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Effects of a Low Intensity, Parent-Delivered Early Start Denver Model Intervention for Families of Children with Autism Spectrum Disorder in Quebec

Effets d'une intervention à faible intensité médiée par les parents basée sur le modèle précoce de Denver pour les familles d'enfants présentant un trouble du spectre de l'autisme au Québec

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Abstract

Parent-delivered, low-intensity interventions such as the Early Start Denver Model (ESDM) could provide a cost-effective solution to excessive delays between a diagnosis of autism and the provision of early intensive behavioural intervention. In this proof-of-concept study conducted in Quebec, 18 families participated in a 13-week ESDM-based training and coaching intervention. Some improvements were observed in terms of children's developmental skills and, to a lesser degree, challenging behaviours. Parents' teaching skills (intervention fidelity), parental sense of competence, and family quality of life also improved between baseline and the end of the program. These preliminary findings are promising and indicate an appropriate level of readiness to conduct the second phase of the evaluation of ESDM for parents (i.e., P-ESDM).

Résumé

Les interventions à faible intensité médiées par les parents tels que le programme de coaching parental basé sur le modèle précoce de Denver (P-ESDM) pourrait offrir une solution économique et efficace en réponse aux longs délais d'attente entre l'obtention d'un diagnostic de trouble du spectre de l'autisme et l'accès à des services d'intervention comportementale intensive précoce. Cette étude de preuve de concept

réalisée au Québec a évalué les effets d'un programme, basé sur le P-ESDM, offert à 18 familles pendant 13 semaines. Des améliorations des habiletés développementales des enfants et, dans une moindre mesure, de leurs comportements problématiques ont été observées. Les habiletés d'intervention des parents (fidélité d'intervention), le sentiment de compétence parentale ainsi que la qualité de vie familiale se sont également améliorés entre le niveau de base et la fin du programme. Ces résultats préliminaires sont prometteurs et indiquent un niveau de préparation approprié pour mener la deuxième phase d'évaluation du programme de coaching parental basé sur l'ESDM (P-ESDM).

Mots-clés : trouble du spectre de l'autisme, coaching parental, intervention médiée par les parents basé sur le modèle précoce de Denver, jeunes enfants

Introduction

The worldwide prevalence of autism spectrum disorder (ASD) has dramatically increased in recent decades. Its rate is now estimated at 1 in 54 in the United States (Knopf, 2020). According to the 2019 Canadian Health Survey of Children and Youth (Public Health Agency of Canada, 2022), 1 in 50 children and youth aged 1 to 17 years were diagnosed with ASD. This coincides with a growing pressure on public health agencies to provide support, diagnostic evaluations, and adapted interventions to families and their young children with ASD. The increasing demand for services is difficult to fulfill with available resources, which limits access to the recommended assessments and interventions and thus leaves a large number of families without support and in distress (McKinsey & Company, 2014; Quebec Ombudsman, 2015). In Quebec, as elsewhere in the world, health and social services institutions offer early intensive behavioural intervention (EIBI). However, in many jurisdictions, families may wait up to four years to access these services (Gordon, 2012; McKinsey & Company, 2014) even though it is recommended that a child receive early intervention services no later than 60 days after confirmation of their diagnosis (Maglione et al., 2012). Whereas the provision of early and intensive intervention facilitates treatment and improves the prognosis of children (Dawson et al., 2008; Klintwall et al., 2015), delayed access has deleterious effects on their development and their parents' well-being (Klintwall et al., 2015; Rivard et al., 2014). During these waiting periods, families feel helpless and have little information to intervene with their child on their own (Abouzeid & Poirier, 2014a, 2014b, 2014c; Flanagan et al., 2012; McKinsey & Company, 2014).

Offering interim services consistent with good practices is imperative to overcome this clinical crisis. In line with the importance of raising parental awareness and involvement, parent-delivered early interventions are emerging as possible solutions to the extended waiting periods between diagnosis and access to EIBI (Rivard et al., 2017b). This approach enables treatment to begin early and families to benefit from support and families to benefit from support as soon as possible. This support is especially important at the time of the child's diagnosis, a period of heightened parental stress (Rivard et al., 2014). Indeed, families must then learn to respond to the new diagnosis, but also to navigate a complex network of services while facing the challenges of reconciling work, family, couple, and care for their child with ASD (Corcoran et al., 2015).

Studies have shown positive results of parent coaching on children's communication behaviours (Green et al., 2010; Kasari et al., 2010; McConachie & Diggle, 2007; Oono et al., 2013; Pickles et al., 2016; Wetherby et al., 2014) and developmental skills, as well as on parents' interaction skills with their child (Rogers et al., 2012b). Although the body of literature on this topic remains small, evidence to date suggests that parent-delivered interventions could help alleviate parents' distress (Estes et al., 2012; Sealy & Glovinsky, 2016), improve parental sense of competence (Estes et al., 2014), and produce significant improvements in the core symptoms of ASD (Oono et al., 2013). This study aimed to evaluate a low-intensity parent coaching program based on current best practices. Specifically, it sought to assess its potential impact on parents and children when it is provided to families shortly after a diagnosis of ASD (i.e., while they are on a waiting list for EIBI). The intent of these types of programs is not to replace EIBI, but to provide support and tools to parents as they await intensive interventions.

Early Intensive Behavioural Intervention and Early Start Denver Model

Among interventions for young children with ASD, there is extensive empirical evidence that EIBI can exert a positive influence on child development and thus reduce the social, financial, and family impact of their diagnosis (Makrygianni et al., 2018; Prior et al., 2011; Reichow et al., 2012; Warren et al., 2011; Weitlauf et al., 2014). This type of intervention is designed to help children with ASD acquire various adaptive and functional skills as well as to reduce challenging behaviours. The term EIBI encompasses several intervention programs that meet specific parameters: 1) early entry (before the age of 5); 2) sufficient intensity (minimum of 25 hours per week); 3) use of a structured curriculum, based on the principles of applied behavioural analysis (ABA) and evidence; 4) specialized training for stakeholders; 5) a low stakeholder-to-child ratio; 6) continuous assessment of progress; and 7) parental involvement (National Research Council, 2001). EIBI is implemented within public services across several Canadian provinces, including Quebec, Ontario, and British Columbia (INESSS, 2014; Perry et al., 2008; Rivard et al., 2014).

Among the programs that correspond to the parameters for EIBI, the Early Start Denver Model (ESDM; Rogers & Dawson, 2010), is one of a few that are designed for a very young clientele: It can be delivered as early as 18 months up to 48 months. Like all EIBI programs, ESDM derives from the principles of the ABA, but it also comprises elements of developmental psychology (Rogers & Dawson, 2013; Schreibman et al., 2015, Vivanti et al., 2014). This intervention takes root in the child's natural living environment to seize learning opportunities on a daily basis. It follows a manualized curriculum according to a precise developmental sequence and targets specific areas of development typically affected in children with ASD (Rogers & Dawson, 2013). The ESDM was first developed so that its intervention strategies could be applied by therapists. This program requires users to receive specific training to implement it, use the curriculum checklist, and understand the different spheres of development involved. Several studies, including randomized controlled trials, have documented the effectiveness of this program by noting improvements in both parents (e.g., parental stress, sense of competence, well-being) and children with ASD (e.g., communication skills, challenging behaviours) compared to community-based interventions (i.e., ABA, individual occupational or speech therapy, and group interventions; Dawson et al., 2010; Estes et al., 2014; Rogers et al., 2012b).

In a study by Dawson et al. (2010), 48 children diagnosed with ASD between the ages of 18 and 30 months were randomly divided into two groups: one group received the ESDM intervention

and the other received any other interventions available in the community. Each week, the first group received 20 hours of interventions by a certified therapist and 5 hours of interventions delivered by parents at home. The control group averaged 9.1 hours of individual interventions and 9.3 hours of various group interventions per week. Data were collected at the beginning, after one year, and then after two years of these interventions. The ESDM group showed a significant increase in terms of intelligence quotient (IQ) at the one- and two-year outcomes as well as significant improvement in terms of adaptive behaviour and diagnosis status at the two-year outcome. The ESDM group also demonstrated improvements in overall communication, autonomy, and motor skills at the two-year outcome (Dawson et al., 2010). To assess whether the gains made during the study by Dawson et al. (2010) were maintained over time, a follow-up study was carried out by Estes et al. (2015). At the time, the children were on average six years old and had completed their respective interventions two years prior. Children in the ESDM group maintained their gains in adaptive behaviour, IQ, autism symptoms, and problem behaviour. They also displayed better social skills and less severe autism symptoms in general than the control group who had received various interventions available in the community; these differences between groups were not immediately noticeable at the end of treatment (i.e., at the time of the original study by Dawson et al., 2010; Estes et al., 2014). It was suggested that the natural learning context provided through ESDM interventions facilitated children's learning in less structured contexts, and thus made one-on-one intervention less necessary (Estes et al., 2014).

