



Act Early Autism Project: The Feasibility of an Early Pathway to Care for Toddlers at Risk of Autism Spectrum Disorder



Le projet *Act Early Autism* : faisabilité d'une trajectoire de soins qui vise la prise en charge précoce des enfants à risque d'avoir un trouble du spectre de l'autisme

KEYWORDS

AUTISM SPECTRUM
DISORDERS

PATHWAY TO CARE

EARLY INTERVENTION

Robin Gaines

Children's Hospital of Eastern
Ontario, Ottawa, ON, CANADA

Yolanda Korneluk

Emerging Minds Treatment
Centre, Ottawa, ON, CANADA

Danielle Quigley

Douglas College, New
Westminster, BC, CANADA

Abigail D. Delehanty

Duquesne University, Pittsburgh,
PA, USA

Laurie A. Vismara

Early Emory Center for Child
Development and Enrichment,
Emory University School of
Medicine, Decatur, GA, USA

Robin Gaines
Yolanda Korneluk
Danielle Quigley
Abigail D. Delehanty
Laurie A. Vismara

Abstract

The *Act Early Autism Project* created and assessed an early pathway to care for toddlers whose parents had informed concerns about their development. The three-step pathway included (1) reliable education provided to the broad Ottawa community about recognizing early signs of Autism Spectrum Disorder, (2) an invitation to a responsive two-level screening for Autism Spectrum Disorder, and (3) the provision of an in-home parent-mediated intervention for those positively identified at risk. This paper describes our evaluation of the pathway feasibility as 15 toddlers progressed to early intervention within 1 year. Parents used a first level paper screening tool to report their concerns to knowledgeable professionals about their toddlers' development and to identify risk for Autism Spectrum Disorder. Professionals then provided second level observational screening to obtain more detailed information about the skills and behaviours of those toddlers identified as high risk at first level screening. A 12-week parent-mediated intervention followed positive second level screening. Pre- and post-standardized parent report measures revealed changes in child behaviours during and immediately following the intervention. Autism Diagnostic Observation Schedule results following the study supported the *Act Early Autism Project* pathway to care as they provided a confirming diagnosis for all children who completed the pathway. Finally, parent perspectives of the pathway were elicited and are discussed.

Editor:

Paola Colozzo

Editor-in-Chief:

David H. McFarland

Abrégé

Le projet *Act Early Autism* a créé et évalué une trajectoire de soins qui visait la prise en charge précoce des enfants dont les parents s'inquiétaient de leur développement. Cette trajectoire comprenait trois étapes : (1) une distribution d'informations fiables à la population de la grande région d'Ottawa sur la façon de reconnaître les signes précoces du trouble du spectre de l'autisme, (2) une invitation à effectuer un test de dépistage du trouble du spectre de l'autisme réalisé en deux étapes et (3) la mise en place d'une intervention réalisée à la maison par les parents des enfants identifiés comme étant à risque d'avoir un trouble du spectre de l'autisme. Cet article décrit la faisabilité de cette trajectoire en examinant le cheminement de 15 enfants lors de leur prise charge précoce qui s'est échelonnée sur un an. Les parents ont d'abord rempli un questionnaire de dépistage visant à transmettre leurs inquiétudes concernant le développement de leur enfant à un professionnel expérimenté et à identifier si leur enfant était à risque d'avoir un trouble du spectre de l'autisme. Les professionnels ont ensuite effectué un dépistage en observant les habiletés et comportements des enfants identifiés comme étant à risque d'avoir un trouble du spectre de l'autisme dans la première étape du dépistage afin d'obtenir des informations détaillées sur ces aspects. Ce second dépistage a été suivi d'une intervention de 12 semaines menée par les parents. Les résultats obtenus pré- et post-intervention à des questionnaires parentaux normalisés ont révélé des changements dans les comportements des enfants pendant et immédiatement après l'intervention. Les résultats obtenus avec l'outil *Autism Diagnostic Observation Schedule* à la fin de l'étude corroborent l'efficacité de la trajectoire de soins du projet *Act Early Autism* puisque tous les enfants ayant participé à toutes les étapes de la trajectoire ont vu leur diagnostic confirmé. Enfin, les points de vue des parents sur la trajectoire ont été recueillis et discutés.

Early screening, diagnostics, and interventions can be accessed by speech-language pathologists (S-LPs) to reliably assist very young children with developmental challenges, including Autism Spectrum Disorder (ASD). Yet, parents and speech-language pathology clinicians may not be aware of current evidence to help them navigate the best available pathways to early intervention (Barnard-Brak et al., 2017; Camarata, 2014). The recent evolution and expansion of ASD diagnostic criteria means there are now broader evidence-based definitions for identification and more reliable early indicators of risk (Zwaigenbaum, Bauman, Choueiri, et al., 2015). However, the rapid development of evidence also means an evidence-to-practice gap that is fully recognized in the field of early intervention (Dingfelder & Mandell, 2011; Lau et al., 2014; Wetherby et al., 2018). Parents and professionals may not be up to date with the changes and may be hesitant when making crucial decisions for toddlers' early interventions (Camarata, 2014; Canadian Association of Speech-Language Pathologists and Audiologists, 2006; Zwaigenbaum, Bauman, Stone, et al., 2015). Thus, informed community awareness becomes an important consideration to enlighten unfortunate "wait-and-see" responses and expedite appropriate choices for early intervention (Lau et al., 2014; Wetherby et al., 2018).

Early identification, including broad community awareness and accurate screening, followed by evidence-based early intervention need to be easily accessible to parents who have concerns (Wetherby et al., 2018). Educated, proactive responses to developmental challenges like ASD can result in optimum long-term outcomes for children (Dawson et al., 2010; Piccininni et al., 2017; Wetherby et al., 2014). The *Act Early Autism Project* aimed to (a) pilot an investigation on how to close the research-to-practice gap for parents and clinicians and (b) provide preliminary evidence for a practical, seamless pathway to evidence-based early intervention for families with toddlers showing concerning behaviours associated with ASD.

ASD as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; American Psychiatric Association, 2013) is a neurodevelopmental disorder that is diagnosed in at least 1 in 66 children, 5–17 years of age, in Canada (Ofner et al., 2018). When left untreated in the early years, ASD can result in cascading deficits in cognition, language, socialization, and adaptive behaviour (Dawson et al., 2012; Wetherby et al., 2007). Children can be identified as at risk of ASD before, and diagnosed by, the age of 2 years because of specific differences in early social orienting, language, and cognitive skill development, as well as unusual body movements, atypical emotional regulation, and reduced motor control in some infants (Dawson et al.,

2012; Zwaigenbaum, Bauman, Choueiri, et al., 2015). Parents may have early concerns in these areas but wait to report them, sometimes on advice of professionals, until children are older and more likely to be positively identified with ASD (Ozonoff et al., 2009; Zubler, 2019; Zwaigenbaum, Bauman, Choueiri, et al., 2015).

The State of Early Intervention for ASD

Though research confirms that early intervention gives children with ASD the best chance for a positive developmental trajectory (i.e., Dawson et al., 2010; Guralnick, 2011; Landa et al., 2013; Wetherby et al., 2014, 2018), in Canada as in other countries children are not diagnosed with ASD as early as they could be (Leew et al., 2012). For example, in the United States concerns about development were retrospectively found in the health records of 85% of children at age 3 years who were later diagnosed with ASD (Zubler, 2019). Only 42% of those 3-year-old children had received a comprehensive developmental assessment by age 3. Canadian children also do not receive timely identification for several reasons, including a lack of current and coordinated information across pediatric providers, a shortage of trained clinicians, long waiting lists, a lack of coordination between agencies, and location-specific access barriers (Ouellette-Kuntz et al., 2009). Moreover, there are significant inter-regional differences in age of diagnosis across Canada (Ouellette-Kuntz et al., 2009). The median age of diagnosis for children with ASD in Canada ranges from 39 to 55 months of age depending on where the child lives; only 19% of children in Canada are identified by 36 months of age and those diagnoses are only in some provinces (Autism Canada, n.d.; Ofner et al., 2018). Even with a valid early diagnosis, Canadian children and families may experience long delays entering interventions especially as toddlers (National Autism Center, n.d.; Wetherby et al., 2018). Since children can be identified as high risk of ASD before 2 years of age and should begin early intervention immediately following identification, Canada needs to facilitate feasible pathways to care and collaborative partnerships among community providers and other experts in the field of ASD (Nachshen et al., 2008).

Reliable parent-mediated early interventions that are straightforward and supportive for parents and that affect basic developmental changes for children, setting them on positive trajectories, do exist (e.g., Landa, 2018; Wetherby et al., 2018; Zwaigenbaum, Bauman, Choueiri, et al., 2015). Providing appropriate and specific early intervention for toddlers with ASD helps them establish foundational learning that diminishes later cascading developmental deficits; that is, parent-mediated interventions in the early years can be impactful beginnings to development

(Wetherby et al., 2018; Zwaigenbaum, Bauman, Stone, et al., 2015). The negative effects of inaction may later become acutely salient for children with ASD because their reduced motivation for social interaction, combined with narrowly focused interests, results in them having missed crucial foundational learning opportunities (Camarata, 2014; Dawson et al., 2012; Landa et al., 2013; Wetherby et al., 2018).

