

UNDERSTANDING SOCIAL SUPPORT FOR PARENTS OF INDIVIDUALS WITH  
AUTISM SPECTRUM DISORDERS

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## Abstract

Parenting an individual with an Autism Spectrum Disorder (ASD) is uniquely challenging and enhancing resources like social support is important for promoting well-being. Within the field of ASD, social support has generally been measured broadly and studies have focused on a single facet of social support rather than incorporating different components, such as received and perceived support. It is unclear how received and perceived support uniquely relate to parent well-being. We also know very little about the factors that lead to higher levels of perceived social support or the potential reciprocal relationship social support has with other factors for parents of children with ASD. With a sample of 249 caregivers of individuals with ASD, this study assessed the strength of association between received and perceived social support, and compared the stress-buffering effects of both support types. This study also assessed the reciprocal relationships between perceived social support and parent perceived stress, self-efficacy, and child behaviour problems across a one-year period using three time points. Results showed perceived and received support were related but distinct concepts. When examined together in a single model, perceived support was significantly associated with stress and received support was not. Neither social support measure significantly moderated the association between stressors and stress. The longitudinal analyses showed less evidence for reciprocal relationships than hypothesized. There was some evidence for a reciprocal relationship between self-efficacy and perceived social support, but significant bi-directional associations were not observed between perceived social support and child behaviour problems or between perceived support and stress. Baseline perceived social support significantly predicted 6-month child behaviour and 6-month stress, but neither of those significantly predicted social support. This

study adds to our understanding of social support and clarifies how perceived social support relates to other family factors longitudinally.

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## Introduction

Raising a child with an Autism Spectrum Disorder (ASD) can have a profound impact on family belief systems, values, and priorities as parents manage the unique difficulties associated with ASD (Myers, Mackintosh, & Goin-Kochel, 2009). With deficits being present early in life, ASD is characterized by persistent difficulties in social communication and restricted or repetitive behaviours (American Psychiatric Association, 2013). Individuals with ASD typically struggle with back and forth conversations, making eye contact, appropriate gestures or facial expressions, and developing friendships or understanding the subtle nuances of social interaction. Restricted or repetitive behaviours may manifest as simple motor movements (e.g., hand flapping or spinning an object), repeated speech, strict adherence to routines, or strong fixations on specific interests. These core diagnostic features of ASD cause impairments in daily life and are present across different settings or contexts. An ASD diagnosis is often associated with difficulties with adaptive skills (Gilotty, Kenworthy, Sirian, Black, & Wagner, 2002), mental health conditions (Simonoff et al., 2008), learning difficulties (Hill, 2004), and medical comorbidities (Billstedt, 2000).

Parenting an individual with ASD is uniquely challenging, and it is well documented that these parents often experience higher levels of stress and depression and lower overall mental health than other parents. Studies have demonstrated differences in well-being for parents of individuals with ASD compared to typically developing children (Brobst, Clopton, & Hendrick, 2009; Rao & Beidel, 2009), and children with other developmental disabilities such as Down Syndrome or fragile X syndrome (Abbeduto, et al., 2004; Dabrowska & Pisula, 2010; Estes et al., 2009; Hartley, Seltzer, Head, & Abbeduto, 2012; Olsson & Hwang 2001; Pisula, 2007). Given these challenges, exploring social support as a resource is a fundamental component of

promoting parent and child well-being. This study examines multiple facets of social support and clarifies how perceived social support relates to family factors over time. The introduction begins with a review of important areas of social support literature, and proceeds to review existing social support research within an ASD context.

### **Defining Social Support**

Social support is one of the most well documented resources known to promote well-being. The foundational work of Cassel (1976), Caplan (1974), and Cobb (1976) brought the concept of social support forward and influenced decades of interest in social support as a resource and intervention focus. Cassel and Cobb both posited that social support strengthens an individual's ability to manage environmental stressors and helps mitigate the negative impact of stress. Cassel, not explicit in defining social support, found that exposure to stressors increases susceptibility to illness and disease, but that supportive social ties lessen the effects of the stressors. Cobb's concept of social support incorporated esteem support, emotional support, and belonging support. Specifically, Cobb reported that individuals feel protected from life transitions and crises when they perceive a sense of belonging and feel they are cared for, esteemed, and valued. Caplan used the term 'support system' in concluding that a durable and reciprocal system of supportive relationships helps an individual's mental health. It was thought that strong social support systems aid by providing tangible support, sharing task demands, and bolstering psychological resources. These early researchers all demonstrated that without social support, stressors have substantial psychological and physiological consequences.

Since the introduction of the term *social support* in the 1970s, there has been an abundance of definitions applied to this construct. The importance of clarifying social support terms and the existing "conceptual ambiguity" (Shumaker, & Brownell, 1984) has been noted

early and often. This conceptual ambiguity was first quantified by Winemiller (1993). In his systematic review of 262 social support articles published between 1980 and 1987, Winemiller reported that operationalized definitions were infrequently used. Few studies used behaviourally referenced instruments and the majority of studies measured support in a global or unspecified way. Similarly, a critical review of social support terms applicable to new parents identified 30 different definitions, with 25 in current use among researchers (Williams, Barclay, & Schmeid, 2004). Williams and colleagues reported social support definitions to be vast, varied, and inconsistent. A more recent review of social support definitions identified a large number of definitions and measures in current use and called for increased precision in measurement (Gottlieb & Bergen, 2010).

Due to the complex nature of social support, researchers often refer to a broad, global concept of social support or do not explicitly reference a definition. This greatly limits the interpretability of results and implications for clinical practice. Moving away from a single, all-encompassing construct, it has been argued that social support is best understood as a multidimensional or multifaceted construct, and research is most useful when the focus is narrowed to specific facets (Gottlieb & Bergen, 2010). The term *social support* encompasses related but distinct facets, as Vaux (1988) explains, "...no single and simple definition of social support will prove adequate because social support is a meta-construct" (p. 28). Within the meta-construct of social support, Vaux identified three support-related concepts: (1) support network resources, (2) supportive behaviours (received support), and (3) subjective appraisal of support (perceived support). This distinction of three support concepts has been echoed by numerous other researchers (e.g., Hobfoll & Stokes, 1988; Sarason, Sarason, & Pierce, 1992; Williams, et al., 2004). *Support networks* have been defined as the social structure through which supportive

interactions occur. When there are strong connections to individuals within the network, a person feels more socially embedded and integrated (Barrera, 1986). *Received social support* is the actual transference of helping behaviours through social networks (Wethington, & Kessler, 1986). Measurement of received support typically involves quantifying concrete supportive behaviours experienced within a specified time frame. Finally, *perceived social support* is the belief that support is adequate or available if needed (Thoits, 1982). Perceived support measures assess how supported one feels rather than specific or concrete behaviours experienced.

Received social support and perceived social support have emerged as the two prominent facets of social support, often included together within broad definitions of social support. Cohen, Gottlieb, and Underwood (2000), in the most frequently cited definition of social support, state that social support is “the social resources that persons perceive to be available or that are actually provided to them by nonprofessionals in the context of both formal support groups and informal helping relationships” (p.4). While perceived and received support are presented together in this definition of social support, they are considered distinct concepts. The relationship between self-reported received and perceived social support has been consistently found to be mild. A meta-analysis of 23 studies found the average correlation between the two to be  $r = .35$  (Haber, Cohen, Lucas, & Baltes, 2007). Social support research is most valuable when we are specific about how we are operationalizing social support and which facets we measure.

### **Received and Perceived Social Support and Benefits**

Social support interventions are typically guided by the assumption that both perceived support and received support should have positive effects, or that improving received support will, in turn, improve perceived support. However, research has demonstrated these are two distinct concepts and social support interventions targeting received support to improve mental

health have had yielded mixed results (e.g., Barrera & Prelow, 2000; Hogan, Linden, & Najarian, 2002; Heller, Thompson, Trueba, Hogg, & Vlachos-Weber, 1991), indicating that the positive effects of social support may be more closely linked to perceived rather than received support. Indeed, the existing research suggests that perceived support has a more consistent association with well-being whereas received support is often either unrelated or even negatively related to well-being.

When perceived and received social support are studied separately, results indicate the two facets may operate differently. Perceived support has been consistently linked to aspects of well-being including lower levels of stress (Tak & McCubbin, 2002), depressive symptoms (Rueger, Malecki, Pyun, Aycocock, & Coyle, 2016), distress (Cohen, Hammen, Henry, & Daley, 2004), increased self-confidence (Freeman & Rees, 2010), physical health (Uchino, 2009). On the other hand, the outcomes have been variable when received support is measured. In a systematic review of received support literature, Nurullah (2012) concluded there is mixed results on the effects of support receipt and further study is warranted. Received support has been associated with some positive outcomes including improved physical functioning (Luszczynska, Sarkar, & Knoll, 2007), life satisfaction (Adriaansen et al., 2011), school engagement (Wang & Eccles, 2012), and decreased depressive symptoms (Schwarzer and Gutiérrez-Doña, 2005). Yet other studies have found received support to be linked to negative outcomes including increased distress (Knoll et al., 2011), anxiety (Shrout, Herman, & Bolger, 2006), depressive symptoms (Frese, 1999), and negative affect (Lepore, Glaser, & Roberts, 2008).

Only a handful of studies have examined effects of perceived and received support together in a single study rather than drawing conclusions after examining a single facet of support. In a study of older Hispanic adults living in Florida, perceived support was negatively

associated with distress, while received support was positively associated with distress (Cruza Guet, et al., 2008). Additionally, Lindorff (2000) reported a negative association between perceived support and strain for 572 Australian men and women, while received support was associated with increased strain among men only. In a study involving 109 women recently diagnosed with breast cancer, perceived support has negative direct effects on depressive symptoms and received support had positive direct effects on symptoms (Komproe, Rijken, Ros, Wnnubst, & Hart, 1997). Wethington and Kessler (1986) showed that perceived support was negatively associated with distress while received support was not in a study of 2169 American adults. Kaul and Lakey (2003) reported similar findings when the two types of support were examined as predictors of distress for 60 mothers caring for children with congenital heart defects. Alternatively, Reinhardt and colleagues (2006) reported a small association between received support and well-being when perceived support was taken into account for older adults with physical impairments.

Various explanations have been proposed for the different associations of perceived support and received support with well-being. It has been suggested that receiving support can decrease a person's feelings of confidence, while perceiving that support is available if needed leaves one feeling in control and empowered (Reinhardt, et al., 2006). Receiving support has been characterized as a "mixed blessing" (Bolger & Amarel, 2007), as it may provide tangible aid and increase closeness, but also contribute to feeling dependent on others and impact self-esteem. Bolger and Amarel (2007) found that received support was only related to improved emotional functioning when provided in subtle or indirect ways, concluding that explicit or visible support is not beneficial and threatens self-esteem. Others have speculated that not all received support is welcome, needed, or even helpful (Coyne, Wortman, & Lehman, 1988),

particularly when supportive actions do not match the support needs of recipients. This matching of support needs was noted in a study where received support was more strongly correlated with increased well-being when support needs were taken into account (Melrose, Brown, & Wood, 2014). Additionally, it has been suggested that people who receive social support are under more stress to begin with than those not receiving support, and thus a positive association between stress and received support would be expected. This idea was introduced decades ago when Barrera reported the negative association between received support and mental health was substantially reduced once an individual's stress severity level was taken into account (Barrera, 1986).

### **Social support's influence on well-being: Buffering versus Main Effects Models**

Two theoretical models have been proposed to explain the process by which the broad concept of social support interacts with an individual's well-being and health. The *stress buffering model* (e.g., Cohen & Wills, 1985) posits that the relationship between stressors and manifestations of stress is mitigated, or buffered, by social support. Thus, social support is a resource that protects individuals from the effects of stressors (Cassell, 1976; Cobb, 1976; Cohen, 1988; Dean & Lin, 1977). Social support is thought to have a greater effect on well-being when stress levels are high as opposed to low. An alternate model, referred to as the *main effect model*, proposes that social support helps individuals regardless of stressor levels (Cohen & Wills, 1985) and that the presence of social support is crucial.

While both models have been extensively studied, neither model has received unequivocal empirical support. It was suggested early on that some of the inconsistencies in supporting evidence appear to be partly due to the multidimensionality of social support and differences in how social support is operationalized across studies (Cohen & McKay, 1984). The models were

developed without specific distinction between perceived and received support, or agreement on social support terms. Despite years of evidence that perceived and received social support are distinct concepts, they are often not distinguished in application of these theoretical models in research. Additionally, only one study to date (Cruza Guet, et al., 2008) includes both measures of social support together in the testing of these models.

In a unique study including both facets of social support, Cruza Guet and colleagues (2008) tested the buffering and main effect models for both types of support. Although studies exist comparing the effects of social support facets on well-being, this is the only study to date to include both facets and also test opposing theoretical models. Evidence was found in support of the main effect model for perceived support (not received support), and neither type of support buffered the effects of stressors. The results did not support the stress buffering model.

**Evidence for Buffering Model.** Several studies using a single measure of social support have reported findings consistent with social support's stress buffering effects. For instance, in a study of 4558 middle-aged Japanese adults, perceived social support had a buffering effect on the relationship between stressors and depressive symptoms (Takizawa, et al., 2006). Using similar measures, a study involving 6715 Mexican university applicants reported perceived social support reduced the impact stressors had on depressive symptoms (Raffaelli, et al., 2013). Additionally, perceived social support buffered the effects of acculturative stress on mental health symptoms for Korean international students studying abroad (N=74; Lee, Koeske, & Sales, 2004). Using a measure of received support, support was found to moderate the relationship between financial strain and physical health for 548 older Christians who attend church (Krause, 2006).



**Evidence for Main Effect Model.** A number of studies testing and comparing the stress-buffering and main effect models have provided evidence for the main effect model. In support of the main effect model, a cross-sectional study of 923 Canadian parents showed that perceived social support was negatively associated with parent stress, but support did not moderate the relationship between stressors (child behaviour and financial hardship) and stress (McConnell, Breitzkreuz, & Savage, 2010). Similarly, the cross-sectional study involving 273 older Hispanic adults living in Florida previously described reported an association between distress and perceived social support, but perceived social support did not buffer the association between the stressor (financial struggle) and distress (Cruza Guet, et al., 2008). In a cross-sectional study involving 212 parents of adults with developmental disabilities, perceived helpfulness of informal social support had a direct effect on parental burden but did not moderate the association between child behaviour problems and burden (Robinson, Weiss, Lunskey, & Ouellette-Kuntz, 2015). Additionally, Östberg and Hageskull (2000) assessed determinants of well-being for 1,081 Swedish mothers of young children in a cross-sectional study. While low support network size was related to maternal stress, no buffering effects were found. A longitudinal study by Burton, Stice, and Seeley (2004) also supported the main effect model rather than stress-buffering model in a study of 496 adolescent girls for perceived social support and depressive symptoms.

After decades of social support research, the benefits of social support, particularly perceived support, are extensive and well documented. Existing research suggests perceived support and received support have unique associations with well-being, yet the specific mechanisms for either support facet remain somewhat unclear, as there is evidence in support of both the stress-buffering model and the main effect model. As early as 1984, it has been evident that a fulsome

assessment of these two models must take into account the multidimensionality of social support (Cohen & McKay, 1984). Application of the social support models will benefit from clarification of the separate effects on well-being from perceived support and received support.

### **Determinants of Perceived Social Support**

While there is ample research to support the benefits of social support, particularly perceived support, we know significantly less about the factors that lead to increased social support over time. The importance of investigating determinants of social support as a broad concept has been acknowledged for decades. Early on, Hobfoll and Stokes (1988) asserted that “only by examining the process of social support and factors associated with its acquisition will we enhance our understanding of what actually occurs under the broad umbrella of constructs that constitute social support” (p. 498). Hobfoll and Freedy (1990) later added “unless we know what contributes to social support and why some people harness it more effectively than others, we remain unaware of the processes that underlie social support's positive effect” (p. 11). Similarly, Sarason and Sarason (2009) called for further information on how social support is created and activated, and added that social support likely has a reciprocal relationship with various factors.

As outlined above, research suggests perceived support has a more consistent association with well-being than received support. Therefore, focused effort on clarifying determinants of perceived social support is particularly important. Barrera (2000) reasoned that if perceived support does indeed have a stronger correlation with psychological adjustment, then the next question to be investigated is obvious: “what are the determinants of perceived support?” (p.226). We need to investigate the process of how perceived social support is effectively garnered in order to fully understand social support as a protective resource against stress. With

this knowledge, service providers could more easily identify individuals at risk of being isolated and requiring supplemental supports or interventions that foster social engagement. Interventions are generally designed to target received social support, assuming it leads to improved perceived support, but if there are other factors more strongly associated with perceived social support, this will inform the most effective targets of social support interventions.