Parent Training and Coaching Programs

Extended delays and waiting lists for EIBI services, which include ESDM, pose a real challenge for service providers. They face the dilemma of prioritizing exposure to quality interventions for all children, avoiding delays, and responding to a diversity of clinical profiles and family situations. Due to a lack of resources, they must choose between serving fewer families consistently with quality standards and best practices or serving a larger number of families but offering supports of insufficient intensity. For this reason, in the last decade parent training and coaching programs have been offered as alternative models to support families of children with ASD while they await EIBI (NICE, 2016; Oono et al., 2013; Rivard et al., 2017b). Coaching parents promotes their involvement and supports their implementation of strategies designed to promote the development of their child (McConachie & Diggle, 2007). To date, studies of parent training and coaching programs have shown positive outcomes including increased parents' knowledge of ASD, improved relationships and the synchronicity of interactions within the family. These studies also were associated with high levels of satisfaction with services received (McConachie & Diggle, 2007; Oono et al., 2013; Patterson et al., 2012; Rivard et al., 2017b). However, the effects of these programs on the developmental abilities of children with ASD and on parental stress remain to be demonstrated (NICE, 2016; Oono et al., 2013; Patterson et al., 2012; Rivard et al., 2017b). In order to address the core symptoms of ASD, these parent training and coaching programs must be enhanced by considering the active ingredients of EIBI programs; however, their service delivery parameters must also be realistic for practice settings with limited resources.

Parent coaching services presents themselves as economical solutions to address issues of access and efficiency within public services and thus reduce the negative effects of EIBI waiting lists on children's development and their families (Cidav et al., 2017; Penner et al., 2015; Pickles et al.,

2016; Smith et al., 2008). Recent studies suggest that ESDM intervention strategies can be implemented by parents and may maximize learning opportunities in families' daily lives in the absence of specialized services (Estes et al., 2014; Rogers et al., 2019). These studies have shown significant gains in child development as well as parenting stress levels and sense of competence with a reduced-intensity parent coaching program (one hour of coaching per week; Estes et al., 2014; Rogers et al., 2019; Zhou et al., 2018).

Parent-Delivered Early Start Denver Model (P-ESDM)

The P-ESDM is a parent-delivered intervention program based on the ESDM. It is a manualized program that teaches parents of young children with ASD (18 to 48 months) simple and effective intervention techniques to help their child interact, communicate, and learn (see Rogers et al., 2012a, 2016) through play activities and sensory and social routines (Rogers & Dawson, 2013). Parents are taught to use these intervention strategies at home in their daily lives. The program addresses core deficits of ASD and all other areas of a child's development, including language, social, play, cognitive, motor, and self-help skills. It helps parents 1) capture their child's attention; 2) have fun with sensory social routines; 3) build back-and-forth interactions; 4) improve their child' nonverbal communication; 5) help their child learn by imitating; 6) develop joint attention; 7) engage in flexible and varied play activities; 8) develop pretend play skills; and 9) promote language development. A trained professional uses the ESDM curriculum checklist (CC) to assess the child's level of development. Then, this coach works with the child's parents to develop an intervention plan to target deficit areas and teaches them to use strategies to improve specific domains. This program is therefore a form of parent coaching: The majority of intervention strategies will be applied at home by parents, who are supervised on a weekly basis by their coach. During these supervision sessions, the coach provides feedback on the strategies taught to and used by the parents.

To date, a small number of controlled trials on the P-ESDM have yielded promising findings in terms of parenting stress and ASD core symptoms (Dawson et al., 2010; Estes et al., 2014; Rogers et al., 2012b). Several studies have examined the effects of P-ESDM on children's intellectual functioning, adaptive behaviour, language, core symptoms of ASD as well as parents' working alliance, stress, and parental sense of competency.

Early in the development of ESDM, Vismara and Rogers (2008) demonstrated that a 12-week P-ESDM curriculum with a 9-month-old baby showing signs of ASD significantly improved the child's vocalizations, imitation behaviours, engagement in social interactions, and eye contact. This case study underscored the potential value of teaching parents specific techniques to strategically interact with their child at risk for ASD (Vismara & Rogers, 2008).

Rogers et al. (2012b) performed a randomized controlled study in which 98 children identified as being at risk for ASD received either services available in the community or low-intensity P-ESDM. In both groups, parents' interaction skills improved and their children acquired new developmental abilities. However, parents in the P-ESDM group developed a stronger working relationship with their coach than parents in the community group (Rogers et al., 2012b). At the end of the study and according to parents' reports, the community group ultimately received more hours of intervention than the P-ESDM group. Most programs offered in the community included a form of parent coaching that may be similar to that of ESDM (Rogers et al., 2012a), which could also explain the lack of significant differences between groups. An important

finding nonetheless emerged from this study: children's age and the number of hours of intervention were correlated with the degree of improvement observed. Indeed, the younger the child and the more intensive the intervention, the greater their developmental, behavioural, verbal, and non-verbal gains (Rogers et al., 2012b). This observation further highlights the importance of early detection and intervention on signs of ASD.

Estes et al. (2014) focused on the impact of P-ESDM on parents, specifically their parental stress and sense of competence, within the sample studied by Rogers et al. (2012b). Their study also sought to identify factors that may contribute to these two outcomes in parents of children with ASD. At the end of the 12-week period, parental stress levels remained stable in the P-ESDM group but the control groups had increased relative to baseline (Estes et al., 2014). No changes or between-group differences were observed for parental competence. The two parental outcomes were statistically unrelated to the number of hours of intervention received or negative events. The decrease in stress noted in the P-ESDM group could be explained by the fact that the ESDM promotes collaboration with parents, follows a detailed curriculum, and ensures that parents receive relevant information from a single source (their coach) instead of several providers (e.g., an occupational therapist, speech therapist, psychologist, etc.; Estes et al., 2014).

Context and Rationale for the Present Study

In Quebec, a community-based organization, the See Things my Way Assessment Centre (funded with the support of the Miriam Foundation), that exclusively provided diagnostic assessment services to families of young children identified a need for complementary developmental interventions. Indeed, although the scientific evaluation of the implementation and social validity of its assessment services (intended to address waiting lists for ASD evaluations in the region) indicated high levels of satisfaction, families expressed urgent need for prompt post-diagnostic services. In order to meet these needs, the organization chose to implement and provide P-ESDM, as a pilot project, to families who recently received a diagnosis of autism for their child and were awaiting EIBI services. With the help of the research team, the organization wanted to ensure that the program would bring clinically significant changes and lead to positive outcomes for children and families before implementing it on a larger scale. The P-ESDM has been investigated in a number of studies since 2010, but in contexts that differed from that of the present study. Indeed, most P-ESDM studies were conducted in the United-States with an English-speaking population. These were all generally led by or executed in collaboration with the authors of the intervention program (Estes et al., 2014; Hernandez-Ruiz, 2020; Rogers et al., 2012b, 2018; Vismara et al., 2012, 2018; Zhou et al., 2018). Moreover, these studies' samples tended to be small (n = 1 to 50) and not ethnically diverse, which limits the external validity of this body of research. Finally, all were carried out in university-based clinics or hospitals, with the exception of two studies that evaluated the effects of parent coaching via tele-practice. The purpose of the present study, conducted in Montreal, Quebec, by a research team that was independent from the authors of P-ESDM, was to contribute generally to the results of previous studies and also to confirm relevance of the P-ESDM for French-speaking and multicultural communities.