S-LPs in ASD Early Interventions

Since parents often become concerned about their child's development during the first 2 years of life (Nachshen et al., 2008; Ozonoff et al., 2009) when social and pragmatic communication behaviours, such as positive affect sharing, coordinated eye gaze, communicative gestures, and language, do not develop as expected (Shumway & Wetherby, 2009; Wetherby & Prizant, 2002), S-LPs often deliver the important initial early assessments and referrals. Indeed, a key diagnostic criterion for children with ASD includes persistent deficits in the acquisition and use of nonverbal and verbal social communication (American Psychiatric Association, 2013). Moreover, ASD may be comorbid with other speech-language developmental disorders that S-LPs identify as primary disorders (American Speech-Language-Hearing Association, n.d.), so it is important for them to be current with developments in identification and intervention. Also, S-LPs often establish important ongoing partnerships with families after assessment and so are well-positioned to help them access appropriate pathways to interventions. Knowledgeable S-LPs are essential for mobilizing vital knowledge about ASD early interventions to benefit their young clients with ASD.

Historically, S-LPs have used increasingly robust methods to train parents to enhance their early interactions with their children, supporting goals of increased social communication and language development (Carter et al., 2011; The Hanen Centre, n.d.; Hwang et al., 2013; MacDonald, 1989; MacDonald & Carroll, 1992; Pickles et al., 2016; Prizant et al., 2003). These methods merge well with current early intervention evidence for children with ASD (American Speech-Language-Hearing Association, n.d.). The extensive body of evidence for parent-mediated interventions includes studies across professions that validate intervention strategies focusing on reciprocal, responsive, parent-child interactions (e.g., Harvard University: Center on the Developing Child, 2007; Kaiser et al., 2000; Natrasony & Teitelbaum, 2016; Rogers & Dawson, 2009; Yoder & Warren, 2002). Parent training is known to be effective in promoting the achievement of family-identified goals for the child (Hwang et al., 2013; Roberts & Kaiser, 2011), enhancing parent-child relationships (Carter et al., 2011), and importantly, improving parents' abilities, confidence, and

satisfaction with care (Oono et al., 2013). Additionally, early childhood professionals have learned that parents want integral information and education within their assessment and treatment experiences as support for them to ensure continuity of care (Natrasony & Teitelbaum, 2016).

Benefits of Parent Education

Providing reliable information to parents results in their decreased stress and better knowledge about their child's development (Carter et al., 2011; M. A. Feldman & Werner, 2002). A Canadian study that investigated a parent-centred treatment for young children with physical disabilities discovered that parents valued learning how to communicate with their infant or toddler by acknowledging behavioural cues. They reported learning positive and age-appropriate behaviour management strategies in enhanced interactions (Natrasony & Teitelbaum, 2016). It seems that when parents and families of children with disabilities learn how to best interact with their child, their stress decreases (Hendriks et al., 2000).

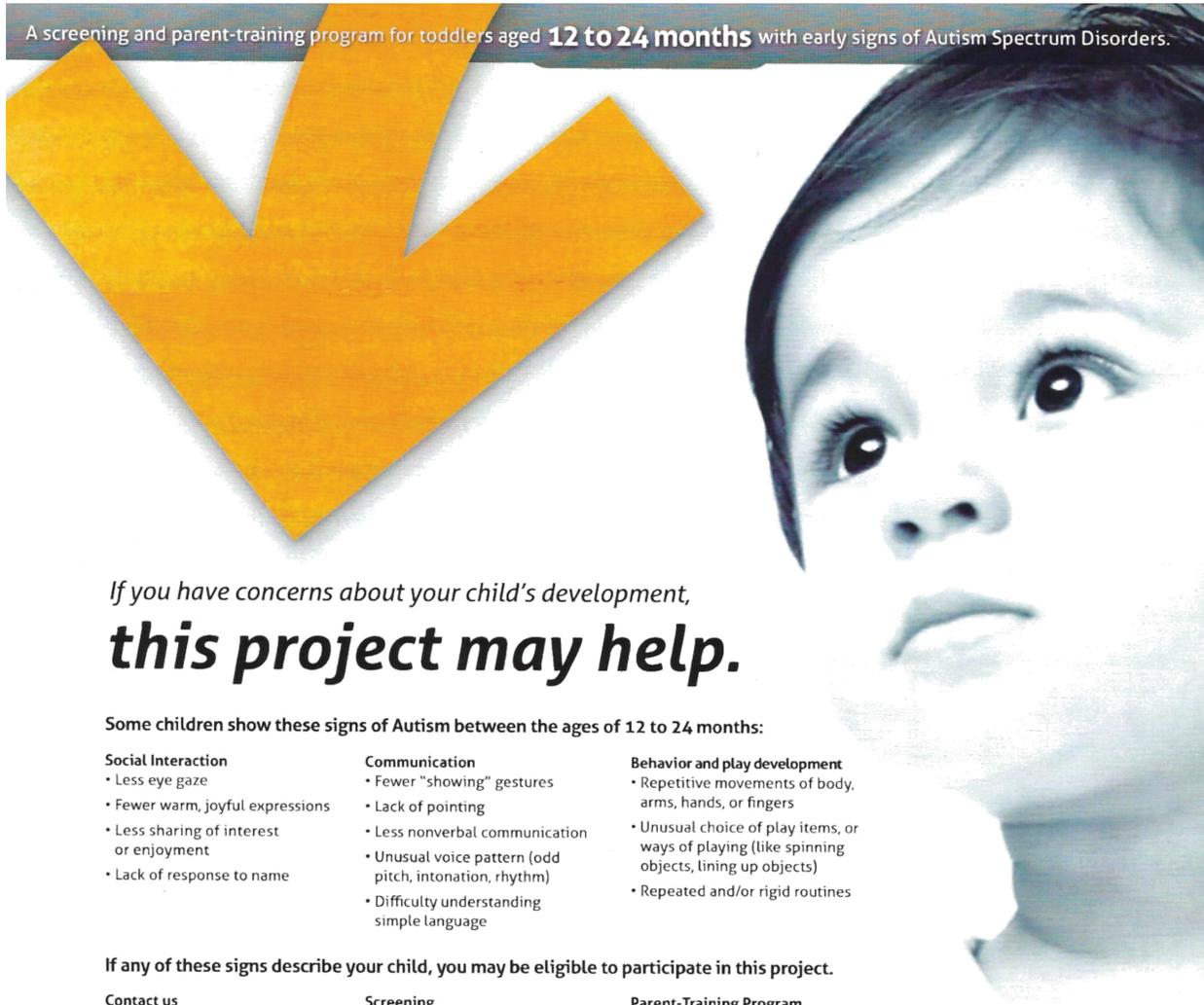
Parents are important facilitators in early interventions because they have the most consistent time to positively and naturally practice with their children (Brookman-Frazee & Koegel, 2004; Minjarez et al., 2013). Oono et al. (2013) found evidence for the effectiveness of parent-mediated interventions within the crucial parent-child interactions for child language comprehension and the reduction in ASD severity. However, even though the results with the child can be rewarding in terms of improved scores on test measures, the impact on their parents and families may be uniquely complicated and challenging (Brookman-Frazee & Koegel, 2004). Oono et al.'s (2013) findings reinforced the need for early intervention that develops parental interaction skills to enhance their child's development, but also highlighted the need to monitor levels of parental stress. Indeed, studying effects on parents when family coaching and teaching imposes responsibility on them is in progress across different fields.

The Act Early Autism Project

The *Act Early Autism Project* explored a potential continuous pathway to care that might address current barriers to early identification of risk and to early intervention for toddlers at high risk of ASD in Canada. Broad knowledge mobilization through television interviews, strategically placed information posters (see **Figure 1**), community talks, and open invitations for queries provided up-to-date information about early signs of ASD. To achieve our goal of reducing false positive screenings for ASD, we implemented a two-level screening process (Khowaja et al., 2018). First, the project sent a validated parent-report

Figure 1

A screening and parent-training program for toddlers aged **12 to 24 months** with early signs of Autism Spectrum Disorders.



If you have concerns about your child's development,
this project may help.

Some children show these signs of Autism between the ages of 12 to 24 months:

Social Interaction

- Less eye gaze
- Fewer warm, joyful expressions
- Less sharing of interest or enjoyment
- Lack of response to name

Communication

- Fewer "showing" gestures
- Lack of pointing
- Less nonverbal communication
- Unusual voice pattern (odd pitch, intonation, rhythm)
- Difficulty understanding simple language

Behavior and play development

- Repetitive movements of body, arms, hands, or fingers
- Unusual choice of play items, or ways of playing (like spinning objects, lining up objects)
- Repeated and/or rigid routines

If any of these signs describe your child, you may be eligible to participate in this project.

Contact us

for more information and to talk to us about available services in the Ottawa region. If you do not qualify for this project, we can help connect you with other services.

Screening

We will screen your child's communication, social and play skills. If you qualify, you and your child will soon participate in a free parent-training program.

Parent-Training Program

With a therapist, you will learn how to help your child learn language, social and play skills in daily routines. The program provides ten weekly sessions in your home.



