

Using Parent and Child Input to Inform a Peer-Mediated Intervention for School-Aged  
Children with Autism Spectrum Disorder

by

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INPUT TO INFORM ASD INTERVENTION

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## INPUT TO INFORM ASD INTERVENTION

### ABSTRACT

There is growing awareness of the research-to-practice gap in evidence-based interventions (EBI) for children with autism spectrum disorder (ASD) at school. Peer-mediated interventions (PMI) are a practical approach for resource-limited schools, and have demonstrated initial efficacy in targeting social-communication impairments of children with ASD. The current study aimed to fill a void in the literature by considering families' perspectives alongside the development of a school-based PMI for children with ASD. Twenty-two participants (six parents of children with ASD; six parents of typically-developing children; 10 youths with ASD) took part in semi-structured interviews regarding acceptability and feasibility of the proposed PMI. Interview data were analyzed using descriptive content analysis. Participants agreed that components of the proposed PMI were acceptable (e.g., intervention target, grade) and provided advice regarding components of intervention implementation. Their feedback will inform the implementation of a novel EBI for children with ASD in schools.

## INPUT TO INFORM ASD INTERVENTION

### LIST OF ABBREVIATIONS AND SYMBOLS USED

Applied Behavioural Analysis (ABA)

Autism Diagnostic Interview-Revised (ADI-R)

Autism Diagnostic Observation Scale (ADOS)

autism spectrum disorder (ASD)

Canadian Institutes of Health Research (CIHR)

educational program assistant (EPA)

effect size (ES)

evidence-based intervention (EBI)

knowledge translation (KT)

peer-mediated intervention (PMI)

Pivotal Response Treatment (PRT)

randomized control trial (RCT)

typically developing (TD)

## Chapter 1: Literature Review

For individuals with autism spectrum disorder (ASD), social interactions can be very challenging to navigate. Significant difficulties with social interactions have been a defining characteristic of ASD since autism was first described by Kanner (1943; Carter, 2005). Social skill deficits continue to be a common area of vulnerability even for the most cognitively able individuals with ASD (Reichow & Volkmar, 2010). These deficits are often observed early in development when children on the autism spectrum are less likely to attend to their name being called (Baranek, 1999), and often fail to demonstrate joint attention (Mundy, Sullivan, & Mastergeorge, 2009) and imitation (Ingersoll & Gergans, 2007). Such social skill difficulties continue for children with ASD when they enter the school system (Boyd, Conroy, Asmus, & McKenney, 2011). When Chamberlain, Kasari, and Rotheram-Fuller (2007) examined the social interactions and relationships of children with ASD in inclusive classroom settings, they found that the level of social involvement with peers was lower for children with ASD compared to their typically developing (TD) peers. Further, the children with ASD were not as accepted by their peers, and they exhibited deficits in social reciprocity. As such, social skills are considered to be an important intervention target for individuals on the autism spectrum.

### **Social Skills Interventions for Individuals with ASD**

Within the past decade there has been a substantial increase in the number of studies evaluating social skills interventions for individuals with ASD (Reichow & Volkmar, 2010). Across these social skills interventions, there is great variation in the focus, structure and theoretical orientation of the interventions. Further, interventions

with children with ASD that do not explicitly aim to improve social skills may still improve these skills to some extent. For example, many interventions with a behavioural focus target joint attention and task engagement as well (Lovaas & Smith, 1988).

Communication-based programs, which inherently target some social skills given the social nature of communication, have also been popular (Reichow & Volkmar, 2010; Tager-Flusberg, Paul, & Lord, 2005).

Reichow and Volkmar (2010) presented a synthesis of the social skills intervention research that comprised 66 studies investigating a number of intervention methods, including Applied Behavioural Analysis (ABA), naturalistic behavioural approaches, parent modeling, peer modeling, social skills groups, and visual and video modeling methods. Of these methods, ABA techniques were the most commonly used. ABA is based in learning theory and principles of operant conditioning (Lovaas, 1987; Wolf, Risley, & Mees, 1964), and its techniques have a long history of being used to improve the social skills of young children with ASD (Strain & Schwartz, 2001). Given the flexible nature of ABA-based techniques, they are often used to augment other intervention types, such as video modeling and peer training. The most common elements of these ABA interventions were identified as prompting and reinforcement schedules, imitation and modeling paradigms, and self-monitoring. The intervention agents typically include parents, peers, or non-parental adults and most of the research has targeted the social skills of preschool children (Strain & Schwartz, 2001).

Reichow and Volkmar (2010) also considered the setting of the interventions examined in the studies they reviewed, which included the child's home, a hospital or clinic, the child's school, and/or a location within the community (e.g., a summer camp

or before- and after-school care settings). The most common intervention setting for preschool and school-aged children was the school. Home and community locations were the most common intervention settings for adolescents and adults. Across all interventions examined in this review, the only type to be considered an established evidence-based practice (i.e., a treatment that is effective across multiple methodologically sound studies conducted by at least two independent research groups; Reichow, Volkmar, & Cicchetti, 2008) was social skills groups for school-aged children with ASD. Whereas the most common intervention setting for school-aged children was the school setting, the most common setting for the only established evidence-based practice (i.e., social skills groups for school-aged children with ASD) was the clinic. Given this, Reichow and Volkmar (2010) noted the need for future research to consider the feasibility of social skills groups delivered in school settings.

Across all intervention studies examined by Reichow and Volkmar (2010), the most studied individuals were those with cognitive functioning that was categorized as being moderate (IQ of 55 to 85 and rudimentary verbal communication skills) or high (IQ > 85 and well-developed verbal communication). This trend was particularly true for intervention participants who were adolescents and adults; no studies investigated social skills interventions for individuals in this age group with lower levels of functioning (IQ < 55 and limited or no verbal language skills). Given that social skills are impaired in all individuals with ASD across levels of functioning, more research is needed on how to target social skills improvement in individuals with lower levels of functioning. Specifically, research should also identify the minimum level of skills (e.g., cognitive or language) needed for an intervention to be effective. Overall, Reichow and Volkmar

(2010) suggested there is “much empirical evidence supporting many different treatments for the social deficits of individuals with autism,” although conclusions cannot be made regarding the superiority of one treatment over another.

More recently, a Cochrane review by Reichow, Steiner, and Volkmar (2012) investigated the effectiveness of social skills groups for participants six to 21 years with ASD. Whereas Reichow and Volkmar (2010) examined a variety of social skills interventions and research designs (randomized control trials, quasi-experimental multiple-group comparison and single-subject experimental designs), this review was limited to randomized control trials (RCTs). Among the five resulting RCT studies, participant age was most commonly in the 7- to 12-year range. A social skills group intervention session typically included the following: a structured lesson on a specific skill, modeling of the skill, role playing with rehearsal or practice of the modeled skill, discussion, and individualized performance feedback. Common topics of the lessons and discussion included emotion recognition and regulation, social competence, social problem solving, and social communication. Overall, some evidence showed that social groups improve social competence (Effect size [ES] = .47) and friendship quality (ES = .41). No differences in emotion recognition or understanding of idioms (a measure of social communication; assessed in only one study) were observed. Further, decreases in loneliness but no effect on child or parental depression were reported. Participants in these groups might make gains in social competence, have better friendships, and experience less loneliness. It was recommended that more research with rigorous methods and measurement of multiple outcomes will be needed to make more specific recommendations about who will benefit most from social skills groups.

In contrast to the overall endorsement of social skills interventions reported above, it has also been reported that social skills interventions for individuals with ASD are minimally effective when conducted in the school environment (Bellini, Peters, Benner, & Hopf, 2007; Kasari & Smith, 2013). Focusing on 55 single-subject design studies, Bellini et al. (2007) conducted a quantitative synthesis of research examining school-based social skills interventions for children with ASD. The interventions were categorized as being *collateral*, *peer-mediated*, *child-specific*, or *comprehensive*. Nine studies involved collateral interventions, which aim to improve untargeted skills (e.g., social interaction) by training other skills (e.g., joint attention, language skills). Ten studies used a peer-mediated intervention (PMI), which involve training TD peers to direct and respond to the social behaviours of children with ASD. Fifteen studies used a child-specific intervention, which include instructional or reinforcement procedures to increase the skill, frequency or quality of social behaviour. Twenty studies used a comprehensive intervention, which included components of two or more of the other intervention techniques. Overall, Bellini et al. (2007) reported low treatment and generalization effects across participants and settings. Similar effects were observed across collateral skills, peer-mediated, child-specific, and comprehensive interventions. Of note, intervention, maintenance and generalization effects were higher for interventions that took place in classroom rather than pull-out settings. It will be important to consider social skills interventions that can be effectively implemented in multiple naturalistic settings (e.g., classroom, playground); this may be particularly important for children with ASD who generally have difficulties generalizing skills across settings (Cunningham, 2012).

**Pivotal Response Treatment (PRT)**

Pivotal Response Treatment (PRT) is an evidence-based approach that improves outcomes for children with ASD (Koegel, Koegel, & McNerney, 2001; National Autism Centre, 2009). PRT is based on the principles of ABA and teaches pivotal behaviours to yield generalized improvements in functioning (Verschuur, Didden, Lang, Sigafos, & Huskens, 2013). Pivotal behaviours are defined as behaviours that, when targeted, lead to collateral improvements in other areas of functioning. Pivotal behaviours include motivation, self-initiations, responding to multiple cues, and self-management (Koegel, Koegel, Harrower, & Carter, 1999). The focus of PRT, specifically, is on improving child motivation for learning and communication (Koegel & Koegel, 2006) by using “real world” intervention mediators (e.g., parents) in natural settings.

The effectiveness of PRT has been documented by many research syntheses; Masiello (2003) concluded that PRT effectively improved social and emotional behaviour of young children with autism. Simpson (2005) considered PRT to be a “scientifically based practice” and the National Autism Centre (NAC, 2009) deemed it to be an “established intervention”. In the first independent review to address the question of whether PRT improves untargeted behaviours by targeting pivotal behaviours, Verschuur et al. (2013) examined 43 PRT studies. Of the four skills that are considered to be pivotal by the developers of PRT (i.e., self-initiations, motivation, responding to multiple cues, and self-management), self-initiation is the only skill that has been studied extensively. Verschuur et al. (2013) presented evidence that PRT leads to increases in self-initiations that are accompanied by collateral improvements in language, communication, and play skills, and decreases in maladaptive behaviour. However, motivation, responding to

multiple cues, and self-management are rarely measured in studies examining PRT, and there is insufficient evidence to determine whether these skills develop as a result of PRT and whether this development would result in improvements in collateral skills. Overall, Verschuur et al. (2013) reported large variability in the PRT techniques implemented across intervention studies, and only two studies included all PRT techniques.

Specifically, “gaining the child’s attention and using contingent reinforcement” are techniques that are often not explicitly reported, perhaps because they are components of all behavioural interventions.

**Implementing PRT in schools.** PRT techniques may be implemented in varying combinations and in varying settings. Although the utility of PRT in inclusive school settings has not been studied extensively (Robinson, 2011), Renshaw and Kuriakose (2011) provided strategies for school psychologists regarding school-based implementation of PRT strategies. These strategies were based on the current understanding of the efficacy of PRT. Strategies include school psychologists’ consultation with teachers and caregivers to improve their knowledge of and use of PRT techniques. The potential for targeting the four skills that are considered to be pivotal was also highlighted; for example, in the classroom the teacher can use motivational procedures by providing child choice (e.g., the child chooses a preferred book) and reinforcing attempts using direct and natural reinforcement (e.g., when the child requests the book, the teacher hands the book to the child). Importantly, school psychologists could adopt a liaison role in encouraging and monitoring the use of PRT techniques in a variety of naturalistic settings (i.e., at home, in the community, and at school). This role is particularly useful given the accumulation of empirical evidence indicating that PRT

interventions occurring within multiple settings and by multiple interventionists are more likely to lead to positive developmental outcomes for children with ASD (Koegel & Koegel, 2006).

Paraprofessionals who work with students with ASD at school (i.e., educational assistants) also have the potential to play a key role in implementing PRT techniques. Given the relative paucity of research examining PRT in the school setting, and that research to date has relied heavily on the presence of an “expert”, Robinson (2011) aimed to train paraprofessionals in PRT techniques to support students with ASD in an inclusive school setting. Training for each paraprofessional took less than 90 minutes, and involved modeling and video-based feedback in the natural environment. That is, the trainer modeled strategies in the school setting, and the trainer and the paraprofessional reviewed videos of the paraprofessional and student interacting in the school setting. Following training, improvements were seen in both the paraprofessionals’ skill in implementing PRT techniques, and in students’ social communication target behaviours (i.e., reciprocal verbal interactions with peers, verbal requests, and spontaneous peer-directed verbalizations). Taken together, these results show promise for the training of paraprofessionals to use PRT techniques effectively to benefit their students with ASD.

### **Peer-Mediated Interventions (PMI)**

Peers of children with ASD also have the potential to implement PRT techniques when interacting with children with ASD. Peer-mediated PRT that targets improvements in peer relationships and social-communication skills are worthy of consideration when it comes to implementing evidence-based interventions (EBI) for school-aged children with ASD. While PRT often has parents and non-parental adults act as intervention agents,

PMI aims to teach peers to facilitate the development of social skills in a natural setting (i.e., school). This approach to treatment is thought to be particularly effective for the generalization of skills (Chan et al., 2009; Peirce & Schreibman, 1995, 1997), as it eliminates the need for transfer of learning from adults to peers (as required in adult-mediated PRT; Rogers, 2000). While five studies have published results of peer-mediated PRT intervention in the treatment of ASD (Chan et al., 2009), there is a larger body of research that supports peer-mediated approaches broadly (Zhang & Wheeler, 2011). These peer-mediated approaches may involve having the TD peer model appropriate behaviours, use prompting strategies, and reinforce target behaviours of the child with ASD (Chan et al., 2009).

Chan et al. (2009) noted a number of unique advantages and potential disadvantages to the use of PMI for children with ASD. A possible advantage includes the wide availability of intervention agents (i.e., TD peers) in the school setting and the potential for this to reduce the burden on teachers and other school professionals who would otherwise act as the intervention agents for children with ASD. Further, the opportunity to practice skills with multiple peers may increase the likelihood that these skills will generalize to other settings and individuals. Chan et al. (2009) also suggested that PMIs could enhance inclusion within schools, as direct interaction between students is facilitated. Noted disadvantages included the potential to 1) emphasize differences in children with ASD; 2) reduce TD peers' exposure to academic instruction; 3) decrease fidelity of implementation compared to interventions that use older agents; and 4) require changes to the classroom routine and consideration of ecological validity (Chan et al., 2009).

**PMIs and children with ASD.** Chan et al. (2009) reviewed 42 PMI studies, and found the reported outcomes to be primarily positive for children with ASD (91%). Study outcomes were coded as “positive” if participants were reported to have demonstrated a beneficial change on a primary outcome measure (e.g., improved social interaction, fewer problem behaviours, improved academic performance). Further, 14 studies (33%) were categorized as providing “conclusive” evidence (i.e., the research design provided experimental control, the dependent variable was reliable, there was evidence of strong treatment integrity; Millar, Light & Schlosser, 2006). Four studies (9%) reported mixed findings, and no studies reported negative findings. However, an overall lack of attention to treatment fidelity across most studies was mentioned as being a primary concern (Chan et al., 2009; Horner et al., 2005). It was noted that a lack of treatment fidelity is particularly concerning for PMI research, given the reliance on children implementing the intervention as opposed to adult interventionists.

