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"I Lost all the Services Offered to my Child Overnight": Families' Experience of the Interruption of Early Intervention Services for Autism During the Covid-19 Pandemic in Quebec

"J'ai perdu l'ensemble des services offerts à mon enfant du jour au lendemain": l'expérience des familles suivant l'interruption des services d'intervention précoce en autisme durant la pandémie Covid-19

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Abstract

Families of young children diagnosed with autism around the spring of 2020 were especially vulnerable as Covid-19 pandemic-related restrictions interrupted the delivery of their specialized early intervention services. This paper examined 34 families' perceptions of the impact of this situation in Quebec on their child and their family using a mixed-methods design. Parents reported largely detrimental effects on their access to, and relationships with, service providers and their child's transition to school. They noted negative changes in several domains of child development. The need to combine childcare responsibilities with telework was also a source of stress. This situation resulted in family adjustment challenges and in the exacerbation of pre-existing vulnerabilities. However, parents also remarked on their family's ability to adapt and mobilize resources.

Résumé

Les familles de jeunes enfants ayant reçu un diagnostic d'autisme au printemps 2020 ont été particulièrement vulnérabilisées par les restrictions liées à la pandémie de Covid-19. Cet article documente, par l'intermédiaire d'un devis mixte et d'une série d'entrevues longitudinales, l'expérience de 34 familles pendant la pandémie, soit plus précisément en regard des répercussions de l’interruption des services d’intervention précoce spécialisés (intervention comportementale intensive, ICI) sur le développement de leur enfant et plus largement sur l’adaptation de leur famille. Les parents ont signalé des effets préjudiciables importants sur l’accès aux soutiens formels et informels, sur le partenariat avec l’équipe d’intervention ainsi que sur la transition de leur enfant à l’école. Ils rapportent des conséquences négatives des mesures et de la situation sur plusieurs domaines du développement de leur enfant. La nécessité de devoir combiner les responsabilités en matière de soins des enfants et le travail a été une grande source de stress pour les familles, situation ayant entraîné des difficultés d’adaptation familiale et l’exacerbation de vulnérabilités existantes avant la pandémie. Les parents ont néanmoins également souligné l’importance des capacités d’adaptation de leur famille ainsi que pour mobiliser leurs ressources.

Mots-clés *:* pandémie de Covid-19, autisme, intervention précoce, développement de l’enfant, adaptation familiale

Introduction

Recent studies on the effect of the Covid-19 pandemic on families have helped to identify groups who were more vulnerable during this type of crisis. The scientific, service, and broader community would benefit from taking stock of their experiences during this particularly challenging time, as these data may potentially assist in the development of future safeguards for these populations in times of crisis. One such group includes parents of young children with autism spectrum disorder (ASD) and other complex needs, who were found to be at greater risk for developing mental health difficulties and experiencing heightened stress during the recent pandemic period (Levante et al., 2021; Neece et al., 2020). Many families experienced the adverse effects of the pandemic, irrespective of their children’s needs or diagnoses. However, the core features of ASD (i.e., social communication challenges and unusual patterns of repetitive behaviour, including a preference for highly predictable environments and routines) and the physical and mental health conditions (e.g., autoimmune or anxiety disorders) that frequently co-occur with ASD were a particular source of vulnerability for these families under such circumstances (Colizzi et al., 2020; Meral ,2021). Furthermore, the public measures put in place in response to Covid-19, such as lockdown periods and a reorganization of health and social services, resulted in an interruption or delay in access to specialized ASD services such as early intervention (Jacques et al., 2022). These stressors experienced by caregivers of children with ASD were compounded by need to reconcile telework and family care and the overall unpredictability of the pandemic situation experienced by many households (Asbury et al., 2021). Parents witnessed setbacks in their child’s development and learning and an exacerbation of pre-existing behavioural challenges (Asbury et al., 2021; Colizzi et al., 2020; Meral,2021).

A number of studies have examined the experiences of families within the context of Covid-19 since lockdown measures were first put in place in the spring of 2020 (see a scoping review by Lee and Meadan, 2021). However, to our knowledge, none have specifically examined the impact of the pandemic on families whose child was recently diagnosed with ASD, a population who was especially at risk (Meral, 2021). The specialized early intervention services that would normally be provided to them through public health and social services networks were interrupted during this period. Yet timely access to these interventions is critical to ensuring the best outcomes for children (e.g., Warren et al., 2011). Several studies conducted prior to the pandemic have shown that delays in ASD interventions are associated with poorer behavioural and cognitive outcomes for children (Klintwall et al., 2015).

The present study sought to describe the experience of Canadian (Québec) families of children aged 4-5 years, recently diagnosed with ASD, who had been receiving early intervention services from public health and social agencies since September 2019 up to their abrupt interruption in March 2020. The timing and duration of this service interruption meant that they did not receive specialized early intervention services during the critical period leading up to their child's transition to school (in September 2020). This research aimed to provide a portrait of changes in the normal course of early childhood services for ASD and describe how parents experienced various repercussions of Covid-19 measures in terms of their child's development, family functioning, and well-being. These families' unique understanding of these events could inform future improvements to service provision under adverse circumstances.

Importance of Specialized Early Intervention Services and the Impact of the Pandemic

Following a diagnosis of ASD, empirical studies and expert opinions all point to the importance of timely access to evidence-based early intervention programs to facilitate children's learning and development, which, in turn, help to improve their prognosis and promote family quality of life (e.g., Guralnick, 2019). Indeed, early childhood represents a brief developmental window within which early intervention can have a critical impact (Guralnick, 2019). Access to these specialized services prior to transition to school is a crucial step in the ASD care and services trajectory (see Fontil & Petrakos, 2015; Marsh et al., 2017; Rivard et al., 2019; 2020) that was disrupted by the pandemic for many children (Jacques et al., 2022; Meral, 2021).

