminary version of the questionnaire, which was then pre-tested on a therapist and a psychologist employed at one of the participating centres.

Table 1
Characteristics of Surveyed Service Providers

	Early childhood programs		Problem behaviour programs	
	<i>N</i>	%	<i>N</i>	%
Roles				
Therapist	31	61	4	17
Specialist	15	29	15	65
Manager	5	10	5	17
Total	51	68	24	32
Years of experience in centre				
1–5	15	29	4	17
6–10	14	27	8	34
11–15	6	12	4	17
16–20	3	6	-	-
21–25	2	4	5	22
26–30	4	8	1	4
More than 30	7	14	2	4
Years of experience in the field				
1–5	27	53	15	65
6–10	16	31	4	17
11–15	4	8	4	17
16–20	1	2	-	-
21–25	1	2	-	-
26–30	1	2	-	-
More than 30	1	2	-	-

The questionnaire included 24 open-ended questions pertaining to personal information about the respondents and about the children they had served during the past year who met the criteria for PBs or severe PBs according to the definitions of Tassé et al. (2010). They also described the types of PBs presented by these children and how these were assessed. Questions on the assessment of PBs pertained to the availability of information and measures to identify PBs prior to and during service delivery, as well as perceived needs in this area. The questions on interventions for children with PBs focused on the type of services that were provided to children with ID/ASD and PBs in comparison those without PBs, the interventions or adjustments to interventions required by the presence of PBs, the nature of intervention strategies adopted, and perceived intervention needs. Participants were also asked about the type of training they had received, and wished to receive, with respect to child development and associated disorders as well as PBs and intervention strategies.

The questionnaire also asked respondents to share their observations on the integration of children with ID/ASD both with and without PBs, to determine whether these children were included in daycare or in regular schools, and to report any integration challenges faced by these children. At the end of the questionnaire, respondents could provide general comments regarding the needs of children with PBs in the context of ID, ASD, and early childhood services. Only the items pertaining to assessment, intervention, and training are reported in the present article. For those pertaining to children's integration and to the nature and impact of their PBs, see Rivard and colleagues (2013).

Procedure

The research coordinators of eight rehabilitation centres invited staff members to participate in the study. Nine respondents were initially targeted at each centre: a manager, a specialist, and a therapist within the agency's early childhood ID, early childhood ASD, and PBs service teams. However, the actual number of respondents depended on the configuration of services offered by each centre. Given the overlap between the two early childhood programs (ID or ASD) in many centres, data from these two programs were pooled. The research coordinators distributed the questionnaire, a pre-addressed and stamped return envelope, and a consent form to potential participants. Completed questionnaires were mailed to the principal investigator. Respondents completed the questionnaires on their own but could contact the researchers as needed. Questionnaires were anonymous and identified by an alphanumeric code.

Analyses

Responses to the questionnaire were analyzed using a coding grid based on the three central questions of this study, which pertained to assessments, interventions, and training in relation to children with ID/ASD and PBs. Prior to data collection, an initial set of response categories was devised for each test item. Two co-investigators independently coded the first ten questionnaires received using this grid and performed content analysis. This step enabled the creation of new categories that were more representative of participants' responses. The revised coding grid was used to analyze all 75 questionnaires. Of these, ten were coded by two independent scorers and attained 100% inter-rater reliability.

Results

With the exception of actual training and training needs, preliminary analyses indicated that the participants who worked in the early childhood and PB programs provided similar responses. Data from both subgroups were therefore pooled unless otherwise specified in the text. The responses collected from therapists, specialists, and managers were likewise combined.

Assessment of PBs

The first research question concerned the tools that rehabilitation centre staff use to evaluate PBs in young children with ID/ASD as well as their needs for assessing PBs in this population. Table 2 presents data regarding assessments used or received prior to intake (i.e., when the child is referred to the rehabilitation centre and placed on a waiting list to receive services), at the beginning of service delivery, and during service delivery.