(613) 286-8079 www.actearlyautism.ca

Community partners

Children's Hospital of Eastern Ontario
 Pincrest-Queensway Community Health Centre
 Emerging Minds Treatment Centre for Children and Youth

Funded by The Provincial Centre of Excellence for Child and Youth Mental Health at CHEO

Recruitment poster distributed throughout the community for the Act Early Autism study

screening tool by mail to anyone who contacted the study office, and we scored all returned forms. Then, children found to be at risk of ASD by parent report were given a second level observational screening for ASD by study professionals. Toddlers who presented significant red flags at the second level screening and whose families met study criteria were invited to participate in a low-intensity parent-mediated intervention, provided in families' homes. All steps in the pathway were meant to be seamless, without waiting. Moreover, the project elicited parents' opinions and perspectives to inform the process and to consider the impact of the pathway on their toddlers, themselves, and their families.

Our main objective was to explore the feasibility and accuracy of providing a continuous pathway to early intervention for toddlers at risk of ASD. Specific aims were to (a) examine numbers and proportions of children who were identified, received the intervention, and were subsequently confirmed as having ASD through gold-standard assessment tools and (b) determine if the parent-mediated early intervention was related to secondary changes in toddlers' development by examining changes on parent report measures. **Figure 2** outlines the *Act Early Autism Project* pathway to care; each assessed step provided key information about feasibility at that point, leading to and through the early intervention.

Method

Using descriptive methods, we explored a continuous pathway to parent-mediated early intervention for toddlers at high risk of ASD. This pathway went from community-wide information translation and mobilization about early signs of ASD, including an open invitation for any inquiries, to a responsive two-level screening for ASD, ending with the provision of a low-intensity 12-week parent-mediated intervention for toddlers who screened positive. We explored available data at each pathway step to inform (a) feasibility of the pathway, (b) utility of the tools, (c) secondary child behavioural changes, and (d) a confirmation of screened ASD status through an assessment that included the Autism Diagnostic Observation Schedule (ADOS). Some data is expressed in simple proportions, but wherever possible we analyzed the data using conservative, appropriate statistical tests. Finally, we explored social validity of the pathway by eliciting and examining a sample of parents' candid opinions about their experiences regarding progression through the pathway. Full descriptions of data collected at each step are provided below.

Identification by Community Education and Screening

Step one on the pathway was a 3-month long community education and awareness initiative aimed

Figure 2

Broad Community Education and Awareness

1. Information dissemination: RED FLAGS for Autism Spectrum Disorders in toddlers
2. Invitation to connect with study experts

Two-phase Screening

1. Parent report checklist for Autism Spectrum Disorders (i.e., Early Screening for Autism and Communication Disorders)
2. Observational Screening for Autism Spectrum Disorders (i.e., Systematic Observation of Red Flags)

Twelve-week, In-Home, Intervention

1. Parent Coaching
2. Two full standardized assessments including the ADOS

Steps in the Act Early Autism Project pathway to care

to provide up-to-date information to the public, parents, educators, and health professionals about evidence-based early signs of ASD. In all community-based meetings and/or via professionally designed information posters that included best evidence early red flags for ASD, people were invited to contact the project for further information and/or to participate in the identification and intervention steps, if appropriate. The community education/awareness initiative included ethically approved information posters which were strategically placed throughout the community in day cares, nursery schools, pediatrician offices, early years centres, and community centres (Figure 1); local television interviews with lead investigators; and newspaper articles. The project coordinator received 47 telephone inquiries during the 3-month information/education step. As mentioned, the poster was placed throughout the Ottawa area for 3 months presenting evidence-based early red flags and an invitation to call the *Act Early Autism Project* for more information.

Step two on the pathway included the Early Screening for Autism and Communication Disorders (ESAC; Wetherby et al., 2009) and the Systematic Observation of Red Flags (SORF; Dow et al., 2017; McCoy et al., 2009; Wetherby et al., 2004) as first and second level screening tools, respectively. The first level ESAC (Wetherby et al., 2009) is a parent questionnaire that screens and rates early red flags of ASD in toddlers using 47 research-tested items. The ESAC covers two critical diagnostic domains of ASD as presented in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; American Psychiatric Association, 2013). The SORF uses the Communication and Symbolic Behaviour Scales (Wetherby & Prizant, 2002) protocol to elicit behaviours and then observational scoring of the video-taped session. It includes 29 items covering diagnostic criteria of ASD as presented in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; American Psychiatric Association, 2013).

Thirty-two ESACs were returned and scored. After scoring, we flagged 29 toddlers as high-risk for ASD and an S-LP in a clinic administered the second level screening tool. Second level screening involved scoring the behaviour sampling protocol of the Communication and Symbolic Behaviour Scales (Wetherby & Prizant, 2002) using the SORF (Dow et al. 2017; McCoy et al., 2009; Wetherby et al., 2004). The SORF includes 29 diagnostic items for ASD (American Psychiatric Association, 2013) to rate early red flags of ASD from the video recorded Communication and Symbolic Behaviour Scales behaviour sample. Categories of behaviours are grouped into five composite areas: (a) reciprocal social interaction, (b) unconventional gestures,

(c) unconventional sounds and words, (d) repetitive behaviours and restricted interests, and (e) emotional regulation. The SORF rates the presence of behaviours that are atypical (i.e., rarely if ever displayed by children developing typically) and the absence of behaviours that are typical (i.e., usually displayed by children developing typically). A cut-off score of eight or more red flags indicates a risk for ASD status, thus warranting assessment for a diagnosis of ASD (Dow et al., 2017; McCoy et al., 2009). The SORF has good psychometric properties as a second level screen for ASD (Dow et al., 2017, 2020; Wetherby et al., 2008).

Intervention Inclusion and Exclusion Criteria

When toddlers screened positive for risk of ASD at both screening levels and families met the intervention inclusion criteria, they were immediately invited to receive the intervention as part of the study. Inclusion criteria included (a) toddlers were at least 14 months old when they began the intervention, (b) parents agreed to participate in research, (c) parents attended an information session, (d) parents agreed to commit to 12 weeks of coaching in their homes (including two assessments), (e) the child had no significant health or physical (e.g., hand use, ambulatory) concerns, (f) the child had no known, comorbid, biological-genetic conditions (e.g., Down Syndrome, Fragile X), (g) English was the child's and family's first language, and (h) the child was not enrolled in an intensive co-occurring intervention (i.e., more than 10 hours per week). When they met inclusion criteria and accepted the invitation to the early intervention, they were formally enrolled in the study for pre-post data collection and analyses.

Intervention

At step three on the pathway, we used the parent-mediated Early Start Denver Model (P-ESDM; Rogers, Dawson, & Vismara, 2012) as our early intervention because of its home-based curriculum and abbreviated coaching intensity to equip parents with immediate interactive tools shown to improve both parent and child behaviours during the intervention (Rogers, Dawson, & Vismara, 2012). The power of the model to affect children's behaviour was demonstrated in Rogers et al. (2019), which showed for the first time a direct positive relationship between parent fidelity of implementation and child growth. Also, parents in P-ESDM have shown high parent-therapist alliances (Rogers, Estes, et al., 2012) with no increase in stress while learning the intervention (Estes et al., 2014). The study provided a 1-hour session with either an S-LP or an occupational therapist and 10, 1-hour sessions in the families' homes with a trained coach.

The P-ESDM model integrates applied behaviour analysis principles with developmental, relationship-based methods, thus providing a comprehensive, manualized, and structured intervention for children with ASD, ages 12 to 48 months (Rogers & Dawson, 2009). The coaches taught parents to use a child-centred, responsive, interactive style while targeting individualized child goals. Parents learned age-appropriate applied behaviour analysis strategies and how to create, embed, and generalize learning opportunities for their toddlers in their daily lives. Parents learned to engage their toddlers in shared experiences to encourage imitation, communication, social-emotional, and play skills (Rogers, Dawson, & Vismara, 2012).

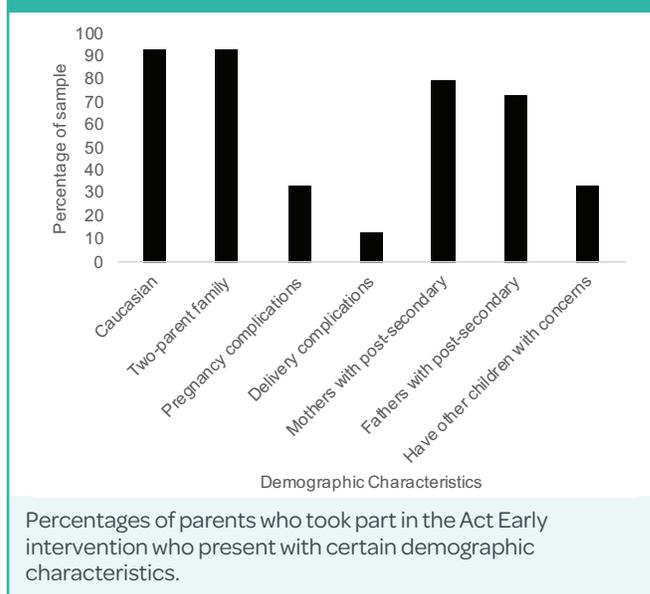
Two trained parent coaches achieved 85% treatment fidelity criteria through instruction provided by a P-ESDM trained lead investigator prior to working with families. The parent coaches were supervised throughout the study by the same lead investigator to ensure ongoing compliance with the intervention. The coaches were early childhood educators with previous training in applied behaviour analysis. Coaches collaborated with the families to establish three to five goals using the ESDM Curriculum Checklist, a criterion-referenced list of skills in developmental sequence, in eight domains, across four levels (Rogers & Dawson, 2009). One new strategy per week was introduced (Rogers, Dawson, & Vismara, 2012). If necessary, the coach would provide a hands-on demonstration of a strategy, but usually parents were coached about how to interact with their toddler. Parents were encouraged to practice all strategies in their natural environments each week, building on previous learnings. Handouts that reinforced new concepts and strategies were provided to support weekly practice (Rogers, Dawson, & Vismara, 2012).

