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Supporting Families of Children with Autism Through School-Based Practices

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A Thesis submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

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Abstract

Research in the field of autism has shown that families of children with ASD are affected in many ways. Recent studies have begun to explore various interventions for siblings of children with developmental disabilities. A systematic review of studies on school-based interventions for families and siblings of children with autism was conducted to evaluate the current state of the literature and inform recommendations for research and practice. Three articles were selected and reviewed according to their experimental design, participant characteristics, intervention or support protocol, and outcomes measured. Using the current search criteria, no studies were found to address school-based services for families and siblings of children with autism. However, included studies report positive indicators for parent-school collaboration with behavior interventions for children with autism. Recommendations for future research are outlined, with a focus on modifying existing intervention and support programs for school settings.

Introduction

Autism Spectrum Disorder (ASD) is defined as a pervasive neurodevelopmental disorder characterized by impairments in social communication and restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). Research in the field of autism has shown that families of children with ASD are affected in many ways as they encounter unique challenges of living with a child with autism (Benson, 2006; Bontinck, Warreyn, Meirsschaut, & Roeyers, 2018; Chan & Goh 2014; Hare, Pratt, Burton, Bromley, & Emerson, 2004). This knowledge has led to an abundance of research focusing on impacts for the entire family. Previous studies have investigated the sibling relationship within families of children with autism, particularly in terms of how the typically developing (TD) child is impacted. Recent research has also begun to explore various interventions for siblings of children with developmental disabilities to further inform how to best support this population (Shivers & Taylor, 2013; Gettings, Franco, & Santosh, 2015; Thomas, Reddy, & Sagar, 2015).

To date, family and sibling interventions have regularly been conducted in the community or in clinic settings. The following literature review shows that programs tailored to families and TD siblings' needs are helpful in a variety of ways. Many services are provided to families and students via school systems, including interventions and support groups. Therefore, this study aims to investigate the availability of school-based support for families and siblings, specifically of children with autism.

Literature Review

Family Impact

Several studies have investigated the challenges that families of children with autism and other disabilities experience. Perry, Harris, and Minnes (2004) found that parents of children with autism reported experiencing less harmony than families of children with other developmental disabilities. In a longitudinal study of parental stress, Baxter, Cummins, and Polak (1995) found that parents of children with developmental disabilities commonly share an increase in stress during specific life events such as time of initial diagnosis and transitions into, throughout, and outside of the public education system. Additionally, families of children with ASD are at an increased risk for poor mental health due not only to the demands of caring for a child with ASD, but also the challenging characteristics that accompany their child's disability (e.g., limited verbal communication, deficits in social behavior, aggressive behavior, restricted and/or repetitive behavior patterns).

Higgins, Bailey, and Pearce (2005) reported that parents of children with autism generally had lower levels of marital happiness, family adaptability, and family cohesion. Hare, Pratt, Burton, Bromley, and Emerson (2004) found a strong correlation between emotional stress and unmet needs in parents of older children and adults with ASD. Furthermore, the economic burden and negative impacts on careers and/or income have also been consistently reported from families of children with ASD (Jarbrink, Fombonne, & Knapp, 2003; Sharpe & Baker, 2007).

According to Chan and Goh (2014), parents find it difficult to spend equal amounts of time with each of their children. They often give full attention to the child

with autism, leaving the typically developing (TD) child to independently problem solve or adjust. TD siblings also reported being unsatisfied with the lack of individual time spent with their parents (Chan & Goh, 2014). Studies show evidence that differences in parenting methods can serve as another source of frustration for the TD sibling. For example, within the family system, the child with autism may be praised excessively for behavior that is simply expected of the TD sibling. At the same time, the TD child can receive harsher punishment when breaking rules (Chan & Goh, 2014; Tsai, Cebula, Liang, & Fletcher-Watson, 2018). The divide in expectations can cause additional stress on the parent-child and sibling relationship.

Sibling Experiences

The sibling relationship is especially important as it is likely to be the longest lasting of all human relationships (Cicirelli, 1994; Orsmond, Kuo, & Seltzer, 2009). Characteristics of ASD often create difficulties in promoting a positive relationship, such as disruptive behavior, stereotyped or fixated interests, and poor social-emotional skills. In a review of literature on interpersonal and social development of adolescents by Smetana, Campione-Barr, & Metzger (2006) siblings reported that their greatest sources of support come from relationships; particularly with their friends and parents. Yet, TD siblings of children with autism experience many unique challenges that create barriers for receiving adequate time with parents, having a meaningful connection with their sibling, and maintaining friendships.

The current literature supports a link between positive indicators of sibling relationship quality and developmental outcomes for both the TD sibling and the sibling with autism. Moyson and Roeyers (2011) also found that a TD sibling's overall opinion

of having a sibling with autism is linked directly to the nature of the existing sibling relationship. Daily interactions help to create a positive or negative perception. Many behaviors exhibited by individuals with ASD inhibit positive interactions. Often, the behaviors that accompany autism are expected to negatively affect the sibling relationship and the social, behavioral, and psychological adjustment of TD siblings. For example, Ross and Cuskelly (2006) investigated problematic experiences, coping skills, and overall adjustment of TD siblings of children with autism. The vast majority of participants (84%) identified regularly experiencing aggressive interactions with their sibling. This category included physical and verbal aggression, destruction of property, and disruption (e.g. annoying and provoking behaviors). Participants also reported what was categorized as “social difficulties”, such as invasion of privacy, lack of appropriate social exchanges, and not understanding sharing or boundaries. Ross and Cuskelly’s (2006) participants further reported deficits in communication skills, odd or stereotypical behaviors, as well as the inability to cope with change in routine as common problems.