To date, programs grouped under the designation of early intensive behavioural intervention (EIBI; based on applied behaviour analysis, see Cooper, 2020) have received the most empirical support in terms of their effectiveness in supporting the development of several skills known to be impaired in ASD during early childhood (Makrygianni et al., 2018; Warren et al., 2011). To ensure their quality, these programs should include: 1) early initiation (prior to 5 years of age); 2) a weekly intervention intensity of at least 20 hours; 3) a structured intervention plan with defined objectives and based on applied behavioural analysis principles (ABA); 4) the involvement of therapists who have received specialized training (e.g., ABA, early childhood, ASD); 5) an individualized intervention; 6) monitoring of the child's progress; and 7) parental involvement (National Research Council, 2001, see also McGahan, 2001).

The pandemic situation brought the delivery of EIBI services to a halt for many families worldwide while shelter-in-place policies meant that parents had to work from home and take care of their children at the same time. Studies on Covid-19 have reported significant reductions, or even the discontinuation, of specialized services and activities for children with ASD (Jeste et al. 2020; Manning et al., 2021; Neece et al. 2020). Parents were then worried that the interruption of their child's interventions would halt the progression of their learning and that previously acquired skills might be lost (Amaral & de Vries, 2020; Eshraghi et al., 2020). In most cases, children's inability to attend daycare, school, and service centres posed serious challenges to the application of EIBI. Concerned about the potential for their child to regress, parents felt the pressure to continue these interventions themselves, with little or no external support (Eshraghi et al., 2020). In their attempts to minimize the consequences of the pandemic on their child, they had to assume multiple roles (e.g., parents, worker, and therapist) at home without any preparation or forewarning.

Challenges for Families of Children with ASD before and During the Pandemic

Research conducted before the pandemic has demonstrated that parents develop coping skills to manage the different sources of stress related to ASD (e.g., its behavioural manifestations, barriers in accessing services) and to support their child's development, promote their family's quality of life, and advocate for their child's rights and interests on a day-to-day basis (Chatenoud et al., 2019). Nonetheless, they also encounter significant challenges in helping their child access inclusive educational environments that provide the same socialization opportunities as the general population. Furthermore, they experience a greater parenting workload (e.g., daily caregiving tasks, efforts to locate high-quality support services; Brewer, 2018; Frantz et al., 2018) and are at greater risk of presenting mental health challenges (e.g., anxiety, depression) than parents of typically developing children or children with other developmental disabilities (Totsika et al., 2011). The observation of bidirectional predictive associations between parents' mental health difficulties and their child's behavioural and emotional problems highlights the importance of providing supports promptly and to the whole family system (Asbury et al., 2021; Patel et al., 2022). As a matter of fact, almost 40 years of research in on developmental disabilities in early childhood emphasize that early intervention must serve to not only support the child directly, but also assist parents and other family members in their interactions with one another (Dunst et al., 2016).

Since the United Nations declared a worldwide pandemic in March 2020, several studies on families of children with ASD, including a scoping review (Lee & Meadan, 2021), have indicated that the threat of Covid-19 and the resulting lockdowns increased the difficulties that individuals with ASD and their families faced. The disruptions in educational services and care provision, social isolation, and the symptoms associated with their child's diagnosis have created uniquely stressful circumstances for families that exacerbated existing vulnerabilities or created new ones (Asbury et al., 2021; Kalb et al., 2021; Manning et al., 2021). Researchers have also warned of the potential long-term impact of prolonged stress on caregivers' mental health and well-being (Alhuzimi,2021; Kalb et al., 2021; Levante et al., 2021; Manning et al., 2021). Parents also mentioned heightened financial stress related to job loss coupled with the need to pay for services out of pocket, which jeopardized their ability to meet the demands of multiple roles at home (Manning et al., 2021; Neece et al., 2020). Families also experienced the loss of recreational opportunities and access to formal (e.g., therapy, respite care) or informal support (e.g., contact with grandparents, or friends; Lee et al., 2021).

Objectives

The overarching goal of the present study was to describe how 34 families (39 parents) perceived the impact of the pandemic on the course of their EIBI services during the early 2020 lockdown period. Specifically, its first objective was to summarize the changes in services that unfolded during the lockdown and how this was experienced by family members. Its second objective was to document the impact of these changes in service provision on children's learning and development, as perceived by their parents. Finally, its third objective was to detail how parents described the effects of the pandemic and related measures (including the interruption of EIBI) on their own mental health.

Method

This investigation was part of a larger longitudinal project on the experiences of families of children with ASD during their transition from EIBI to school. A cohort of parents from this project who had begun receiving EIBI in 2019 and subsequently experienced its interruption during Covid-19 pandemic agreed to share their perspective on this critical 6-month period that preceded their child's enrollment in kindergarten. The protocol for this study was approved by the University of Quebec in Montreal ethics committee.

Setting: EIBI Services

As is the case in several countries, Canada has put forward EIBI programs as a public service to meet the needs of young children with ASD. In the province of Québec, preschool-aged (i.e., under 6 years) children receive EIBI from agencies that specialize in ASD, intellectual disability, and physical disabilities; these fall under the purview of provincial health and social services network. Public EIBI should normally be dispensed at a rate of 20 hours per week to all children with ASD (Gouvernement du Québec, 2003), although substantial delays in access to this service and regional variations in the quality of implementation of these programs have been observed (Dionne et al., 2013, 2016a, 2016b; Gamache et al., 2011; Rivard et al., 2014a; 2015). EIBI is generally delivered by a special education technician (henceforth labelled "therapist" or "educator") who is supervised by a professional holding a master's degree in psychoeducation or a doctorate in psychology. Intervention is most often provided at the child's daycare centre and, in some cases, at home, with a 1:1 child-to-therapist ratio. With some exceptions, most children will only receive EIBI during the year immediately preceding their enrollment in kindergarten.