Systematic Evaluation of a Parent Coaching Program

Our team has adopted a systematic evaluation framework, based on the Obesity-Related Behavioral Intervention Trials (ORBIT) model of behavioural treatment development (see Czajkowski et al., 2015). The ORBIT framework proposes an approach of progressive optimization to develop and evaluate complex, evidence-based behavioural interventions to prevent and treat chronic diseases. It includes four phases. Phase I, Intervention design, aims to define (Phase Ia) the clinically significant milestones and to refine (Phase Ib) the components of the intervention to proceed to preliminary testing (Phase II). In our case, during Phase I, the research team performed a scoping review to identify parent-delivered program options with demonstrated impacts on child development and parental adjustment. A committee of researchers and clinicians with ASD expertise identified the P-ESDM as a potential approach to meet the needs of families of young children with ASD. In this first phase of evaluation, the program was implemented as originally defined by its authors among 11 families (Mestari, 2017). The examination of families' experiences guided revisions to the program, which yielded a definitive intervention model for the subsequent steps of the evaluation process (Phase Ib: Refining the intervention; Abouzeid & Lopes, 2017). The revised intervention protocol included supplemental activities to improve its impact on families (see Method). Following these refinements, P-ESDM was integrated as a post-diagnostic service to support families who had received an ASD diagnosis for their child at the participating community organization.

The goals of Phase II of the ORBIT framework, Preliminary testing, are to determine whether the intervention produces a clinically significant impact on the targeted behaviours (Phase IIa: proof-of-concept) and to assess the feasibility and acceptability of the intervention (Phase IIb: pilot testing). Once these steps have been completed, the intervention is considered ready for an efficacy trial (Phase III) and ultimately, effectiveness research (Phase IV; Czajkowski et al., 2015). The present study is one of two proof-of-concept studies (Phase IIa) performed by the research team. The second proof-of-concept study (Phase IIa) used a quasi-experimental design with five families and showed an increase in challenging behaviours during the postdiagnosis waiting period and a decrease after having received the P-ESDM (Abouzeid et al., 2019). Another, subsequent study (Abouzeid et al., 2020) sought to evaluate the feasibility and the acceptability of the P-ESDM services using the revised intervention (Phase IIb: pilot testing).

Objectives

The purpose of this study was to determine whether the proposed intervention warranted more rigorous and costly testing. It sought to investigate the potential effects of the P-ESDM, implemented in a real-life setting, on children's developmental skills and problem behaviours as well as parents' teaching skills, parental sense of competence (PSOC), and perceived family quality of life (FQOL).

Materials and Methods

The ethics committee of University of Quebec at Montreal reviewed and approved the study protocol. The program was provided to families over a 13-week period at the See Things my Way Assessment Centre.

Research Design

A pretest-posttest design was used to measure the effects of the parent coaching program on children and parent's related outcomes. At intake (T1) and at the end of the 13-week parent coaching program (T2), parents completed questionnaires and children were assessed. Parents' fidelity was measured halfway through the program and at the end of the program.

Participants

Participants included 18 families of toddlers who participated in a low-intensity 13-week parent coaching intervention program based on ESDM. All children were recently diagnosed with ASD by the assessment services team. The evaluation process to establish a formal ASD diagnosis included a diagnostic interview based on the Autism Diagnostic Interview – Revised (ADI-R; Lord et al., 1994) and a standardized observation using the Autism Diagnostic Observation Schedule – Second Edition (ADOS-2; Lord et al., 1989). Intellectual functioning or developmental evaluations, speech and language assessments, motor skills evaluations, and medical exams were also administered to allow for a differential diagnosis and a better understanding of the child's profile. Although the assessment team included speech-language pathologists, occupational therapists, and nurses who contributed to the diagnostic evaluations, only psychologists and developmental pediatricians made ASD diagnoses. At the time of recruitment, children were aged 27 to 44 months (M = 3.1, SD = 0.4); the majority were boys (n = 12). At least one or the other parent (n = 9), if not both (n = 9) of the parents, participated in every step of the 13-week program. Mothers represented 56.7% of our sample and fathers, 43.3%. In one case, the child's grandmother also attended the sessions. When both parents were involved in the intervention, only one of them completed the pre- and postintervention measures. All families spoke English or French as a first or second language, one was bilingual. Many parents in this sample were born outside of Canada (see Table 1 and 2 for additional demographic details).

Table 1

Parents' Characteristics

Variables	Mothers *n* (%)	Fathers *n* (%)
Parents' birthplace		
Canada	5 (27.8)	6 (33.3)
Africa	4 (22.2)	5 (27.8)
Asia (including Middle East)	3 (15.0)	4 (22.2)
Europe	4 (22.2)	2 (11.1)
South America	2 (11.1)	1 (5.6)

Table 2

Children's Characteristics

Variables	*n* (%)	*M* (*SD*)
Age (years)		3.1 (0.4)
Gender		
Boys	12 (66.7)	
Girls	6 (33.3)	
Language		
French	10 (55.6)	
English	7 (38.8)	
French and English (bilingual)	1 (5.6)	
ADOS Total scores		
Toddler Module (*n* = 8)		19.5 (3.5)
Module 1 (*n* = 10)		14.0 (5.7)
Diagnosis		
ASD	10 (55.5)	
ASD with Global Developmental Delay (GDD)	6 (33.3)	
ASD with Attention Deficit Disorder	1 (5.6)	
Provisional ASD	1 (5.6)	

Procedures

Recruitment

Families were recruited through the See Things my Way Assessment Centre. Participants were enrolled in the intervention in two successive cohorts (9 families each). Families were included based on the following inclusion criteria: a) the child was recently diagnosed with ASD, b) aged between 18 and 45 months at the start of the program, c) and on a waitlist for EIBI public services at the time of recruitment; e) families were Anglophone or Francophone; and e) one or both parents could participate. Informed parental consent was obtained for 18 families (toddlers and parents) attending the parent coaching program between May 2016 and November 2018.

Intervention

The intervention was provided in the community-based organization by three of its staff members who had completed postgraduate studies in social work, speech and language pathology, or psychology that met the requirements to deliver ESDM and P-ESDM (ESDM Training Program, 2017). The coaches completed the UC Davis MIND Institute Introductory (1 day) and Advanced (3 days) ESDM workshops. All three had reached satisfactory levels of fidelity. They also had high fidelity of implementation, as assessed in the feasibility and acceptability study (Phase IIb; Abouzeid et al., 2020). Parent coaches attended weekly individual or group supervisory meetings with a Ph.D.-level psychologist trained in ESDM and consulted with a MIND Institute certified trainer who supervised training and implementation of the program. The roles and responsibilities of the parent coaches were defined to ensure the implementation of the program. Parent coaches were to complete a range of clinical activities:

provide support to families throughout the program, complete the initial and postintervention assessments, view the video-recordings, collect data, write clinical notes as well as evaluation and progress reports, and participate in case discussions and interdisciplinary meetings.

The P-ESDM was designed as a 13-week intervention and adapted to the organization's clinical context and resources for ORBIT Phase Ib, as outlined in the introduction. For instance, some activities were added onto the original protocol. These included a family group training on ASD and ESDM principles, an individualized intervention plan, individual meetings with parents to discuss the objectives of the program, teaching steps for parents, data collection by parents, follow-up meetings, and a final progress report. All sessions were conducted individually except for the parent group training. The first and second weekly sessions were used to assess the child's developmental abilities using the ESDM Curriculum Checklist. The third session consisted of a 3-hour parent group training. The fourth session was dedicated to setting individualized objectives and completing the intervention plan with parents. Sessions 5 through 11 consisted of eight one-hour parent-coaching sessions during which the coach introduced theoretical notions and focused on teaching 10 specific intervention strategies to parents as described in the intervention manual (Rogers & Dawson, 2010) through various strategies, including demonstration and modeling. Parents were provided with additional written documentation to support their learning. Session 12 consisted of the postintervention assessment of the child's progress and parents' teaching fidelity (primary outcome measures). Session 13 was a final meeting with parents during which the coach presented the progress of the child over the course of the program, at which time parents were given questionnaires to evaluate the secondary outcome measures.

Measures

Children's Clinical Records

With parental consent, clinical records were obtained through the assessment centre. These provided information on children's characteristics and sociodemographic background (e.g., child's age, gender, diagnosis, and native language).