Hastings and Petalas (2013) focused on TD siblings’ personal behavior, emotional problems, and perceptions of their sibling relationship. The findings from this study indicated peer problems to be the only self-reported domain at an elevated level. Such challenges included feelings of embarrassment in front of peers, peers’ lack of empathetic skills, and peers’ negative attitudes toward the child with ASD. Interestingly, reports from TD siblings differed from their mother’s reports regarding the behavioral and emotional problems of their sibling with ASD (Hastings and Petalas, 2013). This indicates that relying solely on parents as informants can result in incomplete or partially inaccurate conclusions regarding TD siblings’ experiences.

When Bagenholm and Gillberg (1991) compared siblings of children with ASD to those with intellectual disability (ID) or no disability, siblings of children with ASD reported additional stressors that were specific to autism. According to the study, TD siblings engage in play less often, feel significantly more lonely than others, have fewer friendships, and experience increased concern for their brother or sister's future. TD siblings are often concerned with the idea that they will eventually become responsible for the wellbeing of their brother or sister with ASD, especially after parents are no longer able to provide or oversee care (Orsmond et al., 2009).

TD siblings are often left to develop skills for problem solving, coping, and adjusting on their own (Orsmond et al., (2009). How they navigate their unique situation will vary for a number of reasons as they experience a multitude of psychological, social, and emotional difficulties.

Adjustment to Autism

Siblings can develop a variety of coping and problem-solving mechanisms that can be either useful or ineffective. Another part of Ross and Cuskelly's (2006) study involved exploration of coping skills used by the 25 TD siblings. They collected information about coping strategies used by the TD siblings regarding aggressive sibling interactions and asked them to rate how effective they felt the strategies were. Of the common coping strategies reported, 100% felt that cognitive restructuring and distraction were helpful techniques, followed by problem solving (93%), social supports (92%), social withdrawal (89%), emotional regulation and wishful thinking (both 84%). Over half of the participants also reported blaming others, resignation, and self-criticism as effective coping strategies.

Though this is not the case for all sibling relationships, research suggests that many TD siblings need assistance in developing and/or identifying appropriate coping strategies (Ross & Cuskelly, 2006; Orsmond et al., 2009). Problem-focused coping strategies, like obtaining helpful social support, aim to solve problems and reduce effects of stressful events, while emotion-focused coping strategies, such as distraction, relying on food or substances, and suppressing, aim to regulate or eliminate undesirable emotions that are associated with stressful events (Orsmond et al., 2009). Orsmond and Seltzer (2007) found that, when used by the TD siblings, problem-focused coping served as a protective factor against the negative effects of behavior problems of the sibling with ASD. However, it is more common and developmentally typical for children and adolescents to use more emotion-focused coping strategies (Orsmond et al., 2009). While it is clear that TD siblings are able to identify and use effective strategies, Ross and Cuskelly's study provides evidence that siblings are also largely using ineffective, and in some cases harmful, strategies for coping and problem solving.

In their study, Moyson and Roeyers (2011) investigated how TD siblings describe and define their quality of life through interviews and focus groups. They found that the apparent invisibility of ASD (i.e., the "normal" physical appearance) had emerged as an important theme. According to Connell and Connell (2003), invisible disabilities or diseases can result in a lack of understanding from people outside the family system; they often believe that because the child *appears* to be developing typically, complaints of strain on the sibling relationship must be an exaggeration. This can occur across the autism spectrum more often than one would think and might cause some children to resist sharing feelings of stress, anger, and/or sadness (Moyson & Roeyers, 2011).

It is clear that TD siblings of children with autism are at risk for experiencing elevated levels of stress. Skills to manage syndrome specific challenges of autism must be taught as they are not readily accessible through ordinary social experiences.

Interventions and Supports for Typically Developing Siblings

Since TD siblings of children with ASD are at a heightened risk for developing problems, especially internalizing disorders, interventions have been created to assist in healthy development. Thomas, Reddy, and Sagar (2016) suggest that TD siblings benefit from learning more about autism. Support groups can offer psychoeducation along with opportunities for social interaction and understanding in a safe, judgment-free environment (Smith & Perry, 2005; Summers, Bridge, & Summers, 1991). Sibling support groups have been created to help TD siblings learn effective ways of coping and problem solving. Smith and Perry (2005) reviewed Thistletown Regional Centre's sibling support group, one of the first programs to focus specifically on siblings of children with autism. They found that siblings who attended the Thistletown support group had improved self-concept and knowledge of autism after attending the 8-week program. However, there were no significant differences in TD siblings' coping strategies (Smith & Perry, 2005; Shivers & Taylor, 2013).

Sibshops® is a manualized treatment for siblings of children with disabilities (Meyer & Vadasy, 2008). The program has gained popularity in the United States as well as several other countries. Sibshops® is a helpful program for many siblings. An estimated 40% of children who attend Sibshops® programs are there because they have a sibling with autism (Hansford & Harris, 2013). The efficacy of the program has not been evaluated by standardized measures, but instead by asking participants about their

thoughts toward the program. Over 90% of siblings reported positive effects on their feelings toward their sibling with ASD and 60% reported learning coping skills (Shivers & Taylor 2013). School psychologists emphasize the importance of implementing empirically-validated interventions. Therefore, systematic studies on support groups and the application of program techniques are necessary in providing best practices for siblings of children with ASD.

Hansford and Harris (2013) evaluated the efficacy of Project SibSTAR (Straight Talk about Autism Realities), an 8-week support group that incorporates instruction, discussion, and role-play while using thorough research design and psychometrically-sound measures (Hansford & Harris, 2013). The SibSTAR manual was adapted from themes and activities included in the Sibshops® manual, as well as interventions and sibling support groups that were offered at the Douglass Developmental Disabilities Center at Rutgers University for over 30 years. The content for each session was based on empirical studies of support groups for children with autism (Martins, 2006; Meyer & Vadasy, 2008). These sessions were organized into modules designed to target the specific needs of siblings of children with autism: 1) Psychoeducation about Autism Spectrum Disorders, 2) Developing Problem-Solving Skills, 3) Behavioral Skills Training, and 4) Increasing Self-Esteem and Empowering Siblings (Hansford & Harris, 2013).