Table 2
Assessments and Sources of Information Used Throughout Children's Service Trajectory

Assessment or source	Prior to intake		At the beginning of service delivery		During service delivery	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Records (case files)	14	18.7	1	1.3	4	5.3
Direct observation	11	14.7	38	50.7	46	61.3
Other service providers	12	16.0	1	1.3	2	2.7
Tests not related to PBs	10	13.3	3	4.0	-	-
Adaptive behaviour tests	5	6.7	1	1.3	-	-
Tests for socio-emotional problems in children	5	6.7	9	12.0	2	2.7
PB tests for adults	3	4.0	14	18.7	2	2.7
Functional behavior assessment	-	-	8	10.7	-	-

Information on PBs prior to intake. Approximately half of participants said that they received some indication that a child showed PBs prior to intake. This information came primarily from the child's records and direct observation, but also from tests not directly related to PBs, communications with other service providers (e.g., pediatricians or daycare staff), and from PB tests not typically used for children with ID/ASD. Twenty-five percent of participants found this information useful and representative of the children's behaviour. Among those who did not find the information relevant, nine mentioned that parents and daycare or preschool staff struggle with the use and interpretation of assessment tools, refuse to assess PBs, or refuse to give information regarding PBs prior to intake. Specifically, one participant explained that parents often minimize their child's PBs or do not mention these out of fear of losing access to services. Oftentimes, their child has been on a waiting list for these services for an extended period of time and may have already been excluded from daycare. Six participants reported that the assessment data they received concerning children's behaviours was frequently outdated and that follow-up evaluations were often necessary.

PBs assessment at the beginning of, and during, service delivery. Over two thirds of service providers said they had assessed PBs at the beginning of services. They primarily reported using direct observation. Several listed assessments that are not typically used for children with ID/ASD such as Profil Socio-Affectif, a French version of the Social Competence and Behaviour Evaluation (SCBE; Lafrenière & Dumas, 1996; Lafrenière, Dumas, Capuano, & Dubeau, 1992) or for the evaluation of PBs (e.g., the ABAS-II). In fact, over a third of respondents reported that there were no tools to evaluate PBs in children with ID/ASD. At the time of this study, this was indeed the case when considering standardized instruments available in French. Five mentioned that information on PBs is communicated verbally and without any written documentation. During service delivery, participants mainly used direct observation to monitor PBs and to observe the effectiveness of intervention strategies. The other tools used by respondents throughout service delivery included the child’s case files and assessments that are not intended for PBs in children with ID/ASD.

Assessment needs. Table 3 lists the types of assessments that participants reported as desirable prior to intake, at the beginning of service delivery, and during service delivery. The two most often cited needs throughout the child’s entire service trajectory were for observational data and for PB screening tools and assessments specifically geared toward children with ID/ASD. Information from other service providers and on the child’s progression or other diagnoses was primarily requested by participants from the time of referral up to the initial assessment period at the beginning of services. A few participants’ responses concerned the child’s family. Prior to and at the beginning of services, they wished to learn more about the parents’ needs and involvement. During service delivery, they requested user-friendly tools that would help parents monitor the child’s progress and apply interventions at home.

Table 3
Reported Assessment and Information Needs Throughout Children’s Service Trajectory

Assessment or information need	Prior to intake		At the beginning of service delivery		During service delivery	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Observation	11	14.7	14	18.7	7	9.3
PB tests for children	6	8.0	22	29.3	14	18.7
Other specialists	4	5.3	4	5.3	1	1.3
Family needs and involvement	3	4.0	1	1.3	3	4.0
Child’s progression and other diagnoses	8	10.7	4	5.3	-	-
Functional behavior analysis (FBA)	-	-	1	1.3	15	20.0

Regarding the widespread requests for PB assessments adapted for children to be used at all points of the child's service trajectory, a participant's remarks summed up a perception shared by all respondents:

There should be more screening for PBs during childhood. We need to stop thinking that this kind of behaviour is not problematic just because it is easy to control in children. In adults, PBs have become firmly rooted in the person and can no longer be managed as easily.

The availability of such assessments prior to intake are instrumental to planning interventions, as noted by a manager: "Knowing a child's current problems and their severity may influence our choice of therapists for this case, as well as the intensity with which we provide clinical support." Therapists vary in their degree of motivation, experience, and expertise regarding PBs. In fact, one respondent from the early childhood program indicated that he would not work with children with severe PBs, as he believed that this should be the mandate of a team that specializes in these behaviours. Although respondents reported similar needs during service delivery, their primary purpose was to track the child's progress and adapt their interventions. For instance, participants not only noted a need to continue observing the child, but specifically expressed a need for tools that would enable systematic observational data collection as a means of monitoring the effectiveness of ongoing interventions. They likewise cited needing FBA-based tools for this purpose.