In their review of 45 single-subject design studies that investigated PMIs for children with ASD, Zhang and Wheeler (2011) reported that PMIs were highly effective in promoting social interactions. Specifically, Zhang and Wheeler (2011) found that interventions that reported maintenance and generalization effects across participants, settings, and activities were more effective overall. However, specific strategies used to target maintenance and generalization effects were not reported. Interventions that involved all participants (i.e., researchers, peers/siblings, school staff, and parents) were also more effective. Unfortunately, a majority of studies (78.7%) excluded parents and families from the intervention. Zhang and Wheeler (2011) emphasized the importance of actively involving parents and families in the intervention process, as they play an

important role in promoting initial learning of new skills and maintaining gains for children with ASD.

A majority of PMI literature has focused on preschool-aged children, and no studies in the two reviews above included children older than 13 years. Schmidt and Stichter (2012) conducted one of the first studies that investigated the use of a PMI for adolescents with ASD. Using a single-subject, multiple treatment design, social competence outcomes were measured for individuals who participated in a social competence program (based on cognitive-behavioural therapy) followed by PMI to promote generalization of learned skills. The social competence program was based on a cognitive behavioural framework, with lessons that focused on recognition and expression of facial expressions and emotions, sharing ideas, turn-taking in conversation, and problem solving. The PMI included components of skill instruction, adult modeling, skill rehearsal, feedback, and a system for reinforcement. Schmidt and Stichter (2012) noted the lack of focus on generalization of skills acquired during intervention in social competence studies, and aimed to fill this void in the literature. They found that PMI resulted in levels of social interactions above the levels measured in baseline and during the social competence program. As one of the first studies to examine PMIs for adolescents with ASD, findings provide initial support for the use of PMIs with this age group.

**PMIs and typically developing peers.** Prior to reviewing literature that has examined effects of PMIs on TD peers, literature regarding the effects of inclusion (i.e., of children with ASD in regular education classrooms) on TD peers will be reviewed. As the mere physical placement of a child with ASD in a classroom of TD children is not

sufficient to generate acceptance by the TD children (Reiter & Vitany, 2007), the inclusion of children with ASD requires that TD children and school staff take into account their unique needs as opposed to ignore their differences (Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001). Research has shown that children with ASD who are fully included (i.e., not simply placed in close proximity to TD children) display higher levels of social interaction, give and receive more social support, and score higher on social competence measures than children who are segregated (Fisher & Meyer, 2002; Mavropoulou & Sideridis, 2014). However, there is limited focus on the effects of inclusion on TD peers (i.e., their knowledge about ASD and attitudes toward peers with ASD).

Reiter and Vitany (2007) examined relationships between attitudes of TD students in grade four and their level of burnout (i.e., lasting daily pressures that gradually leads to mental fatigue and reduced functioning; Talmor, Reiter, & Feigin, 2005) both before and after a program designed to facilitate the inclusion of children with ASD. The program included activities promoting group cohesiveness, role-play of familiar situations during inclusion, and practice of strategies to promote effective communication. Reiter and Vitany (2007) found that children with a negative attitude toward inclusion showed signs of apathy and did not initially participate actively in inclusion. However, following the program, the level of burnout dropped and the attitudes of TD children toward children with ASD improved. While this is the first investigation of burnout in TD children who are integrated with children with ASD, the program shows promise in improving the overall quality of inclusion for the children involved.

Mavropoulou and Sideridis (2014) examined the effects of contact with integrated students with ASD on the knowledge, attitudes, and empathy of TD children in grades 4-6. They also included a control group of TD children who did not have contact with students with ASD. Their results suggested that, following 3 months of integration, TD children demonstrated greater knowledge of ASD and more positive attitudes toward peers with ASD than did TD children who did not experience integration. The effect of inclusion on attitude was similar across grades, which contributes to inconsistent findings in the area. That is, although Mavropoulou and Sideridis (2014) noted no differences by grade, in another study, third graders rated their hypothetical peers with ASD more favourably than did sixth graders (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2004), and yet others have found that older children demonstrate more positive attitudes (de Boer, Pijl, & Minnaert, 2012). These contradictory findings could be due in part to different methods used across the three studies. For example, Campbell et al. (2004) and deBoer et al. (2012) used videotapes or vignettes of hypothetical peers with ASD, but Mavropoulou and Sideris (2014) used weekly structured contact with a peer with ASD. Further, whereas Campbell et al. (2004) and Mavropoulou and Sideris (2014) used The Adjective Checklist (Swaim & Morgan, 2001) to measure participants' attitudes toward a peer with ASD, de Boer et al. (2012) used the Chedoke-McMaster Attitudes Towards Children with Handicaps questionnaire (CATCH; Rosenbaum, Armstrong, & King, 1986). In addition to findings related to the effects of inclusion on attitudes, Mavropoulou and Sideris (2014) found that the effects of inclusion on empathy were not consistent across grades and sex. Inclusion had a significant effect on boys' cognitive and total empathy, and on girls' affective empathy. Further, inclusion only had a significant effect

on affective empathy for grades five and six students. Taken together, the findings provide encouraging data about TD children's knowledge and attitudes toward integrated peers with ASD.

In a study that looked specifically at the effects of PMI involvement on TD children, Locke, Rotheram-Fuller, and Kasari (2012) examined the social status of TD peers before and after involvement in PMI. Using self-report questionnaires, results indicated that peer implementers could be socially connected to children with ASD and typical classmates, and maintain a strong and positive role within the classroom. Specifically, findings suggested that TD children in PMI scored higher on measures of social network centrality, received friendships, and friendship quality compared to TD children who were not involved in PMI. Further, TD children in PMI demonstrated less loneliness than TD children not involved in PMI. These findings suggest that there is a particular type of child who is more likely to be selected for participation in PMI (e.g., greater social competence and perceived as more "popular" by peers) and that their social outcomes are not negatively impacted by involvement in PMI.

**PMIs in grade primary.** To date, although a majority of the PMI literature has focused on preschool-aged children, as yet no peer-mediated PRT study has focused on school-aged children. There is a similar issue within the PRT research broadly; that is, most studies examining PRT have involved preschool-aged children and there is a relative lack of research involving implementation of PRT in school settings (see Stahmer, Suhreinrich, Reed, Schreibman, & Bolduc, 2011, as an exception). Given this, it is unclear whether PRT approaches using peers as intervention agents can be effectively used with school-aged students with ASD (Bass & Mullick, 2007). Understanding the

efficacy of peer-mediated PRT in the first year of school (henceforth, grade primary) may be particularly important given the difficulty of this transition to the school environment for children with ASD (Forest, Horner, Lewis-Palmer, & Todd, 2004). The change to a new physical, social and academic environment can be particularly challenging given the social-communication difficulties and inflexible behaviour patterns of children with ASD (Fowler, Chandler, Johnson, & Stella, 1998). Further, the maintenance of early intervention gains depend in part on the transition of children with ASD from preschool to grade primary (Hanson et al., 2001; Forrest et al., 2004). The National Research Council (2001) has highlighted the need to maintain preschool gains, given the continued focus on intense and effective support for preschool-aged children with ASD (Forest et al., 2004). An effective transition plan aims to provide continuity of supports from preschool to grade primary (Forest, 2004), and additional research to determine whether peer-mediated PRT can ease this transition for children with ASD would be valuable.

### **Social Validity in ASD Intervention Research**

Although the implementation of PMIs for school-aged children with ASD is a logical and practical approach (Chan et al., 2009), little is known about how acceptable this approach would be for individuals with ASD, their family members (i.e., parents of children with ASD, youths with ASD themselves), or the family members of TD peers. This is worrisome, given the potential disadvantages to PMI that have been noted above by Chan et al. (2009). Given the role families play in the decision to access interventions for their child with ASD, it is imperative that their perspectives be considered. To the author's knowledge, there has yet to be consideration of the social validity of PMIs through consultation with key stakeholders. When a research program considers family

perceptions of the acceptability of an intervention, the social validity of that intervention is being addressed. Social validity refers to the acceptability of the goals, procedures, and outcomes of an intervention (Kazdin, 1977). Social validity is highly correlated with the effective use of interventions in clinics, schools, and homes (i.e., positive outcomes in the real world; Gresham, Cook, Crews, & Kern, 2004).

**Social validity methods.** Perspectives regarding ASD interventions, when they are sought, are typically obtained through surveys after provision of the intervention or service (e.g., Montes, Halterman, & Magyar, 2009; White & Weiss, 2010). This approach does not allow for the active incorporation of feedback as an intervention is developed. Therefore, the ability to address the social validity of the intervention is compromised from the outset. In addition to surveys, family perspectives have been collected using semi-structured discussions in the form of interviews and focus groups (Brookman-Frazer, Baker-Ericzen, Stadnick, & Taylor, 2012; Stahmer et al., 2011). Semi-structured interviews are considered to be an expedient way of gathering richer data than is possible with a survey (Delamont, 2012). This qualitative method of data collection is structured, in that specific issues and questions can be addressed, but with the freedom to probe and provide prompts as necessary (Thomas, 2011). This method can offer particular utility when considering perspectives during the development of an intervention. Indeed, interviews provide the opportunity to capture insights at a depth and level of focus that is not often captured using other qualitative methods (e.g., surveys, observations). As with the collection of parent perspectives, semi-structured interviews are becoming a valued method in consulting with individuals with ASD and have generated rich, informative

accounts from children, adolescents, and young adults with ASD (e.g., Humphrey & Lewis, 2008).

**Perspectives of parents.** Recent efforts have been made to investigate the perspectives of parents of individuals with ASD regarding the availability, accessibility, and effectiveness of current ASD services (Brookman-Frazee, Baker-Ericzen, Stadnick, & Taylor, 2012; Lord et al., 2005; Montes, Halterman, & Magyar, 2009; Shyu, Tsai, & Tsai, 2010; Stahmer et al., 2011; White & Weiss, 2010). This research highlights the frustration and dissatisfaction that families experience when accessing ASD services. Montes, Halterman, and Magyar (2009) surveyed parents of children with ASD and parents of children with other special health care needs in the United States (US). Using the National Survey of Children with Special Health Care Needs (2005 - 2006; Blumberg et al., 2008), they found that more parents of children with ASD reported difficulty using school and community services, and dissatisfaction with those services, than parents of children with other health care needs. It was suggested that more services are needed for children with ASD that are deemed acceptable by parents. Similarly, White and Weiss (2010) conducted a paper survey study of 225 professionals and parents of individuals with ASD examining perceptions of the availability, accessibility and effectiveness of services for adolescents and adults with ASD in Ontario, Canada. They found that professionals rated the availability, accessibility and effectiveness of services more favourably than did parents, though ratings were generally low across both professional and parent groups. These findings highlight the lack of connection between professional and parent perceptions of intervention. Moreover, the extant literature highlights a need

to better understand how families' needs are currently being met, in addition to their overall views of ASD services.

To date, only two studies have sought parent input prior to the implementation of an intervention program (Brookman-Frazee et al., 2012; Stahmer et al., 2011). Stahmer et al. (2011) used parent feedback to facilitate the implementation of community services for children with ASD younger than three years. Focus groups were held to obtain parent perspectives of early interventions for ASD and barriers to access to such services. Specific feedback was also gathered using surveys. Findings indicated that parents noted concerns with intervention strategies that relied exclusively on parent implementation. Parents expressed instead that multiple caregivers should receive intervention training, including siblings. However, parent perspectives regarding the training of peers were not examined. Given the emphasis parents place on increasing peer interactions for their children with ASD (Bellini, Peters, Benner, & Hopf, 2007), and evidence of the effectiveness of PMI (Zhang & Wheeler, 2011), there is a pressing need to investigate parents' perceptions of PMI for children with ASD.

Using semi-structured interviews, Brookman-Frazee et al. (2012) examined perspectives of 23 parents whose school-aged children with ASD had received services at a community mental health clinic. Parents expressed frustration with the accessibility of community services, and with specific barriers to effective care (e.g., a lack of coordination between school and community mental health services and a need for improved training of service providers). Feedback from these interviews, with information from several other sources (i.e., an observational study of services; service provider perspectives; literature on evidence-based interventions for children with ASD),

was used to develop an intervention protocol for community mental health clinics serving children with ASD, and a corresponding therapist training protocol. This line of research emphasizes an effective research-community partnership established at the outset of intervention development.

**Perspectives of individuals with ASD.** To the author's knowledge, the perspectives of individuals diagnosed with ASD have yet to be considered when developing EBIs. Given the paucity of research that has examined the perspectives of children with ASD as part of the development of an intervention, literature that has included the perspectives of those with ASD more broadly will be reviewed. A variety of methods have been used to gain insight into the perspectives and experiences of individuals with ASD. This includes reviews of autobiographies (Causton-Theoharis, Ashby, & Cosier, 2009; Chamak, Bonniau, Jaunay, & Cohen, 2008), blogs (Jones, Zahl, & Huws, 2010), artwork (Robledo, Donnellan, & Strandt-Conroy, 2012), questionnaires (Chamberlain, Kasari, & Rotherham-Fuller, 2007; Jones et al., 2007; Bauminger & Kasari, 2000), semi-structured interviews (Humphrey & Lewis, 2008; Hurlbutt & Chalmers, 2002; Huws & Jones, 2008; Trillingsgaard & Sorensen, 1994; Webster & Carter, 2013), email-facilitated interviews (Benford & Standen, 2011), computer-assisted interviews (Barrow & Hannah, 2012), and discussion groups (Brewster & Coleyshaw, 2010), with many studies involving a combination of these methods of data collection. Given the particular utility of semi-structured interviews (i.e., rich, interactive data collection), the following literature review will focus on studies that have used this qualitative method to consult with individuals with ASD.

An important first step in understanding the school experiences of individuals with ASD is to consider their understanding and acceptance of their diagnosis. These perceptions are likely to affect the way in which they make sense of their school experience (Humphrey & Lewis, 2008). Huws and Jones (2008) interviewed nine individuals with ASD (16 to 21 years), to examine retrospective accounts of the disclosure of their diagnosis of ASD. Interview questions were asked of each individual that probed their knowledge of autism and the meaning of a diagnosis of autism to them. By using an interpretative phenomenological approach (Smith, Jarman, & Osborn, 1999) that focused on the richness of personal accounts, a number of recurring themes relevant to perceptions of autism emerged. Themes pertained to *diagnosis*, *disclosure*, and *having autism*. Individuals with ASD communicated the range of emotions they experienced upon disclosure of their diagnosis, including shock, disappointment, and disbelief. It was reported that having a label of “autism” led to both positive (e.g., the reduction of distressing treatment by others; clarification of previous life events) and negative (e.g., discrimination) effects. These retrospective accounts indicate that reflecting on previous experiences can elicit rich, meaningful information from individuals with ASD. Moreover, understanding the lens through which individuals with ASD view the condition may shape our understanding of school-based experiences.

Carrington and Graham (2001) conducted semi-structured interviews with two 13-year-old boys with Asperger syndrome and their mothers. Specific difficulties in forming relationships, and in understanding and developing friendships with peers were reported. It was also reported that the obsessive interests associated with ASD could be impairing when not adequately controlled and monitored. Finally, it was indicated that

both boys were aware of “not fitting in” and made efforts to hide their differences. These are important issues to consider when implementing an evidence-based intervention in a school setting. That is, social-communication skill deficits have been reported as a clear burden to teenagers with ASD.