Twenty siblings of children with autism were randomly assigned to an active or delayed intervention group. This allowed both groups to receive the same intervention while collecting multiple baseline data. Each participant and one parent completed a questionnaire packet two weeks before sessions began, two weeks after the sessions

terminated, and as a six week follow-up post-intervention. SibSTAR includes a parent and sibling interaction element which encompasses the importance of a family system. Parents and participating children were invited to provide feedback for the program and asked to complete the Project SibSTAR Satisfaction Survey. Parents and participants were also given a checklist to indicate whether they observed improved interaction with the child with ASD. Additionally, siblings with ASD were included in a play interaction task which involved frequency counts of target behaviors (i.e., initiating play, prompting, and praising; Hansford & Harris, 2013). Results indicated TD siblings had increased knowledge of autism, coping and problem-solving skills, and knowledge of behavioral skills (Hansford and Harris, 2013). Hansford and Harris (2013) also found a decreasing trend in internalizing symptoms from baseline to post-intervention, as well as differences in TD siblings' perceptions of social supports and self-competence.

Both Project SibSTAR and the Thistleton Regional Center's sibling support group include psychoeducation as a key component of their interventions. According to a systematic review by Thomas, Reddy, and Sagar (2016), TD siblings greatly benefit from understanding the characteristics, features, and development of autism. The researchers discuss the idea that this may be true no matter how significant the emotional or psychological impact of having a sister or brother with autism may be. However, Tudor and Lerner (2015) argue that age matters when looking for long term effects. In their systematic review to identify overall effects and utility of services for TD siblings, Tudor and Lerner (2015) found that studies involving younger siblings (i.e., age 7 to 11) report that they did not retain much of the education about autism according to post-intervention tests.

Services in Schools

While previous literature has established several community or clinic-based resources for siblings and families of children with disabilities, factors such as time of day, costs, and transportation can cause challenges for some families who wish to support their typically developing child. Present-day students are able to access a multitude of support systems within their school settings. For example, services such as first aid, medication administration, various health screenings, evaluations, special education services, as well as mental health services are available through school-based experts (Allensworth, Lawson, Nicholson, & Wyche, 1997). Additionally, school psychologists and other mental health professionals often facilitate groups targeting a number of topics related to a student's growth and skill building. Support for families and siblings of children with autism is gaining attention from researchers and appropriate application of intervention is necessary.

Purpose of the Current Study

Some time has passed since researchers have systematically reviewed publications related to supporting siblings of children with autism (Tudor & Lerner, 2015; Thomas et. al., 2016). In their quest to identify effective TD sibling support, these reviews provided comprehensive information about important components of interventions. They also mention the importance of family-centered support. However, these reviews did not identify how schools and school-based professionals can support families and siblings of children with autism. Further, limitations from these reviews noted that Grey literature, or unpublished literature, was excluded. Grey literature can include academic papers, research and committee reports, government reports,

conference papers, and ongoing research that may provide data not found in commercial publications. It is important to consider unpublished evidence due to the possibility that much of this research may have been conducted through university program projects. Consequently, the following question remains unanswered: What studies have been conducted on school-based interventions and supports for families and siblings of children with autism? This systematic review aims to answer this question, offer guidelines for future research, and further inform the role of school psychologists in supporting this population.