Toddler participants in the intervention ($N = 15$) ranged in age from 16–27 months ($M = 20.3$ months; $SD = 3.38$); thirteen were boys (87%); and all lived in English as first language homes. Parents reported retrospectively that they first noted a developmental concern when their toddler was about 12 months of age ($M = 10.64$; $SD = 5.42$). Demographic information for the intervention parent participants is presented in **Figure 3**.

Child Measures

Standardized parent report measures were administered pre- and post-intervention to determine if there were any behavioural changes for the toddlers and to assess the efficacy of the intervention on child behaviour changes. Child changes were secondary to the early intervention which was delivered by the parents. Additionally, the gold standard ADOS was administered at

Figure 3



post-intervention to determine the accuracy of our two-level screening in directing families to the early intervention for ASD.

MacArthur Bates Communication Development Inventory

The words and gestures form (Fenson et al., 2007) is a checklist of 396 possible words for parents to report current expressive and receptive vocabulary and gestures in toddlers ages 8–37 months. The MacArthur Bates Communication Development Inventory (MBCDI) is psychometrically sound, as shown by reports that raw scores in young children with ASD are concurrently associated with vocabulary in language samples and in predicting later language in children with ASD (H. M. Feldman et al., 2005; Luyster et al., 2009).

Mullen Scales of Early Learning

The Mullen Scales of Early Learning (MSEL; Mullen, 1995) is a standardized and normed developmental assessment for children, ages birth through 68 months. It provides an overall index of ability (early learning composite score) and subscale scores for receptive language, expressive language, visual reception, and fine motor skills. The MSEL was administered by a qualified psychologist.

Vineland Adaptive Behavior Scales, Second Edition

The Vineland Adaptive Behavior Scales, Second Edition (VABS II; Sparrow et al., 1984) consists of four major domains: communication, socialization, daily living skills, and motor skills (age < 6 years), all of which contribute to an adaptive behaviour composite score, as well as

an optional maladaptive behaviour domain. The VABS II provides an adaptive behaviour composite score, domain and subdomain scores, and age equivalents. The VABS II provides supplementary norms for children with autism (Carter et al., 1998). It demonstrates good psychometric properties including internal consistency, inter-rater reliability, and content validity (Carter et al., 1998). It was administered to the primary caretaker.

ADOS

The ADOS (Lord et al., 1999) was administered to toddlers who completed the intervention to determine or rule out a diagnosis of ASD, to support the screening steps implemented in the pathway to care. The ADOS is a standardized, clinician-administered observation tool, designed to press for social communication and restricted-repetitive behaviours related to ASD. It includes three core areas of observation: language and communication, reciprocal social interaction, and stereotyped/restricted behaviours or interests. Its algorithm scores have acceptable internal consistency and excellent inter-rater and test-retest reliability and excellent diagnostic validity for ASD versus non-spectrum conditions. A qualified psychologist administered the ADOS.

Parent Measures

Standardized self-report measures and a focus group discussion were used to explore parents' experiences in the pathway to care. We evaluated their stress, their opinions about how they were treated in the process, and their candid responses to questions about how the process affected them, their toddler, and their families. The stress measure was administered pre- and post-intervention since parents were learning to be agents of the intervention.

Parenting Stress Index

The Parenting Stress Index (PSI; Abidin, 2012; Loyd & Abidin, 1985) is a screening and triage instrument that measures relative degree of stress in a parent-child system. It is frequently used in ASD studies with parents of children ages 1 month to 12 years and is often used for pretest-posttest measurement in research. The PSI may identify issues that can lead to problems in the child's or parent's behaviour. It focuses on three major domains of stress: child characteristics, parent characteristics, and situational/demographic life stress. The PSI can produce profiles for the child subscales of distractibility/hyperactivity, adaptability, reinforces parent, demandingness, mood, and acceptability and on parent subscales of competence, isolation, attachment, health, role restriction, and spouse/parenting partner relationship. PSI domain and subscale scores may

be confidently used to provide information about specific sources of stress in a parent-child system. Its reported reliability for the child subscale is .78-.88 and for the parent subscale is .75-.87 (Abidin, 2012). Reliability coefficients for the two domains and the total stress scale are .96 or greater, indicating a high degree of internal consistency. The PSI was administered to mothers and fathers of toddlers in the intervention following the intervention step.

Measure of Processes of Care

The Measure of Processes of Care (MPOC-20; King et al., 1995) is a parent questionnaire used to assess the family-centred behaviours of health care providers in interventions. With permission from CanChild, we administered an adapted version of the MPOC-20 following the intervention to assess parents' perceptions of the care they and their toddlers received along the pathway. The MPOC-20 is validated for parents who have children ranging in age from 0 to 17+ years who have neurodevelopmental disabilities or maxillofacial disorders. For the present study, parents were asked to indicate their extent of agreement to various questions about their experiences along the pathway.

Parent Focus Group

A one-time, 1-hour long focus group, led by a professional facilitator who was not involved in the study, occurred with five randomly selected mothers. Questions presented to the mothers were designed to elicit their opinions and experiences about the *Act Early Autism Project* pathway to care. The conversation was recorded for transcription and transcribed in real time for later examination and categorization. Topics addressed concerned major steps on the pathway to care: (a) parents' experiences from concerns to intervention, (b) child outcomes, (c) intervention strategies, and (d) written materials. **Table 1** summarizes all measures used in the *Act Early Autism Project*.

Results

Public Education and Screening

Numbers and proportions of toddlers who screened positive for high risk of ASD at the Level 1 screening suggested that the 3-month broad-reach community education blitz resulted in knowledgeable inquiries by parents. The community education blitz resulted in 29 of 32 toddlers (91%) identified as being at high risk for ASD. Following the Level 2 observational screening using the SORF, 24 of the 29 toddlers (83%) presented with significant red flags for ASD. Therefore, 90% of the toddlers who completed the Level 1 informed parent-report screening were positive for risk of ASD and/or developmental delay

Table 1
Summary of Child, Parent, and Data Measures Used in the Act Early Autism Project

Child	Parents	Coaches	When measure was used
1. ESAC*			Screening
2. SORF*			
1. MBCDI*	1. PSI		Pre-intervention
2. MSEL	2. MPOC		
3. VAB II*			
1. MBCDI*	1. PSI	Criteria treatment fidelity	Post-intervention
2. MSEL	2. MPOC	1. Descriptive	
3. VAB II*	3. Focus group		
4. ADOS*			

Note. *notable findings. ESAC = Early Screening for Autism and Communication Disorders; SORF = Systematic Observation of Red Flags; MBCDI = MacArthur Bates Communicative Development Inventory; MSEL = Mullen Scales of Early Learning; VAB II = Vineland Adaptive Behavior Scales – 2nd Edition; ADOS = Autism Diagnostic Observation Schedule; PSI = Parenting Stress Index; MPOC = Measure of Processes of Care.

and 83% of those who completed Level 2 screening were confirmed as high-risk for ASD.

Seventeen of 24 families with toddlers who screened at high risk at Level 2 screening also met the *Act Early Autism Project* inclusion criteria and were enrolled in the intervention. Seven eligible families declined participation because they chose to pursue other treatment options, lived too far away to be able to receive the intervention, or disagreed with the screening outcome. Toddler participants at screening were 14–29 months of age ($M = 20.28$; $SD = 4.42$). A Kruskal-Wallis test showed no differences on either screening measure between children who completed the intervention and those who declined or were lost to attrition (ESAC: $p = .23$; SORF: $p = .12$).

The numbers of participants entering and progressing through the pathway to care are summarized in **Table 2**. Proportions show feasibility of the pathway to care at this point in terms of differential identification and direction to appropriate early intervention

Intervention

Toddlers

Descriptive statistical analyses were performed on available pre- and post-data to evaluate secondary changes in child behaviours at this final step of the pathway to care. Because of the small sample size, missing child and parent data from families who did not return for follow-up, children who were unable to complete an assessment according to standardized procedures, and non-normal distributions of some variables, we performed non-parametric Wilcoxon

Signed Rank tests. This test allowed us to compare repeated measures on our single sample to assess whether the population mean ranks differed from pre- to post-intervention (i.e., a paired difference test). Test results are tentative given the type and status of our data.

MBCDI and VABS II. Toddlers’ social communication, expressive and receptive vocabulary, developmental, and behavioural/adaptive functioning were compared from pre- to post-intervention (on an individual basis, after 12 weeks of early intervention) using the MBCDI and the VABS II. Eleven of the 15 toddlers who completed the intervention had pre- and post-MBCDI; seven had both for the VABS II. For the 11 toddlers with MBCDI pre- and post-scores, raw scores for phrases and words understood, words produced, and gestures used changed positively from pre- to post-intervention according to parent report. Our large standard deviations represent a wide range of scores amongst a small sample, common in exploratory studies. Moreover, all toddlers whose chronological ages still fell within the testing limits of the MBCDI were within expected normative ranges for gestures-used at the post-intervention assessment.