In the examination of social support determinants, it has been proposed that support processes are influenced by both individual characteristics (e.g., stress, depression, self-efficacy, hardiness) and the environmental context (e.g., hardship, stressors; Vaux, 1990). Pierce, Lakey, Sarason, Sarason, and Joseph's (1997) broad review of social support literature concluded that social support (defined broadly) is indeed determined by a combination of personal and situational factors and that a good understanding of the development of social support should consider both.

**Stress.** The literature suggests stress is an important individual factor that impacts social support. Stress is broadly defined as the distress, discomfort, or arousal in response to perceived demands, and researchers often distinguish between acute and chronic stress. Acute stress is episodic and requires significant adjustment within a short period of time (e.g., a move or health crisis), whereas chronic stress is persistent and recurrent and involves adjustment over an extended period of time (e.g., caregiving burden, poverty, or marital discord). It has long been established that stress in any form has adverse effects on an individual's health and well-being. Aside from the demonstrated emotional toll, exposure to stress can have long-term influences on cardiovascular, immune, and metabolic systems (Lupien, McEwan, Gunnar, & Heim, 2009; McEwen, 2008).

The deterioration model (Dean & Ensel, 1982) has been offered to explain how stress influences perceived social support over time. This model suggests that experiencing chronic stress erodes one's perception of availability of social support or support helpfulness. Acute stress may initially mobilize supports and increase supports, but experiencing multiple acute life events or chronic stress leads to a deterioration of perceived support over time (Thoits, 1995). Thoits described this erosion of perceived support over time in her influential review of the literature on stress and coping resources, where perceived support was identified as a primary resource. Mickleson and Kubzansky (2003) demonstrated this pattern using a nationally representative sample of 8,098 adults. It was reported that experiencing one or two acute life events (serious stresses that started or occurred during the 12 months prior to the survey) was not associated with perceived emotional support, whereas experiencing more than two acute events and chronic life events (serious stresses that began more than 12 months prior) were significantly associated with decreases in perceived emotional support.

A number of studies have shown that perceived stress (e.g., Aneshensel & Stone, 1982; Gracia & Herrero, 2004; Mitchell & Moos, 1984; Quittner, Glueckauf, & Jackson, 1990), distress (Moyer, & Salovey, 1999), chronic negative life events (e.g., Barrera, 1986; Hobfoll & Lerman, 1989; Eckenrode & Wethington, 1990; House et al., 1994; Lepore, Evans, & Schneider, 1991; Vranceanu, Hobfoll, & Johnson, 2007), economic strain (Hobbs, 1997; Turner & Turner, 1999), and experiencing a significant natural disaster (Kaniasty, Norris, & Murrell, 1990; Solomon, Bravo, Rubio-Stipec, & Canino, 1993) all lead to lower levels of perceived social support over time. For instance, Gracia and Herrero (2004) investigated determinants of perceived social support within a community sample of 583 adults. Higher levels of stress and more negative life events were significantly related to lower perceived support six months later

after controlling for initial levels of perceived support. Another study demonstrated through structural equation modeling that experiencing childhood maltreatment and current levels of stress impact perceived social support among a sample of 100 women with low income (Vranceanu et al., 2007). In a longitudinal study of 517 older adults, experiencing a major flood was related to a subsequent decrease in perceived social support after controlling for perceived social support levels prior to flooding (Tyler, 2006). A similar prospective study controlled for pre-flood levels of perceived support and showed individuals reported a decrease in perceived support following the flood (Kaniasty, et. al., 1990).

Very little work has examined the bidirectional relationship between stress and perceived social support longitudinally. Green and Rodgers (2002) surveyed 260 American mothers who were predominantly single, unemployed, and African-American. While baseline perceived social support predicted subsequent perceived stress one year later, stress did not significantly predict social support once baseline stress was controlled. A bi-directional relationship was initially hypothesized, and Green suggested that the study population may have adapted to their high stress environment, and thus the impact of stress on social support over time was reduced. In another study not specifically measuring perceived stress, Moyer and Salovey (1999) found that higher levels of psychological distress predicted subsequent decreases in perceived social support for women undergoing breast cancer treatment after one year. Perceived social support also predicted distress, suggesting a reciprocal relationship between these two variables.

**Perceived self-efficacy.** Self-efficacy is another individual characteristic that may influence social support. Perceived self-efficacy is the belief that one is able to succeed or perform effectively in a particular task and that one has control over life events rather than being ruled by external forces (Bandura, 1977). Bandura's seminal work proposed that self-efficacy

expectations develop from our past experiences with success and failure, observation of others, and, to a lesser extent, social persuasion (e.g., encouragement) and physiological and affective states (e.g., increased heart rate with anxiety over failure; Bandura, 1977). This sense of efficacy has an influence on our motivation to initiate behaviour and persist in the face of obstacles or failures (Bandura, 1977; Maddux & Stanley, 1986). Self-efficacy is thought to have a greater impact on future successes than actual capabilities because our beliefs determine how effectively we use our resources and the persistent effort we put forth (Bandura, 1986). Over the last several decades, self-efficacy has been linked to emotional well-being (e.g., Davis & Yates, 1982), assertiveness (e.g., Lee, 1983; 1984), healthy behaviours (Garcia, Schmitz, & Doerfler, 1990), academic accomplishments (Zajacova, Lynch, & Espenshade, 2005), physical fitness (McAuley, & Blissmer, 2000), resiliency (Masten, & Coatsworth, 1998), problem-focused coping (Sharts-Hopko, Regan-Kubinski, Lincoln, & Heverly, 1996), and goal setting (Reivich, 2010) in the general population.

Through Hobfoll and Freedy's (1990) work on social support and personal resources, self-efficacy has been conceptualized as an "executive resource" which enhances the ability to effectively access and manage other resources (e.g., social support). However, studies involving measures of perceived social support and self-efficacy nearly all been cross-sectional, which greatly limits the ability to assess self-efficacy as a social support determinant (e.g., Kanbara, et al., 2007; Leahy-Warren, McCarthy, & Corcoran, 2011; Major, Cooper, Testa, 1990; Motl, McAuley, Snook, & Gliottoni, 2009; Reigehr, Hill, Knott, & Sault, 2003; Thompson, Kaslow, Short, & Wyckoff, 2002). Global self-efficacy was associated with perceived friend and family social support in a cross-sectional study involving 200 African-American women who had experienced domestic abuse (Thompson, et al., 2002). In another cross-sectional study, self-

efficacy was correlated with perceived support from partners, friends, family after having an abortion (Major et al., 1990). In a study involving 123 Canadian firefighters, a significant association was reported between self-efficacy and perceived social support (Regher, et al., 2003). Self-efficacy and perceived social support were also related for 125 Indonesian diabetes patients (Kanbara et al., 2007) and 292 American individuals with multiple sclerosis (Motl, et al., 2009). Similarly, associations have reported between self-efficacy and perceived social support for parents of 77 preschoolers (Hoven, 2012), and 447 Irish new mothers (Leahy-Warren, 2011). None of these studies were longitudinal, and directionality cannot be confirmed with cross-sectional data. These studies suggest the two concepts are indeed related, and highlight the need for additional longitudinal work.

Only one study to date has examined the relationship between self-efficacy and perceived social support longitudinally (Green & Rodgers, 2002). There is evidence that self-efficacy helps individuals feel confident to effectively access needed supports which, in turn, fosters efficacy. Sarason, Sarason and Pierce (1990) reasoned that to develop self-efficacy, one has to explore the environment and take reasonable risks. A supportive social network provides a secure base from which one can engage in this necessary exploration and risk taking. This reciprocal relationship has been demonstrated longitudinally in Green and Rodgers' (2002) study of 260 mothers of young children which showed that global self-efficacy and specific dimensions of perceived social support had a bidirectional relationship such that initial levels of self-efficacy predicted subsequent levels of perceived tangible supports and initial levels of perceived advice and tangible supports predicted levels of self-efficacy one year later. Feelings of self-efficacy led mothers to perceive that concrete supports were available to them if needed. Additionally, positive social support perceptions appeared to enhance later self-efficacy.

### **Studying Social Support within ASD context**

As outlined above, social support has generally been measured broadly or inconsistently, and there is value in examining how received and perceived support uniquely relate to well-being. Additionally, we know little about the determinants of perceived social support or the potential reciprocal relationship perceived support has with other individual factors such as stress and self-efficacy. These gaps in the literature are pronounced, and even more so within the field of ASD research.

The parenting challenges associated with raising a child with ASD have been well documented. For instance, a meta-analysis of parenting stress demonstrated the stress scores were significantly higher with large effect sizes compared to parents of typically developing children, and significantly higher than parents of children with other disabilities, using data from 15 existing studies (Hayes & Watson, 2013). Studies using other outcome measures have reported consistent patterns. For instance, in a study of 215 preschool children with intellectual disabilities (including ASD, cerebral palsy, Down syndrome and undifferentiated developmental delay) and no disability, ASD status was significantly associated with maternal well-being after controlling for maternal age, child behaviour problems, and cognitive level (Eisenhower et al., 2005). Similar patterns emerged in a study of 24 parents of children with high functioning ASD (aged 7-14), where parents had higher rates of stress and attachment-related anxiety compared to parents of typically developing children. Taken together, these studies suggest there are uniquely stressful aspects to raising a child with ASD (Keenan, Newman, Gray, & Rinehart, 2016).

Specific features of ASD have been reported to be particularly stressful for parents. For instance, parent mental health has been related to child deficits in social communication (Davis & Carter, 2008), restricted or repetitive behaviours (Gabriels, et al., 2005), behaviour challenges



(Estes et al., 2009; Herring et al., 2006), and cognitive or adaptive impairments (Tomanick, Harris, & Hawins, 2004). Children's clinical needs often play a role in parent well-being in that higher autistic symptom severity is associated with more parental psychopathology (e.g., Hastings & Johnson, 2001; Ingersoll & Hambrick, 2011). Although studies have shown parents raising children with high functioning ASD also have lower levels of psychological adjustment compared to parents of typically developing children (e.g., Allik, Larsson, & Smedie, 2006; Lee et al., 2009; Rao & Biedel, 2009). For parents of children with high functioning ASD, the higher level of stress reported appears to be related to internalizing problems and externalizing behaviour. Children with high functioning ASD may also have abilities that mask significant deficits in other areas, creating added difficulty in accessing services. Other common parent stressors associated with an ASD diagnosis include acceptance of diagnosis (Wachtel, & Carter, 2008), acquiring and managing developmental services (Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016), and social stigma (Farrugia, 2009; Gray, 2002).

Several studies have explored the unique and complex experiences of parenting an individual with ASD. Through interviews with 16 Canadian parents, Woodgate, Ateah, and Secco (2008) reported that parents experience feelings of isolation when raising a child with ASD. Parents described "having to go it alone" in all aspects of daily life and feeling as if they were in their own world. These struggles were perceived to be due to loss of a normal way of life and lack of support and understanding from others. Parents also describe positive experiences, dispelling the narrative that parenting a child with ASD is exclusively stressful and challenging (e.g., Altieri & von Kluge, 2009; Myers, 2008). For instance, one study noted feelings of confusion, loss, and devastation among parents after their child's ASD diagnosis, followed by mobilization of resources, problem solving, and emotional growth (Altieri & von Kluge, 2009).

Parents have also described raising a child with ASD to be a positive transformational experience which impacts the way they view their lives (Myers, 2008).

Research within the field of ASD has demonstrated that parent and child well-being has a reciprocal relationship, with continuous interplay between a child and his or her environment. For example, behaviour problems for children with ASD have a direct impact on parent well-being, and in turn, parent stress can also exacerbate problematic child behaviour (Totsika, et al, 2013; Lecavalier, Seone, & Wiltz, 2006). This suggests that improving parent mental health can be an effective route to supporting individuals with ASD. Consistent with this notion, parent-focused interventions often show positive gains extend to the child with ASD or developmental disabilities as well. For instance, parent education programs can enhance child functional communication (Moes & Frea, 2002) and parent mindfulness-based interventions have been associated with improvements in child behaviour (e.g., Neece, et al., 2014). This would suggest helping parents and bolstering their resources may have a positive impact on the child as well. Thus, focused effort on understanding social support for parents could have implications for the family system as a whole.

### **Benefits of Social Support for parents of individuals with ASD**

The benefits of social support are well documented for parents of individuals with ASD (e.g., Barker et al., 2011; Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Ekas, Lickenbrock, & Whitman, 2010; Gray & Holden, 1992; Robinson, Weiss, Lunsky, & Ouellette-Kuntz, 2016). An early study of well-being among Australian parents of children with ASD identified received social support as a predictor of parent depression, anxiety, and anger when socio-demographics, child health status, and other parent coping behaviours were taken into account (Gray & Holden, 1992). In a longitudinal study of 379 mothers of adolescents and adults

with ASD, larger social network size was associated with lower levels of anxiety over time (Barker et al., 2011). Perceived support was associated with lower levels of maternal psychological distress in a study of 68 mothers of children with ASD (Bromley et al., 2004). Another cross-sectional study involving 119 mothers reported links between perceived social support and maternal stress, depression, life satisfaction, and general well-being (Ekas et al., 2010). Boyd's (2002) selective critical literature review on stress and social support for mothers of children with ASD confirmed the protective properties of support as a broad concept, but cited the need for more research to identify factors that influence parents' decision to seek support. Taken together, there are demonstrable benefits of social support for these parents, particularly when perceived social support is assessed.

Studies have examined social support within the main effect and stress buffering models for parents of individuals with ASD using varied measures of social support. With very few exceptions, support for the main effect model has outweighed the stress buffering model. Tobing and Glenwick (2007) found perceived support had a direct association with maternal distress, but did not moderate the effect of stressors on distress for 97 mothers of children with ASD. In a study of 141 parents of children with ASD, perceived availability of informal supports was significantly related to parent stress, but did not act as a moderator of autism symptomatology (Hastings, & Johnson, 2001). Similarly, perceived availability of informal supports was associated with parent stress for 79 Taiwanese parents, and it did not buffer the relationship between child behaviour and stress (Lai, 2013). For 58 parents of children with ASD, received support was not associated with depression, nor did it buffer the effects of stressors (Dunn, Burbine, Bowers, Tantleff-Dunn, 2001). In a 2-year longitudinal study of 90 parents, perceived availability of informal support was associated with decreased depression over

time, and it did not act as a moderator between child symptom severity and parent depression (Benson & Karloff, 2009). In rare support of the buffering model, the association between stress and physical health was moderated by perceived social support among a sample of 109 parents of individuals with ASD or a non-specified developmental disability (Cantwell, Muldoon, & Gallagher, 2014).

To date, only one study has compared the effects of perceived and received social support on parent mental health or well-being. Based on the existing studies within the general population, and extensive literature linking perceived social support to well-being within ASD population, we hypothesize that perceived support is more strongly linked to well-being than received support. Indeed, Wang (2016) examined perceived and received support among 64 US parents of young children with suspected or diagnosed ASD, and 45 Chinese parents. Wang reported that for the US sample, only perceived support was significantly associated with parent stress when included in a model with received support and covariates (income, parent age, parent ethnicity). The association between perceived support and stress was not found in Wang's Chinese sample. This difference across samples was partly attributed to the measures used, which may not have captured how social support is understood in China. This study was unable to assess the potential stress-buffering effects of either type of social support.

### **Determinants of Perceived Social Support for Parents of Individuals with ASD**

Establishing that social support is helpful to parents of individuals with ASD is informative but additional research is needed on how social support is accessed and activated. Further investigation of specific individual and environmental factors and their transactional relationships with social support will help identify effective targets for intervention and inform services for under-supported families. Focused effort on understanding determinants of

perceived social support rather than other facets of support is particularly important given its unique associations with well-being. However, very little work has explored determinants of perceived social support for parents of individuals with ASD, and no studies have considered bi-directional relationships. Building on the existing literature in the general population, a comprehensive study of perceived support determinants should consider both individual characteristics (e.g., stress and self-efficacy), and the environmental context (e.g., stressors such as child behaviour problems; Vaux, 1990).

**Stress.** Stress appears to be uniquely high for parents of individuals with ASD (Hayes & Watson, 2013) and appears to persist at all stages of parenting as children age into adulthood (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Thus, stress is a particularly salient construct to examine as a potential determinant of perceived support for these parents. The deterioration model, as described above, is thought to be particularly relevant for parents and caregivers due to the chronic and longstanding nature of their caregiving stresses. For instance, perceived parenting stress was identified as a predictor of perceived social support for mothers of children with hearing impairments (Quittner, Glueckauf, & Jackson, 1990). Offering some evidence for the deterioration model, greater perceived support has been correlated with lower levels of parenting stress in studies involving parents of individuals with ASD (Hall & Graff, 2011, Hastings, & Johnson, 2001, Lai, 2013). For example, perceived social support from family was negatively correlated with stress for 75 parents of school-aged children with ASD. A negative correlation between perceived support and stress was also reported for 141 parents of young children with ASD participating in intensive home intervention program (Hastings, & Johnson, 2001). This association was also evident for 79 parents of children (6-18 years) with ASD (Lai, 2013). However, these studies were cross-sectional and thus offered no evidence on the direction

of the relationships. To date, no study has examined stress as a determinant of social support longitudinally for parents of individuals with ASD, or considered a bidirectional relationship between stress and perceived social support.