Methodology

Procedure

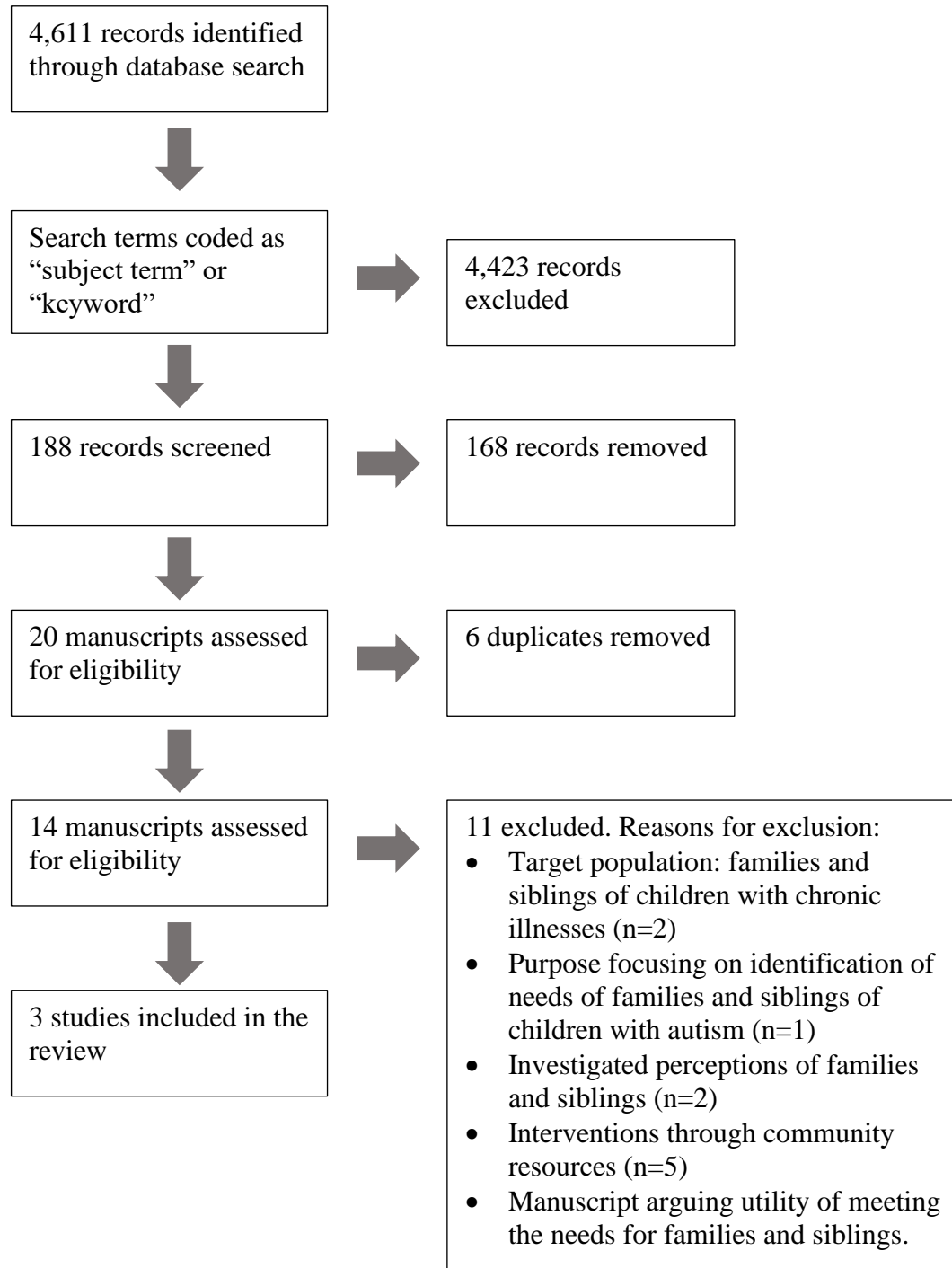
The following database sources accessed through James Madison University Libraries were used to search for and identify literature: Child Development & Adolescent Studies; Dissertations & Theses: Global; EBSCO Open Dissertations; Education Research Complete; ERIC; Family Studies Abstracts; PsychINFO; PsychNET; and Psychology and Behavioral Science's Collection. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to develop eligibility criteria, search strategies, study selection, and data synthesis (Jahan et al., n.d.). Grey literature and published manuscripts were identified using a query of concept terms related to autism (autism or ASD or developmental disabilities or pervasive developmental disability or Asperger's), terms related to the target population (sibling or family), terms related to service provider (schools or k-12 or high-school or elementary school or middle school or secondary school), and terms related to type of intervention (intervention or support group or program). Concept terms were connected with AND,

and were assigned field codes (subject term or keyword). The synonym terms within the key concepts were connected with OR. The Truncation technique was applied to synonym terms to include variations of word form (i.e. sibling*= sibling, siblings). Quotation marks were used around terms that included two or more words to ensure that search results contained those exact words in order (i.e. “elementary school”) (Mariner, 2019).

Manuscripts were selected for review if they met predetermined criteria for inclusion according to their title and abstract. Inclusion criteria were as follows: (1) Studies must have been conducted within the years 2010-2020; (2) the target population must be siblings and families of children with autism; and (3) the service(s) provided to siblings and families must be provided through the public school system. Literature was excluded from this review if the intervention was conducted prior to the specified time period, if the intervention did not include families and siblings of children with autism, and if studies only discussed interventions as implications for future research. Figure 1 illustrates this study’s search strategy using the PRISMA guidelines.

Data Synthesis

This review of literature was accomplished using narrative analysis (Jahan et al., 2016; Snilstveit et al., 2012). Included manuscripts are organized by type of intervention followed by a discussion of the findings. Given the differences in study designs, use of statistical measures, and the small number of manuscripts included in this review, a narrative approach to the synthesis of data was most appropriate.

Figure 1.*Flow chart of selection process*

Results

Study Selection

Altogether, the initial search resulted in a total of 4,611 manuscripts. After terms were assigned field codes, 188 manuscripts remained. Of the 188 remaining manuscripts, only 14 met inclusion criteria and were selected for further review. Two were excluded as they ultimately addressed siblings and families of children with chronic health problems through community agencies. One article focused only on identification of the needs in families and siblings with autism. Two manuscripts discussed perceptions of parents or siblings of children with autism but did not discuss an intervention and was therefore not included. Another five articles reviewed interventions provided through community resources. Lastly, an additional manuscript provided supportive information on implications for school counselors with this population but did not include an intervention as part of the document. A total of 3 manuscripts remained for inclusion of this systematic review. None of the articles focused on siblings in schools; rather, they focused on interventions that addressed behavior, social skills, and language skills for the child with autism and included a parent component. The details of the 3 articles are presented in Table 1 under the headings of Author/Date, Aim, Intervention, Outcome, and Limitations listed by the authors (also see Appendix A).

Table 1.

Characteristics of Studies

Reference (Year)	Study Design	Total No. of Participants	Length of Intervention	Outcomes Measured and Measurement Tools Used	Location of Intervention
Blair, Lee, Cho, and Dunlap (2011)	Multi-site Multiple baseline design	9 (3 child- mother pairs & 3 teachers)	30 weeks	Adult/Child Behavior: 10-second partial interval recording observations during 10-minute sessions Implementation Fidelity: weekly setting observations Social Validity: 11 -item, 5-point Likert scale adapted from the Treatment Acceptability Rating Form -Revised (TARF-R)	Two early childhood classrooms at a public school in a middle-class neighborhood in South Korea. Reverse inclusive educational model serving children with and without disabilities between the ages of 3 and 5
Ingersoll and Wainer (2011)	Multi-site Pretest and posttest design	37 (24 child- parent pairs & 13 teachers)	16 weeks	Social engagement, language, & imitation/play: Social Communication Checklist- parent & teacher reports Autistic Social Impairment: Social Responsiveness Scale- parent & teacher reports Parents' fidelity of implementation: ImPACT Fidelity Rating Scale Parental stress: Parent Stress Index- Third Edition Treatment Acceptability: Behavior Intervention Rating Scale	Three intermediate school districts serving children with autism.