One significant change was found on the VABS II for motor skills and it was a decrease ($p = .02$). Different *ns* reflect missing data at the post-assessment and are problematic for analyses. Only significant changes are presented in **Table 3**. All other changes in other domains were not significant.

The MSEL. No significant changes in development were found using the MSEL for the 11 children who completed

Table 2
Numbers and Proportions of Participants Progressing Through the Pathway to Care

Pathway milestones	<i>n</i>	Proportion
Completed Level 1 screening	32	1.0
Children screened high risk ASD at Level 1	29	0.90 (29/32)
Children confirmed high risk ASD at Level 2 screening	24	0.83 (24/29)
Families entering the intervention	17	0.70 (17/24)
Families lost to attrition	2	0.12 (02/17)
Families completed the intervention	15	0.88 (15/17)
Diagnostic evaluation with ADOS	15	1.0 (15/15)

Note. ASD = Autism Spectrum Disorder; ADOS = Autism Diagnostic Observation Schedule.

Table 3
Changes in Communication and Adaptive Behaviour Developmental Domains

Measure	<i>N</i>	Pre-score <i>M (SD)</i>	Post-score <i>M (SD)</i>	Wilcoxon signed-rank <i>p</i>
MBCDI Raw score	11			
Phrases understood		10.55 (5.99)	17.82 (7.65)	< .01*
Words understood		81.55 (73.21)	167.55 (106.36)	.01*
Words produced		7.18 (12.08)	86.27 (122.26)	< .01*
Gestures used		19.45 (7.15)	32.82 (13.51)	.01*
VAB II Standard score	7			
Motor sub-score		88.00 (13.25)	33.86 (4.53)	.02**

Note. **p* < .05; **negative change. MBCDI = MacArthur Bates Communicative Development Inventory; VAB II = Vineland Adaptive Behavior Scales – 2nd Edition.

a post-intervention MSEL assessment. Twenty is the lowest score that the MSEL can reliably specify at this age, and since some children did not reach this basal in some developmental domains, we created a developmental quotient score (i.e., Age Equivalency/Chronological Age x 100) using age equivalency scores for comparisons (see Rogers, Estes, et al., 2012). A developmental quotient was computed for each subscale and for a composite—the mean of the five subscales. **Table 4** presents the findings.

Functional Communication. Some parents reported during their focus group about qualitative changes they observed in their toddlers’ communication behaviour over the short term of intervention, adding social validity to our study. Eleven of 15 parents reported that their toddler had begun to appropriately use word approximations or words in their communication with others. The development from no words to beginning words signals an important

milestone that can represent potential emergence of oral language aptitude; for a child with ASD and language delays, this may be noteworthy. The proportion of children who were reported by their parents to have reached important communication milestones by the completion of the study are summarized in **Table 5**.

ADOS. All 15 children who completed the *Act Early Autism Project* intervention were administered the ADOS after their 12-week early intervention. All 15 met the cut-off criteria for ASD. These results confirm parents’ very early concerns at the community education phase of the study and the reliability of the *Act Early Autism Project* two-level screening step.

Parents

PSI. No significant changes were observed from pre- to post-early intervention for parents’ stress, measured by the

Table 4

Comparisons of Mullen Scales of Early Learning Developmental Quotients (DQ) From Pre-to Post-Intervention

DQ	<i>n</i>	Pre-DQ <i>M (SD)</i>	Post-DQ <i>M (SD)</i>	Wilcoxon signed-rank <i>p</i>
Gross motor	7	70.39 (26.23)	72.31 (16.79)	.24
Visual reception	11	68.89 (31.30)	61.57 (29.03)	.33
Fine motor	5	76.80 (21.40)	79.11 (7.84)	.89
Receptive language	14	38.05 (28.28)	46.10 (31.53)	.08
Expressive language	14	46.58 (26.79)	46.15 (24.48)	.73

Note. Different *n* values represent missing basals or missing post-assessment data.

Table 5

Social-Communication Milestones Achieved by Toddlers at Pre- and Post-Intervention

Milestone	Proportion of children at pretest (<i>n</i> = 15)	Proportion of children at posttest (<i>n</i> = 11)	Proportion change
Respond to name	.60	.91	+.31
Respond to "no-no"	.80	.91	+.11
Respond to "there's mommy/daddy"	.47	.91	+.44
Imitation	.29	.73	+.44
Labelling	.07	.36	+.29

PSI. There were no differences between participants who reported at both pre- and post-early intervention, and those who did not (Mann Whitney U test: *p* = .23–1.0 for mothers; *p* = .37–.95 for fathers).

MPOC-20. Ten parents used a 7-point Likert response scale to indicate their agreement with statements related to care, ranging from to a *very great extent* (7) to *not at all* (1). A zero meant the question was *not applicable*. Parents rated the following aspects of the pathway to care: (a) enabling and partnership, (b) providing general information, (c) providing specific information about their child, (d) coordinated and comprehensive care for the child and family, and (e) respectful and supportive care. We used individual raw scores and means for exploration rather than converting to subscale scores because we used an adapted version of the MPOC-20 for this study which meant that usual subscale computations were unavailable. We chose to use a stringent lower range score of 2 or less to indicate an area that parents considered insufficient care since our

N was small and the mean would not conservatively reflect a need for future study. Six of the 14 available items (43%) had a lower range score of 2 or less which we feel suggests areas in early intervention to improve. **Table 6** presents the MPOC-20 items and scores.

Focus Group. Five randomly selected mothers participated in a 1-hour follow-up focus group where they answered directed questions about their experiences through the pathway to care. Mothers expressed tiredness, feelings of stress, and being misunderstood by others before they became and remained more positive as they learned to help their child, especially in view of their initial concerns and the changes they observed in their children's social communication during the early intervention. Parents reported more and better interactions with their toddlers, and more child-initiated attention and affection. They found the personal coaching and support helpful and the written materials acceptable.

Table 6**Adapted MPOC-20 Raw Score Ranges**

Graded item	Range
To what extent do the people who work with your child...	
1. help you to feel more competent as a parent?	2–7*
2. provide you with written information about the strategies you were taught in coaching sessions?	6–7
3. help you understand how the use of teaching strategies will help your child develop?	5–7
4. provide a caring, supportive, atmosphere rather than just give you information?	5–7
5. make sure that at least one team member is someone who works with you and your family throughout the study?	6–7
6. fully explain the teaching strategies to you?	6–7
7. provide enough time to talk so you don't feel rushed?	5–7
8. treat you as an equal partner in developing goals for your child?	1–7*
9. provide you with written information about your child's goals and progress?	3–7
10. help you improve your interactions with your child?	3–7
11. help you feel more "connected" to your child?	2–7*
12. fully explain the initial evaluation results?	2–7*
13. fully explain the research process?	2–7*
14. give you information about the types of services offered in your community that will help you address other issues your child is experiencing?	1–6*

Note. *Area of potential future study and improvement for parent-mediated early intervention. MPOC = Measure of Processes of Care.

Discussion

The *Act Early Autism Project* pathway to care aimed to provide an unencumbered way to provide community education on the early signs of ASD, validate parents' early concerns, and quickly steer them to an appropriate intervention given that current early intervention for ASD work reveals that quick responses as soon as concerns are noted give children a better chance of development (Zwaigenbaum, Bauman, Choueiri, et al., 2015). The *Act Early Autism Project* received 47 calls from the greater Ottawa community during the Step 1 3-month long education blitz. At the Step 2 screening–identification of high risk, 29 children were flagged using the first level parent report paper screening; 24 were subsequently confirmed as high risk through the second level observational screening. At Step 3 intervention, 17 families were eligible and invited to enroll in the parent mediated early intervention. Within 1 year of initiating the *Act Early Autism Project* pathway, 15 toddlers under the age of 36 months had completed 3 months of evidence-based early intervention with their parents and received a definitive diagnosis of ASD, possibly

leading to a more positive trajectory by capitalizing on the brain's neuroplasticity at younger ages (Zwaigenbaum, Bauman, Stone, et al., 2015).

In the parent-mediated early intervention, parents were taught P-ESDM strategies to use within their natural interactions to encourage interactional social-communication behaviours in their toddler (Rogers, Dawson, & Vismara, 2012). During the *Act Early Autism Project* low-intensity, low-dose intervention, parents reported positive changes in their interactions with their toddlers and their toddlers' communication behaviours. In a focus group, a sample of the parents reported feeling positive about the pathway and the early intervention, suggesting that an early informed, responsive, and continuous pathway towards integral care can effect positive changes for families with toddlers at risk for ASD.

The Role of S-LPs

The *Act Early Autism Project* presents interesting considerations for speech-language pathology practice and future research in Canada. The first point of access to early intervention services for young children with developmental issues, including those with ASD, is often through speech

and language programs. Thus, S-LPs can be strategic to (a) educate communities and families with reliable information about early signs and evidence-based treatments, (b) differentially identify ASD with valid screening tools, (c) ensure that very young children at high risk of ASD are appropriately referred to expert colleagues and to early intervention quickly, and (d) advocate their community for harmonization and coordination of information and services for toddlers at risk and their families. S-LPs can be vital leaders in ASD early intervention pathways because they can respond sensitively to parents' early inquiries and concerns and critically evaluate interventions with the aim to match individual families to appropriate early interventions. Consequently, the onus is on us to stay current with the ever-evolving evidence. When children receive appropriate and timely care, they experience improved reciprocal interactions with caregivers creating positive foundations for learning.