**Self Efficacy.** In the context of parenting, self-efficacy can have a profound influence on outcomes for both the parent and child (e.g., Coleman & Karraker, 1998; Seigny & Loutzenhiser, 2009). Parents with strong feelings of efficacy are more likely to implement positive parenting practices and strategies which promote child development and well-being (Jones & Prinz, 2005; Coleman & Karraker, 1998). For parents of individuals with ASD, self-efficacy appears to help with stress management (Kuhn, & Carter, 2006), depression (Carter, Martinez-Pedraza, & Gray, 2009), child therapy outcomes (Warren, Brown, Layne, & Nelson, 2011), and maternal guilt (Kuhn & Carter, 2006). Given the benefits of self-efficacy and relevance to parents of individuals with ASD, there is value in exploring self-efficacy as a determinant of perceived social support.

Cross-sectionally, there is evidence that self-efficacy and perceived social support are related. Perceived social support was positively correlated with parent self-efficacy for mothers of individuals (ages 4 to 41 years) with ASD (Weiss et al., 2013). Similarly, maternal self-efficacy was associated with higher levels of perceived social support for a combination of mothers of children with ASD (n=76), ADHD (n=50), and no diagnosis (n=54; Rosenblum, 2013). Additionally, parenting self-efficacy was positively correlated with perceived support from family for 79 parents of children (6-16 years) with ASD. However, these three studies did not address the broader concept of global self-efficacy, which is considered a dispositional trait. In one study, global self-efficacy has been linked to increased perceived social support with a sample of 109 caregivers of individuals with ASD or other developmental disabilities (Cantwell,

Muldoon, & Gallagher, 2014). However, no studies have examined whether self-efficacy determines or has a reciprocal relationship with perceived social support for parents of children with ASD.

**Child behaviour problems.** A determinant of perceived social support especially relevant to parents of individuals with ASD is child behaviour problems. Individuals with ASD may struggle with hyperirritability, regulatory problems, destructiveness, aggression, or self-injurious behaviours, and clarifying how these behaviours impact parent social support is particularly important as behaviour difficulties are frequently reported in this population (Kanne & Mazurek, 2011; Lecavalier, Leone, & Wiltz, 2006; Lecavalier, 2006; Totsika, Hastings, Emerson, Ancaster, & Berridge, 2011). In a population-based investigation involving 18,415 UK children (5 to 16 years old), prevalence rates of behavioural problems were highest for individuals with ASD. An ASD diagnosis increased the odds for hyperactivity symptoms and conduct after age, gender, adversity and maternal mental health were taken into account (Totsika, et al., 2011). Kanne and Mazurek (2010) examined the prevalence and risk factors for aggression in a study of 1,380 parents of children and adolescents with ASD. Nearly 70% of parents reported that their son or daughter had demonstrated aggression towards caregivers, and half had towards non-caregivers.

Existing research suggests that caregivers may struggle to mobilize supports or are more reluctant to seek support when individuals with ASD have more difficult behaviours. Disruptive child behaviour such as tantrums or aggression can isolate a family and parents are often tasked with managing these difficulties at home with little support. Parents may be burdened and preoccupied with these difficult behaviours and may not have time or energy to seek support or may avoid community settings. Additionally, parents may perceive rejection or blame from their

social network due to their child's difficult behaviours. Multiple qualitative studies have demonstrated the complex social difficulties parents face when managing unpredictable child behaviour related to an ASD diagnosis. From interviews with 46 parents of children with ASD, Ryan (2010) described parent reluctance to enter public places and struggles to find social acceptance. Without obvious outward signs of their child's disability, parents often perceived judgement from the community when their child acted out or pushed societal norms. Similarly, Gray's (1994) qualitative study involving 33 Australian parents of school-aged children (4 to 19 years) with ASD found that parents withdrew from their social networks in response to perceived stigma and the stressful nature of public encounters. Many parents in this study reported feeling isolated, but these feelings were more prominent when their child had aggressive or disruptive behaviour, suggesting a potential link between child behaviour and perceived availability of support. A decade later, Gray (2006) interviewed 28 of these families again to examine how coping changes over time. Parents reportedly felt more comfortable engaging in social activities in the community because they perceived their child's behaviours to have improved, but parents also had grown accustomed to the longstanding social restrictions that existed for their families.

The link between social support and child behaviour problems has been described qualitatively and generally, yet very few quantitative studies involve measures of child behaviour and social support for parents and of individuals with ASD. Studies have not longitudinally investigated child behaviour as a potential determinant of perceived support, and the relationship between the two variables has not yet been disentangled beyond describing their association with cross-sectional data. A cross-sectional study examining the well-being of 68 mothers of school-aged children (5 to 18 years) with ASD assessed factors related to perceived social support (Bromley et. al., 2004). Lower levels of perceived social support were correlated with increased



disruptive child behaviour. Similarly, child behaviour problems were negatively correlated with perceived support for 79 parents of children (6-18 years) with ASD (Lai, 2013). In a cross-sectional survey of 135 parents of children (2-17 years) with ASD examining social support and family functioning, child behaviour was significantly associated with perceived support (Lamminen, 2008). Although limited by cross-sectional data, Lamminen framed behaviour as a determinant of social support, hypothesizing that as child behaviour problems increase, perceived social support decreases. Without longitudinal data, the directionality of the relationship remains unclear.

### **Developmental Considerations**

The existing research on social support for parents of individuals with ASD typically involves parents of children with broad age ranges without taking developmental considerations into account (e.g., Bromley et al., 2004; Ekas et al., 2010; Falk et al., 2014; Lamminen, 2008; Siman-Tov & Kaniel, 2010; Siklos & Kerns, 2006). A handful of studies have focused on specific age groups such as parents of preschool-aged children only (McIntyre & Brown, 2018; Zaidman-Zait et al., 2016), or parents of adolescents (Smith, Greenberg, Seltzer, 2012). Only two studies to date have utilised a broad age sample to compare social support among parents of young children with autism to parents of adolescents with ASD (Lai, 2003; Tehee, Honan & Hevey, 2009), and these studies offered limited findings.

Social support research that includes a wide age range of individuals with ASD can have implications for parents across the lifespan of their children. Yet, the lack of studies comparing the experiences of parents of adolescents to parents of younger children is a notable gap in the literature. There are major cognitive, developmental, and social differences between a child and an adolescent, and developmental theorists have identified adolescence as a distinct transitional

period (e.g., Piaget, 1964; Erikson & Erikson, 1998). Additionally, the parenting experiences related to raising a child with ASD appear to vary across the child's lifespan. For instance, parents of younger children with ASD may struggle with adapting to their child's diagnosis, orienting themselves to developmental services, and advocating for their child within the school system. Among adolescents with ASD, parents are faced with the impending transition from the school system to the adult service sector, where waitlists tend to be long and services scant, and embark on the difficult task of long-term planning (Weiss & Lunsky, 2010). Given these differences, it is important to parse out the unique experiences of social support for parents of children and adolescents with ASD.

As mentioned above, two studies have compared social support among parents of young children with autism to parents of adolescents with ASD. In Lai's (2003) study of social support for Taiwanese parents of children with ASD, perceived social support for 30 parents of school-aged children (6 to 12 years old) did not significantly differ from 30 parents of adolescents (13 to 18 years). Lai had anticipated differences in perceived support based on developmental considerations across the two age groups, and hypothesized that support systems for parents in Taiwan may not be fully established, irrespective of child age. Tehee and colleagues (2009) surveyed 42 parents of 24 children with ASD in Ireland to assess the influence of parent gender and child age on parental well-being and social support. Parents were divided into four groups based on child age (3 to 6 years, 7 to 10 years, 11 to 14 years, and 15 to 18 years). Parents of 11 to 14 year olds (n=12) reported higher perceived helpfulness of social support than parents of children 3 to 6 years old (n=14) and parents of 15-18 year olds (n=7). It was suggested that early childhood and adolescence may be particularly vulnerable times as they represent developmental transition periods with changing support needs. The particularly small sample sizes in both

studies and the use of different age comparison groups limits the generalizability of findings. Developmental considerations are rarely taken into account in existing social support research for parents of individuals with ASD.

### **Limitations of Existing Research**

Although social support has been well-studied for over thirty years, numerous gaps in the literature remain, particularly within the field of ASD research. First, we do not yet understand how received and perceived social support differ for parents of individuals with ASD. Social support in ASD research is typically measured broadly, and studies have focused on single facets of social support rather than incorporating different components. Research within the general population has established that perceived and received support are two related but distinct facets of support, and the strength of the association between the two has been a longstanding area of interest (Haber, et al., 2007). However, there has yet to be a study examining the strength of association between received and perceived social support for parents of individuals with ASD.

A thorough examination of social support for parents of individuals with ASD would go beyond simply assessing the strength of association between the two support facets. Existing research within the general population suggests perceived support is more strongly linked to well-being rather than received support. However, this difference has not yet been established for parents of children with ASD. Studying persons who face stressors or are in need of help and assistance is particularly important when examining the effects of received and perceived support on mental health. Parents of individuals with ASD often report a desire for support or report having higher support needs than parents of typically developing children and have unique caregiving experiences so it is a particularly informative population to focus on (Boyd, 2002). To date, only one study has compared the effects of received and perceived social support together

in a study involving parents of young children with ASD (Wang, 2016). As previously described, Wang found that perceived support was significantly associated with parent stress for 64 American parents, while received support was not associated with stress. Although an important first study to examine facets of social support for parents of individuals with ASD, there were a number of limitations. This study was limited by its sample size, and results are specific to parents of preschoolers. Further, this study did not assess the potential stress buffering effects of support and clarify how social support interacts with stress. Further research is needed to better understand how received and perceived social support differ among parents of individuals with ASD.

Additionally, there has yet to be a comprehensive investigation of social support determinants for parents of individuals with ASD. There is some research on determinants of perceived social support in the general population. The existing social support research mainly pertains to general or student populations and these findings are not necessarily applicable to parents of children with ASD due to the chronic and unique nature of their parenting experiences. To date, there are no longitudinal studies of social support determinants for parents of individuals with ASD, and certainly no study has considered the reciprocal effects of perceived social support, stress, self-efficacy, and child behaviour together in a single study. A comprehensive investigation of perceived support determinants must take into account both personal (e.g., parent stress, self-efficacy) and situational (child behaviour) factors, and this research question is best answered using a cross-lagged longitudinal design. Social support research involving parents of children with ASD has mainly used cross-sectional data, which greatly limits the interpretability of results and offers no information on the causal direction of associations. A cross-lagged longitudinal design is needed to better understand determinants of

social support and the potential reciprocal relations each of these variables has with support while considering the continuity of variables over time.

Finally, existing social support research involving parents of children with ASD is typically unable to take developmental considerations into account. The existing studies have focused on broad age ranges or very narrow age groups. Analyses comparing parents of adolescents to parents of younger children with ASD would add to our understanding of how social support experiences may vary across the child's lifespan.

### **Current Study**

Using online survey data collected from 249 parents of school-aged children with ASD, this study assessed the strength of association between received and perceived social support, and compared the stress-buffering effects of both support types. This study also assessed the reciprocal relationships between perceived social support and parent perceived stress, self-efficacy, and child behaviour problems across three time points within a one year period.

### **Study Aims**

The first aim of this study was to better understand how received and perceived social support differ among parents of individuals with ASD. Using baseline data, the specific research questions investigated were:

1. How strongly are received and perceived social support related to each other in a sample of parents of individuals with ASD? Do results differ depending on demographics or family characteristics?

A positive, moderate association was hypothesized, confirming findings from other populations that perceived and received social support are related but not interchangeable concepts.

2. To what extent do self-reported received and perceived social support moderate the association between a known stressor (child behaviour problems) and parent stress, as the stress-buffering model proposes? Do the results differ for parents of younger children compared to parents of older children?

It was hypothesized that perceived support would moderate the relationship between child behaviour problems and parent stress after taking into account control variables. Specifically, with lower levels of perceived social support, child behaviour would be strongly associated with parent stress, whereas when perceived social support is high, the association between child behaviour and parental stress would be weaker. It was hypothesized that received social support would not be an important stress buffer. There was no specific hypothesis pertaining to age comparisons.

The second aim of this study was to examine factors which may lead to perceived social support and the potential reciprocal effects among these variables over time. Determinants of perceived support was the focus given the previous hypothesis that received support would not be an important buffer, and the existing literature indicating perceived support has a more consistent association with well-being than received support. This study aim examined personal (parent's perceived stress and global perceptions of self-efficacy) and situational (child behaviour problems) variables previously linked to social support. This aim was addressed through the following research questions:

3. Is there a reciprocal relation between perceived social support and stress, while controlling for continuity over time for both variables? Do the results differ for parents of younger children compared to parents of older children?

4. Is there a reciprocal relation between perceived social support and perceived self-efficacy, while controlling for continuity over time for both variables? Do the results differ for parents of younger children compared to parents of older children?
5. Is there a reciprocal relation between perceived social support and child behaviour problems, while controlling for continuity over time for both variables? Do the results differ for parents of younger children compared to parents of older children?
6. How do child behaviour, stress, and self-efficacy, measured at baseline, combine to account for changes in perceived social support 6 to 12 months after baseline?

It was expected that there would be reciprocal relations between perceived social support and each of the three study variables. There were no specific hypotheses for how results would differ for age group comparisons. There was no specific hypothesis for which variables would be unique predictors of social support once the variables are considered together in a single model.

## **Methods**

### **Procedure**

Following approval from York University's Research Ethics Board, parents of individuals with ASD were recruited through postings on the Canadian Autism websites, community organizations, and through an ongoing research database available through the researcher's lab. A link to the online consent form and survey was provided and parents were invited to contact the researcher by email or phone to request a paper survey. After parents completed the initial survey, they were invited to complete follow-up surveys 6 and 12 months later.

To be eligible for this study, participants were required to have a school-aged son or daughter (ages 4 to 18 years) with a confirmed diagnosis of ASD and be able to complete the

survey in English. ASD diagnosis was confirmed in two ways. First, the parent confirmed that a professional with the capacity to diagnose provided the child with an ASD diagnosis (selecting one of the of the following: psychologist, psychiatrist, developmental pediatrician, general pediatrician, family doctor, nurse practitioner, multidisciplinary or developmental team, genetic testing, neurologist, or “other and specify”) and provided the date of diagnosis. Second, the parent-reported score on the Social Communication Questionnaire – Lifetime (SCQ; Rutter, Bailey, Lord, & Pickles, 2003) was above a pre-specified cut-off score of 11, indicating a possible ASD (Allen, Silove, Williams, & Hutchins, 2007).

### **Participants**

Baseline data were available for 249 parents who sufficiently completed the survey (i.e., at least 75% of survey items) and met all eligibility criteria (as described above). At time 2 (6 months after baseline), 194 eligible participants responded. At time 3 (12 months after baseline), there were 180 participants (17 of these participants did not respond at time 2). The study had 163 participants complete all three surveys and meet all eligibility criteria. The 163 participants who sufficiently completed all three time points were compared to the 86 parents who did not. The two groups did not significantly differ on the main study variables or on family and child characteristics including parent education, household income, child age, child ASD symptoms, and child adaptive skills.

As shown in Table 1, parent age ranged from 27 to 62 years ( $M=43.98$ ,  $SD=6.2$ , Median =44). Participants were primarily mothers (95.6%) and currently married/common law (83.1%). Most parents (81.9%) had graduated college or university. Parents were from suburban (39.9%), urban (39.1%), rural (16.5%), and remote (4.4%) settings across Canada.



The individuals with ASD ranged in age from 4 to 18 years ( $M= 11.47$ ,  $SD=3.95$ , Median=11) and most were male (83.1%). Additional child diagnoses from a doctor as reported by parents included intellectual disability (42.4%), learning disability (37.8%), attention deficit disorder or attention deficit hyperactivity disorder (38.4%), anxiety or depression (37.1%), and behaviour or conduct problems (29.0%). Nearly half (45.7%) had at least one chronic health condition, including epilepsy, cerebral palsy, or asthma. See Table 2 for full list of reported diagnoses.

## Measures

**Demographics.** Parents reported their own age, gender, marital status, and income as well as their child's age, gender, and diagnoses.

**ASD symptoms.** The Social Communication Questionnaire – Lifetime (SCQ; Rutter, Bailey, Lord, & Pickles, 2003) was used to assess ASD symptom severity. The SCQ is an ASD symptom screener assessing social and communication behaviours and consists of 40 yes-or-no items. Higher total scores indicate greater ASD symptom severity. The SCQ has shown strong internal consistency, as well as good discriminant validity for distinguishing between children with ASD and those without (Berument, Rutter, Lord, Pickles, & Bailey, 1999). In the current study, baseline scores had adequate internal consistency (coefficient  $\alpha = .82$ ).