When lockdown measures were implemented in March 2020, EIBI and other specialized ASD services in Quebec were abruptly discontinued. Several early intervention educators were reassigned to assist medical providers in hospitals or to work in long-term care facilities for seniors. Thus, many families lost not only their EIBI services, but access to therapists with whom they had developed a working relationship. A variety of ad hoc measures were put forward to attempt to respond to emergency situations that arose during lockdown (e.g., severe challenging behaviours at home) but no formal documentation of these measures exist.

Participants

To be eligible to participate in the present study, families were required to have begun receiving EIBI in September 2019 in preparation for the child's enrollment in kindergarten in September 2020. Thirty-four families, consisting of 31 mothers and 8 fathers (*N* = 39; 5 dyads) were recruited. Their 35 children, including two twins, were aged between 4 and 6 years (*M* = 5.2) and were predominantly boys (*n* = 29). Household incomes ranged from under CAD30,000 (17.6%) to CAD90,000 and above (23.5%). Some parents had attempted (*n* = 5) or completed (*n* = 9) high school, some had either obtained an undergraduate (*n* = 10) or graduate degree (*n* = 4). Most participants were born in Canada (*n* = 30), but others had immigrated from Africa (*n* = 4; Morocco, Algeria, Senegal, Cameroon), Europe (*n* = 3; France, Bulgaria, Portugal), or South America (*n* = 1; Venezuela).

Measures

Sociodemographic Questionnaire

Families completed a sociodemographic questionnaire in which they provided information about their child (i.e., age, gender) and both parents (i.e., education, employment, country of origin) as well as approximate household income.

Questionnaire on Specialized Services and Covid-19

A questionnaire was developed to assess parents' experience of their EIBI services trajectory in the context of the Covid-19 pandemic. The questionnaire, which takes between 30 and 45 minutes to complete, includes multiple-choice and open-ended questions. Parents responded to questions organized into three sections: 1) general information on EIBI services received between September 2019 and March 2020 (e.g., number of professionals involved, type of intervention, intensity in terms of hours per week); 2) details about parents' and children's experiences in relation to the interruption of EIBI during the Covid-19 pandemic, beginning with the first lockdown period (March 12, 2020) and leading up to the child's enrollment in kindergarten; and 3) the changes families experienced during the pandemic. In this last section, four questions were asked: 1) What major changes did you experience in terms of the EIBI services that you were receiving before and after the lockdown?; 2) What was the impact of these changes on your family?; and 3) In your own words, did the Covid-19 situation impact your psychological adjustment and, if so, in what way?; and 4) Is there anything else that you want to share about your experience?

Procedure

Coordinators at the agencies dispensing EIBI first contacted families who met the inclusion criteria to obtain their consent to be contacted by the research team. Those who agreed were invited to participate in an individual virtual meeting with a research assistant (5 undergraduate students and 5 doctoral students). These meetings took place between October 2020 and January

2021. In these meetings, the research assistant explained the study and consent procedures to the parents, who then signed the consent form electronically. Next, parents completed the study questionnaires online. In cases where both parents were participants in the study, each parent completed the questionnaires independently.

Analyses

Quantitative analyses consisted of paired samples *t*-tests to compare the number of professionals involved in EIBI and of hours of intervention received each week before and after the onset of the Covid-19 pandemic. Effect sizes were evaluated with Cohen's *d* using the following guidelines (Cohen, 1988): $d \approx .2$ small effect, $d \approx .5$ medium effect, and $d \approx .8$ large effect.

Qualitative analyses were based on procedures for thematic content analysis with a mixed design (deductive and inductive) outlined by Muchielli (see L'Écuyer, 1990). First, participants' responses to each question were segmented into distinct units of meaning. Next, information collected during interviews was separated by question. One interview transcript was used to create a preliminary coding grid that listed mutually exclusive themes and subthemes (i.e., a given unit of meaning cannot be classified into more than one category) for each question. Two members of the research team, doctoral level students, performed this step of content analysis independently. They compared their respective coding grids and, following discussion, revised these until they obtained a single, consensual grid. They then independently applied this revised grid to a second interview transcript and compared their results. Again, they discussed discrepancies in their coding and made modifications to the coding grid as necessary. This process was repeated with a third transcript. Thus, for each question, three versions of the coding grid were iteratively generated, tested, and reviewed, each time on a different interview transcript. At each step of this process, the two coders consulted with two senior members of the research team who were experts in qualitative analysis and in interventions for ASD, respectively. These senior researchers also approved the final coding grid to be used for each question. The two coders independently applied this final grid to all interview transcripts. Any discrepancies in the two coders' categorization of units of meaning were discussed and resolved by the two senior researchers. The reliability of qualitative analyses was further ensured by the involvement of a third coder who was not otherwise involved in the research project. This person independently coded 10% of content to support the computation of interrater agreement ($\kappa = .99$). Finally, the proportion of responses for each theme and subtheme were computed for each question.

Results

The following sections summarize the results stemming from descriptive quantitative analyses regarding the changes in service delivery during the Covid-19 pandemic (Objective 1), qualitative analyses regarding families' experience of these changes (Objective 1) and their perceptions of how these changes impacted their child's development (Objective 2), as well as how the pandemic situation affected family adjustment (Objective 3). Responses to the open-ended questions corresponding to the second objective could be divided into two distinct major themes, namely the impact of changes to EIBI on children's development and on the family. Thus, four major themes emerged from qualitative analyses supporting the three study objectives: 1) perceived changes to EIBI as a result of the pandemic (mentioned by 100% of parents), 2) impacts of changes to services on the child's development (mentioned by 77%) and 3) on the family (mentioned by 90%), and 4) the impact of Covid-19 on family adjustment (mentioned by 92%). Subthemes were identified for each of these major themes. In the following section, percentages denote the proportion of the total sample (i.e., 39 parents) whose testimonials included units of meaning that could be categorized within these subthemes. We provide representative interview excerpts (in some cases, translated from French) to illustrate these subthemes.