When considering the acceptability of school-based interventions, it is critical to understand the school experiences of individuals with ASD. Humphrey and Lewis (2008) also explored perspectives of mainstream schooling by interviewing 20 individuals with ASD (11 to 17 years). A number of facilitators and barriers to a positive school experience were noted. Social isolation and bullying (e.g., name-calling, physical violence) were reported at varying levels of severity and frequency by nearly all participants. However, peer relationships were differentially identified as being both supportive (in the case of understanding friends), as well as impeding (in the case of bullies) toward successful inclusion at school. Moreover, peer support was often cited as a means of counteracting the barriers reported (i.e., social isolation and bullying). Indeed, peer relationships may be more directly related to successful inclusion than teacher relationships (Bauminger & Kasari, 2000). Taken together, these unique and important perspectives from individuals with ASD suggest that peers may offer an important support for children with ASD at school (Cowie & Wallace, 2000). Although experiences with being bullied are reported to be very prevalent in this population, it is currently unknown how peer support early in schooling may mitigate this later trajectory.

The most direct examination of the social validity of school services for children with ASD was conducted by Jones et al. (2007), who asked 35 school-aged children with Asperger syndrome in Northern Ireland about their satisfaction with life at school.

Overall, there were more positive ratings than dissatisfied ratings, although one third of participants indicated they were “not at all satisfied” with some aspects of school (e.g., homework and test results). When asked how they would like their school to be different, many children offered valuable suggestions (e.g., the use of a timetable; extra help from school personnel; more knowledge of ASD amongst teachers). When asked about people who have helped them, over half of the children referred to the support they had received from friends. This insight is particularly relevant when considering the acceptability of school-based interventions that include peer implementers for children with ASD. The perspectives provided by children with ASD highlight the value of asking them about their experiences at school, including facilitators and barriers to their satisfaction, rather than making “educated guesses” about what might help them.

## Chapter 2: Current Study

### Using Parent and Child Input to Inform a Peer-Mediated Intervention for School-Aged Children with Autism Spectrum Disorder

There is a growing body of literature examining the efficacy of school-based interventions for children with autism spectrum disorder (ASD; Callahan, Henson, & Cowan, 2008). However, many interventions delivered to children with ASD in school settings have not been shown to improve adaptive, social, or cognitive functioning (Chasson, Harris, & Neely, 2007). Moreover, these interventions have been tested in controlled research settings, with few attempts to effectively adopt in “real world” school settings (Iovannone, Dunlap, Huber, & Kincaid, 2003). There is a growing awareness of this gap between research and practice in evidence-based school interventions for children with ASD (Dingfelder & Mandell, 2010). In particular, there is a current lack of evidence-based interventions (EBIs) targeting social skills for children with ASD in schools (Hess, Morrier, Heflin, & Ivey, 2008). This is concerning, given that successful peer interactions are among parents’ most valued outcomes for their child with ASD (Bellini, Peters, Benner, & Hopf, 2007). While parents are often the primary intervention agent for children with ASD in preschool years, teaching same-aged peers to implement strategies to increase the skills of children with ASD holds great promise for addressing the research to practice gap. That is, peer-mediated interventions (PMIs) using typically developing (TD) peers as the intervention agents at school are a logical and practical approach for resource-limited schools (Chan et al., 2009). Peer implementers typically take on responsibilities such as modeling appropriate behaviour, using prompting strategies, and reinforcing target behaviours. PMIs have been shown to be efficacious

(i.e., positive outcomes in ideal, lab-based settings) in targeting the social-communication impairments of children with ASD (Chan et al., 2009). However, little is known about how acceptable this approach would be for individuals with ASD, their family members (i.e., parents of children with ASD), or the family members of TD peer implementers. Given the role families play in the decision to access interventions for their child with ASD, it is imperative that their feedback be sought to improve the feasibility and acceptability of school-based interventions and ultimately introduce EBIs into schools effectively (i.e., address the research-to-practice gap in school-based interventions).

### **Social Validity in ASD Intervention Research**

The social validity of an intervention is addressed when a research program considers stakeholders' perceptions of the acceptability of that intervention. Social validity refers to the acceptability of the goals, procedures, and outcomes of an intervention (Kazdin, 1977) and is highly correlated with the effective (i.e., positive outcomes in the real world) use of interventions in clinics, schools, and homes (Gresham, Cook, Crews, & Kern, 2004). Without social validity measures, the likelihood of the intervention being implemented is lessened; that is, more acceptable interventions are considered more likely to be implemented (Brookman-Fraze et al., 2012). When EBIs are not implemented in an acceptable or socially valid way, teachers and other school personnel may be more likely to adapt the intervention once it is implemented, thereby potentially decreasing its effectiveness (Stahmer et al., 2012). Indeed, when users modify evidence-based approaches, positive outcomes may be compromised (Weisz et al., 1995). Alternatively, interventions that lack research-tested efficacy are often implemented, which can be ineffective and potentially harmful (Bellini & Akullian, 2007).

Despite the utility of considering the social validity of school-based interventions for children with ASD, gathering this data is an often-missing step that could improve the feasibility and acceptability of an intervention to bridge the research-to-practice gap in schools (Parsons et al., 2013). Further, when perspectives regarding ASD interventions are sought, they are typically obtained after provision of the intervention or service (e.g., Montes, Halterman, & Magyar, 2009; White & Weiss, 2010). This precludes the ability to actively incorporate social validity data (e.g., stakeholder perspectives) as an intervention is developed to inform intervention adaptations and improve chances of successful intervention implementation.

**Perspectives of parents.** It is important to consider parents' perspectives when addressing social validity, as parents will be instrumental in accessing (in the case of children with ASD) and enabling participation in (in the case of TD peer implementers) school-based interventions. Further, as the popularity of PMIs continues to rise, more attention needs to be paid to the social validity and perceptions of those involved in the intervention. For example, researchers have noted concerns regarding the potential for PMIs to be a burden to peer implementers (e.g., negative social consequences, compromised academic performance; Ferraioli & Harris, 2011; Chan et al., 2009). Studies examining the perspectives of the parents of potential peer implementers regarding PMIs have not been located. Obtaining this perspective serves to fill an important gap, given the large body of PMI research (Chan et al., 2009).

Recent efforts have been made to investigate the perspectives of parents of individuals with ASD regarding the availability, accessibility, and effectiveness of current ASD services (Brookman-Frazee et al., 2012; Lord et al., 2005; Montes et al.,

2009; Shyu et al., 2010; Stahmer et al., 2011; White & Weiss, 2010). These research findings highlight the frustration and dissatisfaction that families experience when accessing ASD services. Importantly, only two studies have sought these perspectives prior to the implementation of an intervention program (Brookman-Frazee et al., 2012; Stahmer et al., 2011).

Stahmer et al. (2011) used parent feedback to facilitate the implementation of community services for children with ASD younger than three years. Focus groups were held to obtain parent perspectives of early interventions for ASD and barriers to access to services. Findings indicated that parents noted concerns with intervention strategies that relied exclusively on parent implementation. As opposed to relying solely on parent implementation, parents expressed that multiple caregivers should receive intervention training, including siblings. However, parent perspectives regarding the training of peers were not examined. Given the emphasis parents place on increasing peer interactions for their children with ASD (Bellini, Peters, Benner, & Hopf, 2007) and evidence of the effectiveness of PMI (Zhang & Wheeler, 2011) there is a pressing need to investigate parents' perceptions of PMIs for children with ASD.

Brookman-Frazee et al. (2012) used semi-structured interviews to examine perspectives of 23 parents whose school-aged children with ASD had received services at a community mental health clinic. Parents expressed frustration with the accessibility of community services, and specific barriers to effective care (e.g., a lack of coordination between school and community mental health services and a need for improvement in training of service providers). Feedback from these interviews, alongside information from several other sources (i.e., an observational study of services; service provider

perspectives; literature on EBIs for children with ASD), was used to develop an intervention protocol for community mental health clinics serving children with ASD, and a corresponding therapist training protocol. This line of research emphasizes an effective research-community partnership established at the outset of intervention development.

**Perspectives of individuals with ASD.** In addition to parent perspectives, obtaining first-hand accounts from individuals with ASD is being increasingly recognized as a valuable source of information in the development of ASD interventions (Billington, 2006; Brewster & Coleyshaw, 2010; Humphrey & Lewis, 2008). However, the perspectives of individuals diagnosed with ASD have yet to be considered when developing EBIs. By inviting individuals with ASD to be more actively involved in research that concerns them (Benford & Standen, 2011), their feedback can be incorporated into interventions. Collaboration with youths with ASD is crucial to the successful implementation of a school-based intervention that captures the complexity and demands of school life and the diversity of its users. Their “insider” knowledge can provide a useful perspective that has the potential to inform the acceptability of school-based interventions.

Along with the unique perspectives that these individuals can provide, there are also unique difficulties inherent in interviewing individuals with ASD. These difficulties may account for the lack of feedback that has been sought from individuals with ASD regarding interventions that aim to improve outcomes of those with a similar diagnosis. Indeed, individuals with ASD have broad difficulties with social interaction, communication, and rigidity of thought (Brewster & Coleyshaw, 2010). More

specifically, difficulties in understanding abstract concepts (e.g., emotions), theory of mind deficits (Baron-Cohen, Leslie, & Frith, 1985) and impairments in the understanding and use of language may have a direct impact on the ability to participate in qualitative interviews. However, with appropriate consideration, interviews with individuals with ASD have the potential to elicit useful and unique insight (e.g., Humphrey & Lewis, 2008; Huws & Jones, 2008). For example, taking an individualized approach to communication can facilitate the interview process for individuals with ASD (Brewster & Coleyshaw, 2010); that is, the language of the interview is modified to suit the participant's verbal ability. This is particularly helpful, given the emerging focus on the importance of developing interventions that are responsive to the wishes and views of individuals with ASD (Billington, 2006).

Given the current lack of research that has examined the perspectives of children with ASD alongside the development of an intervention, literature that has included the perspectives of those with ASD regarding their peer interactions and school experiences (i.e., topics that are relevant to a school-based PMI) will be presented. Calder, Hill and Pellicano (2013) conducted semi-structured interviews with 12 children with ASD aged 9 to 11 years and found that children with ASD reported difficulties in managing their friendships and peer interactions. The researchers learned that the participants had a preference for being alone, though they reported feelings of exclusion and loneliness as well. The participants indicated that they had a small number of friends (between two to four) and described friendship as a type of companionship (e.g., "We like being together"; "They always play with me"), while some descriptions lacked emotional connectedness (e.g., "Well, my best, best friend is going to be moving soon...and my

second best friend, she won't be moving so I can always play with her"; "I helped them once and they were kind so I thought well yeah"). Again, social-communication skills and the ability to manage friendships and peer interactions have been reported as a clear challenge for children with ASD. While PMIs provide a means of improving peer interaction and social-communication skills, more research is needed to determine whether youths with ASD approve of developing these skills, and with the help of a peer implementer.

The development and implementation of school-based PMIs can be guided by considering aspects of the school environment that students with ASD consider helpful (e.g., supportive people, services, etc.) or unhelpful. Humphrey and Lewis (2008) identified a number of facilitators and barriers to a positive school experience by interviewing 20 individuals with ASD (11 to 17 years). Social isolation and bullying (e.g., name-calling, physical violence) were reported at varying levels of severity and frequency by nearly all participants. However, peer relationships were differentially identified as being both supportive (in the case of understanding friends), as well as impeding (in the case of bullies) toward successful inclusion at school. Moreover, peer support was often cited as a means of counteracting the barriers reported (i.e., social isolation and bullying). Indeed, peer relationships may be more directly related to successful inclusion than teacher relationships (Bauminger & Kasari, 2000). Taken together, these unique and important perspectives from individuals with ASD suggest that peers may offer an important support for children with ASD at school (Cowie & Wallace, 2000). Although experiences with being bullied are reported to be very prevalent in this

population, it is currently unknown how peer support early in schooling may mitigate this later trajectory.

The most direct examination of the social validity of school services for children with ASD was conducted by Jones et al. (2007), who asked 35 school-aged children with Asperger syndrome about their satisfaction with life at school. When asked how they would like their school to be different, many children offered valuable suggestions (e.g., the use of a timetable; extra help from school personnel; more knowledge of ASD amongst teachers). When asked about people who have helped them, over half of the children referred to the support they had received from friends. With regard to PMI, recognizing that a majority of children with ASD find their peers to be helpful lends support to the participation of peer implementers in a social skills intervention. However, whether youths with ASD would be accepting of peer support within a PMI has yet to be investigated. Taken together, the perspectives provided by children with ASD provide valuable information about facilitators and barriers to their successful school experience, rather than making “educated guesses” about what might help them.

### **Peer-Mediated Interventions (PMI)**

Limited peer relationships and social-communication skills in children with ASD pose a particular challenge to parents of children with ASD and individuals with ASD themselves. PMIs that target improvement in peer interaction and social-communication skills are worthy of consideration when it comes to implementing EBIs for school-aged children with ASD. A specific approach to PMIs for children with ASD uses Pivotal Response Treatment (PRT), an evidence-based approach that improves outcomes for children with ASD (Koegel, Koegel, & McNeerney, 2001; National Autistm Centre,

2009). PRT is based on the principles of Applied Behaviour Analysis (ABA), an intervention based in learning theory and principles of operant conditioning (Wolf, Risley, & Mees, 1964; Lovaas, 1987). The focus of PRT, specifically, is on improving child motivation for learning and communication (Koegel & Koegel, 2006) by using real world intervention mediators (e.g., parents) in natural settings. Instead of parents, PMI aims to teach peers to facilitate the development of social skills in a natural setting (i.e., school). This approach to treatment is thought to be particularly effective for the generalization of skills (Chan et al., 2009; Pierce & Schreibman, 1995, 1997), as it eliminates the need for transfer of learning from adults to peers (as required in adult-mediated PRT; Rogers, 2000).

Although five peer-mediated PRT studies have been conducted (Chan et al., 2009), there is a larger body of research that broadly supports peer-mediated approaches (Zhang & Wheeler, 2011). The body of PMI literature has been established for over 30 years (e.g., Strain, Kerr, & Ragland, 1979). However, to the author's knowledge, there has yet to be consideration of the social validity of PMIs through consultation with key stakeholders, which could lead to improved acceptability and feasibility of PMIs broadly.

### **Knowledge Translation**

In the consideration of appropriate school-based interventions for children with ASD, researchers typically do not consult with stakeholders until the end of research design. This approach is flawed because information that could be actively incorporated to improve development of the intervention is missed. When trying to understand stakeholders' perspectives on EBIs, knowledge translation (KT) is an approach that can address this gap. Canadian Institutes of Health Research (CIHR) defines two broad types

of KT: 1) end of grant KT and 2) integrated KT. End of grant KT involves those activities that make knowledge users (i.e., policy makers, clinicians, the public) aware of the knowledge gained during a research project (i.e., dissemination and communication activities; CIHR, 2012). Integrated KT is an action-oriented way of doing research that involves collaboration between researchers and knowledge users from the outset of research design (CIHR, 2012). Each stage in the research process is viewed as an opportunity for collaboration with knowledge users (i.e., development of research questions, selection of methodology, data collection, interpretation of findings, approach to dissemination; CIHR, 2012). However, most interventions are designed with little input from key stakeholders in real-world contexts. Thus, it is perhaps not surprising that there is a large research-to-practice gap in EBIs at school (Dingfelder & Mandell, 2010; Parsons et al., 2013). Importantly, when knowledge users (e.g., parents, individuals with ASD, school staff) are consulted at the outset of research design, input can be obtained as an intervention is developed. Understanding the perspectives of knowledge users using an integrated KT approach can provide researchers with information that will enhance the acceptability of an intervention program in community settings (Callahan et al., 2008). By doing this from intervention design to the completion of intervention implementation and beyond, the end result of the collaboration is the integration of research findings into clinical practice in a structured, efficient, and effective manner (McGrath et al., 2009). As part of this two-way communication, knowledge that is obtained throughout the research project can be shared with knowledge users, to fulfill the process of knowledge exchange (Mitton et al., 2007). By exchanging knowledge with the knowledge user once the intervention has been implemented, feedback can be obtained regarding the impressions

of the implemented intervention to effectively “close the loop” of integrated KT.