**Child adaptive behaviour.** Adaptive behaviour was measured using the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013). This is a 17-item measure of an individual's independence in performing daily activities (e.g., dressing and undressing or drinking from a cup). Item responses are given using a 3-point Likert-type scale, with 0 = *Does not do at all* and 2 = *Independent or does on own*. Total scores range from 0 to 34. The WADL has been used with parents of children with intellectual disabilities (e.g., Weiss & Riosa, 2015)

and with adolescents and adults with ASD and no intellectual disability (Taylor et al., 2014). Maenner et al. report good internal consistency and strong validity, as the scale is highly correlated with other measures of adaptive functioning. In the current study, baseline scores had good internal consistency (coefficient  $\alpha = .92$ ).

**Child behaviour problems.** Child behaviour problems were assessed using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The 25 items assess prosocial behaviour, peer relationship problems, conduct problems, hyperactivity, and emotional symptoms. Each item is scored using a 3-point scale (*not true*, *somewhat*, and *certainly true*) and a total difficulties score is calculated by summing the four problem behaviour subscales. Example items include “generally liked by other children”, “easily distracted, concentration wanders”, and “often loses temper”. The scale is meant to serve as a brief behavioural screener and is often used in research involving parents of children with developmental disabilities or ASD (e.g., Emerson, 2005; Totsika, et al., 2013). In the present study, prosocial behaviour and peer subscales were not used because they represent areas of functioning represented in the diagnostic criteria for ASD, consistent with other ASD studies (e.g., Totsika et al., 2011). The SDQ has shown good internal consistency, test-retest reliability, and validity for parents of typically developing children (Goodman, 2001) and internal consistency has been high in a sample of parents of children with ASD (0.97; Totsika et al., 2013). For the current study, coefficient  $\alpha = .78$  for baseline total difficulties (sum of conduct problems, hyperactivity and emotional symptoms), coefficient  $\alpha = .79$  for baseline emotional symptoms,  $\alpha = .70$  for conduct problems, and  $\alpha = .76$  for hyperactivity.

**Parent stress.** The Stress subscale from the Depression Anxiety and Stress Scale (DASS-42; Lovibond & Lovibond, 1995) is a 14-item scale assessing global perceptions of stress. The

stress subscale measures the extent to which individuals had difficulty relaxing, feelings of nervousness, agitation, intolerance, impatience, or irritability in the last week. Item responses are given on a four-point Likert-type scale from 0 (*did not apply to me at all*) to 3 (*applied to me very much or most of the time*), where higher scores suggest more perceived stress. Example items include “I found it difficult to tolerate interruptions to what I was doing” and “I was in a state of nervous tension”. The scale has shown acceptable reliability for parents of children with developmental disabilities or ASD (e.g., Merkaj, Kika, & Simaku, 2013), with coefficient  $\alpha$  of .85 in a similar study sample (Seymour, Wood, Giallo, & Jellet, 2013). Good validity has been demonstrated with a sample of adult psychiatric patients (Clara, Cox, & Enns, 2001) and a non-clinical sample (Crawford & Henry, 2003). In the current study, baseline scores had good internal consistency (coefficient  $\alpha = .94$ ).

**Self-efficacy.** Pearlin and Schooler’s (1978) Mastery scale was used to assess global perceptions of self-efficacy. Each of the seven items is scored using a four-point Likert-type scale ranging from *strongly disagree* to *strongly agree*, with higher scores indicating greater feelings of self-efficacy. Example items include “what happens to me in the future mostly depends on me” and some reverse-scored items including “I have little control over things that happen to me”. Solid internal consistency (coefficient  $\alpha = .77$ ) was reported by Paczkowski and Baker (2007) in a study involving parents of children with developmental disabilities, and it has been used other studies with similar samples (e.g., Cantwell, Muldoon, & Gallagher, 2014). Current study baseline scores had good internal consistency (coefficient  $\alpha = .85$ ).

**Perceived social support.** Perceived social support was measured with the Social Provisions Scale (Cutrona & Russell, 1987). The scale provides a summary score of global perceived availability of social support. The 24 items are scored using a four-point Likert-type

scale ranging from *strongly disagree* to *strongly agree*, with higher scores suggesting greater perceptions of support. Example items include “I feel part of a group of people who share my attitudes and beliefs”, “there are people I can count on in an emergency”, and “there is someone I could talk to about important decisions in my life”. The scale had excellent internal consistency in a large-scale study of its psychometric properties (coefficient  $\alpha = .92$ ) and good convergent and divergent validity (Cutrona & Russell, 1987). The scale has also shown good reliability in studies involving parents of children with behaviour difficulties (McCabe, Yeh, Lau, Garland, & Hugh, 2003) and ASD (Renty & Roeyers, 2007). In the current study, baseline scores had good internal consistency,  $\alpha = .94$ .

**Received social support.** The Inventory of Socially Supportive Behaviours (ISSB; Barrera, Sandler, & Ramsay, 1981) was used to measure the frequency of receipt of socially supportive behaviours during the previous month. The 40 items are scored using a five-point Likert-type scale ranging from *not at all* to *about every day*, with higher scores suggesting greater received of support. Example items include “did some activity to help you get your mind of things” and “suggested some action you should take”. Excellent internal consistency has been reported (coefficient  $\alpha = .93$ ) and the ISSB has been used in studies of parents of children with ASD (e.g., Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001), and is considered the most widely used and well-validated measure of received support (Gottlieb & Bergen, 2010). In the current study, baseline scores had good internal consistency,  $\alpha = .90$ .

## **Data Analysis Plan**

**Research Question 1: Relationship between received and perceived social support in a sample of parents of individuals with ASD.** The association between self-reported received and perceived social support was evaluated with a product-moment correlation coefficient ( $r$ )

using baseline data. Additional analyses were conducted to explore how the relationship between received and perceived social support differs depending on demographic and clinic variables (parent age, gender, marital status, household income, child age, gender, diagnoses, and symptom severity).

**Research Question 2: Stress-buffering effects of self-reported received and perceived social support.** To investigate the moderating effects of perceived and received social support on the relationship between child behaviour problems and parent stress, three separate hierarchical multiple regression analyses were used using baseline data. Disjunctive (single) moderation effects for perceived and received social support effects were specified in the first and second analyses and the third analysis estimated the conjunctive (multiple) moderation effects of received and perceived social support together.

For each hierarchical regression analysis, control variables were entered first, followed by child behaviour problems and the social support measure as the second step, and the third step added the interaction terms (the product of predictor and moderator, for example, child behaviour problems  $\times$  perceived support). Control variables included family and child variables significantly correlated with parent stress measures in preliminary analyses. These analyses were repeated with the sample split according to child age (under 12 years compared to 12 years and older). Variables were mean centered to enhance interpretation.

**Research Questions 3-5: Longitudinal reciprocal relationships between perceived social support and other study variables.** A series of three-wave autoregressive cross-lagged path models was estimated to assess the reciprocal relations between perceived social support and each of stress, self-efficacy, and child behaviour problems across time. This type of statistical model is used to examine transactional relationships between variables and has

recently been used in the field of ASD research (e.g., Green, Ben-Sasson, Soto, & Carter, 2013; Taylor, Smith, & Mailick, 2014; Totsika, et al., 2013). The model allows for examination of the directionality of effects between two variables measured over time while also considering auto-regression, which is variable stability across time points. Three separate cross-lagged models were estimated, allowing for individual examination of stress, self-efficacy, and child behaviour problems with perceived social support across the three time points.

Model fit was assessed using a series of common fit statistics such as comparative fit index (CFI), root mean square error of approximation (RMSEA), and Tucker-Lewis index (TLI). The individual parameter estimates pertaining to the cross-lagged effects were subsequently interpreted. Robust maximum likelihood estimation (MLR; Muthén and Muthén, 2012) was used to account for the possibility of multivariate non-normality and for its effectiveness in dealing with missing data.

Demographic variables that showed a significant association with baseline perceived support at the bivariate level were included as control variables. The models were repeated with the sample split according to child age. The age comparison models were run without control variables to allow for more parsimonious models due to reduced sample sizes.

**Research Question 6: How baseline child behaviour problems, stress, and self-efficacy together account for changes in subsequent perceived social support.** Growth curve modeling was used to examine the change in social support over time, and the extent to which all three study variables (stress, self-efficacy, child behaviour problems) predict any longitudinal change in perceived social support. Consistent with the cross-lagged models, model fit was assessed using multiple fit statistics and MLR estimation was used.

## Results

### Descriptive Analyses

**Outliers.** Data was checked for univariate outliers. Data points outside of 3.29 standard deviations from the mean were considered outliers. No scores were identified as extreme outliers across the time points.

The means, standard deviations, and ranges of scores for the main study variables (i.e., child behaviour problems, parent perceived social support, received social support, self-efficacy, and stress) at all time points are presented in Table 3. Table 4 presents bivariate correlations among variables used in the path models.

#### **Relationships among parent or child characteristics with main study variables.**

Relationships among baseline main study variables with child and parent characteristics were assessed with correlations and independent-samples t-tests. Demographics included child age, child sex, child adaptive level (WADL score), ASD symptoms (SCQ score), child psychiatric conditions, child medical conditions, intellectual disability diagnosis, parent education level, household income, and parent relationship status (married versus not).

Child age was negatively correlated with parent stress,  $r = -.15, p = .02$ , and not significantly associated with any other main study variable, including perceived social support ( $p = .49$ ), received social support ( $p = .91$ ), self-efficacy ( $p = .26$ ), and child behaviour problems ( $p = .20$ ). There were no significant mean differences across child sex for perceived social support ( $p = .24$ ), received social support ( $p = .10$ ), stress ( $p = .27$ ), self-efficacy ( $p = .23$ ), and child behaviour problems ( $p = .22$ ).

Child adaptive skills, as measured by the WADL, were significantly correlated with parent stress  $r = -.19, p = .003$ , perceived social support,  $r = .22, p < .001$ , received social support,  $r = .18, p = .006$ , and self-efficacy  $r = .29, p < .001$ , but not with child behaviour

problems ( $p = .07$ ). Child ASD symptoms, measured by the SCQ, were significantly correlated with all of the main study variables including perceived support  $r = -.18, p = .003$ , received support,  $r = -.14, p = .02$ , stress  $r = .15, p = .02$ , self-efficacy  $r = -.16, p = .01$ , and child behaviour problems,  $r = .15, p = .02$ . There were no significant mean differences between parents of children with ASD and an intellectual disability diagnosis and parents without a child with an intellectual disability diagnosis, including perceived social support ( $p = .09$ ), received social support ( $p = .94$ ), stress ( $p = .90$ ), self-efficacy ( $p = .06$ ), and child behaviour problems ( $p = .38$ ).

Baseline perceived social support was significantly lower for parents of a child with a chronic health condition ( $M=73.42, SD=12.51$ ) compared to parents of a child without ( $M=76.45, SD=11.23; t(244) = 2.0, p = .04$ ). No other study variables significantly differed based on the presence of a child chronic health condition including received social support ( $p = .40$ ), stress ( $p = .15$ ), self-efficacy ( $p = .12$ ), and child behaviour problems ( $p = .19$ ). Reported chronic health conditions included asthma, diabetes, epilepsy/seizure disorder, hearing problems, vision problems not corrected by glasses or contacts, bone/joint and muscle problems, brain injury, chronic gastrointestinal problems, and other (e.g., scoliosis, heart conditions, or kidney disease).

Child behaviour problems were significantly higher when the child had at least one psychiatric diagnosis ( $M=14.13, SD=5.02$ ) rather than no psychiatric diagnosis ( $M=10.86, SD=4.48; t(239) = 5.18, p < .001$ ). No other study variable significantly differed according to the presence of a child psychiatric diagnosis, including perceived social support ( $p = .37$ ), received social support ( $p = .99$ ), stress ( $p = .10$ ), and self-efficacy ( $p = .76$ ). Reported psychiatric diagnoses included ADHD, anxiety/depression, and conduct and behaviour problems. When the three diagnosis categories were examined individually, the same pattern emerged. Specifically, child behaviour problems were significantly higher when there was a diagnosis of ADHD,



anxiety/depression, or conduct and behaviour problems, but the three diagnosis categories were not significantly associated with perceived social support, received social support, stress, or self-efficacy.

Parent education level was significantly associated with perceived social support levels ( $r = .27, p < .001$ ), stress ( $r = -.16, p = .01$ ), and child behaviour ( $r = -.18, p = .005$ ), but not received social support ( $p = .11$ ) or self-efficacy ( $p = .05$ ). Household income was significantly associated with perceived social support levels ( $r = .22, p = .001$ ) and self-efficacy ( $r = .17, p = .01$ ), but not stress ( $p = .57$ ), child behaviour problems ( $p = .67$ ), or received social support ( $p = .22$ ). Married participants did not significantly differ from unmarried participants on any main study variable including perceived social support ( $p = .11$ ), received social support ( $p = .17$ ), stress ( $p = .31$ ), self-efficacy ( $p = .96$ ), and child behaviour problems ( $p = .05$ ).

**Associations among social support and main study variables.** Higher perceived social support was significantly related to lower levels of parent stress ( $r = -.44, p < .001$ ), child behaviour problems ( $r = -.17, p = .01$ ), and increased self-efficacy ( $r = .58, p < .001$ ). Regarding individual subscales of child behaviour, perceived social support was significantly negatively correlated with conduct problems ( $r = -.14, p = .02$ ), but not hyperactivity ( $p = .05$ ) or emotional difficulties ( $p = .17$ ).

Higher received support was also significantly related to lower levels of parent stress ( $r = -.26, p < .001$ ) and higher levels of self-efficacy ( $r = .40, p < .001$ ), but there was no significant association between received social support and the child behaviour overall score ( $p = .60$ ) or any behaviour subscale.

## Main Analyses

Appendix A summarizes the results from both aims (8 research questions). The first research aim was to better understand how received and perceived social support differ among parents of individuals with ASD. Two research questions addressed this aim.

**Research Question 1: Relationship between received and perceived social support in a sample of parents of individuals with ASD.** There was a significant positive association between baseline self-reported received and perceived social support,  $r = .58, p < .001$ . Additional analyses tested whether the relationship between perceived and received social support was consistent across different demographic and clinical subgroups. Pairwise comparisons between two correlations were based on parent marital status (single vs not), home location (rural/remote vs suburban/urban), parent education (graduated university/college vs not), child age (median split of 11 years vs 12 and older), child gender (male vs female), and child diagnoses (presence of chronic health diagnosis vs not; presence of any psychiatric diagnosis vs not; presence of depression/anxiety vs not; presence of conduct/behaviour problems vs not; presence of ADHD vs not; presence of an intellectual disability diagnosis vs not). None of the correlations between received and perceived support significantly differed across these pairwise comparisons using Fisher's  $r$ -to- $z$  transformation to test difference between two correlations, indicating the association between received and perceived support is consistent irrespective of demographic and clinical variables.

**Research Question 2: Stress-buffering effects of self-reported received and perceived social support.** The first regression analysis for this research question estimated the moderating effect of perceived social support on the relationship between child behaviour problems and parent stress. After controlling for variables significantly correlated with stress

(parent education, child age, adaptive skills, and ASD symptoms), both perceived social support and child behaviour were significantly associated with parent stress. Higher levels of child behaviour problems were significantly associated with increased parent stress,  $b = 0.39, p = .001$ , uniquely accounting for 5% of variance in parent stress, and perceived social support was significantly associated with lower levels of parent stress,  $b = -0.30, p < .001$ , uniquely accounting for 13.8% of variance. The interaction between behaviour problems and perceived social support was not significant ( $b = 0.003, p = .61$ ), indicating that perceived social support does not moderate the relationship between stress and child behaviour problems (see Table 5).

For the second analysis assessing received social support as a potential moderator, similar patterns emerged. As shown in Table 6, received social support and child behaviour problems were significantly associated with parent stress. Again, the interaction was not significant ( $b = -0.01, p = .94$ ), indicating that received social support does not significantly moderate the association between child behaviour problems and parent stress. Received social support was associated with decreased parent stress ( $b = -3.67, p = .001$ ), uniquely accounting for 5% of parent stress variance, and child behaviour problems were associated with higher levels of parent stress, ( $b = 0.44, p < .001$ ), uniquely accounting for 6% of variance.

The third planned analysis testing multiple moderation effects of received and perceived social support together was subsequently run with the same covariates included, as shown in Table 7. Parent stress was significantly associated with perceived social support ( $b = -0.28, p < .001, 8.6\%$  unique variance) and child behaviour problems ( $b = 0.40, p = .001, 5\%$  unique variance), but not received social support or control variables. Neither interaction term (received social support  $\times$  child behaviour problems, perceived social support  $\times$  behaviour) was significant.