Changes to EIBI as a Result of the Covid-19 Pandemic

Table 1 summarizes descriptive quantitative data on the types of professionals that families had reported seeing before and after the onset of the pandemic. Families were most likely to work with special education workers, psychoeducators, speech therapists, or occupational therapists. Table 2 identifies significant changes, corresponding to large effect sizes, in the number of professionals seen (from 2.4 to 0.9) and number of hours per week (from 12.5 to 0.8) that coincided with the beginning of lockdown measures.

Table 1

Professionals Consulted by Participants (N = 39) Before and After the Onset of the Covid-19 Pandemic

	Number of Consultations	
Professional	Pre-Pandemic	Post-Pandemic
Special education worker	33	11
Psychoeducator	18	6
Speech therapist	15	5
Occupational therapist	10	4
Other (unspecified or low frequency, e.g., kinesiologist)	10	5
Social worker	1	2
Psychologist	2	1
All	89	34

Table 2

Time Spent by Participants (N = 39) with Professionals and Number of Professionals Consulted Before and After the Onset of the Covid-19 Pandemic

	Pre-Pandemic	Post-Pandemic		
	M (*SD*)	*M* (*SD*)	Change	Cohen's *d*
Hours	12.5 (7.1)	0.8 (1.3)	-11.7***	-1.5
Number of professionals	2.4 (1.1)	0.9 (1.0)	-1.5***	-0.9

Note. Tests are paired-samples *t*-tests with the corresponding effect size (Cohen's *d*).

****p* < .001; **p* < .05.

Table 3 lists the themes and subthemes identified in the qualitative analysis of the first question, which pertained to parents' perception of changes in EIBI services associated with the pandemic. Four subthemes were identified for this question: 1) sudden and total interruption of services to meet the child or the parents' needs, 2) transformation of services into various formats, 3) changes in the relationship with the intervention team, and 4) impact on the child's transition to kindergarten.

Table 3

Changes to Early Intervention Services as a Result of the Covid-19 Pandemic

Theme	Subtheme	Sample Interview Excerpts	*N/39* (% parents)
End of services	Children	"The program had to be ended abruptly." "No regular follow-up. We were completely abandoned."	26 (66,67%)
	Parents	"No support for us parents, because all services are really centered on the child but if the parent isn't doing well the child will not do well either."	3(7,69%)
Transformation of services		"One hour of EIBI per month, but that wasn't really sufficient to be considered real services" "Services were nevertheless available if the mother had questions, but primarily over the phone"	16 (41,03%)

Theme	Subtheme	Sample Interview Excerpts	*N/39* (% parents)
Relationship with intervention team	Positive	"The educators made us feel important and significant in my son's life, which was wonderful." "An educator came to our home to see my daughter because she missed her. This [courtesy] visit was brief but very appreciated."	6 (15,38%)
	Negative	"It was more difficult to communicate with [educator] as well." "The educator, who was going to retire, told me they were not there for us, they didn't care about us, my work is with your son."	6 (15,38%)
Quality of school (kindergarten) support	Negative	"[My child]'s enrollment in school was very difficult without these services. With the pupils and the teacher who was not ready to receive a child with ASD, it was a catastrophe."	7 (17,95)
	Positive	"The [EIBI] educator stayed involved in our case at school, got involved in the school's intervention play"	3(7,69)

Note. EIBI = Early intensive behavioural intervention, ASD = autism spectrum disorder.

Sudden Interruption of Services for the Child or Parents

Many parents (69% of the 39 respondents) spontaneously reported that Covid-19 resulted in the discontinuation of the services they had been receiving: "major change was the end of services due to Covid". Some participants specifically mentioned that the interruption of EIBI happened seemingly overnight. Some participants described that this interruption was "catastrophic", that they felt "completely abandoned" because, for example, they no longer benefited from "follow-up" with respect to supporting their child's development. Three parents (7.7%) perceived an interruption of EIBI-related services that were dedicated to parents, such as parental coaching.

Transformation of Services

Of the 39 participating parents, 41% reported that the changes brought about by the pandemic resulted in a transformation of services. They noted efforts made by EIBI service providers to maintain some level of support to families, but through different means than what had been done prior to the pandemic. The first approach was to shift from a structured, procedural service delivery to an advisory format. Eight parents (20.5%) said that they were offered support by telephone as an alternative to EIBI. Whereas some mentioned this emergency measure was helpful: "There was always someone at the other end of the line who could help me through the difficult days and give me tools to help me through some situations," not all seemed to share this perception: "Phone services were insufficient. We would have liked visual contact." A second approach taken by providers was to reduce the intensity of services by spacing out sessions. For instance, some parents described services as slowing down or decreasing in quantity and quality: "Follow-ups were less rigorous, less effective, just a few home visits by the educator, some visits were skipped." A mother commented on the reduction of intervention intensity down to 1 hour per month by stating "it wasn't enough to be considered a real service."

Quality of Relationships with the Intervention Team

Seven parents (17.9%) mentioned changes due to the pandemic in the nature and quality of their relationship with members of their child's intervention team. Six parents (15.4%) reported being satisfied with these changes. For instance, some discussed providers' professionalism as they labored to maintain communication with families: "three phone calls for each child since March, they care about our well-being, it's good." Some parents praised providers' level of involvement, their caring for families, and that they "gave their time" or "did their best" to continue supporting the child.

Six parents (15.4%) mentioned a difficult collaboration with professionals during the pandemic. For example, some reported communication problems such as a lack explanation of the measures in place. Others described challenges in their interactions, for instance as a result of providers not understanding the situation as experienced with the family. Some parents discussed situations in which they had felt judged by providers or were confronted with a lack of empathy.

Quality of Support to the Transition Toward Kindergarten

Seven parents (17.9%) perceived a discontinuity in EIBI services in relation to their child's upcoming enrollment in school (i.e., kindergarten). For example, some reported a lack of guidance as well as psychological and material support to prepare for this important transition due to the abrupt end of EIBI. Three parents (7.7%) expressed how difficult and stressful the transition was for their family. Of these, two also noted a lack of communication between preschool and school staff during this period. However, three parents (7.7%) raised positive elements related to the transition to school. For example, one said that the child's EIBI therapist was involved in developing the intervention plan to be implemented in school. Another parent expressed gratitude for the therapist's role in ensuring that their child would be enrolled in a regular classroom. The third parent said: "given the situation, the end [of EIBI] was not too bad because afterwards he got to a specialized classroom with a lot of services."