Table 2.

Table 1.

Characteristics Continued

Reference (Year)	Study Design	Total No. of Participants	Length of Intervention	Outcomes Measured and Measurement Tools Used	Location of Intervention
Karaaslan, Diken, and Mahoney (2011)	Single-site Randomized Control Study	38 (19 child- mother pairs)	24 weeks	Child development, self-care, social skills, language, & motor development: Denver Developmental Screening Test & ADOS	Two special education rehabilitation centers in Turkey
				Mother responsiveness, affect, & achievement orientation/ directiveness: Maternal Behavior Rating Scale translated to Turkish	
				Child's interactive behavior with their parent: Child Behavior Rating Scale translated to Turkish	

Table 3. Table 1.

Characteristics Continued

Reference (Year)	Study Design	Total No. of Participants	Length of Intervention	Outcomes Measured and Measurement Tools Used	Location of Intervention
Karaaslan, Diken, and Mahoney (2011)	Single-site Randomized Control Study	38 (19 child- mother pairs)	24 weeks	Child development, self-care, social skills, language, & motor development: Denver Developmental Screening Test & ADOS	Two special education rehabilitation centers in Turkey
				Mother responsiveness, affect, & achievement orientation/	

Study Characteristics

The contents of the included studies have been organized into the appropriate heading below for description and comparison of each topic. The methods, participants, and interventions are described below. Primary outcomes are also reported according to what each study intended to measure.

Methods

Two of the studies (Ingersoll & Wainer, 2013; Karaaslan, Diken, & Mahoney, 2011) selected for review were randomized controlled trials while one used a multiple baseline design (Blair, Lee, Cho, & Dunlap 2011). All three were published in English. The duration of the interventions conducted in the study were 30 weeks for the positive behavior support intervention, 16 weeks for the Project ImPACT intervention, and 24 weeks for the Responsive Teaching intervention.

Participants

The included studies involved 84 participants total. Of those participants, 34 were children with autism, 34 were parent participants, 15 were early childhood special education teachers, and one was a general early childhood teacher. Main inclusion criteria entailed students in an early childhood education program with a diagnosis of autism and a designated parent participant. Two of the studies included teachers of the students. The third intervention was facilitated by an education specialist graduate student in a special education rehabilitation center.

Intervention

The interventions that were implemented took place in various school based programs as well as in the children's' home setting. The positive behavior support

intervention incorporated family and teacher collaboration in identifying target behaviors, developing a plan, and participating in trainings for using positive reinforcement. It took place in two early childhood classrooms at a public school located in a middle-class neighborhood in South Korea. The authors categorized children's target behaviors into appropriate behavior (i.e., engagement in activities and social interaction) and problem behavior (i.e., disruption, noncompliance, aggression, and self-injury) for both the home and school setting. Adult behavior was categorized as positive interactions (i.e., providing social attention and providing specific verbal praise) and negative interactions (i.e., reprimanding, using a harsh tone, "using time-out", and holding or restraining the child). The intervention began with team building: the researchers as facilitators, child participant, relative mother participant, and the early childhood education teacher and/or early childhood special education teacher. The members worked together to complete assessment activities and intervention procedures. They also took part in a total of 10 hours of training over 3 days focused on helping the staff and families learn skills in the areas of collaborative teaming, assessment methods, developing and implementing effective behavior support strategies. The intervention used preventative behavior support strategies such as visual schedules and cues, embedding preferences into existing activities, providing choices on activities and materials, and providing frequent verbal praise for engagement in activities. In addition, parents and teachers were trained to use systematic prompting procedures for teaching the children strategies: requesting attention, help, items, or activities using a picture and verbal communication, following a sequence of activities or routines, waiting for or accepting a delay of positive

reinforcement, and responding to social initiations from peers, siblings, and adults (Blair, Lee, Cho, & Dunlap, 2011).

Project ImPACT was created by Ingersoll & Dyortcsak (2006). In the included study, the intervention was implemented in three intermediate school district programs serving children with autism. Project ImPACT is an evidence-based parent training curriculum whose format is compatible with a classroom-based intervention model and includes instruction for working with parents. The intervention teaches parents to use a blend of developmental and naturalistic strategies to promote their child's pro-social behaviors through group training and individual coaching sessions. Teachers also participate in a 2-day workshop that provides instruction in intervention techniques for use with the child participants and methods for training and supporting parents (Ingersoll & Wainer 2011).

Lastly, The responsive teaching intervention took place in collaboration with services provided through two special education rehabilitation centers in Turkey. The program uses behavior rating scales, developmental screenings, and semi-structured parent interviews to measure outcomes. The facilitator in this study prepared daily plans to be implemented with mother and child participants. These plans included a total of 66 strategies and 132 discussion points supporting the strategies that can be used by mothers during their interactions with their children. During each session, the daily plan was presented to the mother participants through explanation, demonstration, and role-play (Karaaslan, Diken, & Mahoney, 2011).

Outcomes

In all studies, the primary outcomes measured were changes in child's behavior, language use, and social skills as well as parent-child interaction behaviors. One study measured parental stress as an additional outcome. Two of the studies reported on the social validity of family-school collaboration through the intervention. Two of the studies collected data on implementation fidelity of the interventions.

Study Findings

Regarding the effects of an intervention through collaborative family-school efforts, all three studies reported on child behavior, social engagement, and adult effects. Table 2 provides a narrative summary of the findings from each study.

Child Behavior

The positive behavior support intervention used partial interval recording to measure the change in child behavior. During the baseline phase, all children demonstrated high levels of problem behavior, ranging from 63% to 65% of intervals in the classroom and 76% to 78% of intervals at home. During the intervention phase, the children's problem behavior decreased to 18% to 23% in the classroom and 17% to 21% in the home setting. This decrease remained stable during follow-up, with an average of 23% to 31% and 18% to 28% for problem behavior during classroom center time and in the home setting respectively (Blair et. al. 2011).