Community Information

We feel that the broad community awareness initiative was essential to the quality of inquiries we received and enhanced the speed and efficacy of the screening step. Parents received evidence-based information that confirmed or relieved their concerns and helped them begin the pathway through valid identification toward an appropriate intervention. At a time when early identification and intervention were not widely available to families, 90% of our respondents screened positive for a developmental delay, including ASD, and 83% were confirmed, through valid second level observational screening, as high risk for ASD. We feel this demonstrates success of our pathway to care because these children got a 2-year edge on their early learning interactions compared to a "wait-and-see" approach with invaluable time to act and intervene wasted.

Screening

S-LPs need to be aware of evidence-based early red flags that require further investigation so that high-risk children are set on early pathways to intervention. The use of valid screening tools should be universally understood and trusted among speech-language pathology practices and based on recent evidence. Valid screening needs to be understood as essential in an efficient pathway as it serves to direct children, families, and clinicians to the most appropriate assessments and interventions quickly.

A serendipitous finding in our study of the screening step was the discovery of five commonly occurring ASD-specific early marker behaviours in our toddlers using the SORF (American Psychiatric Association, 2013). These behaviours were (a) abnormal gaze; (b) lack of sharing

interest and/or enjoyment; (c) lack of coordination of gaze, facial expression, gesture, and vocalization; (d) lack of the showing gesture; and (e) repetitive movement with objects. These red flags relate to diagnostic markers identified in other early ASD screening studies in Canada (McCoy et al., 2009; Zwaigenbaum, Bauman, Stone, et al., 2015). The first four are features of early joint attention which is important to language and communication development (Murza et al., 2016) and also noted in other research (Zwaigenbaum, Bauman, Choueiri, et al., 2015). We found that the SORF effectively confirmed high risk of ASD in our small sample. Therefore, we recommend further research regarding the use of the SORF by S-LPs as a quick indicator for further focused diagnosis for toddlers demonstrating red flags for ASD (Dow et al., 2017).

Parent-Mediated Intervention

Parent-mediated interventions for children with communication and language acquisition delays are effective in establishing foundational learning opportunities within early interactions (Camarata, 2014; Oono et al., 2013; Rogers, Estes, et al., 2012; Wetherby et al., 2014, 2018). Increasing parental competence through parent-mediated intervention empowers them in the belief that they can be positive agents of change in their children's lives (Guimond et al., 2008). Enhancing ASD early intervention by providing training for all family members and including peer group supports may be a means to further develop parental (and system) capacity. Parent training in groups as well as in-home training improves caregivers' ability to interact with their infants and toddlers in positive ways and helps to increase their knowledge of age appropriate behaviour and development (Natrasony & Teitelbaum, 2016). It may also reduce feelings of isolation and increase perceptions of family and community understanding. Evidence suggests that increasing parental competence promotes their belief that they can assist in their children's development (Guimond et al., 2008). Group education for parents can result in decreased stress, increased positive feelings about interventions, increased knowledge of early child development, and in cost effectiveness for the system (Furlong et al., 2012). Treatment fidelity measures must be explored and included in these early interventions to ensure accuracy and dosage, just as clinicians are trained.

Future Directions for Parent-Mediated Early Intervention

The continuous *Act Early Autism Project* pathway to care appears to have helped parents by validating their earliest concerns while also relieving their initial anxiety about how to immediately and appropriately provide for their toddler. Although the *Act Early Autism Project* intervention did not

target or intervene for parental stress, our findings suggest that mediating parents' stress should be a focus in parent-mediated interventions and future studies. Families who enter parent-mediated early intervention for their toddler with ASD take on major responsibilities for treatment outcomes, which could possibly add to existing high stress (Costa et al., 2017). Our early intervention involved weekly parent training, support, and encouragement and was provided in family homes, making transitions and generalizations to family activities easier. Yet, as noted in other studies, parents' stress levels did not change. Though positive about the *Act Early Autism Project* intervention, parents reported in focus group conversations new family stress because of the intervention that was not captured by the PSI measure.

Nascent research indicates reduced stress and improved mental health for parents of children with ASD when they participate in group discussions, general counselling, and/or interactive training. Parents who receive interactive training show additional benefits in reduced anxiety, insomnia, somatic symptoms, and family dysfunction (Tonge et al., 2006). Moreover, intervention dose does not appear to affect parent stress (Brookman-Frazee & Koegel, 2004; M. A. Feldman & Werner, 2002). Robust measurement and monitoring of parent and family well-being in parent-mediated interventions needs to be considered when designing treatment plans for young children, for setting priorities for dose, and for follow-up evaluation (Bonis & Sawin, 2016; Tonge et al., 2006). More diverse and robust measures for parent well-being could be added to monitor treatment success and to explore parental well-being by child treatment interactions.

Limitations and Future Directions for Research

This exploratory pilot study has several obvious limitations. The short timeframe did not allow for a high intensity–high dose intervention which would have resulted in a clearer picture of parent and child behavioural changes (Pickles et al., 2016; Wetherby et al., 2018). Our timeframe limited our ability to conduct more intensive, objective assessments and long-term follow-up of participants. With more time and larger sample sizes in a follow-up study, more rigorous outcome measures could be applied and analyzed to add confidence in the findings. Further, we advocate for early screening and intervention partnerships with publicly funded programming for greater outreach to families of culturally and socioeconomically different backgrounds than the majority of Caucasian, two-parent household families that made up our sample.

Parent report measures, such as the MBCDI, capture clinically important information about children's

developing abilities in early language, including vocabulary comprehension, production, gestures, and grammar. We recognize that though parent report measures are readily acceptable in clinical settings they are not considered rigorous for research and this adds an element of caution to interpretation of our results. For future research we would aim to strengthen clinical evidence of the MBCDI and MSEL Receptive results by including objective and rigorous measures for all child developmental domains. We realize these are necessary to support child change indicated by parent report measures, especially when parents are the direct objects of the intervention and growth may be secondary to parent sensitivity and responsivity training or to child maturation.

There were no measures of parents' treatment fidelity. Thus, judgements about parents' skill development directly affecting toddlers' changes were not possible. Toddlers may have received different doses of the intervention depending on parents' treatment fidelity relating to consistent training and then use of strategies. Furthermore, no data were collected for individual coaches' treatment fidelity to confirm that the intervention provided to all parents was consistent. In the future, these measures will be important to consider in the exploration of interaction effects: of coaches' behaviour with parents' and parents' with toddlers.' Finally, parent report measures can be valuable, but may have been biased and reflected their own responsivity development, rather than actual toddler development. Objective measurements and tests of generalization need to be included in future assessment batteries. Moreover, frequent behavioural measurements throughout the study would have been beneficial.

The status of our data relating to a small sample size at intervention meant insufficient statistical power to detect child changes with confidence. As a non-experimental, exploratory study, examining differential treatment effects or causation was beyond our scope. Weak findings have been reported elsewhere with low-dose, low-intensity, parent-mediated early intervention for ASD (Carter et al., 2011; Rogers, Estes, et al., 2012; Wetherby et al., 2018).

Conclusion

Foundations for lifelong development are established during the first 3 years of life in language, cognition, and social communication. The *Act Early Autism Project* demonstrated a feasible pathway to care for toddlers with ASD to overcome current barriers to early intervention and help families access evidence-based identification and intervention resources as soon as they had concerns about their child, thus ensuring optimal learning foundations. There

continues to be a need for robust evidence about how to choose, access, and implement parent-mediated early interventions to ensure positive developmental trajectories for toddlers with ASD and attend to family well-being. S-LPs can serve an important role in leading best practice and embedding research in their practice to garner evidence of effective crucial early starts in foundational development for toddlers with ASD.