Consequences of Pandemic-related Changes to Services for Children

When parents were asked about perceived impacts of changes in EIBI related to Covid-19 for their child (Objective 2), 77% of the total sample reported consequences on the child's 1) general development, 2) emotional development, 3) ability to understand the situation, 4) social skills, 5) challenging behaviour, and 6) language and communication skills (see Table 4).

Table 4
Consequences of Pandemic-related Changes to Services for the Child

Theme	Subtheme	Sample Interview Excerpts	*N/39* (% parents)
General development	Negative	"Regression and loss of most learned skills" "The interruption [of EIBI] had a lot of consequences on my child […] it cut short things that were going well."	18 (46,15)
	Positive	"He made a lot of progress."	2 (5,13)
Emotional development	Negative	"She took not being able to see her educator very poorly. We were unable to prepare her for this. She has meltdowns in response to change, so it was a very difficult period."	8 (20,51)
	Positive	"this was a positive period because it is often difficult at preschool because my child is often on time out.	2 (5,13)
Understanding of the Covid-19 situation and changes	Negative	"The lack of explanation is difficult. It is hard to explain to a child with ASD why he cannot go outside, why school is online, why the educators don't come over."	8 (20,51)
Social skills	Negative	"Without services and preschool, he had fewer opportunities to practice his social skills and group skills (instructions, following the group, keeping up with activities)."	7 (17,95)
Challenging behaviour	Negative	"A lot of impact because my child has new behaviours, and I don't know what to do. There are more meltdowns."	5 (12,82)
Language and communication skills	Negative	"very worried about language development"	4 (10,26)
	Positive	"His English language skills have improved because he is spending more time at home."	1 (2,56)

Children's General Development

Eighteen parents (46.2% of the total sample) said that their child had lost competencies, that their progress had been affected, or that they had regressed in terms of skills "acquired a long time ago." Some parents emphasized that these losses were associated with the interruption of services, which “cut short things that were going well” and hindered the “positive evolution” that they had observed in their child over the course of EIBI. Some parents linked some of these losses to the health crisis and the public measures that were put in place to address it, such as the mother who felt that the “health measures” had slowed her child’s learning.

Two parents (5.2%) said that they did not observe any developmental impacts. One of these even said that their child had made progress because the family environment, in the context of the pandemic, had been stimulating for them.

Children’s Emotional Development

Eight parents (20.5%) reported emotional problems in their child during the lockdown period. For instance, one parent said they had observed substantial emotional changes stemming from the abrupt end of their child’s relationship with their EIBI therapist. Other parents similarly stated that not seeing their therapist was a source of anxiety for their children, which was observable in their behaviours: “She took not being able to see her educator very poorly. We were unable to prepare her for this. She has meltdowns in response to change, so it was a very difficult period.” In contrast, two parents (5.2%) mentioned a positive aspect to this interruption of their routine. One said “this was a positive period […] my child is often on time out. This gave us a break.”

Children’s Understanding of the Covid-19 Situation and Changes

Eight parents (21.5%) mentioned that their child had difficulty understanding the changes that took place as their EIBI services were interrupted and in relation to the global pandemic: “It is hard to explain to a child with ASD why he cannot go outside, why preschool is online, why the educators don’t come over.” In this subtheme, parents reported that their child was confused by the absence of providers normally present in their lives, social distancing measures, mask wearing, the interruption of preschool, and fewer outings.

Children’s Social Skills

Seven parents (17.9%) felt that the pandemic situation had repercussions on their child’s social skills. This was attributed, for example, to the fact that discontinuing services also halted socialization, reduced stimulation, and cut off some opportunities for interaction with others. Some parents noted that their child’s social skills had been affected, namely in relation to competencies needed to function well in a group(e.g., listening to instructions). Difficulties in interacting with others prior to the pandemic had been amplified. For three parents (7.7%), the return to social settings between the lockdown periods created some difficulties and required some adjustments. In contrast to these experiences, two parents (5.2%) said that their child, who is generally sociable, was eager to return to these environments.

Children’s Challenging Behaviour

Five parents (12.8%) discussed their child’s behaviour problems (e.g., their nature and frequency) in relation to the pandemic situation. In some cases, parents reported that new challenging behaviours had emerged: “my child has new behaviours and I don’t know what to do. There are more meltdowns.” A mother speculated that her child might have continued to make progress with EIBI, had this service not been interrupted: “behaviours could have improved further before enrolling in school.”

Children’s Language and Communication Skills

Four parents (10.3%) mentioned “more difficult communication” or “poorer communication” with their child. A parent said they felt “very worried about language development” in their child.

Consequences of Pandemic-related Changes to Services for Families

When parents were asked about the impact of the pandemic situation and related changes to services for their child, 90% spontaneously shared impacts on the family overall. They mentioned 1) changes to family life and routines, 2) changes in parenting practices, and the 3) adoption of advocacy practices to receive services (see Table 5). In communicating these ideas, respondents also alluded to factors that exacerbated the negative impact of EIBI interruption and to others that acted as facilitators during this period.