Primary Outcome Measures

Two primary outcome measures were gathered at intake and at the end of the 13-week program. Both were used in previous outcome studies and support the detection of small, proximal changes. Thus, they were considered valid and reliable measures to examine the effects of the intervention on both the children's and the parents' proximal outcomes. The ESDM CC (Rogers & Dawson, 2010, 2013) was used to capture children's skills acquisition between the beginning and end of the 13 week-program. This criterion-based developmental measure comprises four levels corresponding to children's developmental age and is organized into 11 domains affected by ASD: 1) receptive communication, 2) expressive communication, 3) joint attention, 4) social competency language, 5) imitation, 6) cognition, 7) play, 8) fine motor, 9) gross motor, 10) personal independence, and 11) behaviours during interactions. The gross motor and personal independence domains were previously assessed as part of the formal ASD diagnostic evaluation process and were therefore not evaluated for the present study. The remaining domains were

assessed at intake (T1) over two sessions and again at the end of the program (T2). Items were coded in real time as full pass (2), partial pass (1), and failure (0) during the administration of the checklist. Children's total scores at each administration were then computed by summing the number of full and partial pass scores for all domains across all four levels. A child's achievement rate was then computed by dividing the total score by the maximum score across all four levels. Comparison of these percentages obtained at T1 and T2 provides an indication of the child's overall progress. The ESDM CC is not a standardized instrument; however, it was suggested that the standardized and gold standard diagnostic tools used in other studies may not be suited to detect change occurring over a short period of time (Rogers et al., 2019).

The ESDM Fidelity Rating System (ESDM FRS; Rogers & Dawson, 2010) was used to measure changes in parents' teaching skills. This system consists of 13 observational items, rated on a 5-point Likert scale, developed to measure the administration and fidelity of the implementation of the ESDM techniques and strategies. The observational items are as follows: 1) management of child attention, 2) ABC format, 3) instructional techniques, 4) modulating child affect/arousal, 5) management of unwanted behaviours, 6) quality of dyadic engagement, 7) adult optimizes child motivation, 8) adult use of positive affect, 9) adult sensitivity and responsivity, 10) multiple varied communicative opportunity, 11) adult's language for child's level, 12) joint activity and elaboration, and 13) transition between activities. Parents' fidelity was measured twice: halfway through the program (i.e., at the 4th parent-coaching session, 7th week) and at the end of the program (8th parent coaching session, 11th week). During each of these sessions, parents were allocated some time to interact with their child without any interference from the coach. These sessions were recorded and subsequently rated by research staff using the ESDM FRS. Parents' total scores out of 65 were converted into a percentage indicative of the overall fidelity with which parents applied the ESDM curriculum. Consistently with previous studies, the fidelity target for the intervention was set at 80%.

Secondary Outcome Measures

The parent/caregiver version of the Developmental Behavior Checklist for children under 4 years of age (DBC-Under 4; Einfeld & Tonge, 1995) was used to measure children's social-emotional problem behaviours. Items use a 4-point Likert scale (0 = *never*, 1 = *sometime*s, 2 = *often*, 3 = *always*) which yield a total score (based on 93 questions). Higher scores reveal a higher level of problem behaviours. Einfield and Tonge (1995) reported a satisfactory test-retest reliability coefficient of .83.

The Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston, 1977) was used to measure parental sense of competence. The PSOC is a 16-item, self-report measure that assesses the degree to which a parent feels confident and competent in parenting their child. It employs a 6-point Likert scale for each item. A total score is obtained by adding the results of the two subscales (Satisfaction and Efficacy). Scores vary between 16 and 96, with higher scores reflecting a higher sense of competence. As per PSOC interpretation guidelines (Gibaud-Wallston, 1977), total scores of 80 and above are considered "average". Internal consistencies vary across studies. Johnston and Mash (1989) documented an internal consistency of .75 for the Satisfaction scale and .76 for the Efficacy scale. A more recent study (Lovejoy et al., 1997) reported internal consistencies of .82 and .88 for the Efficacy scale in two samples of mothers with young children.

The Beach Center Family Quality of Life scale measured perceived family quality of life (FQOL; Hoffman et al., 2006; French version by Rivard et al., 2017a). This instrument comprises 25 items rated on a 5-point Likert scale and distributed across five subscales (Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-related Support); taken together, these yield an overall score. The internal consistency of the Satisfaction and Importance subscales were .94 and .88, respectively; test-retest reliability ranged from .59 to .63. Convergent validity with existing measures of family well-being and resources was considered satisfactory (.58.-.87; Hoffman et al., 2006).

A portion of data was missing for parents' teaching skills and secondary outcome measures: ESDM-FRS = 39%, DBC-U4 = 22%, PSOC = 22%, FQOL = 28%. Due to a change in the study design, the assessment of parents' teaching skills was only implemented toward the end of the first cohort, therefore there are missing data for this primary measure. Missing data for secondary measures occurred because four parents did not return the questionnaire (by mail or by dropping them off at the assessment center) at the end of the program; another parent returned the questionnaire but had not completed the FQOL measure. Cases with missing data were omitted from specific analyses based on these measures (i.e., pairwise deletion).

Data Analysis

Descriptive quantitative data analyses were performed to examine children's developmental skills and problem behaviour as well as parents' teaching skills, sense of competence, and family quality of life. The mean score, standard deviation, and range were computed for each instrument and compared between T1 and T2, with the exception of the ESDM FRS which was rated halfway through the program (7^{th} week) and at T2. Because the small sample size did not support parametric testing, Cohen's *d* and *h* were used to quantify the size of the difference in scores between the two measurement periods for each measure; effect sizes greater than *d* or $h = 0.20$, 0.50, and 0.80 were considered small, moderate, and large, respectively (Cohen, 1988). Correlation coefficients of $r = .10, .30, .50$, respectively, were interpreted as indicative of small, moderate, or large associations between variables. The unstandardized mean difference (M_D) and standard deviation of the difference (SD_D) between T1 and T2 are also reported in the text.

Results

Primary Outcomes

Children's Developmental Skills

Based on the ESDM CC scores shown in Table 3, an 8.8-percentage point increase ($SD_D = 13.2$), corresponding to a moderate effect size, was observed in children's overall developmental skills; effect sizes ranged from small to moderate across areas. The largest change, a 12.5-percentage-point increase ($SD_D = 13.7$), was observed in the Receptive Communication domain, whereas the smallest difference, a 9.4-percentage-point increase ($SD_D = 30.9$), was observed in Imitation Skills.

Parents' Teaching Skills

Results for teaching skills, which were assessed for 11 parents, are displayed in Table 4. Although not all parents had reached fidelity in this short period of time, there was nonetheless a large increase (M_D = 11.5, SD_D = 11.3) in their overall teaching skills on the ESDM FRS from the 4th session to the end of the program. For some parents, it had increased significantly to achieve the 80% fidelity criterion by the end of the program (M = 79.4, SD = 9.3). There was a moderate increase in the proportion of parents who attained this criterion between baseline (18.2%) and the end of the program (45.5%, Cohen's h = 0.6). All abilities had improved by the end of the program, with effect sizes ranging from moderate to large. The greatest changes were observed in parents' management of the child's attention (M_D = 1.1, SD_D = 0.8), instructional techniques (M_D = 1.1, SD_D = 0.9), modulating of child's affect (M_D = 1.3, SD_D = 1.7) and arousal, as well as management of unwanted behaviours (M_D = 1.4, SD_D = 1.4).

Secondary Outcomes

Children's Problem Behaviours

Fourteen out of 18 families completed the DBC-U4. As seen in Table 3, a 4.6-point (SD_D = 14.2) decrease in problem behaviours, corresponding to a small effect size, was noted between T1 and T2.

Parent Sense of Competence

Fourteen families completed the PSOC scale. As per PSOC interpretation guidelines (Gibaud-Wallston, 1977), mean scores were considered "average" at both T1 and T2, but sense of competence showed a 1.3-point (SD_D = 6.7) increase over time, corresponding to a small effect size. An examination of subscale scores indicates that this shift was attributable to an increase in satisfaction (M_D = 1.6, SD_D = 5.0), with efficacy remaining fairly stable (M_D = -0.3, SD_D = 4.4).