According to pre- and post-treatment results of the Social Responsiveness Scale, parents did not report a significant decrease in social impairment related to autism. However, teacher reports indicate significantly lower scores on the SRS after treatment ($p < .01$; Ingersoll & Wainer 2011).

Table 4.*Summary of Study Findings*

Reference (Year)	Child Behavior	Language Use	Social Engagement	Adult Effects
Blair, Lee, Cho, and Dunlap (2011)	<p>Problematic behavior at baseline (ranging from 63% to 65% of intervals in the classroom and 76% to 78% at home) decreased during the intervention phase (18% to 23% in the classroom and 17% to 21% at home) and was maintained post-intervention (average of 23% to 31% at school and 18% to 28% at home)</p> <p>Changes were maintained after 3 weeks for problem behavior (average 23% to 31% in the classroom and 18% to 28% at home)</p>	N/A	<p>Pro-social behavior at baseline (14% to 16% in the classroom and 11% to 17% home) increased during the intervention phase (59% to 62% in the classroom and 63% to 65% at home)</p> <p>Changes were maintained after 3 weeks for pro-social behavior (50% to 58% at school and 55% to 63% at home)</p>	<p>Positive interactions at baseline (16% to 21% for mothers and 27% to 30% for teachers) increased during the intervention phase (76% to 77% for mothers and 59% to 63% for teachers)</p> <p>Negative interactions at baseline (71% to 74% for mothers and 61% to 63% for teachers) decreased (16% to 17% for mothers and 20% to 22% for teachers)</p> <p>Changes were reportedly maintained after 3 weeks</p>

Table 2.

Summary Continued

Reference (Year)	Child Behavior	Language Use	Social Engagement	Adult Effects
Ingersoll and Wainer (2011)	Varied results on the SRS (Mothers: NS, Teachers: $p < .01$).	Significant increase on the language scale of the SCC from pre- to post- intervention (Parent: $p < .01$, Teacher: $p < .001$)	Significant increase of skills at post-treatment than pre- treatment on the Social Engagement scale of the SCC (Mothers: $p = .001$, Teachers: $p < .01$).	N/A
			Varied results on the Imitation/ Play scale of the SCC (Mothers: NS, Teachers: $p < .001$).	
Karaaslan, Diken, and Mahoney (2011)	Significant increase from pre-intervention scores for both groups ($p < .05$) Treatment group making greater improvements than the control group on the Denver-II Scale Personal–Social ($p < 0.01$)	Significant increase on ADSI Language- Cognitive Scale $p < .01$ and the Denver-II Language Scale $p < .01$	Significant improvement in attention and initiation for control and treatment groups ($p < .001$) on CBRs.	Although both groups made significant changes in MBRs ratings from pre- to postintervention, mothers in the RT group made greater improvements than mothers in the control group on all scales, $p < .001$.

Table 6. Table 2.

Summary Continued

After the Responsive Teaching intervention, children demonstrated significantly higher scores than at pre-intervention for both treatment and control groups according to the Personal-Social scale on the Denver-II ($p < .05$). Univariate analyses of the Time \times Treatment effect indicated that children in the treatment group made significantly greater improvements than those in the control group ($p < 0.01$; Karaaslan et. al., 2011).

Language Use

Two of the studies reported on changes in language use post-intervention. Project ImPACT reported a significant increase on the language scale of the Social Communication Checklist from pre- to post-intervention according to reports from both parents ($p < .01$) and teachers ($p < .001$). As part of the parent implementation fidelity measure, data were collected on the target child's rate of language which occurred at a significantly higher rate with their parent during free play ($p < .05$) and during home-based routines ($p < .05$) (Ingersoll & Wainer 2011).

The responsive teaching intervention continued to show improvement in the Language scale on the Denver-II ($p < .01$), as well as on the Ankara Developmental Screening Inventory (ADSI) Language-Cognitive Scale ($p < .01$). Similar to results of child behavior scales, both treatment and control groups made significant progress with the children in the responsive teaching intervention demonstrating significantly greater improvement than those who had not yet received the intervention ($p < .05$; Karaaslan et. al., 2011).

Social Engagement

All studies found statistically significant improvement in the target child's social engagement and play interaction in both home and school settings. With the positive

behavior support intervention, children demonstrated low levels of pro-social, or “appropriate behavior” at baseline, ranging from 14% to 16% in the classroom and 11% to 17% in the home setting. Their pro-social behavior increased ranging from 59% to 62% in the classroom and 63% to 65% at home. Follow-up data demonstrated maintenance with an average of 50% to 58% and 55% to 63% for pro-social skills during center time at school and at home, respectively (Blair et. al. 2011).

The study implementing Project ImPACT found that children made significant improvements in play skills at post-treatment than at pre-treatment according to teacher reports on the Imitation/Play scale Social Communication Checklist ($p < .001$). Parent reports for the same measure did not yield a significant change for this scale (Ingersoll & Wainer 2011). Additionally, the Social Communication Checklist has a Social Engagement Scale which demonstrated a significant increase of skills at post-treatment and pre-treatment according to both parent ($p = .001$) and teacher ($p < .01$) reports (Ingersoll & Wainer 2011).

Children’s engagement pre- and post-intervention was measured by parent reports on the Child Behavior Rating Scale. According to factors of Attention (i.e., attention, persistence, interest, and cooperation) and Initiation (i.e., initiation, joint attention, and affect), children made significant improvement in both control and treatment groups ($p < .001$). Again, children in the treatment group made significantly greater improvements than those in the control group ($p < .001$; Karaaslan et. al., 2011).