Table 5

Consequences of Pandemic-related Changes to Services for the Families

Theme	Subtheme	Sample Interview Excerpts	N/39 (% parents)
Changes to family life and routine	Negative	“We were putting pressure on ourselves to replace all the stimulation he was getting at daycare, at preschool, and with his educator in addition to having to work and keep the children busy at the same time.” “Forced to stop working for over two months due to the end of [EIBI] services” “My husband was an essential worker; it was difficult to be alone with the kids.”	29 (74,36)
Changes to parenting practices	Negative	“The mother had to look online (educational tools and activities) to try to help him.” “It was a heavy burden to try to recreate with [my child] the services we used to have.”	9 (23,08)

Theme	Subtheme	Sample Interview Excerpts	N/39 (% parents)
	Positive	"I adapted, used my knowledge to help my child every day and to start school." "Otherwise, I learned to keep busy and keep my children busy. I see this as a positive for this reason. I had to work on my patience and find ways to keep busy."	7 (17,95)
Adoption of advocacy practices		"During the pandemic, the mother had to make several phone calls to register [our child] in a specialized classroom (for ASD) without the help of [service agency]. She did this throughout the summer of 2020 and it was a long and complex process."	7 (17,95)
Factors that exacerbated families' difficulties	Isolation	"We had to deprive ourselves of family […] We could not celebrate birthdays as a family."	10 (25,64)
	Employment, finances, academics	"Lately, the father's job loss was another element that added stress for the mother and within the family." "The mother was going to school remotely, she found this difficult but she was able to get through it."	7 (17,95)
	Loss of support from immediate family	"[Because I am a single mother] there was no one to look after him [romantic breakup] was a difficult period, I had no support."	5 (12,82)
	Number of children at home	"Much more responsibility on my shoulders because I have five children." "Because we also have a second child with ASD, ADHD, and Tourette syndrome"	3 (7,69)
	Health concerns	"The mother also had a surgery [another surgery] for cancer on April 31st, so that was really difficult."	5 (12,82)

Theme	Subtheme	Sample Interview Excerpts	N/39 (% parents)
Factors that facilitated families' adjustment		"Financially speaking, we were not impacted, my partner continued to work." "the father being involved directly in this process" "support from the grandmother" "A good collaboration with employers, that was really helpful" "At the beginning of the pandemic, small-group gatherings were permitted so things were going well."	6 (15,38)

Note. EIBI = early intensive behavioural intervention, ASD = autism spectrum disorder, ADHD = attention deficit/hyperactivity disorder.

Changes to Family Life and Routines

The interruption of EIBI services, along with the lockdown, led to changes in families' organization and habits, which had negative effects for 29 parents (74.4%). Fifteen parents (38.5%) said that their or their child's routine was disrupted. For examples, some parents shared that they had to "juggle with uncertainty," "change course," and "adjust constantly."

Thirteen parents (33.3%) reported challenges related to work-family balance. They reported feeling overloaded by their children's constant presence at home and having to "wear many hats at this critical juncture." Parents who were working remotely reported that they had to learn to do so while simultaneously caring for their children. Seven parents (17.9%) had to quit their job temporarily or permanently to do the same in the absence of childcare services or facilities.

Changes in Parenting Practices

Nine parents (23.1%) said that the interruption of their child's intervention made them responsible, or feel responsible, for replacing the work of professionals at home: "All the objectives laid out in the intervention plan had to be accomplished by the mother, alone" or "We had to try to replicate the services we previously received for our child." Some parents explained that they received a "game plan" devised by professionals but nonetheless felt challenged by their own limitations.

Alongside these difficulties, changes in parenting practices were said to have beneficial effects on the family by seven parents (17.9%). Some took these disruptions as an opportunity to spend quality time with their child and facilitate their learning, for instance by providing more stimulation than they had prior to the lockdown. Some parents said they had learned to care for their child and keep their child occupied by using their own resources: their knowledge, creativity, and ability to adapt to changing circumstances.

Adoption of Advocacy Practices

Seven parents (17.9%) said they had to advocate for their family and take a critical stance toward the interruption of services in response to the Covid-19 pandemic. All seven mentioned that they had decided to speak up for their child's right to interventions or to provide these themselves. For instance, one mother took it upon herself to plan for her child's transition to a specialized classroom without the help of professionals, which was a long and complex process. Four others (10.3%) also decried the lack of resources at their disposal and the necessity to seek out help for themselves or else be left without services. More generally, two parents (5.1%) questioned the inconsistency of health measures, for instance that "restaurants were allowed to reopen but my child with special needs cannot receive a service," and concluded that "vulnerable children paid the price during the pandemic."

Factors That Exacerbated Families' Difficulties Or Facilitated Their Adjustment

Nineteen (48.7%) parents reported several challenges in addition to the interruption of services and the pandemic situation, namely 1) social isolation (25.6%); 2) repercussions on their financial situation, work, or studies (18.0%); 3) loss of support from immediate relatives (13.0%); 4) physical health problems (12.8%); 5) the number of children at home (7.7%); 6) attitudes of the population toward children with ASD's difficulty in complying with Covid-19 measures (2.6%).

On the contrary, six parents (15.4%) spontaneously mentioned the resources that facilitated their experience during the pandemic, namely their work (10.3%) and social support from close family members (7.7%).

Consequences of Pandemic-related Changes on Parents' Psychological Health

Thirty-six parents (92.3%) discussed their psychological well-being when the topic of the repercussions of the pandemic on their psychological well-being was raised. Twenty-six parents (66.7%) shared negative consequences on their well-being. However, 21 parents (53.8%) raised positive elements or discussed the use of resources and coping skills.

Parents' Mental Health and Difficult Emotions

The pandemic situation elicited difficult emotions in 26 parents: 1) stress and distress, 2) a sense of abandonment; 3) sadness or depression, 4) fatigue or exhaustion, 5) struggle or powerlessness; and 6) disappointment. For the first subtheme, twenty-five parents (64.1%) expressed having experienced stress or distress as well as fears, uncertainty, or anxiety in relation to their child's development, the pandemic, or their own professional situation. For one family, the elevated stress levels brought conflicts at home. For the second subtheme, twelve parents (30.7%) felt they were excluded from the rest of society. For example, a mother said "we no longer feel important, it is as though we no longer exist." In the third subtheme, eight parents (20.5%) evoked feelings of "sadness" or "depression." They mentioned lacking motivation or experiencing a "blow to morale" that in some cases reached the level of burnout. Some parents sought counselling or medication. In the fourth subtheme, seven parents (17.9%) reported feeling tired, having less energy, experiencing "less than optimal physical health" or "precarious health," or being unable to do anything due to all the effort expended to "endure the situation." In relation to these ideas, two parents (5.1%) said they had less patience with their children. In the fifth subtheme, seven parents (17.9%) said that they struggled or felt powerless: "feeling powerless in the face of the situation," "A great feeling of helplessness lives in us". The sixth subtheme consisted of testimonials from five parents (12.8%) reported feeling disappointed more broadly, such as the mother who discussed "seeing that the government prioritized the welfare of some sectors and abandoned youth with special needs."