The three moderation analyses were repeated with the sample split according to child age. Results were compared for child (under 12 years) and youth/adolescent (12-18 years) subsamples. The pattern of results for the regression analyses remained the same within each age subsample. Specifically, both types of social support were significantly associated with parent stress when analyzed separately, but only perceived social support was significantly associated with stress when both were included in a model. No interactions were significant.

The regression analyses were also repeated with the child behaviour subscales (instead of the total score) as separate predictors to determine whether specific types of child behaviour problems had different relationships with parent stress. All behaviour subscales, except hyperactivity, significantly predicted parent stress in models involving either perceived or received social support. Further, no interactions were significant.

The second research aim was to examine factors which may lead to perceived social support and the potential reciprocal effects among these variables over time. The following five research questions subsume this aim.

**Research Question 3: Is there a reciprocal relation between perceived social support and perceived self-efficacy, while controlling for continuity over time for both variables?**

The initial planned cross-lagged model with perceived social support and self-efficacy and control variables had poor fit to the data (CFI = .88; TLI = .77; RMSEA = .14; SRMR = .11). Residual correlations indicated strong autoregressive relationships between Time 1 and Time 3, and modification indices suggested that adding direct paths from T1 and T3 would substantially improve the model fit. Thus, the model was revised to include direct paths from T1 social support to T3 social support and T1 self-efficacy to T3 self-efficacy. Doing so improved model fit such that the adjusted model adequately fit the data (CFI = .99; TLI = .97; RMSEA = .04;

SRMR = .02). Demographic variables significantly correlated with perceived support at the bivariate level were included as control variables (i.e., household income, parent education, presence of child chronic health conditions, child adaptive level, child ASD symptoms). Age was not included as a covariate as it did not significantly correlate with baseline perceived support at the bivariate level, although additional separate models were estimated to determine if results varied across different child age groups (under 12 years compared to 12 years and older). No covariates were included in age comparison analyses to allow for a more parsimonious model given reduced sample sizes. Complete unstandardized results for these models are in Table 8. See Figure 1 for the corresponding path diagram with standardized parameter estimates.

Autoregressive relationships for perceived social support scores were all significant, indicating that social support was stable over time (baseline support to 6-month,  $b = 0.64, p < .001$ ; 6-month to 12-month social support,  $b = 0.44, p < .001$ ). Similarly, stability was evident for self-efficacy over time (baseline self-efficacy to 6-month,  $b = 0.74, p < .001$ , 6-month to 12-month self-efficacy,  $b = 0.44, p < .001$ ).

Cross-lagged paths showed that baseline self-efficacy predicted social support at 6 months ( $b = 0.41, p = .003$ ) and social support at baseline significantly predicted 6-month self-efficacy ( $b = 0.04, p = .03$ ). The cross-lagged paths from 6 months to 12 months were non-significant. Among covariates, ASD symptoms significantly predicted 6-month social support ( $b = -0.17, p = .03$ ) and no other covariate was significantly associated with perceived social support or self-efficacy.

Models were repeated with the sample split according to age. The model for parents of younger children had good fit (CFI = .98; TLI = .88; RMSEA = .15; SRMR = .03), and excellent fit for the older subsample (CFI = 1.0; TLI = 1.0; RMSEA = .00; SRMR = .01).

For those with children under 12 years of age, autoregressive paths indicated strong stability over time for self-efficacy and social support. In terms of cross-lagged paths, self-efficacy at baseline significantly predicted social support at 6 months ( $b = 0.70, p < .001$ ), with no other significant cross-lagged pathways.

For the participants with children 12 years or older, stability paths similarly indicated strong associations between previous levels and subsequent levels of each variable. Cross-lagged paths showed baseline social support predicted self-efficacy at 6 months ( $b = 0.09, p = .002$ ), with no other significant paths. Complete unstandardized estimates for both models are in Table 9.

**Research Question 4: Is there a reciprocal relation between perceived social support and child behaviour problems, while controlling for continuity over time for both variables?** Similar to the original model with self-efficacy, initial model fit for this model was poor (CFI = .86; TLI = .56; RMSEA = .17; SRMR = .09). Residual correlations again showed strong autoregressive relationships between variables at Time 1 and Time 3, and modification indices suggested that adding direct paths between T1 and T3 would substantially improve the model fit. The adjusted model fit the data well (CFI = 1.0; TLI = 1.0; RMSEA = .00; SRMR = .01). The same covariates as the self-efficacy model were included (household income, parent education, presence of child chronic health conditions, child adaptive level, child ASD symptoms). See Table 9 for unstandardized estimates and Figure 2 for the corresponding path diagram with standardized parameter estimates.

There were significant autoregressive effects for both perceived social support and child behaviour problems, indicating that the prior levels of either variable were strongly related to the same variable's subsequent levels. Specifically, baseline to 6-month social support ( $b = 0.72, p <$

.001), 6-month to 12-month social support ( $b = 0.43, p < .001$ ), baseline to 6-month child behaviour ( $b = 0.58, p < .001$ ), and 6-month to 12-month behaviour ( $b = 0.70, p < .001$ ) were all significant autoregressive effects.

Cross-lagged effects showed baseline social support significantly predicted child behaviour problems at 6 months ( $b = -0.06, p = .02$ ), but baseline behaviour did not significantly predict 6-month social support. There were no significant cross-lagged paths from 6 to 12 months. ASD symptoms were negatively associated with perceived social support at baseline ( $b = -0.19, p = .02$ ), and no other covariates significantly predicted social support or child behaviour problems.

When the path models were estimated with age subgroups and no covariates, and model fit was good for both the under 12 group and the 12 and older group. The models for parents of younger children and older children both had excellent fit (CFI = 1.0; TLI = 1.0; RMSEA = .02; SRMR = .02; CFI = 1.0; TLI = 1.0; RMSEA = .00; SRMR = .01, respectively).

For both models, stability paths for social support and behaviour problems were significant, indicating that previous levels predicted subsequent levels of support, and previous levels predicted subsequent levels of behaviour problems. For both age groups, the pattern of results was consistent with the full sample model, where baseline social support significantly predicted 6-month child behaviour problems. All other cross-lagged effects were non-significant.

**Research Question 5: Is there a reciprocal relation between perceived social support and parent stress, while controlling for continuity over time for both variables?** The initial planned model with perceived social support and parent stress had an inadequate fit to the data (CFI = .84; TLI = .70; RMSEA = .14; SRMR = .10). Based on residual correlations and modification indices, direct paths from social support at time 1 to time 3 and from stress at time

1 to time 3 were added to the model. This modification improved model fit such that the adjusted model fit the data well (CFI = 1.0; TLI = .99; RMSEA = .03; SRMR = .02). Again, the same demographic variables included in previous models were included as covariates. Unstandardized results for this model are reported in Table 10. See Figure 3 for the path diagram with standardized parameter estimates.

Both perceived social support and stress were stable over time. Specifically, autoregressive coefficients from baseline to 6-month social support ( $b = 0.71, p < .001$ ), 6-month to 12-month support ( $b = 0.47, p < .001$ ), baseline to 6-month stress ( $b = 0.57, p < .001$ ), and 6-month to 12-month stress ( $b = 0.33, p < .001$ ) were all significant.

The cross-lagged path from baseline social support to stress at 6 months was significant ( $b = -0.15, p = .006$ ), indicating that higher baseline social support is associated with lower levels of stress at 6 months. All other cross-lagged paths were nonsignificant. For covariates, parent education and household income significantly predicted 6-month stress ( $b = 1.76, p = .02$ ;  $b = -0.44, p = .02$ , respectively), and ASD symptoms were significantly associated with 6-month perceived social support ( $b = -0.17, p = .03$ ).

Models were subsequently estimated within the two separate age groups. The models for parents of younger children and older children had adequate fit (CFI = 1.0; TLI = 1.0; RMSEA = .00; SRMR = .01 and CFI = .98; TLI = .84; RMSEA = .18; SRMR = .04, respectively). In the older subgroup, cross-lagged patterns were comparable to the full sample, with baseline perceived social support predicting 6-month stress ( $b = -0.19, p = .01$ ) and otherwise nonsignificant cross-lagged paths. There was high stability over time for social support and stress. For the younger subgroup, cross-lagged effects were all non-significant. Stability over time was high for social support and stress.



**Research Question 6: How do child behaviour, stress, and self-efficacy, measured at baseline, combine to account for changes in perceived social support 6 to 12 months after baseline?** Growth curve models were used to assess perceived social support's pattern of change over time, and how child behaviour, self-efficacy, and stress account for these changes. The initial model had an improper solution such that estimated variance of the slope was negative. Therefore, the model was re-specified by fixing the slope variance to a very small positive number, and the covariance between slope and intercept was fixed to 0. The re-specified model had good fit to the data, CFI = .99; TLI = .99; RMSEA = .07; SRMR = .04. The mean of the slope factor was nonsignificant, indicating that there is no systematic change in perceived social support across the year.

Subsequently, a conditional linear growth model was fitted with baseline self-efficacy, stress, and child behaviour problems as predictors of the intercept and slope factors. Model fit was also excellent, CFI = .99; TLI = .98; RMSEA = .05; SRMR = .03. Self-efficacy and parent stress were significantly associated with the intercept factor ( $b = 1.42, p < .001$ , and  $b = -0.22, p = .01$ , respectively), indicating that the level of perceived social support at baseline is associated with higher levels of baseline self-efficacy and lower levels of stress. Child behaviour problems were not significantly associated with the intercept factor ( $b = 0.002, p = .84$ ). There were no significant predictors of the slope factor due to the fact that there was essentially zero variance in the slope factor. The unstandardized parameter estimates of the conditional linear growth curve model are reported in Table 11.

## Discussion

This is one of first longitudinal studies of social support for parents of individuals with ASD. Further, it is the only study to explore both received and perceived support in parents of

children and adolescents with ASD. This study moved beyond cross-sectional bivariate associations previously reported in the literature to a sophisticated examination of reciprocal relationships over time. After decades of research, it is abundantly clear social support is an important resource in alleviating stress, and the current research helps to clarify how social support specifically applies to parents of children with ASD. As aforementioned, a summary of analyses results is provided in Appendix A.

**Research Question 1: Relationship between received and perceived social support in a sample of parents of individuals with ASD**

The first research question aimed to assess the strength of association between received and perceived social support. As hypothesized, received and perceived social support were positively correlated. The strength of association did not significantly vary according to any demographic and clinical characteristics. Thus, the supportive enacted behaviours and subjective appraisal of support appear to be enduring and related but distinct concepts across child and parent features.

This correlation between perceived and received social support is stronger than reported in most social support studies. The association is higher than reported in Haber et al.'s (2007) meta-analysis of 23 studies. This difference may have occurred for several reasons. Some studies have suggested that the relationship between perceived and received support is affected by support needs (e.g., Melrose, Brown, & Wood, 2015). Specifically, the association between perceived and received support should be stronger when the support needs match support received (Cutrona & Russell, 1990). Consistent with this, Melrose and colleagues reported that the correlation between received and perceived support was higher when support received *when needed* was measured compared to when received support was traditionally measured without

considering need. Although support needs were not specifically measured in the current study, parents of individuals with ASD are faced with unique stressors and often report high support needs than other adults (Chiri & Warfield, 2012; Pickard & Ingersoll, 2016). Other studies have addressed the potential influence of support needs by focusing on clinical populations with known stress and needs including daughters of patients with Alzheimer's (Lakey, Adams, Neely, Rhodes, Lutz, & Sielky, 2002), survivors of interpersonal trauma (Kouky, 2013), parents of children with congenital heart defects (Kaul & Lakey, 2003), and older adults with chronic physical impairments (Reinhardt, Boerner, & Horowitz, 2006). For instance, Kouky (2013) found that the relationship between received and perceived social support was stronger for those meeting diagnostic criteria for PTSD compared to those with subthreshold symptoms. There is demonstrable value in focusing on particularly stressed populations with demonstrated support needs, yet the articles included in Haber et al.'s meta-analysis almost entirely focused on convenience samples from local universities, which may partly explain the lower average correlation than reported in the current study.

### **Research Question 2: Stress-buffering effects of self-reported received and perceived social support**

The first research question confirmed a demonstrable link between perceived and received support, and the second research question extended this work, aiming to clarify how the two types of support uniquely relate to parent stress. Both types of support were significantly associated with decreased stress when the two support types were examined individually. When considered together in a single model, received support was not uniquely associated with stress. Counter to our hypothesis and the stress-buffering model, neither support measure significantly moderated the association between child behaviour and parent stress. The pattern of results was

consistent for parents of younger children (under 12) and older children (12 and older). The current findings are consistent with research showing that perceived support is more consistently linked to mental health than is received support. Numerous studies have shown robust relationships between perceived support and various mental health outcomes within the general population (e.g., Lakey & Cronin, 2008; Uchino, 2009), while there is substantially less evidence for received support's influence on well-being (Barrera, 1986; Bolger & Amarel, 2007; Bolger, Zuckerman, & Kessler, 2000). Our results are consistent with the only existing study of perceived and received social support for parents of individuals with ASD (Wang, 2016). As previously described, perceived support was significantly associated with parent stress when received support was taken into account for 64 American parents of young children.

This was the first study involving parents of individuals with ASD assessing the main-effect model and stress-buffering model using two types of social support measures. The current study results support a main-effect model rather than stress buffering model. Specifically, there was a direct association between support and stress with neither type of support buffering the effect of child behaviour on stress. There is ample support for the main effect model for various populations, and the current study shows a similar pattern for parents of individuals with ASD. Although the stress-buffering model is prominent in social support literature, it does not appear to be the most accurate depiction of the social support process for parents of individuals with ASD.

Consistent with the existing literature, overall child behaviour problems were significantly related to increased parent stress. Research has continually shown that parents of children with ASD who have behavioural difficulties are at an increased risk for poor mental health and high stress (Davis & Carter, 2008; Estes et al., 2009; Hastings, 2003; Lecavalier et al.,

2006; Manning, Wainright, & Bennett, 2011; Osrmond, Seltzer, & Greenberg, 2006). All behaviour problem types were associated with parent stress with the exception of hyperactivity. In the current study, hyperactivity problems were highest, with lower rates of emotional and conduct difficulties reported. The rates of hyperactivity difficulties in the current study were comparable to other studies reporting on ADHD symptomology in children with ASD. For instance, in Leyfer et al. (2006), over half of the sample of children with ASD showed elevated ADHD symptoms. Some studies involving parents of children with ADHD and no ASD have shown that parent stress is higher when the child has additional behavioural difficulties such as oppositional defiant behaviours, suggesting that the child behaviour difficulties may account for parent stress rather than the diagnosis of ADHD alone (e.g., Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Harrison & Sofronoff, 2002). In the current study, it appears emotional and conduct difficulties are sources of stress for parents while hyperactivity symptoms are not.

The current study's first research question demonstrated that received and perceived support are related but distinct concepts. Results from the second research question suggest that the two types of support do not have the same association with stress, specifically, received support is not associated with stress when perceived support is taken into account. Given these results, it is unlikely that received support entirely explains the effect of perceived support on stress. Existing social support interventions typically focus on increasing received support as a mechanism for improving emotional well-being, although current results and past research suggest that perceived support may have a more robust link to well-being and stress. Identifying other determinants of perceived social support with longitudinal data (research questions 3 to 6) helps clarify the most effective targets of social support interventions and increases our understanding of perceived social support for parents of individuals with ASD.

**Research Question 3: Is there a reciprocal relation between perceived social support and perceived self-efficacy, while controlling for continuity over time for both variables?**

To date, no studies have determined whether self-efficacy is a determinant of, or has a reciprocal relationship with, social support for parents of individuals with ASD. A small number of cross-sectional studies involving parents of children with ASD indicates that the two variables are related (e.g., Ekas et al., 2010; Weiss et al., 2013), but this link had yet to be explored further. Self-efficacy is a particularly salient construct for individuals experiencing difficult situations or having struggles in their life without obvious solutions (Raikes, & Thompson, 2005), so it is particularly valuable to understand and enhance self-efficacy for parents of individuals with ASD. The current study showed a bidirectional, reciprocal relationship between self-efficacy and perceived social support, although the relationship did not persist over time. Specifically, baseline self-efficacy significantly predicted perceived social support at 6 months and baseline social support was significantly associated with 6-month self-efficacy, with non-significant paths from 6 months to 12 months. These results partially confirm the hypothesized reciprocal relationship between self-efficacy and perceived social support. The current results are consistent with Green and Rodger's (2002) one-year longitudinal study of 260 low income mothers. Initial levels of self-efficacy were associated with increased tangible and advice giving support, and initial levels of tangible support were linked to subsequent self-efficacy. Individuals with high levels of self-efficacy may manage and access social support resources more efficiently when needed and, in turn, perceiving supports to be available if needed may lead to increased self-efficacy.