Family Quality of Life (BEACH-FQOL)

Thirteen families completed the BEACH-FQOL scale. As seen in Table 4, parents' mean total satisfaction with FQOL showed a 0.2-point increase (SD_D = 0.3) over time, corresponding to a moderate effect size. Large increases were observed for the Parenting (M_D = 0.4; SD_D = 0.5) dimension of FQOL; satisfaction with other aspects of FQOL remained stable.

Relations Between Primary and Secondary Outcomes

Children's developmental skills as measured by the ESDM CC were correlated with mother's intervention skills (r= .47), both parents' sense of competence ($r_{mothers}$ = .44, $r_{fathers}$ = .41) and children's problem behaviours (r = -.49). In addition, the development of mothers' intervention skills was correlated with an improvement in FQOL (r = .85).

Table 3

Descriptive Statistics and Effect Sizes for Child Outcome Variables at T1 and T2.

Variables	Intake (T1)		Post-test (T2)		
	M (SD)	Range	*M (SD)*	Range	*d*
Overall Developmental Skills - Achievement rate (%)	21.3 (16.6)	4.5-73.5	30.1 (14.2)	7.6-61.1	0.6
Receptive communication - Achievement rate (%)	17.6 (18)	2.6-31.0	30.2 (16.9)	6.0-41.4	0.7
Expressive communication- Achievement rate (%)	23.1 (22.3)	1.4-77.0	31.2 (15.4)	1.4-7.4	0.4
Social Skills - Achievement rate (%)	25.5 (18.5)	6.8-84.1	36.6 (16.6)	10.2-65.9	0.6
Imitation Skills - Achievement rate (%)	25.2 (31.1)	0-100	34.6 (36.1)	0-100	0.3
Cognitive skills - Achievement rate (%)	12.9 (14.3)	0-38.2	20.0 (18.4)	0-58.8	0.4
Play skills - Achievement rate (%)	20.7 (23.6)	0-95.2	31.5 (20.3)	6.5-77.4	0.5
Fine motor skills - Achievement rate (%)	20.1 (16.4)	1.8-62.5	25.7 (14.9)	4.5-59.8	0.4
Gross motor skills - Achievement rate (%)	11.3 (15.6)	0-60.9	18.2 (20.8)	0-57.8	0.4
Problem Behaviours - Total score	43.1 (16.5)	23.0-71.0	38.4 (12.3)	23.0-68.0	0.3

Table 4

Descriptive Statistics and Effect Sizes for Parent Outcome Variables at T1 and T2

Variables	Intake (T1)		Posttest (T2)		
	M (SD)	Range	*M (SD)*	Range	*d*
Teaching Skills[a]					
Overall fidelity (total score)	40.1 (12.9)	17.0-62.0	51.6 (6.1)	41.0-61.0	1.1
Overall fidelity (%)	61.7 (19.8)	26.2-95.4	79.4 (9.3)	63.1-93.8	1.2

Management of child attention[b]	3.1 (0.9)	2.0-5.0	4.2 (0.6)	3.0-5.0	1.4
ABC Format[b]	2.6 (1.3)	1.0-5.0	3.6 (0.9)	2.0-5.0	0.9
Instructional techniques[b]	2.7 (1.3)	1.0-5.0	3.8 (0.9)	3.0-5.0	1.3
Modulating child affect/arousal[b]	2.8 (1.2)	1.0-5.0	4.1 (0.7)	3.0-5.0	1.3
Management of unwanted behaviours[b]	3.1 (1.2)	1.0-5.0	4.5 (0.7)	3.0-5.0	1.4
Quality of dyadic engagement[b]	3.1 (1.1)	1.0-5.0	3.8 (1.1)	2.0-5.0	0.6
Adult optimizes child motivation[b]	3.3 (1.0)	1.0-5.0	4.1 (0.8)	3.0-5.0	0.9
Adult use of positive affect[b]	3.6 (1.1)	1.0-5.0	4.5 (0.7)	3.0-5.0	1.0
Adult sensitivity and responsivity[b]	3.4 (1.3)	1.0-5.0	4.0 (0.8)	3.0-5.0	0.6
Multiple varied communicative opportunity[b]	3.0 (1.2)	1.0-5.0	3.7 (0.9)	3.0-5.0	0.7
Adult's language for child's level[b]	3.7 (0.6)	3.0-5.0	4.2 (0.8)	3.0-5.0	0.7
Joint activity and elaboration[b]	2.5 (1.1)	1.0-4.0	3.3 (0.7)	2.0-4.0	0.9
Transition between activities[b]	3.1 (1.1)	1.0-5.0	4.1 (0.7)	3.0-5.0	1.1
Parental Sense of Competence (PSOC)					
Efficacy (out of 42)	27.3 (3.7)	20-35	27.2 (5.2)	17-36	0.1
Satisfaction (out of 54)	33.8 (6.0)	23-45	35.4 (6.3)	21-45	0.3
Overall competence (PSOC)	61.3 (7.1)	49-74	62.6 (8.0)	48-78	0.2
Family Quality of Life (FQOL)					
Family interaction[c]	3.9 (0.5)	3.5-4.2	3.9 (0.3)	3.3-4.4	0.0
Parenting[c]	3.7 (0.5)	3.3-4.0	4.1 (0.2)	3.7-4.3	1.1
Emotional well-being[c]	3.1 (0.9)	2.9-3.5	3.3 (0.7)	4.0-4.2	0.2
Physical/Material well-being[c]	4.1 (0.5)	3.9-4.4	4.1 (0.5)	3.0-3.5	0.0
Disability-related support[c]	3.7 (0.6)	3.5-4.2	3.7 (0.7)	3.8-4.4	0.0
Overall FQOL[c]	3.7 (0.4)	3.3-4.6	3.9 (0.3)	3.6-4.0	0.6

Note. [a]Parents' teaching skills were assessed during the 4th and 8th coaching sessions for T1 and T2, respectively. [b]Items used a 5-point rating scale 1 (no competent teaching) to 5 (extremely competent teaching). [c]Items used a 5-point rating scale 1 (very dissatisfied) to 5 (very satisfied).

Discussion

This study sought to assess the potential clinical utility of a short-term, low-intensity intervention for children and their parents while they await more intensive support such as EIBI. Specifically, it aimed to evaluate changes in children (i.e., core symptoms of ASD, problem behaviour) and parents (i.e., teaching skills, sense of competence, and FQOL) when P-ESDM is provided in a community-based setting within a structured service trajectory (specifically, between diagnostic confirmation and the provision of EIBI). If this type of interim service is found to be effective, it could fill a critical gap in services: significant waiting periods (up to four years) for EIBI and an urgent need for support by parents have been extensively documented (Gordon, 2012; McKinsey & Company, 2014).

In the present study, a moderate increase in children's overall developmental skills and a large increase in parents' teaching skills, the two primary outcomes, were observed. Parents' teaching skills improved rapidly throughout the program and almost half of parents had reached the intervention fidelity target. It is possible that the group training helped them to better understand their role and the purpose of the intervention, which contributed to children's developmental and behavioural improvements. Although parents' overall teaching skills improved, their overall skill level was lower than would be desired by the end of the program. Yet increased parental teaching skills are instrumental to the program's impact on the development of the child's developmental skills and other secondary outcomes. Thus, higher teaching skills levels could have yielded more positive outcomes in terms of child development (see Jhuo & Chu, 2022). The low level of parental fidelity of intervention at intake (61.7%) and its wide range (26.2% to 95.4%) may account for modest results. Other studies have also reported poor teaching skills at the beginning of the program and teaching skills below the criterion by the end of the program (Hernandez-Ruiz, 2020; Vismara et al., 2012, 2018; Waddington et al., 2020).

In terms of secondary outcomes, a small reduction in problem behaviours was observed. This is a noteworthy clinical finding in that it suggests that the use of P-ESDM, which focuses on social communication skills in children and parent-child interaction, may also be associated with changes in maladaptive behaviours. These were found to be an important factor in parents' psychological distress (Griffith et al., 2010; Hastings, 2003; Mello et al., 2021) and a barrier to children's learning and integration in early childhood (Machalicek et al., 2007; McGill et al., 2006; Wodehouse & McGill, 2009). It suggests that a more rigorous evaluation of the effectiveness of P-ESDM should examine changes in both desirable positive behaviours and challenging behaviours.