As a second subtheme, six parents (15.4%) said the pandemic had little effect on their psychological well-being.

Parents' Resilience in Facing Adversity Related to the Pandemic

Twenty-one (53.8%) parents discussed how they maintained their psychological health when facing adversity. They did so by 1) developing their personal resources and 2) by being understanding. Twelve parents (30.7%) called upon or bolstered their resources and competence to adapt to change, for instance in anticipation of further lockdown periods. Some said that they learned to put their situation in perspective: "We are all in this situation and this is part of our reality at the moment." Some also said that they had been "able to manage, confront, or adapt to their circumstances", or to display "resilience", retain a "sense of balance," and "focus on the positives." This required them to use their "creativity and flexibility," and "to let go." Five respondents (12.8%) emphasized the positive aspects of the situation. For example, a parent said "we are together, it brings us closer together and we can watch them grow up."

For the second subtheme, ten parents (25.6%) said they "understood" the situation and were able to be forbearing with service providers because it "wasn't their fault." Some said that they had to accept the restructuring of public services that took place during the pandemic. This reframing of the situation was nonetheless difficult to achieve: "However, that kind of understanding took a lot of energy."

Discussion

Recent studies have indicated that families of children with developmental disabilities such as ASD were especially vulnerable to the disruptions of formal (e.g., health, social, and educational services) and informal (e.g., extended family, social networks) support systems that were observed across the globe during the Covid-19 pandemic (e.g., Manning et al., 2021). The importance of access to high-quality early intervention services for ASD to ensure children's optimal prognosis is well-documented (Guralnick, 2019; Klintwall et al., 2015; Rivard et al., 2014a). However, families of children recently diagnosed with ASD experienced disruptions, if not a complete interruption, of EIBI services along with other supports during the Covid-19 pandemic. The present study sought to provide insights into the experience of families in Québec during a societal crisis that occurred at a sensitive period in their child's development and the family lifecycle. To this end, it documented the perspective of 39 parents on the impact of the interruption of EIBI in the context of the Covid-19 pandemic.

Children's Development, Access to Early Intervention, and the Pandemic

Prior to the pandemic, the participants in the present study had been receiving, on average, 12.5 hours of EIBI per week from a public agency. The provision of EIBI was abruptly interrupted at the beginning of the pandemic. At that moment, families' formal support was reduced to 0.8 hours per week, primarily in the form of telephone consultations for parents. Thus, families experienced changes in the nature, time, and accessibility of specialized ASD resources. Previous studies have shown that parents are aware of the importance of early intervention for their child's prognosis, particularly in preparation for their transition to school (Rivard et al., 2015; 2020). Therefore, delayed access to EIBI is associated with parenting stress (Rivard et al., 2014b). In relation to changes to services resulting from the pandemic, parents enrolled in the present study feared, or directly observed, a reduced rate of learning in their child, a loss of previously acquired competencies, or an interrupted progression in some developmental domains. Similar concerns were identified in research conducted during the pandemic in other countries, among families of children of various ages (e.g., Meral,2021). Aware of the critical impact of early intervention and the potential consequences of its interruption, parents in the present study reported feeling abandoned by the system. They found themselves without resources to contend with the abrupt end to the formal support their child had previously received. Considering these experiences, it will be important to reflect, over the long term, on strategies to mitigate the negative consequences of crisis situations (such as a global pandemic) on access to early intervention and consequently, on children's development and functioning at school and within the family.

The issue of loss of skills previously acquired in early intervention was also raised in other situations, such as when EIBI is terminated upon children's enrolling in school (e.g., Rivard et al., 2019; Préfontaine et al., 2022). These observations and those of the present study underscore the importance of integrating into interventions such as EIBI mechanisms that would allow children and families to consolidate learning continuously, concurrently with the services they receive. Thus, the goal is to develop a system that builds and bolsters parenting skills conducive to the optimal development of children with special needs and to family adjustment more broadly (Mello et al., 2022). Several studies emphasize a need for training programs that are adapted to parents' unique situation and help them intervene with their child in their natural environment (e.g., Abouzeid et al., 2020; Gore et al., 2022). However, as observed in the present study and in several others, parent-mediated or parent-delivered interventions cannot be the only solution, as these require substantial investment from parents who are already juggling multiple responsibilities (see Granger et al., 2012; Grindle et al., 2009).

Another important concern by parents raised in relation to the disruption of specialized ASD services was the drastic decrease in the diversity and scope of interventions and supports provided to them. As some participants alluded to in their testimonials, prior to the pandemic, children and families were accompanied by a multidisciplinary team, which included a range of professionals according to their specific needs (e.g., nutritionists, physical therapists). This enabled them to receive highly individualized and multicomponent EIBI services and related supports, for instance from specialists for food selectivity or for motor or coordination problems that are not planned as part of EIBI programs. In losing access to their multidisciplinary teams, parents had to find solutions for existing issues or new difficulties that emerged during the pandemic that would they have otherwise been able to discuss with experts.

The Transition to School During the Pandemic

For parents of young children with ASD who would soon enroll in kindergarten, the potential impact of discontinuing EIBI on their child's integration in school was an important preoccupation. Thus, several parents raised concerns about this upcoming change. They felt they had been deprived of a service that could have ensured the best chance of a smooth transition into the school system and, with it, of the opportunity to receive professional support to intervene with their child during a critical period. This heightened sense of discontinuity in services during the transition to school may have contributed to negative experiences for children and their families.