Adult Effects

According to observation data of the positive behavior support intervention effects on adults, mothers’ positive interactions increased from an average of 16% to 21%

during baseline to 76% to 77% during the intervention phase across mothers. Their negative interactions decreased from an average of 71% to 74% during baseline to 16% to 17% during the intervention across mothers. The teachers' positive interactions increased from an average of 27% to 30% during baseline to 59% to 63% during intervention, while their negative interactions decreased from an average of 61% to 63% during baseline to 20% to 22% during intervention. Follow-up data demonstrate, the positive and negative interactions in both mothers and teachers were found to be maintained at the levels above or below base- line. Overall, the levels of mothers' interactions improved more than those of teachers' interactions. The mothers engaged in the positive interactions at lower levels than those of teachers during baseline, but their positive interactions increased over time at levels higher than those of teachers. (Blair et. al. 2011).

While both groups of mothers had average ratings on Responsiveness and Affect at the beginning of intervention, during intervention mothers in the treatment group made a 93% and 71% increase on these two measures respectively, whereas mothers in the control group made a 20% and 13% increase. Similarly, at the beginning of the intervention, both groups of parent participants had average ratings on Directiveness/ Achievement Orientation that were slightly above the midpoint. After intervention, ratings on this measure for mothers in the treatment group decreased by 4%, whereas ratings for control group mothers increased by 9%. A repeated-measures MANOVA examined group differences across the three Maternal Behavior Rating Scale (MBRS) subscales. There were significant effects for control group and treatment group. Although both groups made significant changes in MBRS ratings from pre- to post-intervention,

mothers in the Responsive Teaching (RT) group made greater improvements than mothers in the control group ($p < .001$). Univariate ANOVA indicated that Time \times Treatment differences were significant for all three MBRS factors: Responsiveness, ($p < .001$), Affect ($p < .001$), and Achievement Orientation/Directiveness ($p < .01$). At postintervention, mothers in the RT group had significantly higher ratings on Responsiveness and Affect and lower ratings on Achievement Orientation/ Directiveness than mothers in the control group (Karaaslan et. al., 2011).

Social Validity

Two of the studies reported on the acceptability of the interventions through schools. The results are summarized in Table 3. Almost all participants engaged in interventions in their entirety. Those who did not were excluded from data collection and reporting. One study (Blair et. al., 2011) used an 11- item 5-point Likert scale and found that teachers and parents rated the intervention at a 3.7 indicating that the overall intervention experience was highly usable and effective. The second study (Ingersoll & Wainer, 2011) measured the acceptability using the Behavior Intervention Rating Scale (BIRS) which is a 6-point Likert scale. Parents rated the intervention highly in terms of acceptability (5.04), effectiveness (4.66), usability (5), increased social support (4.41), and improvement in parent-teacher relationship. Teachers also rated the intervention as highly acceptable (4.91), effective (5.34), usable (5.23). They also reported parent improvement in target skills (5.67) as well as “other areas” (5.17).

Table 7.*Social Validity Summary*

Blair, Lee, Cho, & Dunlap 2011	Ingersoll & Wainer 2011	Karaaslan, Diken, & Mahoney 2011
<p>All participants viewed that the individualized behavior support process through family-school collaboration and outcomes were acceptable and effective.</p> <p>According to Social validity (11 item 5 point likert scale adapted from the Treatment Acceptability Rating Form - Revised (TARF-R))</p>	<p>The majority of parents who began the program (89%) completed the training. Of these families, 87% missed two or fewer sessions and 13% missed three or four sessions.</p> <p>At post-treatment, parents and teachers both rated the program as highly acceptable and effective on the BIRS (Table 1). Parents indicated that the program was highly usable and led to increased social support and improvement in the parent-teacher relationship. Teachers also rated the program as highly usable and indicated that they perceived that the parents learned the targeted skills and that the intervention led to improvements in other parent behaviors.</p>	N/A

Discussion

Summary of Evidence

The manuscripts included in this review each addressed ways that schools can support families of children with autism. All three studies described interventions for children with autism that included a parent component. The purpose of this review was to investigate services provided specifically to siblings and families of children with autism. Using the current search criteria, no studies were found that address support for the family members of children with autism. However, the studies that were included provided insight into the way schools assist families in supporting children with autism. The large difference in the amount of evidence available for behavioral interventions for children with autism versus family or sibling support services speaks to the current culture of public school systems. School personnel are perhaps more motivated to manage behavioral challenges as research has focused on and produced data for behavior interventions for decades (Zaky 2017). The needs of families and siblings require school personnel and school-based mental health professionals to proactively respond to the social and emotional aspects of living with a child with autism. Assisting families and siblings in their own positive mental health management can help them become emotionally available in their relationship with the child with autism. Since children with autism succeed through various levels of long-term family support, an enjoyable family connection is important for all members.

Despite the inability to fully answer the research question, results of the reviewed studies indicate that family-school collaboration for intervention yields decreased problematic behavior in both the home and school settings. In one study, teacher

participants reported decreased social impairment in the classroom setting. However, in the same study parent participants did not endorse a significant change in social impairment. According to two of the studies, language skills and rate of use can greatly improve through family-school partnered intervention. Language skills are typically a concern for young students with autism and these results are hopeful for recommending an approach to intervention. Furthermore, positive results were reported in regard to social engagement and interactions of children with autism. For one of the studies, it is certainly worth noting that similarly to student behavior, differences occurred between parent and teacher reports of student play skills. The difference in results could be due to a variety of factors; this study reported that some children had siblings while others did not. Perhaps parent raters were not able to observe the same change in social engagement as their child did not have access to a peer or sibling in the home setting. Another consideration is that demands change between home and school settings making it possible to observe a more obvious change in one particular setting, but not the other.