In addition, parents' satisfaction with their parenting improved greatly, despite the intervention's brief duration. This suggests that the intervention may be effective in improving these aspects of family quality of life, which is emerging as another important outcome to consider in assessing family-centered interventions (Granger et al., 2012; Hoffman et al., 2006; Hume et al., 2005; Mackintosh et al., 2012).

Greater changes were observed on primary outcomes than on secondary outcomes. This may be explained in part by the specificity of the project-based tools and the proximal behaviours they target, as well as the short period of time during which changes were measured for the present study. The secondary outcomes were associated with more distal, global concepts (e.g., family adjustment) that are not specifically related to the goals of the intervention and for which

changes may occur more slowly and indirectly (i.e., partly a result of changes in proximal variables).

In addition to its practical and clinical contributions, this study is one of the few on the P-ESDM to be carried out independently of the authors of the model and on an implementation of this program within a network of public services. The use of the ESDM CC, which indicated large proximal effects of the intervention on children's developmental skills, also supports comparisons with other studies adopting this measure in other contexts. For instance, in a recent study, Rogers et al. (2018) used a shorter version of the ESDM CC (PATH CC) and observed significant improvements in children's development.

Several authors have mentioned that parent-delivered interventions are promising avenues to contend with delays in accessing EIBI and facilitate interactions between family members when a child has ASD (Green et al., 2010; Kasari et al., 2010; McConachie & Diggle, 2007; Oono et al., 2013; Pickles et al., 2016; Wetherby et al., 2014). However, there is at present limited empirical evidence on the effects of such interventions on the core symptoms of ASD and parents' psychological well-being (Oono et al., 2013; Patterson et al., 2012). Results according to the ESDM CC and measures of well-being across several studies (Estes et al., 2012, 2014; Rogers et al., 2019), including the present work, indicate that the P-ESDM may impact these outcomes, which are rarely assessed in the context of low-intensity parent-delivered programs.

Prior to conducting this study, our team pretested the P-ESDM in 11 families (Mestari, 2017) in order to assess the possibility of implementing this program at the participating center and finalize its format to meet the needs of the target population. As a first pilot study of the resulting adaptation of the P-ESDM, this study presents some limitations which are typical of a first-phase trial. The small number of participants did not allow for more robust statistical analysis and rendered the calculation of some correlation and differences impossible. Furthermore, the study employed a pre-post design without a comparison group (e.g., treatment as usual) and thus did not support statistical testing compared to what may be expected by chance or through brain maturation. Both the small sample and the lack of comparison group are limitations to internal and external validity. Additionally, the present study assessed primary outcomes through project-based curriculum checklists. Although these instruments are not standardized and therefore do not provide score thresholds or age-appropriate normative data, it was suggested that in pretest, post-test research designs they could support the detection of small, proximal changes that may not be detectable through standardized instruments (see Rogers et al., 2019). Furthermore, these scales provide an objective, direct measure of operationalized behaviours which reflect the skills being taught to children and parents. Therefore, these tools appear to be valid for the purposes of this study. In future studies, it may be beneficial to use the Dyadic Communication Measure for Autism (DCMA, Aldred et al., 2004) to examine interactions between parent and child in a free play context. A problem behaviour observation grid (Rivard et al., 2016) would also serve as an additional outcome measure of social, verbal, and challenging behaviours based on direct observation. Another potential limitation of this project is inherent to the intervention model itself: the P-ESDM requires that parent coaches possess specific qualifications, such as holding an advanced degree and working regularly with young children with ASD. In contrast to other low-cost parent-focused programs (e.g., based on peer mentoring), this may pose challenges for recruitment in larger-scale trials and, eventually, the widespread implementation of the program. The present study, although limited in scope, was necessary to prepare for more comprehensive and rigorous evaluations of the model's various outcomes (and their interrelations) as a proof-of-

concept study for the definitive version of the P-ESDM. The findings of improvements across primary and secondary outcomes are promising and indicate that the model is ready for the second phase of its evaluation, which includes a feasibility and acceptability study on a larger number of participants.

Key Messages From This Article

People with Disabilities: You deserve to be provided with intervention services as soon as possible after having received a diagnosis of autism spectrum disorder (ASD).

Professionals: The post-diagnostic period is considered a crucial period as families are dealing with their child's ASD diagnosis and are often left to themselves while waiting for specialized and intensive interventions.

Policymakers: It is important to develop services that will bridge the gap between an ASD diagnosis and access to intensive behavioural intervention, with interventions that support individuals with ASD and their families and can promote their well-being and quality of life.

Messages clés de cet article

Personnes présentant un trouble : Vous méritez de bénéficier de services d'intervention dès que possible après avoir reçu un diagnostic de trouble du spectre de l'autisme (TSA).

Professionnels : La période post-diagnostique est considérée comme une période cruciale car les familles doivent faire face au diagnostic de TSA de leur enfant et sont souvent laissées à elles-mêmes en attendant des interventions spécialisées et intensives.

Décideurs politiques : Il est important de développer des services qui combleront le manque de services entre le moment où l'enfant reçoit son diagnostic de TSA et qu'il accède à une intervention comportementale intensive, en proposant des interventions qui soutiennent les personnes présentant un TSA et leurs familles et qui favorisent leur bien-être et leur qualité de vie.

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References

Abouzeid, N., & Lopes, T. (2017). *Post-diagnostic intervention for families of children with autism spectrum disorder* [Poster Presentation]. Canadian Autism Leadership Summit, Ottawa.

Abouzeid, N., & Poirier, N. (2014a). Perceptions de mères d'enfant présentant un trouble du spectre de l'autisme ayant reçu une intervention comportementale intensive: leurs ressources et leurs défis [Perceptions of mothers of children with autism spectrum disorder who received intensive behavioural intervention: Their resources and challenges]. *Revue de psychoéducation, 43*(2), 201 – 233. https://doi.org/10.7202/1061182ar

Abouzeid, N., & Poirier, N. (2014b). L'intervention comportementale intensive: les services reçus par des enfants ayant un trouble du spectre de l'autisme [Intensive behavioural intervention: Services received by children with autism spectrum disorder]. *Journal on Developmental Disabilities, 20*(3), 42–56.

Abouzeid, N., & Poirier, N. (2014c). Perception des effets de l'intervention comportementale intensive chez des enfants présentant un trouble du spectre de l'autisme [Perception of the effects of intensive behavioural intervention in children with autism spectrum disorder]. *Enfance en difficulté, 3*, 107–137. https://doi.org/10.7202/1028014ar

Abouzeid, N., Rivard, M., Mello, C., Mestari, Z. Boulé, M., & Guay, C. (2020). Parent coaching intervention program based on the Early Start Denver Model for children with autism spectrum disorder: Feasibility and acceptability study. *Research in Developmental Disabilities, 105*, 103747. https://doi.org/10.1016/j.ridd.2020.103747

Abouzeid, N., Rivard, M., Mestari, Z., & Boulé, M. (2019). Effets d'une intervention médiée par les parents basée sur le modèle précoce de Denver pour les parents d'enfants ayant un diagnostic récent de trouble du spectre de l'autisme. *Approche neuropsychologique des apprentissages chez l'enfant, 31(*162), 619-632.

Aldred, C., Green, J., & Adams, C. (2004). A new social communication intervention for children with autism: Pilot randomised controlled treatment study suggesting effectiveness. *Journal of Child Psychology and Psychiatry, 45*(8), 1420–1430. https://doi.org/10.1111/j.1469-7610.2004.00338.x

Cidav, Z., Munson, J., Estes, A., Dawson, G., Rogers, S., & Mandell, D. (2017). Cost offset associated with Early Start Denver Model for children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*(9), 777–783. https://doi.org/10.1016/j.jaac.2017.06.007

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences.* Hillsdale.