Interventions for Children with PBs

The second research question concerned the types of interventions used for children with PBs. When respondents were asked about the types of programs or services provided for children with PBs (regardless of any modifications noted previously), 84.4% identified EBI, and 4.7% responded that these children received intervention based on a FBA. The majority (62%) of participants said that children with ID/ASD and PBs received the same services as their peers without PBs, but most spontaneously qualified this response by identifying several differences they observed in practice. These comments were consistent with the reports of the remaining 38%, who believed that children with PBs received different interventions. The majority (72.7%) of respondents perceived that current service offerings were appropriate for children with ID/ASD and PBs, but three (4%) specified that they were not suited for children with more severe PBs. A total of 88.7% of participants stated that they had to modify their services or interventions in one way or another to better meet the needs of children with PBs.

Table 4 presents a summary of the ways in which participants said they had to adapt their interventions to better meet the needs of children with PBs. The most commonly reported changes were involving multiple specialists in the case (e.g., multidisciplinary teams and occupational therapists) and adopting different, individualized, or more proactive strategies. Several also mentioned changes to the venue used for EBI, for instance by providing this service at the rehabilitation centre rather than in an integrated daycare environment. They also increased the intensity, that is, the total number of hours per week of interventions; and they provided support to the child's family, although this was sometimes at the expense of time spent with the child.

Table 4
***Reported Practices and Needs in Adapting Interventions for
 Children With Problem Behaviours***

Practice or need	Current interventions		Intervention needs	
	<i>n</i>	%	<i>n</i>	%
Collaboration among multiple specialists	28	36.4	37	48.1
Adapted intervention strategies	26	33.8	16	22.2
Adapted venue for interventions	8	10.4	-	-
Support and training for families	8	10.4	11	15.3
Increased intensity	7	9.1	8	11.1

Note. Some participants mentioned making or needing to make more than one type change to interventions; others reported none. Percentages are based on the total number of mentions.

When participants were asked what would facilitate interventions, their most frequently mentioned needs concerned training (17 comments), a topic addressed in the subsequent section. Participants' other responses were otherwise consistent with the modifications that service providers said they already implemented (see Table 4). For instance, they required more access to various specialists and experts in PBs and wished for a more widespread implementation of multidisciplinary teams (the preferred, but not universal, practice in PB programs). They also expressed the need to further modify existing interventions, for instance by addressing PBs before beginning EBI, by improving the coordination between EBI and PB services, and by using appropriate assessment tools (primarily: observations, PB tests for children, and FBA) to guide interventions. In discussing these changes to intervention practices, several participants also mentioned the need to strengthen collaboration and communication with families and with external service providers. They also acknowledged that families required more support from the rehabilitation centre or from community service centres, as well as respite services specifically. Finally, several respondents noted that additional resources and staff were needed to increase the intensity of interventions offered to children with PBs. Although these responses did not directly pertain to adapting interventions for children with PBs, six participants reported that additional support was needed for therapists, citing concerns about isolation and burnout.

Training and Training-Related Needs

The third research question concerned service providers' prior training and areas in which they felt additional training was needed. EBI is the primary service offered to young children with ASD (with or without ID) by rehabilitation centres in Québec. Yet only 4% of the respondents in these centres' specialized PB programs and 10% of those

in the early childhood programs had been trained in EBI. Furthermore, 52% of the respondents who worked in specialized PB programs mentioned having received training in child development, a larger proportion than what was observed within the early childhood programs (14%). Between 4% and 13% of respondents across the two programs said they had been trained to assess and intervene with this age group. Among those working in early childhood programs, 2% had been trained to work with families. FBA is the preferred model for assessing and intervening with persons with PBs in Québec's rehabilitation centres. However, only 29% of early childhood workers had received training in this area, compared to 79% of those in the specialized PB program. Unsurprisingly, the latter group had received more training with respect to PBs in general.