References

- Abidin, R. R. (2012). *Parenting Stress Index* (4th ed.). Psychological Assessment Resources.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.) <https://doi.org/10.1176/appi.books.9780890425596>
- American Speech-Language-Hearing Association. (n.d.). *Autism*. https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935303§ion=Treatment#Family_Involvement
- Autism Canada. (n.d.). *Screening tools*. <https://autismcanada.org/autism-explained/screening-tools/>
- Barnard-Brak, L., Richman, D., Ellerbeck, K., & Moreno, R. (2017). Health care provider responses to initial parental reports of autism spectrum disorder symptoms: Results from a nationally representative sample. *Child and Adolescent Mental Health, 22*(1), 30–35. <https://doi.org/10.1111/camh.12194>
- Bonis, S. A., & Sawin, K. J. (2016). Risks and protective factors for stress self-management in parents of children with autism spectrum disorder: An integrated review of the literature. *Journal of Pediatric Nursing, 31*(6), 567–579. <https://doi.org/10.1016/j.pedn.2016.08.006>
- Brookman-Frazee, L., & Koegel, R. L. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions, 6*(4), 195–213. <https://doi.org/10.1177/10983007040060040201>
- Camarata, S. (2014). Early identification and early intervention in autism spectrum disorders: Accurate and effective? *International Journal of Speech-Language Pathology, 16*(1), 1–10. <https://doi.org/10.3109/17549507.2013.858773>
- Canadian Association of Speech-Language Pathologists and Audiologists. (2006, November 9). *CASLPA brief to the Standing Senate Committee on Social Affairs, Science and Technology: Funding for the treatment of autism*. Speech-Language and Audiology Canada. https://www.sac-oac.ca/system/files/resources/SenateCommittee_brief_nov2006.pdf
- Carter, A. S., Messinger, D. S., Stone, W. L., Celimli, S., Nahmias, A. S., & Yoder, P. (2011). A randomized controlled trial of Hanen's 'More Than Words' in toddlers with early autism symptoms. *The Journal of Child Psychology and Psychiatry, 52*(7), 741–752. <https://doi.org/10.1111/j.1469-7610.2011.02395.x>
- Carter, A. S., Volkmar, F. R., Sparrow, S. S., Wang, J.-J., Lord, C., Dawson, G., Fombonne, E., Loveland, K., Mesibov, G., & Schopler, E. (1998). The Vineland Adaptive Behavior Scales: Supplementary norms for individuals with autism. *Journal of Autism & Developmental Disorders, 28*(4), 287–302. <https://doi.org/10.1023/A:1026056518470>
- Costa, A. P., Steffgen, G., & Ferring, D. (2017). Contributors to well-being and stress in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 37*, 61–72. <https://doi.org/10.1016/j.rasd.2017.01.007>
- Dawson, G., Bernier, R., & Ring, R. H. (2012). Social attention: A possible early indicator of efficacy in autism clinical trials. *Journal of Neurodevelopmental Disorders, 4*(1), 1–12. <https://doi.org/10.1186/1866-1955-4-11>
- 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*(1), 17–23. <https://doi.org/10.1542/peds.2009-0958>
- Dingfelder, H. E., & Mandell, D. S. (2011). Bridging the research-to-practice gap in autism intervention: An application of diffusion of innovation theory. *Journal of Autism & Developmental Disorders, 41*(5), 597–609. <https://doi.org/10.1007/s10803-010-1081-0>
- Dow, D., Day, T. N., Kutta, T. J., Nottke, C., & Wetherby, A. M. (2020). Screening for autism spectrum disorder in a naturalistic home setting using the Systematic Observation of Red Flags (SORF) at 18–24 months. *Autism Research, 13*(1), 122–133. <https://doi.org/10.1002/aur.2226>
- Dow, D., Guthrie, W., Stronach, S. T., & Wetherby, A. M. (2017). Psychometric analysis of the Systematic Observation of Red Flags for autism spectrum disorder in toddlers. *Autism, 21*(3), 301–309. <https://doi.org/10.1177/1362361316636760>
- Estes, A., Vismara, L., Mercado, C., Fitzpatrick, A., Elder, L., Greenson, J., Lord, C., Munson, J., Winter, J., Young, G., Dawson, G., & Rogers, S. (2014). The impact of parent-delivered intervention on parents of very young children with autism. *Journal of Autism and Developmental Disorders, 44*(2), 353–365. <https://doi.org/10.1007/s10803-013-1874-z>
- Feldman, H. M., Dale, P. S., Campbell, T. F., Colborn, D. K., Kurs-Lasky, M., Rockette, H. E., & Paradise, J. L. (2005). Concurrent and predictive validity of parent reports of child language at ages 2 and 3 years. *Child Development, 76*(4), 856–868. <https://doi.org/10.1111/j.1467-8624.2005.00882.x>
- Feldman, M. A., & Werner, S. E. (2002). Collateral effects of behavioral parent training on families of children with developmental disabilities and behavior disorders. *Behavioral Interventions, 17*(2), 75–83. <https://doi.org/10.1002/bin.111>
- Fenson, L., Marchman, V. A., Thal, D. J., Dale, P. S., Reznick, J. S., & Bates, E. (2007). *The MacArthur-Bates Communicative Development Inventories: Second Edition. User's guide and technical manual*. Brookes.
- Furlong, M., McGilloway, S., Bywater, T., Hutchings, J., Smith, S. M., & Donnelly, M. (2012). Behavioural and cognitive-behavioural group-based parenting programmes for early-onset conduct problems in children aged 3 to 12 years. *Campbell Systematic Reviews, 8*(1), 1–239. <https://doi.org/10.4073/csr.2012.12>
- Guimond, A. B., Wilcox, M. J., & Lamorey, S. G. (2008). The Early Intervention Parenting Self-Efficacy Scale (EIPSES): Scale construction and initial psychometric evidence. *Journal of Early Intervention, 30*(4), 295–320. <https://doi.org/10.1177/1053815108320814>
- Guralnick, M. J. (2011). Why early intervention works: A systems perspective. *Infants & Young Children, 24*(1), 6–28. <https://doi.org/10.1097/IYC.0b013e3182002cfe>
- The Hanen Centre. (n.d.). *The Hanen centre*. <http://www.hanen.org/>
- Harvard University: Center on the Developing Child. (2007). *InBrief: Early childhood program effectiveness*. <https://developingchild.harvard.edu/resources/inbrief-early-childhood-program-effectiveness/>
- Hendriks, A. H. C., De Moor, J. M. H., Oud, J. H. L., & Franken, W. M. (2000). Service needs of parents with motor or multiply disabled children in Dutch therapeutic toddler classes. *Clinical Rehabilitation, 14*(5), 506–517. <https://doi.org/10.1191/0269215500cr353oa>
- Hwang, A.-W., Chao, M.-Y., & Liu, S.-W. (2013). A randomized controlled trial of routines-based early intervention for children with or at risk of developmental delay. *Research in Developmental Disabilities, 34*(10), 3112–3123. <https://doi.org/10.1016/j.ridd.2013.06.037>
- Kaiser, A. P., Hancock, T. B., & Nietfeld, J. P. (2000). The effects of parent-implemented enhanced milieu teaching on the social communication of children who have autism. *Early Education and Development, 11*(4), 423–446. https://doi.org/10.1207/s15566935eed1104_4
- Khawaja, M., Robins, D. L., & Adamson, L. B. (2018). Utilizing two-tiered screening for early detection of autism spectrum disorder. *Autism, 22*(7), 881–890. <https://doi.org/10.1177/1362361317712649>
- King, S., Rosenbaum, P., & King, G. (1995). *The Measure of Processes of Care-20: A means to assess family-centred behaviours of health care providers*. McMaster University, Neurodevelopmental Clinical Research Unit.
- Landa, R. J. (2018). Efficacy of early interventions for infants and young children with, and at risk for, autism spectrum disorders. *International Review of Psychiatry, 30*(1), 25–39. <https://doi.org/10.1080/09540261.2018.1432574>
- Landa, R. J., Gross, A. L., Stuart, E. A., & Faherty, A. (2013). Developmental trajectories in children with and without autism spectrum disorders: The first 3 years. *Child Development, 84*(2), 429–442. <https://doi.org/10.1111/j.1467-8624.2012.01870.x>
- Lau, R., Stevenson, F., Ong, B. N., Dziedzic, K., Eldridge, S., Everitt, H., Kennedy, A., Kontopantelis, E., Little, P., Qureshi, N., Rogers, A., Treweek, S., Peacock, R., & Murray, E. (2014). Addressing the evidence to practice gap for complex