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities, 19*(4), 356–366. https://doi.org/10.1177/1744629515577876

Czajkowski, S. M., Powell, L. H., Adler, N., Naar-King, S., Reynolds, K. D., Hunter, C. M., Laraia, B., Olster, D. H., Perna, F. M., Peterson, J. C., Epel, E., Boyington, J. E., Charlson, M. E. (2015). From ideas to efficacy: The ORBIT model for developing behavioral

treatments for chronic diseases. *Health Psychology*, *34*(10), 971–982. https://doi.org/10.1037/hea0000161

Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology, 20*(3), 775–803. https://doi.org/10.1017/S0954579408000370

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., & Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics, 125*, e17–e23. https://doi.org/10.1542/peds.2009-0958

Einfeld, S. L., & Tonge, B. J. (1995). The Developmental Behavior Checklist: The development and validation of an instrument to assess behavioral and emotional disturbance in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders, 25*, 81–104. https://doi.org/10.1007/BF02178498

ESDM Training Program. (2017). *ESDM Advanced Workshop: Early Start Denver Model, UC Davis MIND*. https://www.esdm.co/advanced-workshops

Estes, A., Munson, J., Rogers, S. J., Greenson, J., Winter, J., & Dawson, G. (2015). Long-term outcomes of early intervention in 6-year-old children with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *54*(7), 580-587. https://doi.org/10.1016/j.jaac.2015.04.005

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2012). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain & Development, 35*(2), 133–138. https://doi.org/10.1016/j.braindev.2012.10.004

Estes, A., Vismara, L., Mercado, C., Fitzpatrick, A., Elder, L., Greenson, J., Lord, C., Munson, J., Winter, J., Young, G., & Dawson, G. (2014). The impact of parent delivered intervention on parents of very young children with autism. *Journal of Autism and Developmental Disorders, 44*, 353–365. https://doi.org/10.1007/s10803-013-1874-z

Flanagan, J. E., Landa, R., Bhat, A., & Bauman, M. (2012). Head lag in infants at risk for autism: A preliminary study. *American Journal of Occupational Therapy, 66*(5), 577–585. https://doi.org/10.5014/ajot.2012.004192

Gibaud-Wallston, J. (1977). *Self-esteem and situational stress: Factors related to sense of competence in new parents* [Doctoral dissertation]. College for Teachers,

University of Rhode Island.

Gordon, A. (2012, November 23). The autism project: Children face up to four-year wait for therapy. *The Star*. www.thestar.com/news/gta/2012/11/23/the_autism_project_children_face_up_to_fouryear_wait_for_therapy.html

Granger, S., des Rivières-Pigeon, C., Sabourin, G., & Forget, J. (2012). Mothers' reports of their involvement in early intensive behavioural intervention. *Topics in Early Childhood Special Education, 32*, 68–77. https://doi.org/10.1177/0271121410393285

Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., Le Couteur, A., Leadbitter, K., Hudry, K., Byford, S., & Barrett, B. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): A randomized controlled trial. *The Lancet, 375*, 2152–2160. https://doi.org/10.1016/S0924-9338(11)73601-X

Griffith, G. M., Hastings, R. P., Nash, S., & Hill, C. (2010). Using matched groups to explore child behaviour problems and maternal well-being in children with Down syndrome and autism. *Journal of Autism and Developmental Disorders, 40(*5), 610–619. https://doi.org/10.1007/s10803-009-0906-1

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4–5), 231–237. https://doi.org/10.1046/j.1365-2788.2003.00485.x

Hernandez-Ruiz, E. (2020). Feasibility of parent coaching of music interventions for children with autism spectrum disorder. *Music Therapy Perspectives*, *38*(2), 195-204. https://doi.org/10.1093/mtp/miz016

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family, 68*, 1069–1083. https://doi.org/10.1111/j.1741-3737.2006.00314.x

Hume, K., Bellini, S., & Pratt, C. (2005). The usage and perceived outcomes of early intervention and early childhood programs for young children with autism spectrum disorder. *Topics in Early Childhood Special Education, 25*(4), 195–207. https://doi.org/10.1177/02711214050250040101

Institut national d'excellence en santé et en services sociaux (INESSS). (2014). *Addenda à L'efficacité des interventions de réadaptation et des traitements pharmacologiques pour les enfants de 2 à 12 ans ayant un trouble du spectre de l'autisme (TSA)* [Addendum to Effectiveness of rehabilitation interventions and pharmacological treatments for children aged 2 to 12 years with autism spectrum disorder]. INESSS. https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/ServicesSociaux/INESSS_Addenda_TSA.pdf

Jhuo, R. A., & Chu, S. Y. (2022). A review of Parent-Implemented Early Start Denver model for children with autism spectrum disorder. *Children*, *9*(2), 285. https://doi.org/10.3390/children9020285

Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of clinical child psychology*, *18*(2), 167–175. https://doi.org/ 10.1207/s15374424jccp1802_8

Kasari, C., Gulsrud, A.C., Wong, C., Kwon, S., & Locke, J. (2010). Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism. *Journal of Autism and Developmental Disorders, 40*, 1045–1056. https://doi.org/10.1007/s10803-010-0955-5

Klintwall, L., Eldevik, S., & Eikeseth, S. (2015). Narrowing the gap: Effects of intervention on developmental trajectories in autism. *Autism, 19*(1)*,* 53–63. https://doi.org/10.1177/1362361313510067

Knopf, A. (2020). Autism prevalence increases from 1 in 60 to 1 in 54: CDC. *The Brown University Child and Adolescent Behavior Letter, 36*(6), 4–4. https://doi.org/10.1002/cbl.30470

Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). Austism diagnostic observation schedule: A standardized observation of communicative and social behavior. *Journal of Autism and Developmental Disorders, 19*(2), 185–212. https://doi.org/10.1007/BF02211841

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 24*(5), 659–685. https://psycnet.apa.org/doi/10.1007/BF02172145

Lovejoy, M. C., Verda, M. R., & Hays, C. E. (1997). Convergent and discriminant validity of measures of parenting efficacy and control. *Journal of Clinical Child Psychology*, *26*(4), 366–376. https://doi.org/10.1207/s15374424jccp2604_5

Machalicek, W., O'Reilly, M. F., Beretvas, N., Sigafoos, J., & Lancioni, G. E. (2007). A review of interventions to reduce challenging behaviour in school settings for students with autism spectrum disorders. *Research in Autism Spectrum Disorders, 1*(3), 229–246. https://doi.org/10.1016/j.rasd.2006.10.005

Mackintosh, V. G., Goin-Kochel, R. P., & Myers, B. J. (2012). ''What do you like/dislike about the treatments you're currently using?'' A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 27*(1), 51–60. https://doi.org/10.1177/1088357611423542

Maglione, M. A., Gans, D., Das, L., Timbie, J., & Kasari, C. (2012). Nonmedical interventions for children with ASD: Recommended guidelines and further research needs. *Pediatrics, 130*(Suppl. 2), S169–S178. https://doi.org/10.1542/peds.2012-0900O

Makrygianni, M. K., Gena, A., Katoudi, S., & Galanis, P. (2018). The effectiveness of applied behavior analytic interventions for children with autism spectrum disorder: A meta-analytic study. *Research in Autism Spectrum Disorders, 51*, 18–31. https://doi.org/10.1016/j.rasd.2018.03.006

McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: A systematic review. *Journal of Evaluation in Clinical Practice, 13*(1), 120–129. https://doi.org/10.1111/j.1365-2753.2006.00674.x

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behavior. *Child: Care, Health and Development, 32*(2), 159–165. https://doi.org/10.1111/j.1365-2214.2006.00600

McKinsey & Company. (2014). *A bold strategy for autism spectrum disorder and intellectual disabilities*. Miriam Foundation. https://www.miriamfoundation.ca/DATA/TEXTEDOC/141020-PDF-McKinsey-rollout-ENGLISH.pdf

Mello, C., Rivard, M., Morin, D., Patel, S., & Morin, M. (2021). Symptom severity, internalized and externalized behavioural and emotional problems: Links with parenting stress in

mothers of children recently diagnosed with autism. *Journal of Autism and Developmental Disorders*, *52*(6), 2400–2413. https://doi.org/10.1007/s10803-021-05131-4

Mestari, Z. (2017). Effets d'un programme de coaching parental Parent Early Start Denver Model (P-ESDM). Rapport d'analyses préliminaire.