The patterns of results within each age group differed from the bi-directional relationships seen with the full sample. For the parents with younger children, baseline self-

efficacy significantly predicted perceived support at 6 months. For the older group, baseline social support significantly predicted 6-month self-efficacy. There is very little existing research to explain the differing results, although it may be due to greater sampling error. Some research has examined the development of self-efficacy across the lifespan in the general population (e.g., Berry & West, 1993), and studies have suggested that parents of children with ASD develop more effective coping resources, including self-efficacy, as they age, and gain a greater understanding of their child's disability and service system (Kuhn & Carter, 2006). Although associations between self-efficacy and social support varied for the two age groups in the current study, the groups did not significantly differ on either measure at any time point. This result is consistent with a study of social support for Taiwanese parents of children with ASD, where parenting self-efficacy (global self-efficacy was not measured) and perceived social support for the 30 parents of school-aged children (6 to 12 years) did not differ from 30 parents of adolescents (13-18 years; Lai, 2003). Unfortunately, the association between self-efficacy and social support was not compared for the two age groups in Lai's work. Some cross-sectional studies have shown an association between self-efficacy and social support among parents of typically developing preschool children (e.g., Suzuki, Holloway, Yamamoto, & Mindnich, 2009; Winkworth, McArthur, Layton, & Thompson, 2010), although these results are not necessarily applicable to our school-aged subsample up to 12 years of age, who are considerably older. Researchers have yet to focus on perceived social support and self-efficacy among parents of adolescents.

**Research Question 4: Is there a reciprocal relation between perceived social support and child behaviour problems, while controlling for continuity over time for both variables?**

The existing research framing child behaviour problems as a determinant of perceived social support posits that caregivers may struggle to mobilize supports or are more reluctant to seek support when their children with ASD have more difficult behaviours (e.g., Bromley et. al., 2004). This pattern was evident in our bivariate correlation analyses, as perceived social support was negatively associated with increased child behaviour problems. However, results did not confirm this pattern longitudinally. Specifically, baseline perceived social support significantly predicted subsequent child behaviour problems at 6 months such that higher levels of perceived social support led to lower levels of child behaviour problems, but child behaviour did not predict subsequent social support.

There is limited research on the association between child behaviour problems and social support, and this was the first longitudinal study identifying perceived social support as a predictor of child behaviour for parents of individuals with ASD. Cross-sectional studies show inconsistent associations between the two constructs for parents of individuals with ASD. A correlation between child disruptive behaviour and received family support was reported with a sample of 71 mothers (Bromley et. al., 2004). McIntyre and Harrison (2018) also reported a correlation between child atypical behaviour and perceived helpfulness of informal support for 78 mothers of young children under 6 years old. Similarly, an association between child behaviour problems (internalizing and externalizing) and perceived social support was reported for 283 parents of young children (under 5 years; Zaidman-Zait et al., 2017). In another cross-sectional study, the associations between social support and hyperactive, conduct, and aggressive behaviour problems were evident for fathers ( $n = 229$ ), but only evident for hyperactive



behaviour among mothers ( $n = 250$ ; Falk, Norris, & Quinn, 2014). Lamminen (2008) reported that child behaviour was not associated with perceived social support with a sample of 135 parents.

Research is also scant on the potential mechanisms leading from social support to child behaviour in the general population. One explanation is that perceived social support influences parenting practices which, in turn, affects child behaviour. For instance, Hashima and Amato (1994) found that perceived support was negatively associated with punitive parenting practices. Correspondingly, higher levels of parent social support have been associated with increased child praising and less controlling parent behaviour (Jennings, Stagg, & Connors, 1991). Increased social support and a rich social network may expose parents to positive practices or reinforce parenting norms through social pressure (McConnell, Breitreuz, & Savage, 2011). The association between parenting practices and social support was noted in one study involving parents of children with ASD, where perceived social support was correlated with increased perceived limit setting ability, maternal involvement, and satisfaction with parenting (Falk et. al., 2014).

Behaviour problems in the current sample were comparable to rates reported elsewhere for individuals with ASD (e.g., Milosavljevic et al., 2016). More than a third (36.5%) of the current study sample had elevated rates of behaviour problems at baseline. These rates are unsurprisingly higher than non-ASD populations, as a recent study confirmed SDQ scores reliably differentiate youth with ASD from youth without (Salayev & Sanne, 2017). The current study suggests that benefits from parent-focused social support interventions could potentially extend to child outcomes. This association is of particular importance given the higher rates of child behaviour

problems among children with ASD and the known impact these behaviours can have on family functioning.

**Research Question 5: Is there a reciprocal relation between perceived social support and parent stress, while controlling for continuity over time for both variables?**

Consistent with analyses using baseline data, results from this research question indicated that baseline support leads to decreased stress at 6 months. The path from 6-month support to 12-month stress was not significant, however. Results suggest that social support is a resource that may alleviate parent stress, even when past stress levels and known stressors are controlled (e.g., education level, income, child ASD symptoms, adaptive skills). There was no evidence that stress predicts perceived support. Thus, the hypothesis of a bidirectional relationship between the two constructs was not confirmed. These results are consistent with the single existing study examining this bidirectional relationship longitudinally for mothers of typically developing children. Green and Rodgers (2002) reported that baseline perceived social support predicted perceived stress one year later but stress did not predict subsequent social support over and above baseline social support.

Although cross-sectional research is abundant, this is one of the only longitudinal studies confirming that perceived social support leads to lower levels of stress among parents of individuals with ASD over time, and the only cross-lagged design study to test a potential reciprocal relationship. In a longitudinal study involving 283 Canadian mothers of young children with ASD, higher perceived social support at baseline was associated with lower levels of subsequent parent stress two years later (Zaidman-Zait et. al., 2017), but the opposite effect was not investigated. These findings are consistent with cross-sectional studies involving individuals with ASD. For instance, perceived helpfulness of social support was negatively

related to stress among 176 parents (Siman-Tov & Kaniel, 2010). Similarly, Lamminen (2008) showed that perceived social support was associated with lower levels of stress for 135 parents. Ekas (2012) also reported a correlation between parent stress and support from friends, partner, and family for 123 parents. Additionally, stress was negatively associated with social support in a study that examined mothers ( $n = 250$ ) and fathers ( $n = 229$ ) separately (Falk, et al., 2014). Perceived social support appears to consistently relate to lower levels of parent stress for parents of individuals with ASD.

The cross-lagged analyses did not identify stress as a predictor of social support, offering no evidence in support of the deterioration model (Dean & Ensel, 1982). With the deterioration model, one would expect earlier levels of stress to be associated with lower levels of perceived social support over time. Thus, the deterioration model (Dean & Ensel, 1982) was not supported. It is possible that a measure of negative life events more accurately captures the nature of stressors applicable to studying how stress deteriorates perceived social support over time. For instance, Mickleson and Kubzansky (2003) found that experiencing one or two acute life events was associated with increased social support, while experiencing more than two acute life events and chronic serious stressors that began more than 12 months prior was related to decreased perceived emotional support with a nationally representative sample of 8,098 adults. Alternatively, it is possible that parent stress levels were not high enough to deteriorate perceived social support in the current study. These scores were higher than community samples (Lovibond & Lovibond, 1995) but lower than clinical samples (Brown, Chorpita, Korotitsch, & Barlow, 1997) and lower than reported in a number of other studies involving parents of individuals with ASD (e.g., Falk, et al., 2014; Lunsy, Hastings, Weiss, Palucka, Hutton, & White, 2017; Seymour, et al., 2013).

Parent education and household income measured at baseline also significantly predicted stress at 6 months. Household income was associated with lower levels of subsequent stress, while an increase in education was related to increased levels of stress. The positive association between education and stress is counterintuitive, but may be explained by how education is correlated with the other model covariates. Socioeconomic deprivation has been associated with worsened parent mental health in other studies (e.g., Emerson, 2012), and these associations are particularly relevant for families of individuals with ASD, as research has shown that these families face increased economic burden compared to others (e.g., Cidav, Marcus, & Mandell, 2012).

Cross-lagged results varied when parents of older and younger children were analyzed separately. Analyses for the second research question showed strong baseline associations between stress and perceived social support irrespective of child age, yet the association was not consistent in longitudinal analyses. For the older subsample (parents of children 12 years and older), results were comparable with the full sample, with baseline perceived support predicting stress at 6 months. Yet when the younger sample (parents with children under 12 years) was examined on its own, perceived social support did not significantly predict stress. Existing research on social support and stress for parents of individuals with ASD has almost entirely involved school-aged children with broad age ranges (e.g., Ekas et al., 2010; Falk et al., 2014; Lamminen, 2008; Siman-Tov & Kaniel, 2010) or pre-school aged children (Zaidman-Zait et al., 2016). Little attention has been given to parents of adolescents and adults with ASD and their experiences with social support. Two longitudinal studies (of one common dataset) investigated trajectories of well-being for mothers of individuals 10 years and older with ASD. Although not specifically assessing stress and perceived support, these studies showed that social network size

and availability of positive support were related to later levels of anxiety, depressive symptoms, and negative affect (Barker, 2011; Smith, Greenberg, & Mailick Seltzer, 2013). The current study adds to the literature suggesting that social support can help relieve parent stress, specifically for parents of adolescents.

**Research Question 6: How do child behaviour, stress, and self-efficacy, measured at baseline, combine to account for changes in perceived social support 6 to 12 months later?**

This research question explored how factors account for change in social support, but social support was extremely stable over time, making it difficult to assess predictors of change. The mean of the growth curve slope was nonsignificant, indicating that there is no systematic change in the level of perceived social support across the year. Furthermore, this slope factor representing the change in social support cannot be predicted because it had near zero variance. Thus, child behaviour, stress, and self-efficacy did not predict the slope factor.

One study has reported on changes in social support over time for parents of individuals with developmental disabilities. In a 4.5-year study of change in social support and its effect on emotional well-being for 251 older mothers of adults with developmental disabilities, social network size and received emotional support did not change over time, with high stability across time points, although perceived support was not measured (Hong, Seltzer, Krauss, 2001). The two studies investigating trajectories of well-being for mothers of individuals 10 years and older with ASD previously reported on (Barker, 2011; Smith, Greenberg, & Mailick Seltzer, 2013) used the same dataset as Hong et al., but neither examined the trajectories of social support.

Outside of the field of ASD, there are a small number of studies to suggest that perceived support may be stable over time and linked to early familial influences (e.g., Newcomb, 1990; Sarason, Sarason, & Shearin, 1986; Graves, Want, Mead, Johnson, & Klag, 1986). For instance,

Sarason, Sarason and Shearin (1986) suggested being raised in a positive familial environment (e.g., warmth, closeness, involvement from parents) establishes stable and enduring positive relational schemas, and would theoretically provide stable perceived social support in adulthood. In a longitudinal study of medical students, measures of emotional closeness with parents and early childhood stability significantly predicted perceived social support assessed 40 years later in midlife (Graves, et al., 1998). The link between early childhood experiences and perceived support stability has not been investigated for parents of children with ASD.

### **General Discussion**

This study adds to our understanding of social support for parents of individuals with ASD in a number of ways. Results shed light on how received and perceived support uniquely relate to parent stress. The results also speak to the value of modeling social support longitudinally with advanced analysis methods which can represent the complexity of relationships. Cross-lagged models are unique in that they control for autoregressive associations, variable stability across time points, and are better equipped to assess reciprocal relationships. This methodology has recently become invaluable to the field of ASD research and has increased our understanding of the reciprocal relationships among expressed emotion and behaviour problems in adults (Greenberg, Seltzer, Hong, & Orsmond, 2006), child anxiety and over-responsivity (Green, Ben-Sasson, Soto, & Carter, 2012), adolescent behavioural development and vocational engagement (Taylor, Smith, & Mailick, 2014), and child behaviour and parent well-being (Neece, Green, & Baker, 2012; Totsika et al., 2013).

Our bivariate correlations showed that perceived social support is associated with stress, child behaviour, and self-efficacy. There is ample cross-sectional literature demonstrating these relationships for various populations. However, the longitudinal analysis results were more

complex than the simple correlations indicated, and cross-lagged models showed less evidence for reciprocal relationships than hypothesized. There was some evidence for a reciprocal relationship between self-efficacy and perceived social support, but bidirectional associations were not observed between perceived social support and child behaviour problems or between support and stress. Baseline perceived social support significantly predicted 6-month child behaviour and 6-month stress, but neither of the latter variables predicted subsequent social support.

Controlling for previous levels of the same variable over time allowed for a more precise estimation of prospective associations between perceived social support and the other main study variables. The strong autoregressive effects likely accounted for the fact that no significant relationships were noted between variables from 6 to 12 months. Although significant cross-lagged associations were seen from baseline to 6 months, no models showed any significant cross-lagged effects from 6 to 12 months. In fact, when 6-month data were removed and supplementary analyses were conducted with only baseline and 12 month data, significant associations were noted between these two time points. Definitive explanations for the lack of associations cannot be drawn, but longer measurement intervals and larger sample sizes would help clarify prospective associations.

Using a cross-lagged longitudinal design also allowed for further examination of family and child characteristics as predictors of social support. In preliminary baseline analyses, perceived social support was significantly correlated with parent education, household income, child medical conditions, adaptive skills, and child ASD symptoms. These patterns are generally consistent with the existing ASD literature (e.g., Bromley et al., 2004; Falk et al., 2014; McIntyre & Brown, 2018; Smith et al., 2013; Zaidman-Zait et al., 2017). Yet these associations were

generally not evident in longitudinal models, indicating that these characteristics may be related cross-sectionally, but do not uniquely predict social support over time. Across all longitudinal cross-lagged models, there were no significant associations between the covariates and perceived social support, with the exception of ASD symptoms. ASD symptoms measured at baseline were negatively associated with 6-month perceived social support. This association has been reported in ASD research (e.g., Falk et al., 2014), but more frequently not (e.g., Benson & Karlof, 2009; Lai 2013; McIntyre & Brown, 2018; Rutstein 2014; Zaidman-Zait et al., 2017).

### **Limitations and Future Studies**

This study has a number of limitations. Participants were recruited through community organizations and a research lab database, and thus parents were likely engaged with ASD services or had previously been active in research activities. Parents were mainly well-educated mothers living in suburban or urban locations and nearly all children were born in Canada. Further work with more diverse samples and comprehensive national recruitment strategies is needed as the current study results may not generalize to all parents of children with ASD. Second, the data were collected through self-report surveys and it is possible associations among variables are inflated due to shared method variance. Future research should use multiple methods of data collection. Due to our method of data collection, we relied on parent report of the ASD diagnosis source (e.g., pediatrician, psychologist), diagnosis date, and parent report SCQ scores. Although the SCQ has been found to a valid screener for ASD symptoms, in-person diagnostic testing is ideal. Additionally, the current study investigated social support over a 12-month period and future research should study social support over longer periods of time to better understand patterns of change. It would be particularly interesting to study times of anticipated transition or potentially stressful periods for parents of children with ASD, including



time of diagnosis, or transitioning from high school to the adult service sector. Further, we are unable to conclude these results apply to parents of individuals with ASD specifically without other comparison samples included (e.g., parents of individuals with developmental disabilities or parents of typically developing children). Additionally, survey measures used different time periods of reference and this may have influenced the strength of associations. For instance, the measure of stress asked participants to consider the previous week, while the received support measure focused on the previous four weeks. Adjusting the time point reference for consistency would be something to consider for future studies. Finally, future studies could examine other dimensions of social support (e.g., social network characteristics, support needs support from specific sources), assess stress and self-efficacy within specific contexts (e.g., parenting stress and parenting efficacy), or consider other social support determinants such as date of ASD diagnosis (Zaidmain-Zait et al., 2017), familial interactions from early childhood (Sarason, et al., 1986), parenting practices (e.g., Izzo, Weiss, Shanahan, & Rodriguez-Brown, 2000), and personal predispositions (e.g., Dunkel-Schetter & Skokan, 1990).

### **Implications of Findings**

This study adds to our understanding of social support as a construct and clarifies how perceived social support relates to other family factors longitudinally. The findings have clinical implications for parents of individuals with ASD. Perceived social support, self-efficacy, stress, and child behaviour are each potential targets of intervention, and the benefits of modifying one may be expansive.

If self-efficacy is indeed a determinant of social support, as seen with the current study's full sample and younger subsample, then interventions aimed at bolstering self-efficacy may also influence perceived social support. A large number of promising self-efficacy interventions have

targeted a variety of goals and populations (Allison & Keller, 2004; Luszczynska, Tryburcy, & Schwarzer, 2006; McQueen, Dennis, Stremmer, & Norman, 2011; Multon, Brown, & Lent, 1991), and future studies should investigate adapting existing self-efficacy programs to be appropriate for parents of individuals with ASD. Additionally, parent social support interventions may lead to increased feelings of self-efficacy, relieve stress, and improve child behaviour. To our knowledge, there is no existing evidence-based intervention program specifically targeting parent perceived social support in the field of ASD. Some multi-component programs for parents of individuals with ASD may have incorporated discussions on accessing social support (Bitsika & Sharpley, 2000; Clifford & Minnes, 2013; Elfer & Mirenda, 2015), but none were designed to enhance perceived social support or measured social support constructs. Given the current study results indicating perceived social support's influences self-efficacy, stress, and child behaviour, social support intervention programs are an important direction for future work.