Planning for a child's transition to school includes specific interventions that focus on child readiness, but also requires adjustments on the part of parents and the family (Chatenoud et al., 2022; Marsh et al., 2017). In the present study, parents were especially concerned about the loss of professional guidance on this subject that coincided with the interruption of EIBI. Even under normal circumstances and with typically developing children, a child's first year in school is a period rife with strong emotions, expectations, and worries for all parties involved; the pandemic situation may have heightened this stress for many families. However, at least some parents experienced the opposite phenomenon: the pandemic and associated lockdown measures created a sort of "pause" that gave them the opportunity to work with their child and prepare them for the transition to school.

Families' Well-being in a Pandemic

When parents were asked about the impact of the pandemic on their family's overall adjustment, one of the main themes they discussed was their own mental health and feelings. The stressful context of a pandemic paired with constantly changing health and shelter-in-place measures, the abrupt changes in access to formal and informal support, and financial stressors were perceived as intense for the participating families. This was especially the case when consideration that throughout the pandemic they also had to help their children adjust to these changes and provide them education and intervention. Prior to the pandemic, the mental health and adjustment of parents of children with ASD had already been associated with the behavioural manifestations of ASD (Mello et al., 2022; Patel et al., 2022), the systemic barriers families face in accessing services (Brewer, 2018; Rivard et al., 2021), social exclusion (Brewer, 2018), and financial or employment challenges (Courcy & des Rivières-Pigeon, 2013). The pandemic and lockdown measures created a context in which these multiple risk factors for poor mental health were pooled together and exacerbated. "Having to wear many hats" was frequently mentioned by participants as a source of difficult emotions and stress. Parents had to take on multiple roles at home, by themselves, to minimize negative impacts on their child's development. They felt pressured to act as EIBI therapist, for which they had not been trained or prepared in any way, in addition to their other family responsibilities. The pandemic also created other disruptions to family life, such as the need for some parents to put work on hold to care for their children at home or to educate themselves on intervention practices. As reported by other studies, several parents in the present study would have benefited from telehealth support to better meet their child's educational needs during this period but also to respond to their own needs (e.g., peer support groups, psychological counseling and social work services).

For some parents, the shift in EIBI service provision was accompanied with more positive perceptions of the parent-provider partnership: they felt that what limited support was given to them was offered with empathy and a genuine desire to help despite limited resources. This attitude had a determining impact on how families responded to the interruption of EIBI and their appreciation of the initiatives that were implemented to fill this gap. This observation is consistent with the literature's emphasis on providing education and early intervention services based on a family-centred model, which is responsive to parents' needs and seeks to support their own competencies on a day-to-day basis (Sukkar et al., 2017). The findings of the present study echo those of work conducted prior to the pandemic in suggesting that the parent-provider partnership that develops in the context of child-centred interventions, when it is based on trust, mutual respect, commitment, and open communication, may act as a protective factor for families experiencing difficult situations (e.g., Rivard et al., 2020). The pandemic thus highlighted not only many existing and new problems for families and ASD service provision, but also essential ingredients to provide high-quality support to families of children with ASD, namely the strong collaboration between educators and parents toward a shared goal of supporting the child's development.

Limitations

The ability to generalize the findings of the present study is limited by its small sample size and the specificity of the situation experienced by participants. Additionally, it should be noted that participants had initially volunteered to take part in a longitudinal study and, subsequently, agreed to additional ad-hoc data collection related specifically to Covid-19. These parents may not be representative of the broader population of families receiving EIBI services in that they are likely to be especially invested in their child's services and, for example, more actively involved in advocacy. Furthermore, the sample as a whole presented a slightly higher level of education that the population of the province. However, a strength of the study is the wide range of income levels and national origins of participants, which reflects the diverse body of service users.

Conclusion

The experiences and testimonials of parents in the present study emphasize the importance of developing or improving formal supports centred on the needs of families of children with ASD. This perspective requires providers to look beyond the organizational constraints and obstacles that are typically present and can be exacerbated by crises such as the Covid-19 pandemic. These findings also point to the importance of positive parent-provider partnerships in not only promoting the development of children with ASD, but also bolstering their caregivers' resourcefulness and strengths. Thus, early intervention should be seen as an opportunity to pool resources (i.e., parents' and professionals') toward a common goal. This also means that parents' experience and competence can play a facilitating role in other families' service trajectory (for initiatives in line with this idea, see Gore et al., 2022).

Key Messages from this Article

People with Disabilities: The pandemic was difficult for everyone. You and your family have the right to advocate for help and support that meets your needs in difficult times.

Professionals: Disruptions of formal and informal support during Covid-19 were particularly difficult for families of young children with autism. Children who received a diagnosis during the lockdown period were unable to receive early intervention and services before their transition to school.

Policymakers: Pandemic-related disruptions of early childhood autism services had substantial impacts on child development, family dynamics, and parental mental health. It is imperative to develop long-term strategies to mitigate these negative consequences.

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Messages clés

Personnes en situation de handicap : La pandémie de Covid-19 a été difficile pour beaucoup de familles et de personnes. Votre famille et vous-mêmes avez droit à l'aide et au soutien qui répondent à vos besoins dans les moments difficiles comme lors de la pandémie.

Professionnels : L'interruption abrupte des soutiens formels et informels pendant la Covid-19 ont été particulièrement difficiles pour les familles de jeunes enfants autistes et les services doivent s'adapter à cette situation. Notamment, beaucoup de familles ayant reçu un diagnostic près de la période pandémique n'ont pas pu recevoir les services d'intervention précoces avant l'école, services importants pour le pronostic des enfants et des familles.

Décideurs : Les perturbations dans la dispensation des services spécialisés en autisme et en petite enfance liées à la pandémie ont eu des répercussions importantes sur le développement de l'enfant, la dynamique familiale et la santé mentale des parents. Il est impératif d'élaborer des stratégies à long terme pour atténuer ces conséquences négatives.

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