National Institute for Health and Care Excellence (NICE). (2016). *Surveillance report 2016 – Autism spectrum disorder in under 19s: Support and management.* https://www.nice.org.uk/guidance/cg170/documents/surveillance-review-proposal

National Research Council. (2001). *Educating children with autism*. The National Academies Press. https://doi.org/10.17226/10017

Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Evidence-Based Child Health, 8*(6), 2380–2479. https://doi.org/10.1002/ebch.1952

Patterson, S. Y., Smith, V., & Mirenda, P. (2012). A systematic review of training programs for parents of children with autism spectrum disorders: Single subject contributions. *Autism, 16*(5), 498–522. https://doi.org/10.1177%2F1362361311413398

Penner, M., Rayar, M., Bashir, N., Roberts, S. W., Hancock-Howard, R. L., & Coyte, P. C. (2015). Cost-effectiveness analysis comparing pre-diagnosis autism spectrum disorder (ASD)-targeted intervention with Ontario's autism intervention program. *Journal of Autism and Developmental Disorders, 45*(9), 2833–2847. https://doi.org/10.1007/s10803-015-2447-0

Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., LaRose, L., Managhan, T., Reitzel, J., & Williams, J. (2008). Effectiveness of intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders, 2*(4), 621–642. https://doi.org/10.1016/j.rasd.2008.01.002

Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., Gammer, I., Lowry, J., Vamvakas, G., Byford, S., & Aldred, C. (2016). Parent-mediated social communication therapy for young children with autism (PACT): Long-term follow-up of a randomised controlled trial. *The Lancet, 388*, 2501–2509. https://doi.org/10.1016/S0140-6736(16)31229-6

Prior, M., Roberts, J. M., Rodger, S., Williams, K., & Sutherland, R. (2011). A review of the research to identify the most effective models of practice in early intervention for children with autism spectrum disorders. *Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)* https://www.dss.gov.au/sites/default/files/documents/10_2014/review_of_the_research_report_2011_0.pdf

Public Health Agency of Canada. (2022, June 21). *Autism spectrum disorder: Highlights from the 2019 Canadian health survey on children and youth*. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-canadian-health-survey-children-youth-2019.html

Quebec Ombudsman. (2015). Service *access, continuity and complementarity for young people (0-18 years) with an intellectual disability or autism spectrum disorder*. (Special Report, March 23). Assemblée Nationale.

https://protecteurducitoyen.qc.ca/sites/default/files/pdf/communiques/2015-03-24_autisme-deficience-intellectuelle.pdf

Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 10*. https://doi.org/10.1002/14651858.CD009260.pub2

Rivard, M., Forget, J., Giroux, N., Mello, C., Kerr, K., & Regli, G. (2016). Observation of socially appropriate and inappropriate behaviours among children with autism spectrum disorder during an early behavioural intervention program. *Journal on Developmental Disabilities, 22*(1), 52–67.

Rivard, M., Mercier, C., Mestari, Z., Terroux, A., Mello, C., & Bégin, J. (2017a). Psychometric properties of the Beach Center Family Quality of Life Scale in French-speaking families with a preschool-aged child diagnosed with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities, 122*(5), 439–452. https://doi.org/10.1007/s10882-016-9477-1

Rivard, M., Morin, M., Mercier, C., Terroux, A., Mello, C., & Lépine, A. (2017b). Social validity of a training and coaching program for parents of children with autism spectrum disorder on a waiting list for early behavioural intervention. *Journal of Child and Family Studies, 26*(3), 877–887. https://doi.org/10.1007/s10826-016-0604-5

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*(7), 1609–1620. https://doi.org/10.1007/s10803-013-2028-z

Rogers, S. J., & Dawson, G. (2010). *Early Start Denver Model for young children with autism: Promoting language, learning, and engagement*. Guilford Press.

Rogers, S, J. & Dawson, G. (2013). *L'intervention précoce en autisme, le Modèle de Denver pour jeunes enfants* [Early intervention in autism: The Denver Model for young children]. Dunod.

Rogers, S. J., Dawson, G., & Vismara, L. A. (2012a). *An early start for your child with autism: Using everyday activities to help kids connect, communicate, and learn*. Guilford Press.

Rogers, S. J., Dawson, G., & Vismara, L. A. (2016*). L'intervention précoce en autisme pour les parents: avec le modèle de Denver* [Early Intervention in Autism for parents: The Denver Model]. Dunod.

Rogers, S.J., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., Guo, M., & Dawson, G. (2012b). Effects of a brief Early Start Denver Model (ESDM)–based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(10), 1052–1065. https://doi.org/10.1016/j.jaac.2012.08.003

Rogers, S.J., Estes, A., Vismara, L., Munson, J., Zierhut, C., Greenson, J., Dawson, G., Rocha, M., Sugar, C., Senturk, D. & Whelan, F. (2019). Enhancing low-intensity coaching in parent implemented Early Start Denver Model intervention for early autism: A randomized comparison treatment trial. *Journal of Autism and Developmental Disorders*, *49*(2), 632–646. https://doi.org/10.1007/s10803-018-3740-5

Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., Kasari, C., Ingersoll, B., Kaiser, A. P., Bruinsma, Y., McNerney, E., Wetherby, A., & Halladay, A. (2015). Naturalistic developmental behavioural interventions: Empirically validated treatments for autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(8), 2411–2428. https://doi.org/10.1007/s10803-015-2407-8

Sealy, J., & Glovinsky, I. (2016). Strengthening the reflective functioning capacities of parents who have a child with a neurodevelopmental disability through a brief, relationship-focused intervention. *Infant Mental Health Journal, 37*(2), 115–124. https://doi.org/10.1002/imhj.21557

Smith, M., Rogers, S., & Dawson, G. (2008). The Early Start Denver Model: A comprehensive early intervention approach for toddlers with autism. In J. S. Handleman & S. L. Harris (Eds.), *Preschool education programs for children with autism* (3rd ed., pp. 65–101). Pro-Ed Corporation.

Vismara, L. A., & Rogers, S. J. (2008). The Early Start Denver Model: A case study of an innovative practice. *Journal of Early Intervention, 31*(1), 91–108. https://doi.org/10.1177/1053815108325578

Vismara, L. A., Young, G. S., & Rogers, S. J. (2012). Telehealth for expanding the reach of early autism training to parents. *Autism research and treatment*, *2012*. https://doi.org/ 10.1155/2012/121878

Vismara, L. A., McCormick, C. E., Wagner, A. L., Monlux, K., Nadhan, A., & Young, G. S. (2018). Telehealth parent training in the Early Start Denver Model: Results from a randomized controlled study. *Focus on Autism and Other Developmental Disabilities*, *33*(2), 67-79. https://doi.org/10.1177/1088357616651064

Vivanti, G., Paynter, J., Duncan, E., Fothergill, H., Dissanayake, C., Rogers, S. J., the Victorian ASELCC Team. (2014). Effectiveness and feasibility of the Early Start Denver Model implemented in a group-based community childcare setting. *Journal of Autism and Developmental Disorders*, *44*(12), 3140–3153. https://doi.org/10.1007/s10803-014-2168-9

Waddington, H., van der Meer, L., Sigafoos, J., & Whitehouse, A. (2020). Examining parent use of specific intervention techniques during a 12-week training program based on the Early Start Denver Model. *Autism*, *24*(2), 484-498. https://doi.org/ 10.1177/1362361319876495

Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics, 127*(5), e1303–e1311. https://doi.org/10.1542/peds.2011-0426

Weitlauf, A. S., McPheeters, M. L., Peters, B., Sathe, N., Travis, R., Aiello, R.,Williamson, E., Veenstra-VanderWeele, J., Krishnaswami, S., Jerome, R., & Warren, Z. (2014). Therapies for children with autism spectrum disorder. https://www.ncbi.nlm.nih.gov/sites/books/NBK241444/

Wetherby, A.M., Guthrie, W., Woods, J., Schatschneider, C., Holland, R.D., Morgan, L., & Lord, C. (2014). Parent-implemented social intervention for toddlers with autism: An RCT. *Pediatrics, 134*(6), 1084–1093. https://doi.org/10.1542/peds.2014-0757

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behavior: What stops it being helpful? *Journal of Intellectual Disability Research, 53*(7), 644–653. https://doi.org/10.1111/j.1365-2788.2009.01163.x

Zhou, B., Xu, Q., Li, H., Zhang, Y., Wang, Y., Rogers, S. J., & Xu, X. (2018). Effects of parent-implemented Early Start Denver Model intervention on Chinese toddlers with autism spectrum disorder: A non-randomized controlled trial. *Autism Research, 11*(4), 654–666. https://doi.org/10.1002/aur.1917