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## Appendices

### Appendix A: Summary of Analyses and Results

**Research Aim 1: To better understand how received and perceived social support differ among parents of individuals with ASD. Two research questions address this aim.**

**1) How strongly are received and perceived social support related to each other in a sample of parents of individuals with ASD?**

**Analysis:** Product-moment correlation coefficient and Fisher's r-to-z transformation to test difference between two correlations

**Results:**

- There was a significant positive association between baseline self-reported received and perceived social support.
- The association between received and perceived support did not significantly differ for demographic and clinical variable subgroup comparisons.

**2) To what extent do self-reported received and perceived social support moderate the association between a known stressor (child behaviour problems) and parent stress, as the stress-buffering model proposes**

**Analysis:** Three separate hierarchical multiple regression models. Models repeated with age subsamples.

**Results:**

- In the first model, perceived social support and child behaviour were significantly associated with parent stress. The interaction between behaviour problems and perceived social support was not significant.
- In the second model, received social support and child behaviour problems were significantly associated with parent stress. The interaction between behaviour problems and received social support was not significant.
- In the third model, perceived social support and child behaviour were significantly associated with parent stress, while received support was not. No interaction terms were significant.
- The pattern of results for the regression analyses remained the same within each age subsample.

**Research Aim 2: To examine factors which may lead to perceived social support and the potential reciprocal effects among these variables over time. Four research questions addressed this aim.**

**3) Is there a reciprocal relation between perceived social support and perceived self-efficacy, while controlling for continuity over time for both variables?**

**Analysis:** Three-wave autoregressive cross-lagged path model, models repeated with age subsamples

**Results:**

- Autoregressive relationships indicated perceived social support and self-efficacy were stable over time
- Baseline self-efficacy predicted social support at 6 months.
- Social support at baseline significantly predicted 6-month self-efficacy.
- Among covariates, ASD symptoms significantly predicted 6-month social support.
- The cross-lagged paths from 6 months to 12 months were non-significant.
- For those with children under 12 years of age, self-efficacy at baseline significantly predicted social support at 6 months, with no other significant cross-lagged pathways.
- For the participants with children 12 years or older, social support at baseline significantly predicted self-efficacy at 6 months, with no other significant cross-lagged pathways.

**4) Is there a reciprocal relation between perceived social support and child behaviour problems, while controlling for continuity over time for both variables?**

**Analysis:** Three-wave autoregressive cross-lagged path model

**Results:**

- Autoregressive relationships indicated perceived social support and child behaviour were stable over time
- Baseline social support significantly predicted child behaviour problems at 6 months, but baseline behaviour did not significantly predict 6-month social support
- Among covariates, ASD symptoms significantly predicted 6-month social support.
- The cross-lagged paths from 6 months to 12 months were non-significant.
- The pattern of results was consistent for the under 12 group and over 12 group, where baseline social support was a significant predictor of 6-month child behaviour problems

**5) Is there a reciprocal relation between perceived social support and stress, while controlling for continuity over time for both variables?**

**Analysis:** Three-wave autoregressive cross-lagged path model, models repeated with age subsamples

**Results:**

- Perceived social support and stress were stable over time.
- Social support at baseline significantly predicted 6-month stress.
- For covariates, parent education and household income significantly predicted 6-month stress, and ASD symptoms were significantly associated with 6-month perceived social support
- In the older subgroup, cross-lagged patterns were comparable to the full sample. For the younger subgroup, cross-lagged effects were all non-significant.

**6) How do child behaviour, stress, and self-efficacy, measured at baseline, combine to account for changes in perceived social support 6 to 12 months after baseline?**

**Analysis:** Growth curve modeling

**Results:**

- The mean of the growth curve slope was nonsignificant, indicating that there is no systematic change in the level of perceived social support across the year. The slope factor representing the change in social support cannot be predicted because it had near zero variance. Thus, child behaviour, stress, and self-efficacy did not predict the slope factor.



## Appendix B: Consent

**RESEARCH CONSENT**

**INTRODUCTION:** We are researchers at York University, who are interested in learning about the social support received by parents of individuals with Autism Spectrum Disorders (ASD). Parents of individuals with ASD often experience challenges in parenting their children, and it is important to explore the supports that may help reduce feelings of stress. Social support has been shown to help parents, but it is not clear what factors lead to good social support. The aim of this study is to examine parent and family factors that may lead to social support and in turn, how social support influences these factors.

**RESEARCHERS:** Principal Investigator, Suzanne Robinson, M.A., [REDACTED]  
 Graduate Supervisor, Dr. Jonathan Weiss, Ph.D., C.Psych, [REDACTED]  
 [REDACTED]  
 [REDACTED]  
 [REDACTED]

**TOPIC:** “Understanding Social Support for Parents of Individuals with Autism Spectrum Disorders”

**PARTICIPATION:** Your participation in this study would involve completing a survey online or by paper. You will also be invited to complete follow-up surveys 6 months and 12 months later. The surveys will ask you questions about you and your child, your social support network, and how you are managing in your day-to-day life. The initial survey and follow-up surveys will each take approximately 30 minutes to complete.

There are very few risks to this research. You may experience feelings of discomfort generated from the content of the questions asked. **You may withdraw from this study at any time**, even after having signed this form. You have a right to refuse to answer any questions. If you withdraw from the study, all information collected will be immediately destroyed where possible. Your decision not to participate will not influence your relationship with the researchers or York University, now or in the future.

While this study does not directly help you and your family right now, we hope to inform efforts to better support families of individuals with Autism Spectrum Disorders in the future. Additionally, you will be entered in a raffle to receive one of ten \$50 gift cards after completing the survey.

**CONFIDENTIALITY:** Any information that is collected will be kept confidential to the full extent of the law, in a secure location, for 10 years. Your name will be removed from any data collected from you. Instead, a number will be assigned and only the principal investigator and her assistant(s) will have access to the list of names of participants. The information you share will be combined with other participants’ information, and **you or your child will never be identified in any way** if/when the results of this study are published.

If you have questions about the research in general or about your role in the study, please feel free to contact Suzanne Robinson either by telephone [REDACTED] or by email ([REDACTED] or you can contact Dr. Jonathan Weiss either by telephone at [REDACTED] or by e-mail [REDACTED]). The graduate program of Psychology at York University can be reached by telephone [REDACTED] by email [REDACTED]. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, [REDACTED], York Research Tower, York University (telephone [REDACTED] or e-mail [REDACTED]).

**Please indicate below your agreement to participate in this research.**

Parent Name: \_\_\_\_\_

Phone  
Number: \_\_\_\_\_

**I UNDERSTAND THE PURPOSE AND THE TERMS OF THE PROJECT DESCRIBED ABOVE AND AGREE TO PARTICIPATE IN THIS RESEARCH STUDY:**

“Understanding Social Support for Parents of Individuals with Autism Spectrum Disorders”

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Date

## Appendix C: The Social Provisions Scale (Cutrona &amp; Russell, 1987)

In answering the following questions, think about your current relationships with friends, family members, co-workers, community members, and so on. Please indicate to what extent each statement describes your current relationships with other people. Use the following scale to indicate your opinion.

So, for example, if you feel a statement is very true of your current relationships, you would respond with a 4 (strongly agree). If you feel a statement clearly does not describe your relationships, you would respond with a 1 (strongly disagree).

<u>STRONGLY DISAGREE</u>	<u>DISAGREE</u>	<u>AGREE</u>	<u>STRONGLY AGREE</u>
1	2	3	4

		<b>Rating</b>
1.	There are people I can depend on to help me if I really need it.	
2.	I feel that I do not have close personal relationships with other people.	
3.	There is no one I can turn to for guidance in times of stress.	
4.	There are people who depend on me for help.	
5.	There are people who enjoy the same activities that I do.	
6.	Other people do not view me as competent.	
7.	I feel personally responsible for the well-being of another person.	
8.	I feel part of a group of people who share my attitudes and beliefs.	
9.	I do not think other people respect my skills and abilities.	
10.	If something went wrong no one would come to my assistance.	
11.	I have close relationships that provide me with a sense of emotional security and well being.	
12.	There is someone I could talk to about important decisions in my life.	
13.	I have relationships where my competence and skill are recognized.	
14.	There is no one who shares my interests and concerns.	
15.	There is no one who really relies on me for their well-being.	
16.	There is a trustworthy person I could turn to for advice if I were having problems.	
17.	I feel a strong emotional bond with at least one other person.	
18.	There is no one I can depend on for aid if I really need it.	
19.	There is no one I feel comfortable talking about problems with.	
20.	There are people who admire my talents and abilities.	
21.	I lack a feeling of intimacy with another person.	
22.	There is no one who likes to do the things I do.	
23.	There are people who I can count on in an emergency	
24.	No one needs me to care for them.	

Appendix D: The Inventory of Socially Supportive Behaviours (ISSB; Barrera, Sandler, & Ramsay, 1981)

We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over *the past four weeks*. Below you will find a list of activities that other people might have done for you, to you, or with you in recent weeks.

Please read each item carefully and indicate how often these activities happened to you during *the past four weeks*.

During *the past four weeks*, how often did other people do these activities for you, to you, or with you:

<u>NOT AT ALL</u>	<u>ONCE OR TWICE</u>	<u>ABOUT ONCE A WEEK</u>	<u>SEVERAL TIMES A WEEK</u>	<u>ABOUT EVERY DAY</u>
1	2	3	4	5

		<b>Rating</b>
1.	Looked after a family member when you were away.	
2.	Was right there with you (physically) in a stressful situation.	
3.	Provided you with a place where you could get away for awhile.	
4.	Watched after your possessions when you were away (pets, plants, home, apartment, etc.).	
5.	Told you what she/he did in a situation that was similar to yours.	
6.	Did some activity with you to help you get your mind off of things.	
7.	Talked with you about some interests of yours.	
8.	Let you know that you did something well.	
9.	Went with you to someone who could take action.	
10.	Told you that you are OK just the way you are.	
11.	Told you that she/he would keep the things that you talk about private - just between the two of you.	
12.	Assisted you in setting a goal for yourself.	
13.	Made it clear what was expected of you.	
14.	Expressed esteem or respect for a competency or personal quality of yours.	
15.	Gave you some information on how to do something	
16.	Suggested some action that you should take.	
17.	Gave you over \$25.	
18.	Comforted you by showing you some physical affection.	
19.	Gave you some information to help you understand a situation you were in.	
20.	Provided you with some transportation.	
21.	Checked back with you to see if you followed the advice you were given.	

22.	Gave you under \$25.	
23.	Helped you understand why you didn't do something well.	
24.	Listened to you talk about your private feelings.	
25.	Loaned or gave you something (a physical object other than money) that you needed.	
26.	Agreed that what you wanted to do was right.	
27.	Said things that made your situation clearer and easier to understand.	
28.	Told you how he/she felt in a situation that was similar to you.	
29.	Let you know that he/she will always be around if you need assistance.	
30.	Expressed interest and concern in your well-being.	
31.	Told you that she/he feels very close to you.	
32.	Told you who you should see for assistance.	
33.	Told you what to expect in a situation that was about to happen.	
34.	Loaned you over \$25.	
35.	Taught you how to do something.	
36.	Gave you feedback on how you were doing without saying it was good or bad.	
37.	Joked and kidded to try to cheer you up.	
38.	Provided you with a place to stay.	
39.	Pitched in to help you do something that needed to get done.	
40.	Loaned you under \$25.	

<u>NOT AT ALL</u>	<u>ONCE OR TWICE</u>	<u>ABOUT ONCE A WEEK</u>	<u>SEVERAL TIMES A WEEK</u>	<u>ABOUT EVERY DAY</u>
1	2	3	4	5

Appendix E: The Stress subscale from the Depression Anxiety and Stress Scale (DASS-42; Lovibond & Lovibond, 1995)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

I found myself getting upset by quite trivial things	0	1	2	3
I tended to over-react to situations	0	1	2	3
I found it difficult to relax	0	1	2	3
I found myself getting upset rather easily	0	1	2	3
I felt that I was using a lot of nervous energy	0	1	2	3
I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting)	0	1	2	3
I felt that I was rather touchy	0	1	2	3
I found it hard to wind down	0	1	2	3
I found that I was very irritable	0	1	2	3
I found it hard to calm down after something upset me	0	1	2	3
I found it difficult to tolerate interruptions to what I was doing	0	1	2	3
I was in a state of nervous tension	0	1	2	3
I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
I found myself getting agitated	0	1	2	3

## Appendix F: The Mastery scale (Pearlin &amp; Schooler, 1978)

<u>STRONGLY</u> <u>DISAGREE</u>	<u>DISAGREE</u>	<u>AGREE</u>	<u>STRONGLY</u> <u>AGREE</u>
1	2	3	4

	<b>Rating</b>
There is really no way I can solve some of the problems I have.	
Sometimes I feel that I'm being pushed around in life.	
I have little control over the things that happen to me.	
I can do just about anything I really set my mind to.	
I often feel helpless in dealing with the problems of life.	
What happens to me in the future mostly depends on me.	
There is little I can do to change many of the important things in my life.	

Table 1

<i>Parent, Household and Child Characteristics</i>	
	N (%) or M (SD)
<i>Parent/Household Variables</i>	
Age (n=233)	43.98(6.21) Range: 27-64
Gender	
Female	238 (95.6)
Male	10 (4.0)
Transgender	1 (.4)
Relationship status (n=248)	
Married/common law	210 (83.1)
Single (never married)	10 (4.0)
Separated/Divorced	31 (12.5)
Widowed	1 (.4)
Education level (n=248)	
High school or less	23 (9.2)
Partial college (at least one year)	22 (8.9)
College diploma/ university undergraduate degree	150 (60.5)
Graduate degree	53 (21.4)
Annual household income after taxes (n=244)	
\$45,000 or less	57 (23.4)
\$45,000-95,000	105(43.0)
\$95,000 or more	82 (33.6)
Geographical Location (n=248)	
Suburban area	99 (39.9)
Urban area	97 (39.1)
Rural	41 (16.5)
Remote	11 (4.4)
<i>Child Variables</i>	
Age	11.47 (3.95) Range: 4-18
Gender	
Female	41 (16.5)
Male	207 (83.1)
Transgender	1 (0.4)
Born outside of Canada	12 (4.8)
Activities of daily living skills (WADL )	16.69 (7.11) Range: 0-33
Autism Symptoms (SCQ)	22.17(6.34) Range: 11-38

*Note. N=249.*



Table 2

*Parent Reported Diagnoses of Son or Daughter with ASD*

<b>Diagnosis</b>	<b>n</b>	<b>%</b>
Intellectual and/or developmental disability	104	41.8
Learning disability	93	37.3
Attention deficit hyperactivity disorder	94	37.8
Behaviour or conduct problems	71	28.5
Anxiety	91	36.5
Depression	20	8.0
Tourette syndrome	6	2.4
Asthma	39	15.7
Epilepsy	18	7.2
Chronic gastrointestinal problems	51	20.5
Hearing impairment	11	4.4
Vision problems, cannot be corrected with glasses/contact lenses	17	6.8
Bone, joint, muscle problems	20	8.0
Sleep problems/disorder	50	20.1
Brain injury or concussion	9	3.6
Other psychiatric diagnoses (e.g., OCD, anorexia)	9	3.6
Other medical diagnoses (e.g., diabetes, cerebral palsy)	19	7.2

*Note.*  $N=249$ . Diagnoses are not mutually exclusive.

Table 3

*Descriptive Information for Main Study Variables Across All Time Points*

	Baseline (n=249)		6 Months (n=194)		12 Months (n=180)	
	M (SD)	Range	M(SD)	Range	M(SD)	Range
Perceived social support (SPS)	75.06 (11.85)	42-96	76.33 (11.46)	39-96	74.46(12.29)	37-96
Received social support (ISSB)	1.87 (.57)	1-4	1.87(.58)	1-5	1.85(.60)	1-4
Self-Efficacy	18.78(4.20)	7-28	19.09(4.48)	8-28	18.91 (4.33)	8-28
Stress (DASS)	15.46(8.91)	0-41	15.75(9.43)	0-42	14.55(8.90)	0-42
Child behaviour (SDQ)	12.86(5.09)	0-27	13.55(4.72)	4-26	13.17(4.90)	3-27
Hyperactivity	6.64(2.51)	0-10	6.64(2.51)	0-10	6.69(2.32)	1-10
Conduct	2.46(2.01)	0-9	2.69(1.96)	0-9	2.58(2.11)	0-10
Emotional	3.77(2.78)	0-10	4.27(2.64)	0-10	4.0(2.78)	0-10

Table 4.