Integrated KT can be beneficial when developing an ASD intervention for use in school settings. By collaborating with key stakeholders from the outset of research design, the opportunities for acceptable interventions to be implemented in school settings are maximized (Stahmer et al., 2012).

### **Current Study**

The current study aims to fill a void in the ASD literature by considering perspectives of knowledge users (i.e., parents of children with ASD, parents of TD children, and youths with ASD) during the development of an intervention. Perspectives of TD youths were not obtained, as it is unlikely that their school experiences could provide sufficient context for discussing school-based supports for children with ASD. The larger study will develop, and examine the effects of, a peer-mediated PRT intervention on the social-communication behaviour of young children with ASD (Boudreau, in preparation) within an integrated KT approach. Whereas the present study explored perceptions of parents and youths with ASD regarding the proposed intervention, another investigator examined school stakeholder perspectives (Boudreau, in preparation). These critical school and family stakeholder experiences will be used to inform a peer-mediated PRT targeting social communication skills for students with ASD in their first year of school. Within this context, the current study addressed one stage of integrated KT (i.e., collaboration with knowledge users regarding the proposed methodology). Specifically, consultation with parents and individuals with ASD took place at the outset of research design to investigate their perceptions of the proposed intervention. The larger study will continue with integrated KT by conducting interviews

with the same participants once the intervention is complete to share initial findings and gain knowledge users' impressions of the findings (i.e., knowledge exchange).

The present study considered the importance of families' perspectives, and of the school experiences of individuals with ASD, on the acceptability of a specific form of peer-mediated social skills intervention for children with ASD in the school system. Examination of the perspectives of parents of children with ASD, parents of TD children, and individuals with ASD is expected to help bridge the current research-to-practice gap in the implementation of school-based ASD interventions. Through consideration of the social validity of the PMI, this study represents a first step in collaborating with families to implement an EBI for children with ASD in the first year of school. The feedback received through the interviews is expected to inform the way in which the intervention will be framed to parents and their children with ASD who will use the intervention, as well as parents and their TD children who will serve as peer implementers of the intervention. This opportunity to frame the intervention appropriately for families may improve their willingness to access such an intervention. Moreover, maximizing the acceptability of the intervention strategies will potentially improve the approach to implementation and effectiveness of the intervention.

### **Overall Aim and Objectives**

The overall aim of the present study is to inform the development of a peer-mediated social skills intervention using PRT for children with ASD starting school. Through interviews with parents of children with ASD, parents of TD children, and individuals with ASD, there is the potential to increase the acceptability of the proposed intervention. The study will also inform peer-mediated and social-communication

interventions more generally by considering the school experiences of individuals with ASD, an under-examined area.

Specific objectives for the information gathered from parents of children with ASD and parents of TD children are:

1. To examine perceptions of EBIs for children with ASD.
2. To identify facilitators and barriers to using a specific form of ASD intervention, PRT, in a school setting.
3. To identify facilitators and barriers to using the proposed intervention and related components (i.e., intervention target skills, location, role of peer implementers) in a school setting.

With regard to individuals with ASD, the objectives are:

1. To identify perceptions of their ASD diagnosis that will provide a context for their school experiences.
2. To identify preferred methods of learning and, more specifically, being taught social skills (e.g., peer-mediated vs. teacher-mediated).
3. To examine perceptions of components of the proposed intervention (i.e., intervention target skills, intervention grade, role of peer implementers).

## Method

### Participants

Twenty-two participants were recruited across three groups (six parents of children with ASD, six parents of TD children, and 10 youths with ASD). This sample size is large enough that important perceptions were discovered but not so large that the data became repetitive (Creswell, 1998; Glaser & Strauss, 1967). The sample size is also congruent with prior literature using similar methodology (interviews) with similar populations. For example, Stahmer et al. (2011) interviewed nine parents of children with ASD, and Huws and Jones (2008) interviewed nine youths with ASD.

**Parents of children with ASD.** Six mothers with a child diagnosed with ASD between 5 and 10 years participated. Of 12 parents of a child with ASD who were initially contacted, five did not respond to emails or telephone messages and one could not participate due to a scheduling conflict. The remaining six parents were English-speaking (at a level that permitted understanding of semi-structured interview questions and an ability to provide coherent responses). Their children's diagnoses of ASD were made by qualified professionals using standardized measures (i.e., Autism Diagnostic Interview-Revised [ADI-R; Rutter, Le Couteur, & Lord, 2003], Autism Diagnostic Observation Scale [ADOS; Lord et al., 2000]) and accepted diagnostic criteria. Their children also participated in the provincial Early Intervention Behavioural Intervention (EIBI) program, prior to beginning elementary school. The parent interviewees were not related to the interviewed youth with ASD.

**Parents of TD children.** Six mothers who have a TD child between ages 5 and 10 years participated. Of 17 parents of a TD child who were initially contacted, 10 did

not respond to emails or telephone messages and one declined participation due to time constraints. The remaining six parents were English-speaking (at a level that permitted understanding of semi-structured interview questions and an ability to provide coherent responses) and their child did not have a known history of a developmental or psychiatric disorder. See Table 1 for additional parent background information.

**Youths with ASD.** Ten youths with ASD (9 M, 1 F) between the ages of 10 and 12 years ( $M = 11.92$  years,  $SD = 0.71$ ) participated. Of 11 parents of youths with ASD who were initially contacted, one declined participation, citing removal of the child's ASD diagnosis. For the remaining 10 participants with ASD, the diagnosis was made by a qualified professional using standardized measures and accepted diagnostic criteria. Participants were English-speaking and demonstrated sufficient verbal ability to respond to questions during the semi-structured interview. Estimation of participants' verbal ability was informed by consulting with lab personnel who had interacted with the youths during their participation in previous research studies. See Table 2 for additional background information for participants with ASD.

### **Research Design**

Descriptive content analysis methods (Krippendorff, 1980) using semi-structured interviews (see Appendices A – B) were used to investigate the acceptability of a peer-mediated intervention for school-aged children with ASD. A semi-structured interview approach was chosen to capture the depth and complexity of participants' experiences. This approach is ideally suited for research that is collaborative and action-oriented (i.e., a KT approach), as is the present study. Using a KT approach, participants were interviewed before the intervention was implemented. As part of the larger study of

which this was a component, participants will be interviewed again once the intervention phase of the study has been completed.

### **Measures**

**Background information form.** Parent participants (parents of children with ASD and parents of TD children) provided basic demographic information (e.g., age, occupation) and rated their familiarity with selected ASD interventions. Parents of the participants (interviewees) with ASD provided basic demographic information about themselves, in addition to information about their son/daughter's diagnosis and early schooling (e.g., time spent in Resource or Learning Centre). See Appendices C – E.

**Semi-structured interview.** The semi-structured interview included questions to inform a peer-mediated social skills intervention for school-aged children with ASD, as it applied to each participant group (i.e., parents of children with ASD, parents of TD peers, youths with ASD). Questions for the interview guide were generated based on the study goals, literature review, and CIHR's Integrated KT plan (CIHR, 2012). Two interview guides were used: one for parents (of children with ASD and TD children) and one for youths with ASD (see Appendices A – B). For parents, the interview guide included an introduction to the topic (i.e., an outline of PRT and the proposed intervention) and specific questions about EBIs, PRT, and components of the proposed intervention. For youths with ASD, the interview guide included a brief introduction to the topic (i.e., a summary of the proposed intervention and nature of the interview questions) and questions about their ASD diagnosis and school experiences. The interviews were conducted before the implementation of a school-based social skills intervention for children with ASD.

To address the potential difficulties inherent in interviewing youths with ASD who may have difficulty communicating their perspectives, the proposed project maximized the contribution of these participants by asking concrete, direct questions whenever possible. A copy of the semi-structured interview guide was e-mailed to the participants' parent in advance of the interview to reduce the novelty of the questions and to allow for preparation. Participants were also provided with the opportunity to provide additional information or clarify their perspectives at the end of the interview and/or by contacting the researcher (via phone or email) once the interview was complete.

### **Procedure**

All data were obtained in accordance with study protocols approved by the IWK Health Research Ethics Board and the Mount Saint Vincent University Research Ethics Board. Participants were recruited by contacting families who had participated in research at the IWK Health Centre (in the Autism Research Centre) or at Dalhousie University (in Dr. Shannon Johnson's lab) and consented to contact for future research. With assistance from lab personnel, the author accessed the Autism Research Centre's participant database and compiled a list of previous participants who had consented to future research contact. For participants recruited through the Autism Research Centre, the author made initial contact via telephone or email. For participants recruited through Dr. Shannon Johnson's lab, research personnel in her lab compiled a list of previous participants who met the current studies' inclusion criteria. Initial contact was made by research personnel in her lab and interested participants were directed to contact the author by telephone or by email to learn more about the study. Interviews were scheduled for individuals who expressed an interest in participating. After consent was obtained,

including consent to audio-record interviews (using a Sony IC audio recorder) to facilitate transcription, participants took part in a semi-structured interview. Individual interviews took place at a time and location that was convenient to the participants (i.e., the participant's home, the Autism Research Centre at the IWK, or a location within the community). The interview guide was read verbatim to participants, with probes from the interviewer (i.e., the author) as necessary. Interviews with parents ranged from 24 to 47 minutes ( $M = 35.00$ ,  $SD = 7.78$ ), and the interviews with youths with ASD ranged from 17 to 41 minutes ( $M = 29.00$ ,  $SD = 9.58$ ).

Participants were also asked to fill out a Background Information form, which differed for each participant group (i.e., parents of TD children, parents of children with ASD, youths with ASD; see Appendices C - E). The form took approximately 5 to 10 minutes to complete. In the case of participants with ASD, their parents completed the Background Information Form (see Appendix E). Overall, the sessions (including an informed consent discussion, the semi-structured interview, and completion of the Background Information form) lasted approximately 45 to 60 minutes.

Participants will be provided with a \$10 gift card following completion of the proposed intervention (i.e., the topic around which these interviews were structured). This token of thanks will be provided regardless of whether they choose to participate in the previously mentioned second interview component of the larger study.

### **Data Analyses**

**Background information form.** Descriptive statistics from the participant background information (i.e., age, grade, etc.) were used to describe the participant groups. Select questions (e.g., parents' familiarity with ASD interventions; provision of

an educational program assistant for youths with ASD) were used to provide context for the semi-structured interview results.

**Semi-structured interviews.** Analysis of semi-structured interview data used a descriptive content analysis method. More specifically, the constant comparative method of the grounded theory tradition (i.e., theory derived from data and then illustrated by characteristic examples of data; Glaser & Strauss, 1967) was followed. This method is *constant*, in that the data were reviewed repeatedly, comparing each element of the interview (phrase, sentence, paragraph) to all of the other elements (i.e., the *comparative* method). The audio-recordings of each interview were transcribed by the author and a trained volunteer research assistant, with all identifying information removed. First, the author reviewed each transcript independently and condensed the data into codes (i.e., important, recurring ideas). The assignment of codes was guided by questions from the semi-structured interview guide and emerging themes within the transcripts. Codes were created until no more codes were needed to cover the relevant themes within the interviews (Boeije, 2002). Following initial coding of the interviews, two project investigators provided input on coding decisions. The codes were then compared across interviews within each group of participants (i.e., parents of children with ASD, parents of typically developing children, and youths with ASD) to establish themes. Using a deductive process, the questions from the interview guide were used to organize themes. The author reviewed the coded results and themes with two senior project investigators who made recommendations for refinement of themes, unbiased wording and for the selection of relevant quotes from participants.

Finally, data triangulation (i.e., viewing the data from multiple perspectives; Miles & Huberman, 1994) was carried out. In this approach to data triangulation, two (or more) groups were compared with regard to the experience of a specific phenomenon (i.e., components of peer-mediated interventions). To aid in the broader conceptualization of the perspectives of specific components of peer-mediated interventions (e.g., peer implementers, target age and setting), the content of similar themes within each group were compared to understand the similarities and differences in perspectives across the three groups.

### **Results**

Following analyses of interviews with parents of a TD child, parents of a child with ASD, and youths with ASD, several themes emerged regarding important components of school-based interventions for children with ASD. Most themes were similar across the two parent groups; therefore the parent data were collapsed (Stahmer et al., 2012). However, background knowledge and perspectives occasionally differed between the two parent groups, and these differences are outlined in the presentation of the results. Themes that emerged from parent responses are presented in the categories identified in the initial aims of the study (i.e., EBI, PRT, and specific components of the proposed interventions). When relevant, representative quotes are included to provide descriptive examples of specific themes. The parent themes are summarized in Table 3.

The themes that emerged across youths with ASD were distinct from those that emerged within the parent groups. As such, responses from parents and responses from youths with ASD are presented separately. Responses from youths with ASD are organized within the following categories: perceptions of ASD diagnosis, relationships

with peers, and school experiences. The themes for youths with ASD are summarized in Table 4.

### **Parent Perspectives**

**Evidence-based interventions (EBIs).** Themes related to parents' understanding of EBIs and their opinions regarding the importance of EBIs are described below.

*Understanding of EBIs.* Parents' understanding of EBIs was generally accurate (i.e., an intervention supported by research), yet lacked depth about sufficient research criteria. As one parent noted, EBIs involve having "concrete proof" to support carrying out the intervention. While most parents provided such a definition of EBI, four parents (two parents of TD children, two parents of children with ASD) were unable to define the term EBI. The interviewer provided a definition in order to complete subsequent portions of the interview.

*Importance of EBIs.* All parents perceived the use of EBIs as important. One reason for using an EBI included the opportunity to maximize an intervention's chances of success. For example, one parent indicated that, "If research can help you ensure its [the intervention's] chances of succeeding then by all means. I don't know why we wouldn't want to have a sense of whether it's going to work." The efficient use of resources was also a commonly reported reason for using EBI:

I would say it's most important, because if you've already researched it and you know it works then that would be more effective than starting with a new program. My thought is that you'd need more resources when you're first starting out with a new program.

Some parents indicated that, while the use of EBIs is important, there may be other factors to consider when selecting an intervention. The consideration of an individual child's experience and environment, and how this may influence the selection of an intervention, was noted.

I think it's important that the fundamentals would be based on research, so that the main foundation is laid and you know it's working. But I do think that often times, real life and actual experiential stuff plays a big role. So I think you have to go with some of the things that work for the kid that's involved.

Similarly, some parents reported that the size of the intervention group may impact the ability to individualize treatment. For example, parents shared that when working with one child, as opposed to a larger group, there is the opportunity to modify an intervention for that individual child. In explaining the importance of EBI for a larger group, one parent also emphasized the importance of using an EBI to maximize resources and the intervention's chances of success.

I think if you're working with one child then you have a bit more room for trial and error and ... tailoring things more specifically to that one child. But when you're looking at a group of kids that's going to be effective overall, especially when there's not a whole lot of funding for intervention and for extra support in schools, you want to know that you're investing in something that has a good chance of being effective.

Finally, the consideration of a potential mismatch between the goals of an evidence-based intervention and the goals for a child was mentioned by one parent.