Adult participants demonstrated positive changes from pre- to post-intervention. Although not at the same level of intensity, both teachers and parents were able to build skills from the reviewed interventions. This suggests that relative trainings for both teachers and parents could positively impact intervention outcomes for the child as well as the collaborative partnership between adults.

According to these study results, educating and partnering with parents created positive change that likely maximized positive student outcomes. When family members play key roles in intervention, results are more effectively generalized across settings (Blair et. al., 2011; Ingersoll & Wainer, 2011). This contributes to the knowledge of the

utility of interventions provided through schools for children with autism and their families.

Limitations

Several limitations of the included studies should be noted. The studies included in this review all involved small sample sizes. These authors, along with Thomas, Reddy, and Sagar (2016), advocate for larger sample sizes to improve the generalizability of results (Blair et. al., 2011; Ingersoll & Wainer, 2011; Karaaslan et. al. 2011). The manuscripts represent intervention studies conducted in three different countries, which show promise for overall usability for diverse populations. However, this assumption cannot be confirmed until larger studies are conducted using uniform, standardized measures.

Two of the studies relied on rating scales from the adult participants for at least part of their results. Those studies noted the possible subjectivity of those results as parents and teachers may be overly optimistic about the interventions. In all of the studies parents chose to participate which could suggest that these families were more motivated to be involved in the interventions. One study discussed the positive impact of involving siblings and peers in interventions; however, the authors discussed the importance of creating and providing appropriate trainings to these youth.

These studies all discussed the issue of limited empirical data on school-based interventions for families and siblings of children with autism. Tudor and Lerner (2015) suggest adopting a collaborative and consistent approach to future research regarding siblings of children with autism. Being able to compare similar measures can help researchers draw more definitive conclusions on the effectiveness of such interventions.

Although this review provides evidence of the importance of family-school partnerships, there remains a lack of information in the literature for how schools are directly supporting families and siblings of children with autism. Family members also have needs that are separate from the child with autism, which creates the necessity for support for parents and siblings specifically.

Implications for Practice and Future Research

While many interventions and services are available, empirically validated school-based support for the specific needs of siblings and families of children with autism is still missing from the literature. The current study did not include private school or alternative education settings. Directions for future research could involve broadening search terms to capture more literature about sibling support in schools. Expanding the search for studies conducted prior to 2010 may also yield additional results.

Through a review of the literature on the effects of autism on sibling relationships and wellbeing, Gold & McCabe (2012) encourage school psychologists to assess the level of support that their schools provide for siblings of children with autism. Specifically, they state, “Implementing sibling support groups within the schools and the community will allow siblings of children with autism and other pervasive developmental disabilities the opportunity to share experiences and coping methods” (Gold & McCabe, 2012, p. 12). Access to community supports can be a barrier for some families, limiting their ability to benefit from needed services. Schools have continually played a critical role in meeting a variety of needs for students and families in general. National associations for school counselors, psychologists, and social workers have identified the

utility of school-based mental health professionals regarding the support of this population.

Outlined in The Professional Standards of the National Association of School Psychologists 2020, Domain 4 of Part 1: Professional Practices states that school psychologists use their knowledge of psychological development, strategies, and educational impacts to collaborate with others to design, implement, and evaluate services that enhance resilience and positive behavioral, social, and emotional functioning for all students (*NASP 2020 Professional Standards Adopted*, 2020). Furthermore, the section titled Principles for Professional Ethics, guiding principle IV.5 encourages school psychologists to contribute to the knowledge base through participation in, assistance with, or conduction and dissemination of research (*NASP 2020 Professional Standards Adopted*, 2020). Given these standards and the lack of information in the literature regarding school-based sibling support, school psychologists could investigate the effect and acceptability of services to this population. Existing literature demonstrates positive outcomes for siblings of children with autism who participate in an intervention that includes psychoeducation, social interaction, and coping and problem solving skill building.

A direction for future research would be to adapt existing community resources for school-based interventions. Due to the experience of its developers, the sound measures included in the program, and years of fine-tuning the activities, the SibSTAR project shows promising outcomes for generalized use to support siblings and families of children with autism (Hansford & Harris, 2013). In order to fit the daily schedule of public schools, Project SibSTAR's modules could be broken into shorter weekly sessions

over a period of 8 weeks. For example, school practitioners could implement one of the four modules targeted in Project SibSTAR such as Coping and Problem-Solving. Groups could meet for 30 minutes, once weekly for eight weeks to engage in activities and discussions that support their daily life experiences as well as increase their knowledge and use of appropriate coping and problem-solving skills. Project SibSTAR also has a parent component that could be implemented along with the sibling intervention. When used as a family-centered intervention, SibSTAR may be best implemented through an afterschool program. School psychologists must consider their responsibility to this population and assess the appropriateness of an intervention in their building(s).

Conclusions

Families and siblings of children with autism operate within a very unique family system. They experience a higher risk for mental health and coping problems (Policarpio, 2014). Overall, this systematic review supports what is believed to be best practices for supporting families of children with autism and the students themselves. Intentional family-school collaboration is a key component to successful outcomes in meeting the needs of families and students. Schools are actively engaging families in decision making and educational planning for their child with autism and are connecting families with community resources for a variety of supports. It is encouraging to find studies of schools accepting adaptations of interventions into practice to better support families of students with autism. However, according to the literature, school support or intervention for the family appears to happen only in conjunction with a program for the child with autism. Siblings, in particular, tend to play only a partial role in family interventions for children with autism for a variety of reasons. It is important that school practitioners pay attention

to the typically developing sibling's experience. TD siblings' needs are unique as is their connection to their sibling with autism (Moyson & Roeyers, 2011). Chan and Goh (2014) strongly recommend that practitioners incorporate elements of the TD sibling's experience when developing their scope of psychological intervention work. Evidence-based interventions will emerge as researchers continue to investigate this potentially at-risk population.

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