- interventions in primary care: A systematic review of reviews protocol. *BMJ Open*, 4(6), 1–6. <http://dx.doi.org/10.1136/bmjopen-2014-005548corr1>
- Leew, S., Baker, K., Bond, S., Fong, A., Heinrichs, R., Lock, K., Nelles, T., Reid, J., & Di Gironimo, C. (2012, October). *Position paper on early identification of speech & language disorders*. Speech-Language and Audiology Canada. <https://www.sac-oac.ca/sites/default/files/resources/EarlyID-PositionPaper-ENGLISH.pdf>
- Lord, C., Rutter, M., DiLavore, P., & Risi, S. (1999). *Autism Diagnostic Observation Schedule*. Western Psychological Services.
- Loyd, B. H., & Abidin, R. R. (1985). Revision of the Parenting Stress Index. *Journal of Pediatric Psychology*, 10(2), 169–177. <https://doi.org/10.1093/jpepsy/10.2.169>
- Luyster, R., Gotham, K., Guthrie, W., Coffing, M., Petrak, R., Pierce, K., Bishop, S., Esler, A., Hus, V., Oti, R., Richler, J., Risi, S., & Lord, C. (2009). The Autism Diagnostic Observation Schedule - toddler module: A new module of a standardized diagnostic measure for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(9), 1305–1320. <http://doi.org/10.1007/s10803-009-0746-z>
- MacDonald, J. D. (1989). *Becoming partners with children: From play to conversation*. Special Press.
- MacDonald, J. D., & Carroll, J. Y. (1992). A partnership model for communicating with infants at risk. *Infants and Young Children*, 4(3), 20–30.
- McCoy, D., Wetherby, A. M., & Woods, J. (2009, May 7–9). *Screening children between 18 and 24 months using the Systematic Observation of Red Flags (SORF) for ASD: A follow-up study* [Oral presentation]. International Meeting for Autism Research. Chicago, IL, United States.
- Minjarez, M. B., Mercier, E. M., Williams, S. E., & Hardan, A. Y. (2013). Impact of pivotal response training group therapy on stress and empowerment in parents of children with autism. *Journal of Positive Behavior Interventions*, 15(2), 71–78. <https://doi.org/10.1177/1098300712449055>
- Mullen, E. M. (1995). *Mullen Scales of Early Learning*. American Guidance.
- Murza, K. A., Schwartz, J. B., Hahs-Vaughn, D. L., & Nye, C. (2016). Joint attention interventions for children with autism spectrum disorder: A systematic review and meta-analysis. *International Journal of Language and Communication Disorders*, 51(3), 236–251. <https://doi.org/10.1111/1460-6984.12212>
- Nachshen, J., Garcin, N., Moxness, K., Tremblay, Y., Hutchinson, P., Lachance, A., Beaurivage, M., Breitenbach, M., Bryson, S., Burack, J., Caron, C., Condillac, R. A., Cornick, A., Ouellette-Kuntz, H., Joseph, S., Rishikof, E., Sladeczek, I. E., Steiman, M., Tidmarsh, L., ... Ruttell, P. L. (2008). *Screening, assessment, and diagnosis of autism spectrum disorders in young children: Canadian best practice guidelines*. Miriam Foundation. https://www.goldlearningcentre.com/handbook_english_web-final.pdf
- National Autism Center at May Institute. (n.d.). *National Standards Project*. <https://www.nationalautismcenter.org/national-standards-project/>
- Natrasony, C., & Teitelbaum, D. (2016). Watch Me Move: A program for parents of young children with gross-motor delays. *Physical & Occupational Therapy in Pediatrics*, 36(4), 388–400. <https://doi.org/10.1080/01942638.2016.1205163>
- Ofner, M., Coles, A., Decou, M. L., Minh, D. T., Bienek, A., Snider, J., & Ugnat, A.-M. (2018, March). *Autism spectrum disorder among children and youth in Canada 2018: A report of the National Autism Spectrum Surveillance System*. Public Health Agency of Canada. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html>
- Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD009774.pub2>
- Ouellette-Kuntz, H. M. J., Coe, H., Lam, M., Yu, C. T., Breitenbach, M. M., Hennessey, P. E., Holden, J. J. A., Brown, H. K., Noonan, A. L., Gauthier, R. B., & Crews, L. R. (2009). Age at diagnosis of autism spectrum disorders in four regions of Canada. *Canadian Journal of Public Health*, 100(4), 268–273. <https://doi.org/10.1007/BF03403945>
- Ozonoff, S. J., Young, G. S., Steinfeld, M. B., Hill, M. M., Cook, I., Hutman, T., MacAri, S., Rogers, S. J., & Sigman, M. (2009). How early do parent concerns predict later autism diagnosis? *Journal of Developmental and Behavioral Pediatrics*, 30(5), 367–375. <https://doi.org/10.1097/DBP.0b013e3181ba0f0c>
- Piccinini, C., Bisnaire, L., & Penner, M. (2017). Cost-effectiveness of wait time reduction for intensive behavioral intervention services in Ontario, Canada. *JAMA Pediatrics*, 171(1), 23–30. <https://doi.org/10.1001/jamapediatrics.2016.2695>
- Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., Gammner, I., Lowry, J., Vamvakas, G., Byford, S., Aldred, C., Slonims, V., McConachie, H., Howlin, P., Parr, J. R., Charman, T., & Green, J. (2016). Parent-mediated Social Communication Therapy for young children with autism (PACT): Long-term follow-up of a randomized controlled trial. *The Lancet*, 388(10059), 2501–2509. [https://doi.org/10.1016/S0140-6736\(16\)31229-6](https://doi.org/10.1016/S0140-6736(16)31229-6)
- Prizant, B. M., Wetherby, A. M., Rubin, E., & Laurent, A. C. (2003). The SCERTS Model: A transactional, family-centered approach to enhancing communication and socioemotional abilities of children with autism spectrum disorder. *Infants & Young Children*, 16(4), 296–316. <https://doi.org/10.1097/00001163-200310000-00004>
- Roberts, M. Y., & Kaiser, A. P. (2011). The effectiveness of parent-implemented language interventions: A meta-analysis. *American Journal of Speech-Language Pathology*, 20(3), 180–199. [https://doi.org/10.1044/1058-0360\(2011\)10-0055](https://doi.org/10.1044/1058-0360(2011)10-0055)
- Rogers, S. J., & Dawson, G. (2009). *The Early Start Denver Model for young children with autism: Promoting language, learning, and engagement*. Guilford Press.
- Rogers, S. J., Dawson, G., & Vismara, L. A. (2012). An early start for your child with autism: Using everyday activities to help kids connect communicate and learn. Guilford Press.
- Rogers, S. J., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., Guo, M., & Dawson, G. (2012). 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 and 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., Greenon, J., Dawson, G., Rocha, M., Sugar, C., Senturk, D., Whelan, F., & Talbot, M. (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 Disorder*, 49(2), 632–646. <https://doi.org/10.1007/s10803-018-3740-5>
- Shumway, S., & Wetherby, A. M. (2009). Communicative acts of children with autism spectrum disorders in the second year of life. *Journal of Speech, Language, and Hearing Research*, 52(5), 1139–1156. [https://doi.org/10.1044/1092-4388\(2009\)07-0280](https://doi.org/10.1044/1092-4388(2009)07-0280)
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales*. American Guidance Service.
- Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: A randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(5), 561–569. <https://doi.org/10.1097/01.chi.0000205701.48324.26>
- Wetherby, A. M., Brosnan-Maddox, S., Peace, V., & Newton, L. (2008). Validation of the infant-toddler checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism*, 12(5), 487–511. <https://doi.org/10.1177/1362361308094501>
- 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>
- Wetherby, A. M., Lord, C., Woods, J., Guthrie, W., Pierce, K., Shumway, S., Thurm, A., & Ozonoff, S. (2009, May 7–9). *The Early Screening for Autism and Communication Disorders (ESAC): Preliminary field-testing of an autism-specific screening tool for children 12 to 36 months of age* [Abstract]. International Meeting for Autism Research, Chicago, IL, United States.
- Wetherby, A. M., & Prizant, B. M. (2002). *Communication and Symbolic Behavior Scales Developmental Profile*. Paul H Brookes Publishing. <https://imfar.confex.com/imfar/2009/webprogram/Paper4166.html>
- Wetherby, A. M., Watt, N., Morgan, L., & Shumway, S. (2007). Social communication profiles of children with autism spectrum disorders late in the second year of life. *Journal of Autism and Developmental Disorders*, 37(5), 960–975. <https://doi.org/10.1007/s10803-006-0237-4>
- Wetherby, A. M., Woods, J., Guthrie, W., Delehanty, A., Brown, J. A., Morgan, L., Holland, R. D., Schatschneider, C., & Lord, C. (2018). Changing developmental trajectories of toddlers with autism spectrum disorder: Strategies for bridging research to community practice. *Journal of Speech, Language, and Hearing Research*, 61(11), 2615–2628. https://doi.org/10.1044/2018_JSLHR-L-18-0028

- Wetherby, A., Woods, J., Nottke, C., Stronach, S., Dow, D., & McCoy, D. (2004). *SORF: Systematic Observation of Red Flags for autism spectrum disorders in young children*. Florida State University.
- Yoder, P. J., & Warren, S. F. (2002). Effects of prelinguistic milieu teaching and parent responsivity education on dyads involving children with intellectual disabilities. *Journal of Speech, Language, and Hearing Research, 45*(6), 1158–1174. [https://doi.org/10.1044/1092-4388\(2002/094\)](https://doi.org/10.1044/1092-4388(2002/094))
- Zubler, J. M. (2019). *Early identification of autism*. Medscape. <https://www.medscape.com/viewarticle/908580>
- Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Fein, D., Kasari, C., Pierce, K., Stone, W. L., Yirmiya, N., Estes, A., Hansen, R. L., McPartland, J. C., Natowicz, M. R., Buie, T., Carter, A., Davis, P. A., Granpeesheh, D., Mailloux, Z., Newschaffer, C., Robins, D., & Roley, S. S. (2015). Early identification and interventions for autism spectrum disorder: Executive summary. *Pediatrics, 136*(Supplement 1), S1–S9. <https://doi.org/10.1542/peds.2014-3667B>
- Zwaigenbaum, L., Bauman, M. L., Stone, W. L., Yirmiya, N., Estes, A., Hansen, R. L., McPartland, J. C., Natowicz, M. R., Choueiri, R., Fein, D., Kasari, C., Pierce, K., Buie, T., Carter, A., Davis, P. A., Granpeesheh, D., Mailloux, Z., Newschaffer, C., Robins, D., ... Wetherby, A. (2015). Early identification of autism spectrum disorder: Recommendations for practice and research. *Pediatrics, 136*(Supplement 1), S10–S40. <https://doi.org/10.1542/peds.2014-3667C>

Authors' Note

Correspondence concerning this article should be addressed to Robin Gaines, Speech/Language Pathology, Department of Development and Rehabilitation, Children's Hospital of Eastern Ontario, 401 Smyth Road, Ottawa, ON, K1H 8L1. Email: gaines@cheo.on.ca.

Laurie A. Vismara is now an independent researcher and consultant with *ESDM Online*.

Acknowledgments

This research was funded by The Provincial Centre for Excellence in Children's Mental Health Research, Ottawa, ON, Canada.

We acknowledge the children and families who so willingly participated in this research. We are also grateful to WRITT® for help in preparation of this manuscript and to Ashley Sokalski for her editorial assistance.

Disclosures

Laurie Vismara receives royalties for sales of the book: Rogers, S. J., Dawson, G., and Vismara, L. A. (2012). *An early start for your child with autism: Using everyday activities to help kids connect communicate and learn*. Guilford Press.

No other conflict of interest, financial or otherwise, are declared by the other authors.