I don't consider compliance to be a goal, and yet an evidence-based research program might have had compliance as being one of the main goals ... So if your evidence-based research yields a very specific result, I think it's worth considering sometimes that there are intangibles, there are immeasurables that are very important to families.

Taken together, while EBIs were considered to be valuable by all parents, some parents provided examples of other factors that may need to be considered when selecting and implementing a research-based intervention (i.e., consideration of the individual child and the intervention goals for that child).

**Pivotal Response Treatment (PRT).** Several themes related to parents' understanding of PRT, and potential benefits and barriers to the use of PRT within a school setting emerged.

***Understanding of PRT.*** Parents' level of understanding of PRT differed between the two groups (i.e., parents of a TD child and parents of a child with ASD). While four parents of TD children could not provide a definition of PRT, only two parents of children with ASD could not. For these six parents, a definition was provided. Of the parents who provided a definition, their understanding of PRT focused on its utility in teaching language and communication skills. Specifically, parents most often described the requirement of a specific response (e.g., child verbalizes a request) before providing a natural reward (e.g., the requested item) as a key component of PRT.

***Benefits of PRT.*** Parents of children with and without ASD agreed that PRT is an approach that "makes sense" and "seems obvious", and would likely be easy to teach to peers and/or school staff. Parents also suggested that PRT can be used to benefit many

students (i.e., not just students with ASD). Aside from observations that PRT would be easy to teach and could benefit many students, parents of TD children generally did not provide specific reasons as to how PRT could be beneficial. Parents of children with ASD provided more specific indications of PRT's potential benefits. For example, parents of children with ASD indicated that PRT specifically helps children with ASD by improving their communication skills and/or their peer interaction skills. One parent mentioned that, "...it [PRT] would help with communication with other kids and with the teacher and it would just all in all make it more comfortable for the child."

Some parents also mentioned that the components of PRT are flexible and adaptable. In particular, one parent of a child with ASD provided an example of how the skill(s) that PRT targets can be modified if needed.

...we kind of had to modify the PRT we were doing with [our child] along the way and really focus more on the play based side of things. I think our experience ... kind of hints at some of the ways that PRT can be adapted for the school. Where ... you might be working with more kids who have a higher language level. Kids for whom it's the more subtle social nuances and the peer play that they need to be working with.

***Barriers to PRT.*** Most parents reported that school capacity may be a barrier to the implementation of PRT interventions. Commonly reported school capacity issues included lack of funding and resources, as well as lack of understanding of ASD and of staff training regarding ASD and effective supports for children with ASD. One parent indicated that introducing something new (e.g., a school-based PRT program) could be challenging for schools, as it will require changes to an already established routine.

...there could be certain situations ... where they're [school staff or students] just used to things working a certain way, so any time you try to introduce something new or get somebody to change ... some aspect of how they're doing their job or how their daily routine goes ... I can't think of anything specific to PRT that would be different than introducing any new program, but just in general, introducing something new.

### **Recommendations regarding specific components of the proposed**

**intervention.** Parents provided several recommendations regarding specific components of the proposed intervention (i.e., target skills, location, grade, time of day, intervention agent, and effective communication with the school/families). Intervention component themes are outlined below.

***Target Skills.*** All parents indicated that communication skills and/or peer interaction skills are an important intervention target for individuals with ASD. They indicated that social-communication skills could help a child with ASD fit in with his or her peer group, make friends, succeed in school, and gain employment. One parent of a child with ASD emphasized the importance of social-communication skills, and their utility in finding employment.

...your whole life you're going to be interacting with people and beginning to communicate appropriately with your peers at this age [grade primary] is a skill you need to acquire because you're going to need it when, you know, you want to work and stuff like that and that's my goal, you know, I want to have my son be able to fit in and be able to work.

In addition to communication skills and peer interaction skills, some parents reported that emotion regulation skills are another important intervention target for children with ASD.

If it's frustrating or they feel alienated or upset or something then...tools for, maybe, self-soothing...it seems that you'd want things to help them as much deal with themselves as to be able to interact with others.

The biggest thing that they've [adults with ASD] had to use is emotion regulation skills. And that is a very practical tool that will serve them very well throughout their entire lives.

**Location.** Parents recognized the school as being a “natural setting” for social skills intervention. Specifically, parents describe the school as a location where social interactions happen and social skills are needed.

... that's where it's needed, so if you do it somewhere else then it's not really going to translate into the school setting if you're not in the school. I mean it would have to be at the school. I can't picture it anywhere else.

Parents' opinions were divided regarding intervention settings within the school environment (i.e., the students' classroom, a separate room, or the playground). Some parents indicated that the students' classroom would be an ideal setting, as it provides more structure than the playground and encourages integration with TD peers. Other parents suggested that a separate room would offer more structure than the students' classroom by avoiding classroom distractions and allowing the children to work in a one-on-one environment. Of note, these parents suggested a step-wise pattern of intervention implementation by starting in a separate room until children are comfortable playing with

one another in a distraction-free environment prior to moving to environments with more distractions (i.e., the classroom, playground). Some parents noted the importance of incorporating the playground setting when carrying out the intervention. Specifically, it was recognized that the classroom and the playground require different sets of social skills.

I think it's important for the child to have, the autistic child, to be able to learn the skills in both the structured classroom environment as well as the social environment at school. So if you could do both that would be ideal. I think in both environments it's going to be a benefit to the child to have because they're completely different social rules and whatnot ... you know if you're learning you put up your hand to speak in the classroom that's not going to work on the playground with friends ... right? It's two different skill sets.

Of note, each parent group (i.e., parents of TD children and parents of children with ASD) was similarly divided in their preferences for a specific intervention location (i.e., the classroom, a separate room, or on the playground). That is, there was not a strong preference for any location in either parent group.

**Grade.** Parents agreed that grade primary was the ideal time to implement social skills interventions for children with ASD at school. Specific recommendations were also commonly provided regarding the timing of intervention within the first year of school. Specifically, all parents recommended that social skills intervention begin early in the first year of school. While some parents indicated that the intervention could begin right at the outset of the school year, others suggested that the intervention would not have to be introduced immediately (e.g., October and November were suggested).

I would think maybe not immediately but on the earlier side. So, giving them time to know what's expected of them in terms of their classroom routine and what school is like and get that initial adjustment, but then have it be just another one of, "this is part of school", rather than introduced later as "okay, you've just got this routine down, now we're going to change it".

Regardless of preference for immediate intervention implementation, parents reasoned that it would be beneficial for the intervention to be viewed as part of the school routine. Parents who suggested that the intervention would not have to start immediately indicated that the school routine is chaotic at the beginning of the year and it may be beneficial for the routine to settle before implementing a new intervention.

Reasons for beginning the intervention in the first year of school were reflected in three main themes: 1) the opportunity to provide early and continued support following earlier interventions; 2) peer relationships are still forming in grade primary; and 3) young children are less likely to notice differences in their peers. Parents felt that the early development of social skills would allow for these skills to build throughout subsequent grades. Parents of children with ASD specifically mentioned the importance of continued intervention at school for children with ASD who have completed early intervention programs.

It's that additional support. You know, you were supported, supported, supported and then the kid starts school and then the support isn't, you know, you get a few appointments here and there but really ... it's really lacking, I would say ... it just goes from like 'all' to like 'you are flying solo'.

The two remaining themes had to do specifically with peer-mediated social skills interventions. Some parents referred to the advantage of having peer relationships that are new and are still developing when children are in grade primary.

I also think going into grade primary, a large number of the students are going to be making new friends and not know each other and so if you're asking a student to be a helper ... you're just helping them develop another one of their friendships rather than pulling them away from time that they'd be spending with the friends that they have already.

Some parents also suggested that children in grade primary are less likely to be judgmental toward peers who display developmental differences, and are less likely to notice these differences. Therefore, it is recommended that peer-mediated social skills interventions begin in the first year of school.

I would think that it would be better to start very early as opposed to wait until second or third grade where kids ... form opinions as they become more sociable ... Eventually they become more judgmental just like everybody else. So I think it's essential to start early before they understand what being judgmental is all about.

Most parents offered one disadvantage to implementing peer-mediated social skills interventions in grade primary: the capability and maturity level of the TD peers. Specifically, some parents suggested that it may be difficult for the TD peers to learn and apply the PRT strategies, in addition to adjusting to the new school environment.

***Time of day.*** Most parents indicated that the morning would be the best time to have children participate in a peer-mediated social skills program. Parents reported that

children are more likely to be alert and receptive to participating in the program at the beginning of the day, and this was parents' primary reason for scheduling the intervention in the morning. Some parents indicated that the afternoon could be a beneficial alternative to the morning as a time for peers to play with one another. Three parents suggested that if children are not as alert in the afternoon and are less willing to engage in academic tasks, then social and play-based activities might be preferred.

***Intervention agent.*** With regard to school-based social skills interventions for children with ASD, the most prominent themes indicated that educational program assistants (EPAs) and peers would be effective intervention agents. Teachers (i.e., in the classroom and the learning centre) were mentioned to a lesser extent. Many parents indicated that EPAs could facilitate social skills training in children with ASD. However, most parents also indicated the need for EPAs to receive more autism-specific training before being given such a responsibility.

... EPAs, but they need training. EPAs desperately need autism specific and facilitator specific training. They're there. They're right on the ground with this work. They are under-utilized and under-trained in terms of what they could be providing.

Some parents indicated that the school's learning centre teacher would be a "natural fit" for facilitating a social skills intervention. Some parents also indicated that classroom teachers would be too overwhelmed by other responsibilities to take on the implementation of a social skills intervention for children with ASD. One parent reported, "I'd love to say the teacher but I feel like they do have a lot on their plates already and ... they don't always have the time to take on an additional responsibility."

Of note, when parents discussed school staff members as implementers of social skills programs for children with ASD, it was difficult to determine whether they were referring to the school staff member as being the individual to practice social and play skills directly with the child with ASD, or to facilitate social and play time with the child's peers.

Overall, parents considered peers to be suitable intervention agents for social skills interventions for children with ASD. When parents discussed peer-mediated social skills programs for children with ASD, it was clear that they were referring to the peer as being the individual to practice social and play skills directly with the child with ASD. Encouragingly, parents of TD children reported that they could imagine their child participating in and enjoying the proposed intervention.

I think he would think it was really cool. Like, he loves having jobs ... he likes that responsibility and ... he very much likes to play and if the game is fun, it doesn't matter as much who the other kids are. So, if you're teaching something new and it is something engaging and interesting, then he's going to want to do it.

Parents also reported several advantages of peer-mediated social skills interventions for children with ASD, with some advantages being specific to the child with ASD and others being specific to the TD child. Parents commonly noted enhanced generalization of skills and reduced social skills teaching for the child with ASD. For example, parents appreciated the fact that learned skills would not have to transfer from interactions with adults to interactions with children. Parents also recognized PMIs provide an opportunity for the child with ASD to build a positive relationship with a peer.

The advantage for that child if they're struggling to integrate socially is you can ... be, you know, piloting that for them. So, creating some relationships where they didn't exist.

When discussing the nature of the relationship between the intervention's TD peer and the child with ASD, parents suggested the importance of facilitating a *peer* relationship rather than having the TD peer adopt a teacher role.

... empowering them to be equal partners in the relationship has been important. And that's something that we've been working with them to really support and encourage. That they're partners ... it's not a student-teacher relationship being played out with their peers.

Parents also recognized the positive learning experience that is offered to TD peers who would be involved in the intervention. Specifically, they indicated that the intervention provides TD peers with the opportunity to help, to develop empathy, self-esteem, and patience, and to gain a better understanding of ASD.

In addition to advantages of including peers as intervention agents, parents noted a disadvantage of including peers as intervention agents. That is, there is the potential for TD peers to be burdened by participation in the intervention. Specifically, some parents reported the potential for TD peers to be exposed to difficult behaviour. For example, one parent suggested that, "... if the child with autism is having ... any kind of physical outcry or temper tantrum, that can be scary for small kids ... if they [TD peers] know what to expect and they're prepared then that's okay." Some parents also indicated that it may be burdensome for the TD peer to miss class time by taking part in a PMI. One

parent noted that, “The only thing I can think of is if it would take away from the learning of the child who has been asked to mentor or to help the other child.”

*Effective communication with schools and families.* Many parents spontaneously reported the importance of ample and effective communication with the school and participating families as the intervention is introduced and implemented.

I think keeping families in the loop is really, really important ... Coaching the families on how to develop a good working relationship with their schools.

Because it’s got to be everybody, everybody’s got to be on the same page.

Parents also indicated that it will be important to consider how the intervention is framed for parents of TD children. While specific advice regarding how to frame the intervention was limited, some parents suggested that it would help to provide parents of the TD peer with an overview of the potential benefits to their child. However, a parent of children with ASD specifically noted that it would be important to avoid having the child with ASD be viewed as a “charity case”; rather, that both children will benefit by developing relationships and positive personal characteristics.

I think how it’s presented to them [parents of TD children] is important. And part of that ... is them seeing the benefit to their child. Because it’s very easy to sell it to parents on the terms of, “Oh your child is helping another child” and then you set up that power dynamic again ... I wouldn’t want my children to be viewed as charity cases for other people, but that this is a relationship development and this is a personal development for my kids, but it’s also a personal development for the typical kids as well.

Two parents of TD children noted that their child could become frustrated or upset if the intervention was not “going the way it was expected to go”. It will be important to consider how the intervention is communicated to the TD peers and how the goals of the intervention are framed for them.

I think if at any point there was something that he thought maybe he wasn't good at ... I could see him getting kind of frustrated in that way. If he was doing his part and it wasn't going the way it was expected to go.

... my kid would feel terrible when he [the child with ASD] is not [responding to TD child's prompts]. He would take on a poor outcome. But the majority of kids aren't like that. But there are some that are so empathetic and would think “Oh my gosh, we haven't achieved what we're supposed to, and I've been part of that”... But it can all be addressed with kids and how you relay it all to them.

**Acceptability of the proposed intervention.** The parent interview concluded with a multiple choice question that asked parents whether they would recommend pilot testing the proposed intervention in the school system (“definitely yes”; “yes with reservations”; “no opinion”; “no, but with improvement/revision might be worth consideration”; “definitely no”). Five parents of a child with ASD and four parents of a TD child responded “definitely yes.” One parent of a child with ASD and two parents of a TD child responded “yes, but with reservations”. A noted reservation by the parent of a child with ASD was the potential for a student-teacher relationship to develop between peers involved in PMI. A parent of a TD child noted reservations regarding the potential burden on the TD peer (e.g., handling difficult behaviours exhibited by child with ASD;

missing other educational experiences; add to the stress of the transition to school).

Another parent of a TD child noted reservations regarding selection of schools for intervention implementation. That is, she recommended implementing the intervention in a school that has “a stronger foundation” to address issues that are likely to happen regardless of whether the school is already well-managed.

### **Perspectives of Youths with ASD**

The themes that emerged across youths with ASD were distinct from those that emerged within the parent groups. Responses from youths with ASD are organized within the following categories: awareness and perceptions of ASD diagnosis, relationships with peers, and school experience (refer to Table 4 for a summary of the themes).

**Awareness and perceptions of ASD diagnosis.** Several prominent themes emerged related to youths’ awareness and perceptions of their ASD diagnosis. Generally, youths were accepting of their ASD diagnosis, but most preferred that their peers remained unaware of their diagnoses.