Approximately 88% of respondents said they needed additional training in child development and its associated disorders. Almost 90% of staff across the two programs mentioned needing some form of additional training in PBs as they related to their professional activities. The most frequently mentioned training needs related to FBA, severe PBs in childhood, the causes and prevention of PBs, and intervention strategies for PBs specifically. To put these responses in perspective, 13 respondents reported that therapists are not trained to assess PBs or to intervene among children with PBs. More specifically, none of those who worked in early childhood programs had been trained in FBA. One manager also said that "we really need training on ASD and the implications of PBs. Our therapists regularly face this issue but do not know how to respond to it. There have been several cases of burnout because of this."

Discussion

Several studies have documented families' perceptions of the services offered to them and their children with PBs. However, the status of the assessment, intervention, and training practices in the context of public rehabilitation and special education services is poorly understood. Service providers' needs in these areas are likewise not well documented. The present study sought to address this gap in the literature by surveying staff's perception of current practices and needs with respect to serving children with ID/ASD and PBs. This type of investigation is a first step toward proposing concrete improvements to services, including the creation of specialized assessment and intervention tools. To the extent that service providers and families' perceptions were generally consistent, these improvements are likely to benefit children with PBs as well as the natural carers and professionals who help them.

The first research question addressed by this study concerned the assessment of PBs. Only a quarter of respondents reported having obtained useful, representative information about the PBs of children at the time of referral. This information mostly came from reports by previous service providers and families. Several participants felt that this information was, at times, lacking or inaccurate; and one attributed this to a fear that the child might lose access to the rehabilitation centre's services if his or her PBs were disclosed. Studies conducted among families support this possibility: Children with PBs and their families routinely experience exclusion from services (McGill et al., 2006; Wodehouse & McGill, 2009). Another reason for the lack of assessment data prior to

intake is the absence any validated French translations of standardized instruments for the assessment of PBs in young children with ID/ASD, a problem currently being remedied by our group. Service providers expressed wanting more information on children's PBs at the beginning of service delivery, namely through direct observation and standardized instruments. This knowledge would assist in the planning and organization of services in terms of intervention intensity, required staff training, therapist workload, and the matching of therapists to children. Most participants assessed PBs at the beginning of services through direct observation. Observation was also the primary means of monitoring the effectiveness of ongoing interventions throughout service delivery. All respondents expressed a need for standardized instruments to supplement these observations and thereby assist their efforts to further adapt their intervention strategies as they continue to work with a child. Families' dissatisfaction with the effectiveness of specialized services (Knox, 2000; McGill et al., 2006; Wodehouse & McGill, 2009) may partially stem from the fact that these cannot be adequately tailored to individual children's situation due to insufficient information at intake and at the beginning of service delivery. This issue persists as service providers lack the necessary resources to accurately gauge whether intervention strategies are effective in managing the child's PBs.

The second research question pertained to the forms of intervention offered to young children with PBs. The majority of respondents reported that children receive the same services as other children with ID/ASD who do not have PBs. In most cases, these services consist of EBI, with very few children being involved in interventions derived from FBA despite the fact that is recognized as a best practice for PBs in Québec and should take place before EBI (Fédération québécoise des centres de réadaptation en déficience intellectuelle et troubles envahissants du développement, 2010; Rivard et al., 2013). None of the participants surveyed reported that young children were enrolled in specialized services for PBs, despite a widespread acknowledgement that several children would benefit from these before the age of 6. This is partially attributable to the structure of programs within rehabilitation centres and to the lack of standardized instruments to enable the early identification of PBs. Although most respondents said that the current service offerings were appropriate for children with PBs, many also mentioned adapting their intervention strategies to this population. Some qualified this perception by adding that these interventions may not be appropriate when children's PBs are more severe. It thus appears that staff share, at least to some extent, families' perception that current service offerings are inadequate or ineffective for children who present PBs (Knox, 2000; McGill et al., 2006; Wodehouse & McGill, 2009). The service providers surveyed in this study took it upon themselves to address this issue. Notably, they offered children with PBs more intensive interventions, devised individualized intervention strategies, provided more support to families, involved additional partners from multiple disciplines, and used different intervention venues. Unfortunately, participants acknowledged lacking the support or resources needed to implement these adjustments. For instance, some acknowledged that they had to reduce the number of hours of intervention offered to children in order to better support their families (a service often perceived as lacking by these; see McGill et al., 2006; Rivard, Lépine, Mercier, & Morin, in press; Rivard, Mercier, Morin, & Lépine, in press; Québec Ombudsman, 2009; Wodehouse & McGill,

2009). This suggests that these two services presently compete with each other for resources and that there may be a need for a separate program catering to families' needs independently of services allocated to their child. In light of limited resources and their desire to be more involved in treatment, families could also be trained to apply interventions at home.