***Acceptance of ASD diagnosis.*** Most youths with ASD indicated that they were accepting of their diagnosis when they first learned about it. Two youths with ASD mentioned that, while they eventually accepted the diagnosis, they were initially scared and confused by it. Of note, both of these individuals initially worried that being diagnosed with ASD meant they were sick.

I was a little scared at first because I wasn’t sure what it was. Like I was kind of scared because I thought maybe something was wrong with me or something like

that ... Yeah I was very scared and I thought I was probably sick with a disease or something.

Yeah, I was confused. I didn't know what it meant. I thought it was like, "Oh do I have the flu? Can I stay home from school?" ... I wasn't understanding what it meant, I didn't know if it was like a disease or something, which kind of made me panic.

One youth with ASD conveyed that he was impartial about his diagnosis when he learned about it, explaining that, "I didn't really care. I just thought that I had it, and I didn't exactly know what autism was." Three youths with ASD were unable to recall learning about their diagnosis and did not convey any specific feelings they had about being diagnosed with ASD. Of note, none of the youths with ASD reported having any long-lasting negative associations related to receiving a diagnosis of ASD.

***Peer knowledge of ASD diagnosis.*** Most youths with ASD reported that their peers were unaware of their diagnosis in the first years of elementary school. Some youths indicated that they thought their peers would have been too young to understand the diagnosis of ASD. For example, one youth explained that, "they probably didn't even know what it meant back then cause they're like, grade 1 ... grade primary they probably don't even know what that is." Another youth reported, "No, like it wasn't any of their business anyway. Even if they did know, they were too young to care or anything." Two youths believed that their peers knew about their diagnosis of ASD. One of these youths did not report a specific reason for believing his peers knew about his diagnosis, explaining that, "I think it was just ... the way that I was acting, they just figured, 'Hey

this guy's got autism. Why don't we help him out with school and stuff'." Three youths indicated that they were unsure whether their peers knew about their diagnosis when they started school.

***Sharing information with peers about ASD/diagnosis.*** Most youths with ASD preferred that their diagnostic information remain private. The primary reason for keeping diagnostic information private was to avoid teasing from their peers. For example, one participant reported that, "I was kind of scared that if they knew I had autism they'd make fun of me." On the contrary, three youths suggested that it would be helpful to tell their peers that they have ASD, yet none provided specific reasons as to why they felt this way.

When asked what they would like to tell their peers about ASD, some youths thought it would be helpful to explain that they exhibit particular kinds of behaviour (e.g., reflecting shyness, frustration) because of their ASD diagnosis. For example, one youth suggested that, "I could say like the reason why I'm very shy with people is that I have autism." One youth would describe a positive characteristic about having ASD, saying he would explain that, "autism sometimes allows you to be really smart." Most youths with ASD were not sure what they would tell their peers about ASD, and one youth indicated that he would not like to tell his peers anything about ASD.

**Relationships with peers.** Themes related to youths' current peer relationships emerged in explanations of their school experiences. Although the interviewer did not ask directly about the quality of their peer relationships, many youths spontaneously provided descriptions of these relationships. The resulting themes were related to the nature of

their friendships and social preferences, or involved specific challenges within peer relationships.

*Friends.* Some youths with ASD described friends as being younger children, or explained that they have a limited number of same-age friends (i.e., one or two). Other youths reported a preference for playing alone. For example, one youth explained, “To be honest, I’m not so much of a social kid. So, like, I like mostly prefer to do stuff on my own.” Similarly, another youth reported, “I really like hanging out by myself, most oftenly.” One youth mentioned that he is used to interacting with adults as opposed to children, saying, “I don’t usually like other kids for some reason. I’ve been around adults pretty much all my life so I’m not like ... I’m not the average guy for children so that’s why I don’t play ...”

Some youths with ASD also provided specific advice regarding how young children with ASD can make friends. These suggestions were often specific and concrete. For example, one youth suggested that young students with ASD and their peers could make lists of their favourite activities and compare the activities for similarities.

I was thinking, like, if there’s a certain person that you want to be friends with, you can make a list of the things you like to do and the other person can make a list of things they like to do and anything from the lists that are the same, they could do together.”

The same youth also suggested that a list would be helpful when trying to determine how to best start a conversation with a peer.

They could, like, learn how to make a conversation with others. They could meet, like, there could be a person at school they want to play with but they’re not really

sure how to make friends with them so they could just have a list of conversation starters.

Another youth simply stated, “Well, you gotta be nice or else they’re not going to want to be your friend.”

**Challenges.** Some youths with ASD indicated that peer relationships have been difficult (i.e., difficulty developing relationships; bullying), and were particularly difficult in grade primary. One youth reported that, “Most of the time I wouldn’t talk to anybody when I was younger, just people I knew really well ... especially in grade primary because in grade primary I was just still getting to know people.” Another youth expressed his desire for friendship, but his difficulty in forming such friendships when he said, “I mean, I found it hard to make friends, but ... I wanted to make friends.” Further, although questions were not asked regarding bullying, two youths spontaneously mentioned bullies at school. One youth indicated that he was bullied previously, “... in grade 4, oh my gosh, that year was honestly terrible ... because of the bullying problem and I was one of the little kids that was bullied by an equal grade.”

**School experience.** Several prominent themes emerged related to youths’ school experiences. Generally, youths had some difficulty recalling specific aspects of early school experiences, but many commented on what they have experienced more recently at school. Specifically, themes emerged related to helpful aspects of school.

**Supportive people.** Most youths with ASD had difficulty recalling who was helpful when they first started school. However, in considering individuals who helped recently, many indicated that EPAs have generally been supportive. In particular, they mentioned that EPAs currently assist with organization, classwork, and managing their

behaviour. For example, one youth reported, “[My EPA] helps me out with ... not getting too upset or too, like, excited or stuff.” Some youths indicated that their teachers (classroom teacher and/or learning centre teacher) have helped them, but they did not provide specific information. Two youths spontaneously reported that they have found their same-aged peers to be helpful. However, only a few youths could articulate how their peers have helped, which included recent assistance with classwork and following class schedules. One youth reported that, “Some other boys in my class sometimes ... they help me with the work we’re doing right now ... usually math, science, health, or mostly language arts.”

When asked from whom youths with ASD would have preferred to receive help when interacting with other children, many spontaneously reported that their teacher or EPA filled this role. For example, one youth said, “Well I don’t know any other people who could have done it, but the EPA just helps me the most.” When asked explicitly whether a classmate could have helped them learn to play and be a good friend, youths agreed. Participants mentioned that this could help them make a friend, and that they could learn from their classmates. For example, when asked what would have been nice about learning how to play with their peers, one youth said, “That I finally have a friend.” One youth also indicated that he would rather play with a classmate who was a friend or who does not already have someone to play with, saying “[It] depends if it’s my friend or all that kind of stuff. Or if they already have someone to play with, maybe I’d play with someone else.”

Some youths with ASD were probed regarding their preferences, and indicated that this kind of intervention from older children would make them uncomfortable.

I would say that, unless it's like a relative or something, I would probably leave the older kids out because ... I don't know why. Just because they may not feel comfortable talking to someone older than them ... Because when you're in grade primary, like, you don't know a lot of people. So yeah, I just say unless the older kid is family then I just don't think that practicing with an older kid is a good idea.

Another child indicated that he has not enjoyed being paired with older children at school, saying "... when we have buddies with like older kids, I felt so uncomfortable."

***Helpful locations at school.*** Youths with ASD spontaneously reported that the learning centre was a supportive place to spend time at school. However, when probed, youths did not provide specific reasons as to how being in the learning centre helped them.

***Useful information learned at school.*** When youths with ASD were asked what they were glad to have learned when they first started school, most youths specified an academic subject such as math or language arts. One youth with ASD indicated that it was helpful to learn about specific aspects of peer relationships when he said, "... learning people's names ... learning what they liked to do. And, most importantly, ... learning how to get along." When asked directly whether peer interaction skills would have been helpful to learn, youths agreed. One youth said, "Yes, especially when I was first starting. Really then because that's when I was just meeting the other kids and I was just kind of, you know, scared to talk to them and stuff." Another youth suggested the importance of selecting the TD peer when he said, "Well of course, they could teach us

some stuff. They could teach you some stuff. As long as you find the right kid, you're pretty good."

While most youths did not have specific ideas regarding what they would have preferred to learn when they first started school, one youth spontaneously reported that he would like to learn how to cope with stress when he said, "I'm pretty stressful at school ... My mom always says ignore [my stress], and so does every other adult. And that's pretty stressful. But I really have anxiety. How can you help me with my stress?"

***Best grade to learn peer interaction skills.*** Youths reported that it would be ideal to learn peer interaction skills as soon as school begins. One youth suggested that, "one time that's better than primary, like when you first start school, you should learn how to ... get along with people and preschool is when you should start because preschool is when you start to be around other kids." One youth suggested that it would be helpful to begin making friends in grade primary to be able to spend time with them throughout subsequent grades.

Because there's going to be a lot of kids. And you want to try to get to know as many as you can before the end of school ... I think the good thing about it is, once you start one particularly good grade ... and they're a particularly good friend, and ... you will be able to see them lots of times. Like ... from grade primary all the way up to grade ... all the way up ...

Another youth thought it would be best to learn these skills as soon as possible saying, "Considering it's easier to learn things when you're younger. Probably when you're as young ... like probably as soon as possible. Considering the brain is younger then ... it's easier."

### **Discussion**

This study examined families' (i.e., parents and youths with ASD) perspectives of a proposed peer-mediated social skills intervention using PRT for children with ASD. Interviews were conducted with parents (who have either a child with ASD or a typically developing child, since the intervention involves typically developing children implementing the intervention) and youths with ASD. Interview questions aimed to clarify parents' and youths' perspectives regarding specific components of the proposed intervention and youths' school experiences. The goal of the interviews was to inform understanding of stakeholder perspectives of PMIs and to potentially adapt the intervention so that it is more feasible and acceptable. This is the first study to incorporate consultation with families about their perceptions of PMI, regarding which a body of research has been established for over 30 years (e.g., Strain, Kerr, & Ragland, 1979). By considering the perspectives of parents and youths with ASD, several key findings may lead to improved acceptability and feasibility of the proposed intervention. Specifically, parents and youths with ASD considered primary-aged peers to be suitable intervention agents and were able to provide specific recommendations regarding components of the proposed intervention (e.g., intervention target and grade). Encouragingly, parents also indicated that they would recommend a pilot implementation of the proposed intervention in schools.

Youths' perceptions regarding their diagnosis of ASD were examined to provide a context for their perceptions of school experiences and components of PMI. The findings suggested that although the youths were generally accepting of their ASD diagnosis, a majority had negative feelings toward disclosing this information. Similarly, Jones et al.

(2007) and Humphrey and Lewis (2008) found that some school-aged children would refrain from disclosing their ASD diagnosis to school staff, given a choice. For the proposed intervention, and social skills interventions more broadly, it will be important to help parents of primary-aged children consider the advantages and disadvantages of diagnosis disclosure. If parents and/or children with ASD are uncomfortable with sharing the diagnostic information, it may be useful to consider whether this information must be shared. For example, in PMIs, it is not necessary for the diagnosis to be disclosed to the typically developing peer. PMIs typically focus on goals that include “how to be a good friend” and “kids helping kids” (Pierce & Schreibman, 2007) that do not necessitate disclosure of the peer’s diagnosis. However, a component of the proposed intervention involves informing parents of TD peers of the diagnosis of the peer with ASD. Therefore, there is the potential for the parents of TD peers to share this diagnostic information with their child. Examining strategies to ensure careful navigation of diagnosis disclosure may be particularly important given that parents in the current study viewed enhanced peer understanding and acceptance of ASD as an advantage of PMIs for primary-aged children. It may also be helpful to inform the school-aged child with ASD of the potential benefits of sharing this information (see Murray, 2006 for more information regarding advantages and disadvantages; Jones et al., 2007), particularly when diagnosis disclosure is considered necessary. Taken together, findings suggested that children with ASD are not always comfortable sharing their diagnostic information with school staff and peers, and careful consideration of how and/or if this information is disclosed may influence the acceptability of PMIs for children with ASD.

With regard to parent perceptions of EBIs, parents perceived the use of EBIs as

important, primarily to maximize the intervention's chances of success and to ensure efficient use of resources. This finding provides valuable information to the literature on attitudes toward EBIs, as parents' perceptions regarding EBIs have received limited attention to date (Stadnick, Drahota, & Brookman-Fraze, 2013). Rather, healthcare providers' (e.g., occupational therapists, nurses, physicians; Miles, 2006; Upton & Upton, 2006) and education professionals' (e.g., teachers; Hess, 2008; Reinke, 2011) perceptions have been the focus of recent research. While a majority of the parents in the current study provided a generally accurate definition of EBI, Reinke (2011) found that, of 292 elementary school teachers surveyed, over half had never heard the term "evidence-based practices." It is important to note that parents in the current study and teachers in Reinke's (2011) study were not asked identical questions. That is, it is unclear whether teachers may have been able to provide a simple definition of the term "evidence-based intervention" (as parents in the current study were asked to do), as opposed to responding to a yes/no question (i.e., have you heard of the term "evidence-based practices"). It may also be possible that greater focus on adoption of EBIs in school settings in recent years (George, Taylor, & Schmidt, 2013) increased the likelihood that parents in the current study had heard the term EBI. While EBIs were considered valuable by all parents, some parents also mentioned the utility of modifying an intervention to fit the needs of an individual child. Given this, when framing an intervention for parents, it may be useful to highlight the modifiable nature of several intervention components (e.g., PRT emphasizes principles and naturalistic strategies over highly structured procedures, unlike some other behavioral interventions for individuals with ASD; Dingfelder & Mandell, 2011; Renshaw & Kuriakose, 2011; Verschuur et al., 2013), in addition to highlighting the fact

that an intervention is based on research evidence.

Although parents of children with ASD demonstrated a more detailed understanding of PRT than parents of typically developing children, parents from both groups believed PRT strategies could easily be taught to peers and/or school staff. This is an encouraging finding for the proposed intervention that aims to use a PRT model of service delivery to incorporate primary-aged peers as intervention agents. That is, PMI strategies should be easy to learn and be applied without difficulty by young children (Zhang & Wheeler, 2011). Parents also noted the possibility of using a PRT approach to benefit many children, and not just children with ASD. This is in line with findings from Stahmer et al. (2012), which indicated that teachers believed PRT could be used successfully in classrooms serving children with a broad range of needs, with one teacher reporting that, “A lot of these are things all kids need, not just children with autism” (p. 4). The positive feedback from parents regarding the use of PRT strategies in a school setting indicated that this model of service delivery for school-based social skills interventions may be particularly feasible and acceptable to families.

Parents consistently reported that communication and peer interaction skills are important intervention targets for young children with ASD. This is not surprising, given that successful peer interactions have previously been reported as among parents’ most valued outcomes for their child with ASD (Bellini et al., 2007). Participating youth also indicated that peer interaction skills would be helpful for younger children with ASD to learn. Given the focus of the ASD literature on interventions that target the development of social skills (Cunningham, 2012; Reichow & Volkmar, 2010), it is valuable to know that parents and youth with ASD consider this to be an important target. Further, as the

proposed intervention aims to improve peer interaction skills, and parents and youths with ASD view these skills as important, it appears that the target of the intervention is likely to be considered acceptable by families.

Parents in the current study also mentioned the importance of providing emotion regulation skills to children with ASD. Of note, one youth with ASD spontaneously mentioned his desire to receive help in regulating his own emotions. Emotion regulation difficulties are commonly reported in children with ASD (Jahromi, Meek, & Ober-Reynolds, 2012; Jahromi, Bryce, & Swanson, 2013; Loveland, 2005). Further, Jahromi et al. (2013) found that emotion regulation is a significant predictor of prosocial peer engagement for children with ASD. Despite this, there is a paucity of empirically validated interventions for improving emotion regulation skills in children with ASD (Scarpa & Reyes, 2011). However, the current study highlights the potential need to consider individualized interventions and a range of intervention targets (e.g., emotion regulation, communication, peer interaction skills) as being important to parents. Findings also suggested a potential benefit to informing parents that targeting improvements in communication and peer interaction skills (e.g., by implementing peer-mediated PRT) may naturally improve children's ability to regulate their emotions (Masiello, 2003; Verschuur et al., 2013).

Parents and youths with ASD agreed that grade primary was the ideal time to teach social skills to children with ASD. Parents noted the importance of continuity of services following early intervention programs for children with ASD (i.e., continued support from preschool to elementary school). This suggestion is well founded, as the long-term impact of effective early intervention depends in part on navigating the

transition of young children with ASD from preschool to grade primary (e.g., navigating changes in service eligibility requirements, reduced supports, and a shift from parent-centred to school-centred support; Fox, Dunlap, & Cushing, 2002; Forest et al., 2004). Children with ASD often experience difficulty in transitioning to the school environment (Forest et al., 2004). These difficulties are not surprising given the current lack of EBIs for children with ASD once they enter school (Kasari & Smith, 2013; Parsons et al., 2013). Given this, implementing the proposed intervention in the first year of school may be a source of much-needed support for children with ASD, and is in line with recommendations from parents and youths with ASD and supported by literature (Forest et al., 2004).

Parents and youths with ASD commonly reported that EPAs would be an effective social skills intervention agent for children with ASD. Further, youths with ASD indicated that they value the support that EPAs currently provide, which includes help with organization, classwork, and managing their behaviour. Similarly, Jones et al. (2007) found that school-aged children with ASD commonly reported EPAs as having helped “a lot” (as opposed to “a little” or “has not helped”). However, parents also indicated the need for EPAs to receive more autism-specific training. This is not surprising, in light of research indicating that a majority of EPAs lack necessary training to deliver effective support to children with ASD (Carter et al., 2009; Robinson, 2011). Further, this lack of training could have a negative effect on the social and academic growth of the students with whom EPAs work (French, 2004; Robinson, 2011). Given this, models of effective training for EPAs, including training that supports the development of social skills for children with ASD, are sorely needed. Robinson (2011)

provides evidence for the utility of a training program that uses modeling and video-based feedback to teach PRT strategies to EPAs and subsequently improve target behaviours in their students. Providing such training to EPAs, perhaps concurrently with the implementation of a PMI, would be consistent with recommendations from parents.

Peers were regarded as potentially effective social skills intervention agents by parents and youths with ASD. This is promising, given that studies had not yet incorporated consultation with families about their perceptions of PMI. Youth perceptions of peers as being helpful are also in line with findings from Jones et al. (2007), which indicated that school-aged children reported their friends as having most frequently helped “a lot” as opposed to “a little” or “has not helped”.

Perceptions of parents and youths with ASD regarding intervention agents indicated the importance of fostering a child (i.e., peer)-to-child relationship, as opposed to a tutor (i.e., teacher)-to-child relationship. That is, it was suggested that PMIs should not encourage a teacher role for the typically developing peer. Importantly, youths with ASD noted their lack of comfort in receiving help from older children, particularly when the help involved support with social skill development. This is worrisome, given that a majority of PMIs do involve older children as the intervention agents (Zhang & Wheeler, 2011). Of note, relationships with older students in the school setting often resemble a student-teacher relationship. For example, the “book buddy” program involves pairing an older student with a younger student to help the younger student learn how to read (i.e., a responsibility similar to that of a teacher). Youths’ familiarity with older children as being among those with whom they typically engage in student-teacher relationships (i.e., a relationship that parents have recommended avoiding in PMI), and their discomfort in

receiving help from older children, highlights the utility in incorporating same-age peers in PMI. Moreover, the inclusion of same-aged peers is in line with parents' suggestion that PMIs foster *peer* rather than *teacher* relationships.

Parents suggested benefits to both the child with ASD as well as the typically developing child acting as the intervention agent in the PMI. For the typically developing child, parents indicated that participation in a PMI could provide the opportunity to help, to develop empathy, self-esteem, and patience, and to gain a better understanding of ASD. Indeed, anecdotal data from studies examining PMI have suggested that typically developing peers learned valuable skills and would enjoy participating in PMIs again. Of note, these data from typically developing peers were not collected using well-described measures (e.g., standardized questionnaires, semi-structured interviews) nor were they analyzed using systematic procedures (e.g., normative statistics, descriptive content analysis).

Parents also suggested potential benefits of PMI for children with ASD. Parents noted that the skills would not have to transfer from adult to child. While this is a commonly reported benefit to PMI in the research literature (e.g., Chan et al., 2009), it is impressive that parents were aware of and spontaneously reported this. Parents also suggested that PMIs provide an opportunity for the child with ASD to build a positive relationship with a peer. Similarly, a youth with ASD noted that an advantage of participating in a PMI would be "that I finally have a friend." These findings are not surprising given research that indicates significantly higher levels of loneliness in children with ASD compared to their TD peers (Locke, Ishijima, Kasari, & London, 2010). Youth with ASD also have poorer friendship quality, a lower social network status

than their TD peers, and spend less time engaged in co-operative interaction with peers (Humphrey & Symes, 2011; Locke et al., 2010). The potential for PMIs to create and/or improve peer relationships is considered to be a possible benefit of the proposed intervention, and a component of the intervention that may contribute to its overall acceptability by participating families.

Parents reported a possible disadvantage of PMI as being the potential for participation to be burdensome for typically developing peers (e.g., by being exposed to difficult behaviour; missing class time). Chan et al. (2009) also noted missed class time as a “reasonable concern” for typically developing peers participating in PMI. However, preliminary research on the effects of PMI on typically developing peers suggested that they are not hindered academically by PMI participation (Cushing, Clark, & Kennedy, 2005). Parents’ concerns regarding the potential burden of PMI on TD peers that are not related to academics (i.e., exposure to difficult behaviour during interactions with peer with ASD) is a concern that, to the author’s knowledge, has not yet been acknowledged or addressed in the PMI literature. Therefore, future research should examine the frequency and/or nature of the exposure of typically developing peers to challenging behaviour exhibited by the peer with ASD, and consider the impact of such behaviour on the typically developing peer.

Parents also provided important suggestions regarding the process of implementing EBIs at school to ensure success. Their recommendations are similar to the focus of research literature that has highlighted the importance of EBI implementation within school settings (Dingfelder & Mandell, 2011; Kasari & Smith, 2013). Many parents spontaneously reported the importance of ensuring effective communication with

the school and the families involved in the intervention. While parents did not provide advice regarding specific means of improving communication, Tucker and Schwartz (2013) reported advice from parents regarding effective home and school communication. Specifically, Tucker and Schwartz (2013) surveyed parents of children with ASD and found that increasing the type and frequency of communication, valuing parent input, and providing valuable resources to the parent were strategies that may improve the effectiveness of communication between parents and the school. Further, by interviewing elementary school teachers about family-school communication, Farrell and Collier (2010) reported the importance of assessing and accommodating family availability and preferred modes of communication, establishing family support resource libraries, and providing regular, predictable updates (e.g., newsletter, email). To ensure that parents consider the proposed intervention acceptable, implementing such strategies to improve communication with the school and families involved in the intervention may be beneficial.

### **Implications**

Taken together, the current study's findings suggested that parents and youths with ASD perceived a peer-mediated social skills intervention as acceptable for primary-aged children with ASD. Specifically, parents and youths indicated that communication and peer interaction skills (i.e., skills addressed in the proposed intervention) are important intervention targets, and that grade primary is the ideal time to teach social skills to children with ASD (i.e., as in the proposed intervention). Parents and youths also provided specific advice regarding components of PMI and social skills interventions broadly. Recommendations regarding how to frame the proposed intervention for

families included: (a) explaining the benefits of participation for the TD peer; b) addressing potential burdens on the TD peer; and c) highlighting the modifiable nature of several intervention components (e.g., PRT emphasizes principles and naturalistic strategies over highly structured procedures). Recommendations from parents and youths also indicated the importance of fostering a child-to-child relationship rather than a teacher-to-child relationship when implementing a PMI. Parents suggested that EPAs be provided with ASD-specific training, perhaps concurrently with implementation of a PMI. Parents also noted the importance of effective communication with the school as the intervention is implemented. Taken together, these insights are expected to contribute to improved feasibility and acceptability of the proposed intervention, and to the development of PMIs in general.

Information regarding acceptability of intervention components is important, as more acceptable interventions are considered more likely to be implemented (Brookman-Frazer et al., 2012). Further, when EBIs are not implemented in an acceptable way, peers, teachers or other school personnel may be more likely to adapt the intervention once it is implemented, and potentially reduce its effectiveness (Stahmer et al., 2012).

Alternatively, interventions that lack research-tested efficacy are often implemented, which can be ineffective and/or harmful (Bellini & Akullian, 2007). Moreover, parents will be instrumental in accessing (in the case of children with ASD) and enabling participation in (in the case of typically developing peer implementers) school-based PMIs. Therefore, their perception of the acceptability and feasibility of PMIs is crucial. To date, only two studies have sought parent perspectives alongside the development of an intervention program for children with ASD, and no published studies have sought the

perspectives of youths with ASD as an intervention is developed. The current study contributes to the literature by considering family perspectives of a proposed intervention during intervention design, and the result of this collaboration is the integration of research findings into clinical practice in a structured, efficient, and effective manner (McGrath et al., 2009).

### **Limitations**

There are limitations to the study that should be noted. The interviews revealed some challenges that may be encountered when interviewing individuals with ASD, specifically. For example, the author noted that when participants responded to yes or no questions, they often provided brief responses (i.e., “yes”, “no”, “I don’t know”) and had difficulty providing reasons for their answer. Further, it was observed that some participants were more likely to provide a “yes” response to certain questions (e.g., “Would it be helpful to...”), and it was not always possible to determine the extent to which participants truly agreed with each suggestion. It is recommended that the use of yes/no questions be minimized, while keeping the language of each question concrete. Reminding participants that there is no correct or incorrect answer also seemed to be beneficial. The current study may have also benefited from additional measures (e.g., participant diaries, blogs, drawings; Humphrey & Lewis, 2008) or methods of data collection (e.g., computer-assisted interviewing; Barrow et al., 2012). In addition, interviews with parents of participants with ASD may have supplemented study findings.

### **Future Directions**

The current study has elucidated the perceptions of parents (of children with ASD and TD children) and youths with ASD regarding peer-mediated and school-based social

skills interventions using PRT. The current study also provides direction regarding future research that may need to be conducted in examining the feasibility and acceptability of PMIs. It is recommended that future projects continue to consider the input of families and other key stakeholders alongside the development of interventions. With regard to PMIs in particular, some reservations were noted with regard to the involvement of typically developing primary-aged peers specifically (e.g., capability in their first year of school; potential burden on peers). These reservations may impact the acceptability of PMIs, and gathering information and taking steps to ensure that these reservations are addressed will continue to be important.

It will be particularly important to examine school stakeholders' perceptions of the proposed PMI. Given the utility of examining family perceptions of the proposed PMI in the current study, and the utility of examining school stakeholders' perceptions in the ASD intervention literature broadly (e.g., Stahmer et al., 2012; Stahmer & Aarons, 2009), incorporating school stakeholder perceptions to PMIs is recommended. Researchers are also encouraged to continue to consider the views of individuals with ASD to inform interventions, in addition to learning about their broader experiences as individuals living on the autism spectrum. As seen in the current study, their insights offer unique and valuable information to those working with individuals with ASD. Moreover, it is critical to consider the perspectives of youth with ASD when designing, implementing, and evaluating interventions, as this is an area of intervention development is otherwise unexamined.

Through consideration of the social validity of PMIs, this study represents a first step in collaborating with families to implement an EBI for children with ASD in the first

year of school. Importantly, it was indicated that parents and youths with ASD considered the intervention target (i.e., communication and peer interaction skills) to be an important skill to develop for primary-aged children with ASD. The positive feedback from parents regarding the use of PRT strategies in a school setting indicated that this model of service delivery for school-based social skills interventions may be particularly feasible and acceptable to families. Key findings provided important direction with regard to the how the intervention may be implemented within the schools and framed to parents and their children with and without ASD. It is hoped that framing the intervention appropriately for families will improve their willingness to access such an intervention. Taken together, it is hoped that the potential to maximize the acceptability of the intervention strategies will improve the approach to implementation and effectiveness of this novel EBI for children with ASD in schools.

Table 1

*Background Information for Parents*

Parent Characteristics	Parents of Typically Developing Children (N = 6)	Parents of Children with ASD (N = 6)
Age		
31-40	3	2
41-50	3	4
Relationship to child		
Mother	6	6
Highest Level of Education	0	1
High school degree	1	2
Trade/technical/vocational school	3	3
Bachelor degree	2	0
Master's degree		
Number of School-Aged Children		
1	2	0
2	4	3
3	0	3
Grade(s) of School-Aged Children		
Primary	3	1
1	3	2
2	1	3
3	2	2
4	0	2
5	1	5

Table 2

*Background Information for Youth with ASD*

Characteristics - Youth with ASD	Individuals with ASD (N = 10)
<hr/>	
Current Grade	
5	4
6	2
7	4
Age at ASD Diagnosis	
2	2
3	4
4	1
5	3
Resource or Learning Centre (Grade Primary)	
Yes	9
No	1
EPA Support (Grade Primary)	
Yes	9
No	1

Table 3

*Summary of Key Themes from Interviews with Parents (of TD Children and of Children with ASD)*

Category/subcategory	Theme
Evidence-based interventions (EBI)	
Understanding of EBI	<ul style="list-style-type: none"> <li>• Research supports implementation of intervention</li> </ul>
Importance of EBI	<ul style="list-style-type: none"> <li>• Important (maximize resources, success)</li> <li>• Other considerations (individual child differences; mismatch between goals of intervention and personal goals for child; best approach for a large group)</li> </ul>
Pivotal Response Treatment (PRT)	
Understanding of PRT	<ul style="list-style-type: none"> <li>• Used to teach language/communication skills</li> <li>• Requires a response before providing a natural reward</li> </ul>
Benefits of PRT	<ul style="list-style-type: none"> <li>• Follows a common sense approach</li> <li>• Improves communication skills, peer interaction skills</li> <li>• Flexible and adaptable</li> </ul>
Barriers to PRT	<ul style="list-style-type: none"> <li>• Capacity (lack of funding, resources, staff training/understanding of autism)</li> <li>• Established school routine</li> </ul>
Recommendations regarding components of proposed intervention	
Target skill	<ul style="list-style-type: none"> <li>• Communication skills, peer interaction skills</li> <li>• Emotion regulation skills</li> </ul>
Location	<ul style="list-style-type: none"> <li>• School as a natural setting for social skills interventions</li> <li>• Divided opinions regarding location within the school (separate classroom, classroom, or playground)</li> </ul>

## Recommendations re: components of proposed intervention (cont'd)

Grade

- Primary (early in the year), with advantages (continued support following early intervention; peer relationships still forming; young children less likely to be judgmental) and disadvantages (capability)

Time of day

- Morning (children more alert)
- Afternoon (children less alert and playing may be a positive alternative to academics)

Intervention agent

- Learning centre teachers (natural fit)
- Educational program assistants (additional training required)
- Peers, with advantages (skills do not have to transfer from adult to child; facilitates peer rather than teacher relationship; build positive peer relationship; benefit to typically developing peer) and disadvantages (potential burden on typically developing peer)

Effective communication with school, families

- Ensure communication with school, families
- Ensure careful consideration of how intervention is framed for parents, TD peers

Table 4

*Summary of Key Themes from Interviews with Youths with ASD*

Category/subcategory	Theme
Awareness and perceptions of ASD diagnosis	
Acceptance of ASD diagnosis	<ul style="list-style-type: none"> <li>• Accepting</li> <li>• Initially scared and confused</li> <li>• Impartial</li> </ul>
Peer knowledge of ASD diagnosis	<ul style="list-style-type: none"> <li>• Peers unaware (too young to understand; prefer not to tell them)</li> <li>• Peers aware (class presentation; peers “just knew”)</li> </ul>
Sharing information about ASD	<ul style="list-style-type: none"> <li>• To explain reason for behaviour (e.g., shyness, frustration)</li> <li>• To explain a positive characteristic (i.e., being smart)</li> <li>• Most were not accepting of telling peers of their diagnosis (desire to keep diagnosis personal; fear of being teased)</li> </ul>
Relationships with peers	
Friends	<ul style="list-style-type: none"> <li>• Friends as mostly younger children or one or two same-age friends</li> <li>• Preference to play alone</li> <li>• Tendency to interact with adults</li> <li>• Advice re: how to make friends (specific, procedural advice)</li> </ul>
Challenges	<ul style="list-style-type: none"> <li>• Difficulty developing relationships</li> <li>• Bullying</li> </ul>
School experience	
Supportive people	<ul style="list-style-type: none"> <li>• Educational program assistants (helped with organization, classwork, behaviour)</li> <li>• Classroom teacher (provides explanations)</li> </ul>

## School experience

Supportive people (cont'd)

- Peers (with classwork, schedules)
- Teacher, EPAs, peers regarded as ideal support people.