Therapists, specialists, and managers identified the following paths to improving interventions: increasing the intensity of services, implementing specialized interventions for children with PBs, integrating PB services with EBI, training staff to intervene on PBs, and forming or involving multidisciplinary team to work on these cases. They also wished to increase therapists' access to teams that specialize in PBs and to experts such as psychologists or social workers, and to improve collaboration across the various services received by children and their families. Many participants also perceived that families and therapists alike would benefit from additional support, due to the stress and challenges of working with children who display PBs (Hastings, 2005; Hastings & Brown, 2002b; Lambrechts et al., 2009; Lecavalier et al., 2006; Mitchell & Hastings, 2001; Tassé et al., 2010). Several participants also expressed a need for greater communication and collaboration with children's families, who often feel inadequately informed or otherwise excluded from decisions regarding their child (e.g., Wodehouse & McGill, 2009). In fact, many of the deficiencies identified by service providers in this study are echoed in the literature on families' perceptions of services: support and respite care for families, specialized psychological support, partnership and collaboration across services and with families, and expertise in PBs (Knox, 2000; McGill et al., 2006; Warfield & Hauser-Cram, 1996; Wodehouse & McGill, 2009). Thus, the needs identified by families and by those serving children are generally consistent; this widespread agreement confirms that these needs are real.

The third research question addressed the training received by service providers. Almost all respondents said that staff needed additional training in child development and in PBs. Importantly, participants working in both the specialized early childhood programs and in the PB programs felt poorly trained to intervene with young children with PBs. One of the few differences noted between staff in early childhood programs and those in PB programs was that the latter reported having received more extensive training. For instance, almost four times as many of them had been trained in child development compared to those working in a program dedicated to young children. More than half of the respondents from the PB programs had trained in FBA, the preferred approach to PBs in Québec, compared to less than a third of the early childhood service providers. This discrepancy can be attributed to the fact that the widespread occurrence of PBs in young children has only recently begun to be acknowledged in rehabilitation centres' *modus operandi*. Few participants from either program had received training to intervene with families, despite the fact that this was identified by several as being an important area for improving current services and was also found to be lacking by the families themselves (Rivard, Lépine, et al., in press; Rivard, Mercier, et al., in press). The most commonly reported training needs across both programs were PBs and severe PBs in children, again a point of dissatisfaction among families (McGill et al., 2006; Warfield & Hauser-Cram, 1996; Woodhouse & McGill, 2009).

The results of this study should be interpreted with caution due to limitations inherent to its participant selection and data collection procedures. Indeed, convenience sampling resulted in an overrepresentation of therapists from early childhood programs compared to those specializing in PBs. Overall, staff working with children with ASD, as opposed to ID, were also disproportionately represented. The questionnaire used to collect participants' responses was constructed according to the scientific literature on families' perceptions and the three research questions guiding this study. Although the use of open-ended questions enabled respondents to share varied and nuanced points of view, this also constituted a weakness of the study. Indeed, participants may have been more likely to forget to address certain topics when presented with this type of items, such that the data reported here may not be an exhaustive survey of service providers' perceptions.

Since 2003, public rehabilitation centres specializing in ID/ASD in Québec have offered EBI programs for young children diagnosed with ASD. This population is more likely to engage in PBs than children without ASD, thus increasing the need for the staff in these centres to simultaneously possess expertise in ASD (and, given high comorbidity rates, ID), EBI, FBA, and PBs. The present study demonstrates that service providers face numerous challenges regarding assessments and interventions adapted to this age group and diagnosis. This gap in specialized training and resources must be bridged if these workers are to provide children and their families with individualized services, effective assessments and interventions, and consistent support.

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