Useful information learned

- Academic subjects (e.g., math, language arts)
- Peer interaction skills noted as preferred knowledge to gain.

Helpful locations at school

- Learning centre (reasons unspecified)

Best grade to learn peer interaction skills

- As soon as possible (easier to learn when younger; when interactions with children start)

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**Appendix A**  
**Semi-Structured Interview Guide**  
Parents

**Introduction of Topic:**

**Autism (for parents of typically developing children):** Children with autistic spectrum disorders (ASDs) have differences in the way they talk and interact socially with others, as well as repetitive patterns of behaviours and interests. The term ASD refers to the range of ways these differences present themselves across individuals. The number of children diagnosed with ASD is rising – about one in 100 children have an ASD. Children with ASD do have quite an impact on school system resources, but special education funding continues to decrease.

In Nova Scotia, a province-wide early intervention program for preschool-aged children with ASD uses Pivotal Response Treatment (or PRT). Pivotal Response Treatment is one of the most-studied behavioral treatments for ASD. PRT is based on applied behavioral analysis (or ABA) and is play-based and child-led. Its goals include the development of children’s communication, language and positive social behaviors and reducing disruptive behaviors. PRT works by creating learning situations in natural settings, like at home or at school. A “learning situation” typically looks like this: 1. The parent presents the child with an instruction/question/other opportunity to respond (e.g., the child is playing outside and wants to be pushed on the swing, so the parent pauses while holding the swing and prompts, “Push?”), 2. Child responds (e.g., the child requests “Push”), 3. Parent provides what the child has requested (e.g., pushes the child on the swing).

Some intervention needs of preschool aged-children are met by the PRT-based early intervention program, but fewer interventions that have strong research evidence supporting them (e.g., evidence-based-interventions) are available for children after they go to school. Research tells us that positive peer interactions and making friends are one of parents’ most valued goals for their children with ASD. They are also important skills that are linked with real-world success.

We have designed a pilot/test study that would look at the effects of a short PRT-based social skills program for young elementary-school-aged children with ASD. Instead of having parents or teachers deliver PRT, which are often done, this would involve teaching classmates to coach children with ASD to improve their social interaction skills. Peer coaches would be taught to play with / help develop the social skills of children with ASD at school (e.g., on the playground, in classrooms at recess, at lunch). Using these “natural settings” is thought to increase children’s motivation, learning, and ability to apply their skills. The goal is to help kids with ASD make a successful transition to school and learn to interact with other children, as well as to encourage peers’ acceptance of and ability to interact well with children with developmental differences. Our hope is that if we invest early in children’s development during an important transition (into Grade Primary) that we may be able to help to decrease children’s difficulties at school and need for intensive supports in later school years.

I think that it is very important to get advice about our proposed intervention from parents who have children within the school system. Please give us your honest opinions.

I would like to begin this interview by asking:

### **PERCEPTIONS OF EVIDENCE-BASED INTERVENTIONS (EBI)**

1. What does the term “evidence-based intervention” suggest to you?
2. How important is it that interventions for children with ASD in the school system are based on research evidence?

### **PERCEPTIONS OF INTERVENTION**

#### **[Pivotal Response Treatment]:**

3. Have you heard of PRT? *If yes: What is your understanding of PRT? If no: repeat definition of PRT from the interview guide introduction above.*
4. What potential benefits would you envision to using PRT in schools?
5. What potential barriers to using PRT in schools do you think might arise?

#### **[Intervention Target]:**

6. What do you think are important skills to target for children with ASD at school?
7. Why or why not might peer interaction skills be an important intervention target?

#### **[Location of Intervention]:**

8. What advantages or disadvantages can you see of providing social interventions for children with ASD at home? at school? elsewhere?

[Probe: locations at school: playground, classroom; time of day]

[Pros/Cons]

#### **[Age/Grade Range for Providing Intervention]:**

9. What are the pros and cons of the first year of school as a time to provide social interventions to children with ASD? What point during the first year might be best?

[Why or why not; better time?]

[Pros/Cons]

**[Intervention Agent]:**

10. Who in the school setting is best positioned to facilitate play and social skills in children with ASD? What are the potential advantages and disadvantages of teaching same-aged typically developing peers to be social ‘coaches’ for children with ASD?

[Why or why not]

[Pros/Cons]

*[For parents of individuals with ASD: Does your child have siblings or friends who you think have helped with developing their play and social skills? How have they helped/could they help?]*

*[For parents of typically developing children: What do you think your child’s reaction would be to the idea of learning to play in new ways with a child with ASD? Can you think of any reasons why your child would like to help a child with ASD as part of an intervention like this? Reasons why your child might be uncomfortable with this role?]*

**[Ecological Feasibility]:**

11. Can you picture the proposed intervention study being carried out in your child’s school?

[Why or why not]

[Pros/Cons]

**[Putting it all Together: Overall Perceptions]**

12. Overall, what do you see as the potential strengths of this intervention approach?
13. What do you think would improve the chances of success?

**[Endorsement]:**

14. Overall, would you recommend that this intervention be piloted in HRSB schools

Please choose the best descriptor:

- Definitely yes
- Yes with reservations  
[Probe: reservation]
- No opinion/neutral opinion
- No, but with improvement/revision might be worth consideration  
[Probe: revisions]
- Definitely no

**Appendix B**  
**Semi-Structured Interview Guide**  
 Individuals with Autistic Spectrum Disorder

**Introduction of Topic:**

I am interested in talking to you today about children with autistic spectrum disorders (ASD; substitute ASD for interviewee's preferred term, i.e., autism, Asperger syndrome; wording will be adapted to match the age and language abilities of each interviewee) who are just starting school. I am especially interested in learning about what you think could help these young children at school as they start grade primary.

For most of the questions, please think back to your first couple of years of school (i.e., primary, first grade). Looking back, think about your own time at school and what might have help you get along better with other children. You could think about your time spent on the playground, or in the classroom/library/gym/music class, or at recess /lunch time. We will focus on what did or could have helped you play and get along with children. We will also focus on how other children at your school did or could have helped you.

Before we start, do you have any questions about the study or about what we're going to do today?

**AWARENESS AND PERCEPTIONS OF ASD DIAGNOSIS**

**[Self Awareness/Perception]**

1. What and when do you remember being told first about (your diagnosis of) ASD?

[Pros/Cons to timing and the content of this news]

**[Peer Awareness/Perception]**

2. (During the first few years of school) did other children know about your ASD?  
How do you know that?

[If so, do you know how were they told?]

[Pros/Cons to peers knowing]

3. What would you have liked to tell other children about ASD?

[Is there anything else that would have been helpful for them to know?]

**PERCEPTIONS OF INTERVENTION AGENT**

4. Tell me about anyone at school who was helpful to you during the school day.

[Probe: Who (e.g., educational program assistant, resource teacher, friend)? How did they help?]

5. Was there anything other children did that helped you to get along better at school?

[Was there anything they did or could have done to make playing and getting along with others easier for you?]

6. If you had a choice when you were in your first years of school, who would you have liked to get help from (in getting along with other children)? [Teacher? EPA? Classmates? Older children?]

**PERCEPTIONS OF INTERVENTION TARGET**

7. What were the most important things you learned in the first years of school? Are there other things you wish you had been taught this early? [Would it have been helpful to be taught/shown how to play/get along with other children at school?]

[Do you remember any kind of help you were given?]

**PERCEPTIONS OF INTERVENTION AGE/GRADE RANGE**

8. Would it have been helpful to learn about playing and getting along with other children when you first started school (i.e., grade primary)?

[Pros/Cons]

[Better time to learn (grade/age)?]

**CONCLUSION**

9. Is there anything else we should know about helping young children with ASD at school?

**Appendix C**  
**Parent: Background Information**  
**[For Parents who Have a Child (or Children) with Autistic Spectrum Disorders]**

**1. Age** (circle the category that applies):      <30      31 – 40      41 – 50      51 – 60      >60

**2. Gender:**     M     F

**3. Ethnicity (optional)**     Caucasian                       African-Canadian     First Nations  
     Asian                                       Other: \_\_\_\_\_

**4. What is your highest level of education?**  
 Grade school (less than Grade 12)                                       High school completion  
 Some trade, technical or vocational school, business college or community college                       Bachelor’s degree (BA, BSc, BEd)  
 Master’s degree (MA, MSc)     Doctoral or Professional degree (PhD, MD)

**5. Occupation:** \_\_\_\_\_

**6. What grade are your children in?**                      \_\_\_\_\_  
    \_\_\_\_\_

**7. As a preschooler, did your child receive Nova Scotia Early Intensive Behavioral Intervention (NS EIBI) or other specialized programs for ASD?**     YES     NO  
**Please describe:**

\_\_\_\_\_

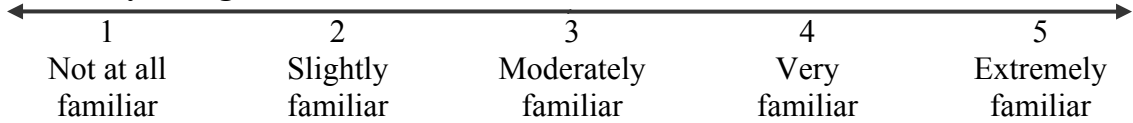
**8. While school-aged, has your child received any autism-specific interventions (in or outside of school)?**  
**Please describe:**

\_\_\_\_\_

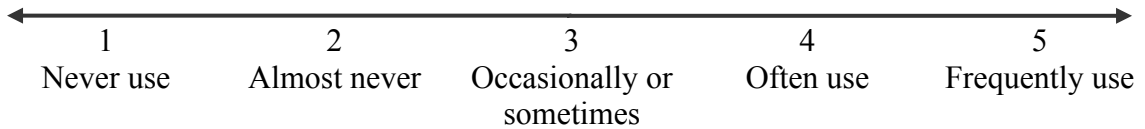
**9. How many years has your child (children) with ASD received intervention in a professional capacity?** \_\_\_\_\_

**10. Using the table below, rate your *familiarity* and *frequency* with which you use the ASD interventions/educational approaches listed. Frequency is based on *current* use; i.e., within the past 12 months:**

**Familiarity ratings:**



**Frequency ratings:**



<b>Intervention/Approach</b>	<b>Familiarity</b>	<b>Frequency</b>
Strategies for Teaching based on Autism Research (STAR)	1 2 3 4 5	1 2 3 4 5
Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)	1 2 3 4 5	1 2 3 4 5
Social Stories	1 2 3 4 5	1 2 3 4 5
Applied Behavioral Analysis (ABA) Based/Behaviour Therapy	1 2 3 4 5	1 2 3 4 5
<b>Specific ABA/Behavioural Approach</b>		
Picture Exchange Communication System	1 2 3 4 5	1 2 3 4 5
Pivotal Response Treatment	1 2 3 4 5	1 2 3 4 5
Discrete Trial Teaching	1 2 3 4 5	1 2 3 4 5
Positive Behavior Supports/Behavior Plan	1 2 3 4 5	1 2 3 4 5
Exposure therapy, relaxation training	1 2 3 4 5	1 2 3 4 5

<b>Broad Approaches</b>	<b>Familiarity</b>	<b>Frequency</b>
Cognitive-Behavioral Therapy (combines cognitive and behavioral principles; e.g., challenging negative thoughts, fear hierarchy; “Face Your Fears”, “Coping Cat”)	1 2 3 4 5	1 2 3 4 5
Sensory Diet (i.e., various planned sensory experiences throughout the day)	1 2 3 4 5	1 2 3 4 5
Speech-Language Pathology	1 2 3 4 5	1 2 3 4 5
Note specific approach, if applicable: _____ _____		
<b>Other ASD-related educational program / intervention approach(es). Please Specify:</b>		
_____	1 2 3 4 5	1 2 3 4 5
_____	1 2 3 4 5	1 2 3 4 5



Social Stories	1 2 3 4 5
Applied Behavioral Analysis (ABA) Based/Behaviour Therapy	1 2 3 4 5
<b>Specific ABA/Behavioural Approach</b>	
Picture Exchange Communication System	1 2 3 4 5
Pivotal Response Treatment	1 2 3 4 5
Discrete Trial Teaching	1 2 3 4 5
Positive Behavior Supports/Behavior Plan	1 2 3 4 5
Exposure therapy, relaxation training	1 2 3 4 5

<b>Broad Approaches</b>	
Cognitive-Behavioral Therapy (combines cognitive and behavioral principles; e.g., challenging negative thoughts, fear hierarchy; “Face Your Fears”, “Coping Cat”)	1 2 3 4 5
Sensory Diet (i.e., various planned sensory experiences throughout the day)	1 2 3 4 5
Speech-Language Pathology	1 2 3 4 5
Note specific approach, if applicable: _____ _____	
<b>Other ASD-related educational program / intervention approach(es). Please Specify:</b>	
_____	1 2 3 4 5
_____	1 2 3 4 5



9. How old was your son/daughter when he/she was formally diagnosed with an autistic spectrum disorder?

\_\_\_\_\_

**10. The following questions pertain to your child's first years of schooling (i.e., primary/elementary school):**

- A. Did your son/daughter attend:

- Public School    Private School  
 Home School    Other:

\_\_\_\_\_

- B. How old was your son/daughter when he/she started school (i.e., grade primary)?

\_\_\_\_\_

- C. Did your son/daughter spend time in a Resource/Learning Centre or other Special Education class?

- YES    NO

Additional comments (not required):

\_\_\_\_\_

- D. Did your son/daughter have an Educational Program Assistant (EPA)?

- YES    NO

Additional comments (not required):

\_\_\_\_\_