*Bivariate Correlations Among Panel Model Variables*

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. SS T1	1	-	-	-	-	-	-	-	-	-	-	-
2. SS T2	.77*	1	-	-	-	-	-	-	-	-	-	-
3. SS T3	.80*	.78*	1	-	-	-	-	-	-	-	-	-
4. S-E T1	.58*	.53*	.56*	1	-	-	-	-	-	-	-	-
5. S-E T2	.51*	.56*	.53*	.77*	1	-	-	-	-	-	-	-
6. S-E T3	.54*	.48*	.61*	.74*	.77*	1	-	-	-	-	-	-
7. SDQ T1	-.17*	-.15*	-.12	-.17*	-.14	-.14	1	-	-	-	-	-
8. SDQT2	-.30*	-.25*	-.36*	-.29*	-.27*	-.37*	.65*	1	-	-	-	-
9. SDQ T3	-.21*	-.24*	-.28*	-.24*	-.22*	-.30*	.62*	.78*	1	-	-	-
10. Stress T1	-.44*	-.37*	-.40*	-.45*	-.36*	-.37*	.31*	.38*	.34*	1	-	-
11. Stress T2	-.39*	-.41*	-.39*	-.47*	-.56*	-.45*	.11	.28*	.22*	.60*	1	-
12. Stress T3	-.35*	-.30*	-.43*	-.41*	-.34*	-.45*	.26*	.40*	.36*	.65*	.61*	1

*Note.* SS= perceived social support, S-E= self-efficacy, SDQ=child behaviour problems; \*  $p < .05$ .

Table 5

*Perceived social support predicting stress*

	$\beta$	<i>B</i>	<i>SE B</i>	<i>p</i>
Constant		16.31	4.60	< .001
Child behaviour problems	0.23	0.40	0.10	< .001
Perceived social support	-0.40	-0.30	0.04	< .001
Behaviour x support	-0.08	-0.01	0.01	.61
Child age	-0.13	-0.29	0.15	.06
Adaptive skills (WADL)	0.03	0.03	0.09	.72
Autism symptoms (SCQ)	0.06	0.09	0.08	.30
Parent education	-0.03	-0.03	0.61	.96

Note.  $N=249$ .  $\beta$  = standardized slope estimate.  $R^2 = .30$ ,  $F=12.96$ ,  $p<.001$

Table 6

*Received social support predicting stress*

	$\beta$	<i>B</i>	<i>SE B</i>	<i>p</i>
Constant		21.10	4.79	< .001
Child behaviour problems	0.26	0.44	0.11	< .001
Received social support	-0.24	-3.67	0.94	< .001
Behaviour x support	-0.01	-0.01	0.18	.94
Child age	-0.12	-0.28	0.16	.09
Adaptive skills (WADL)	-0.02	-0.02	0.09	.82
Autism symptoms (SCQ)	0.08	0.10	0.09	.24
Parent education	-0.07	-0.76	0.64	.23

Note.  $N=249$ .  $\beta$  = standardized slope estimate.  $R^2 = .19$ ,  $F=8.02$ ,  $p<.001$

Table 7

*Perceived and Received social support predicting stress*

	$\beta$	<i>B</i>	<i>SE B</i>	<i>p</i>
Constant		16.28	4.64	< .001
Child behaviour problems	0.23	0.40	0.10	< .001
Perceived social support	-0.38	-0.28	0.05	< .001
Behaviour x perceived support	-0.07	-0.01	0.01	.45
Received social support	-0.03	-0.41	1.09	.70
Behaviour x received support	-0.04	0.12	0.22	.58
Child age	-0.13	-0.30	0.16	.06
Adaptive skills (WADL)	0.03	0.03	0.09	.72
Autism symptoms (SCQ)	0.06	0.09	0.08	.29
Parent education	-0.01	-0.02	0.62	.98

*Note.*  $N=249$ .  $\beta$  = standardized slope estimate.  $R^2 = .28$ ,  $F=10.07$ ,  $p<.001$ .

Table 8

*Unstandardized Estimates of the Relationships between Perceived Social Support and Self-Efficacy*

	Full Sample		Young Sample		Older sample	
	Estimate (SE)	<i>p</i>	Estimate (SE)	<i>p</i>	Estimate (SE)	<i>p</i>
<i>SS 6 month</i>						
SS baseline	.64(.05)	<.001	.53(.06)	<.001	.84(.07)	<.001
S-E baseline	.41(.14)	.003	.70(.19)	<.001	.12(.19)	.54
Education	.36(.62)	.57				
Household income	-.09(.19)	.62				
Child health condition	-.71(1.02)	.49				
Autism symptoms	-.17(.08)	.03				
Adaptive skills	.06(.08)	.44				
<i>S-E 6 month</i>						
S-E baseline	.74(.05)	<.001	.78(.08)	<.001	.70(.06)	<.001
SS baseline	.04(.02)	.04	.003(.03)	.91	.09(.03)	.001
Education	-.44(.24)	.09				
Household income	.13(.07)	.09				
Child health condition	-.60(.42)	.16				
Autism symptoms	.04(.03)	.30				
Adaptive skills	.01(.03)	.71				
<i>SS 12 month</i>						
SS 6 month	.44(.08)	<.001	.50(.11)	<.001	.34(.10)	<.001
SS baseline	.41(.07)	<.001	.32(.09)	<.001	.53(.10)	<.001
S-E 6 month	.25(.17)	.16	.16(.30)	.59	.29(.16)	.08
<i>S-E 12 month</i>						
S-E 6 month	.44(.08)	<.001	.32(.15)	.03	.44(.09)	<.001
S-E baseline	.39(.07)	<.001	.53(.12)	<.001	.37(.09)	<.001
SS 6 month	.01(.02)	.74	-.03(.04)	.40	.04(.03)	.17

*Note.* SS = perceived social support; S-E = self-efficacy; SE = standard error

Table 9

*Unstandardized Estimates of the Relationships Between Perceived Social Support and Child Behaviour Problems*

	Full Sample		Young Sample		Older sample	
	Estimate (SE)	<i>p</i>	Estimate (SE)	<i>p</i>	Estimate (SE)	<i>p</i>
<i>SS 6 month</i>						
SS baseline	.72(.05)	<.001	.65(.05)	<.001	.88(.06)	<.001
Behaviour baseline	.08(.10)	.44	-.04(.15)	.78	.05(.13)	.71
Education	.40(.68)	.55				
Household income	-.07(.19)	.70				
Child health condition	-.82(1.04)	.43				
Autism symptoms	-.18(.08)	.02				
Adaptive skills	.10(.08)	.21				
<i>Behaviour 6 month</i>						
Behaviour baseline	.58(.06)	<.001	.50(.07)	<.001	.65(.08)	<.001
SS baseline	-.06(.02)	.02	-.06(.03)	.04	-.07(.04)	.04
Education	.04(.30)	.97				
Household income	-.03(.09)	.71				
Child health condition	.19(.53)	.67				
Autism symptoms	-.01(.04)	.95				
Adaptive skills	-.01(.04)	.64				
<i>SS 12 month</i>						
SS 6 month	.43(.07)	<.001	.44(.11)	<.001	.40(.09)	<.001
SS baseline	.46(.07)	<.001	.37(.08)	<.001	.55(.09)	<.001
Behaviour 6 month	-.24(.12)	.05	.75(1.0)	.14	-.18(.14)	.19
<i>Behaviour 12 month</i>						
Behaviour 6 month	.70(.07)	<.001	.75(1.0)	<.001	.63(.11)	<.001
Behaviour baseline	.22(.06)	<.001	.18(.09)	.04	.27(.08)	.001
SS 6 month	-.01(.02)	.72	-.03(.04)	.35	.04(.03)	.14

*Note.* SS = perceived social support

Table 10

*Unstandardized Estimates of the Relationships Between Perceived Social Support and Stress*

	Full Sample		Young Sample		Older sample	
	Estimate (SE)	<i>p</i>	Estimate (SE)	<i>p</i>	Estimate (SE)	<i>p</i>
<i>SS 6 month</i>						
SS baseline	.71(.05)	<.001	.61(.06)	<.001	.86(.06)	<.001
Stress baseline	-.04(.06)	.43	-.13(.07)	.07	-.02(.08)	.79
Education	.29(.65)	.66				
Household income	-.04(.19)	.81				
Child health condition	-.67(1.04)	.52				
Autism symptoms	-.17(.08)	.03				
Adaptive skills	.09(.08)	.29				
<i>Stress 6 month</i>						
Stress baseline	.57(.07)	<.001	.60(.09)	<.001	.53(.10)	<.001
SS baseline	-.15(.05)	.006	-.09(.07)	.19	-.18(.07)	.01
Education	1.76(.72)	.02				
Household income	-.44(.19)	.02				
Child health condition	-.01(1.14)	.99				
Autism symptoms	-.10(.09)	.31				
Adaptive skills	-.06(.08)	.48				
<i>SS 12 month</i>						
SS 6 month	.46(.08)	<.001	.45(.11)	<.001	.43(.11)	<.001
SS baseline	.44(.07)	<.001	.38(.09)	<.001	.51(.11)	<.001
Stress 6 month	-.05(.06)	.36	-.08(.10)	.42	-.04(.08)	.64
<i>Stress 12 month</i>						
Stress 6 month	.33(.09)	<.001	.52(.12)	<.001	.18 (.11)	.11
Stress baseline	.41(.08)	<.001	.22(.09)	.02	.61(.13)	<.001
SS 6 month	-.01(.04)	.77	.01(.07)	.91	-.01(.06)	.92

*Note.* SS = perceived social support



Table 11

*Results for Linear GCM of Perceived Social Support Over One Year Conditioned on Self-Efficacy, Stress and Child Behaviour Problems*

Parameter	Estimate	Robust <i>SE</i>	<i>Z</i>	<i>p</i>
coefficient for self-efficacy effect on intercept factor	1.42	.18	8.13	.00
coefficient for stress effect on intercept factor	-.22	.09	-2.51	.01
coefficient for child behaviour effect on intercept factor	-.08	.14	-.54	.59
coefficient for effect of self-efficacy on slope factor	-.03	.08	-.381	.71
coefficient for effect of stress on slope factor	-.01	.04	-.29	.77
coefficient for effect of child behaviour on slope factor	.04	.06	.74	.46
intercept of intercept factor	52.83	4.55	11.6	.00
intercept of slope factor	-.10	1.99	-.05	.96
intercept factor error variance	66.36	8.98	7.39	.00
SPS T1 error variance	29.36	5.23	5.62	.00
SPS T2 error variance	31.82	5.20	6.11	.00
SPS T3 error variance	29.83	5.38	5.55	.00

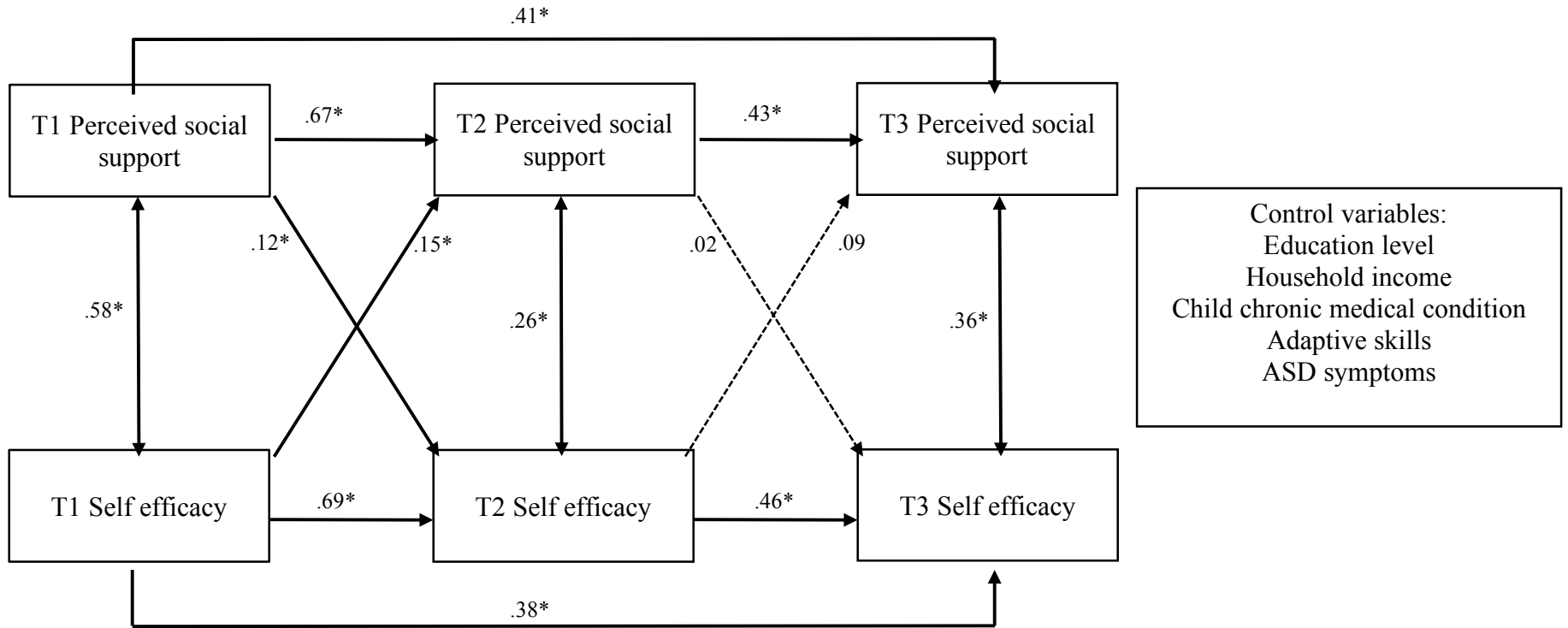


Figure 1. Standardized coefficients of the relationships between perceived social support and self-efficacy across three time points.

Note. T1= baseline; T2= 6 months; T3 = 12 months; Dotted lines represent non-significant associations; \*  $p < .05$ .

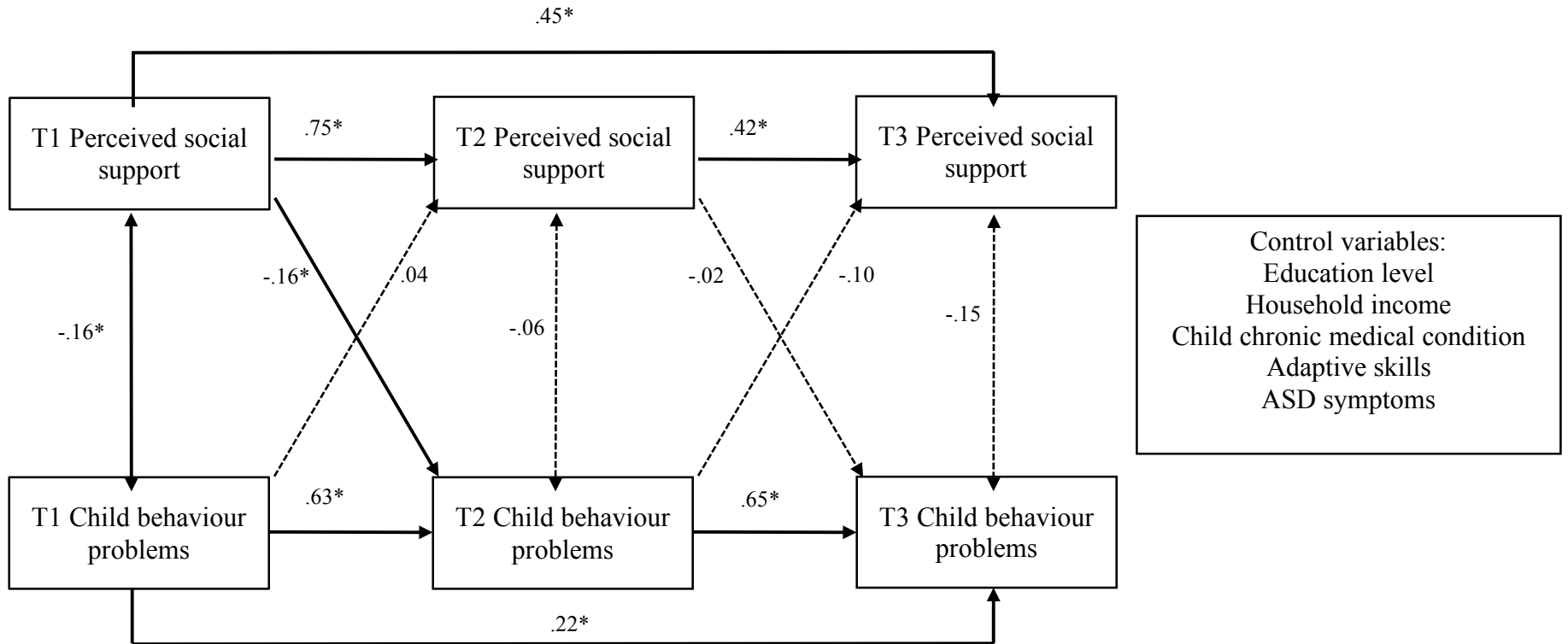


Figure 2. Standardized coefficients of the relationships between perceived social support and child behaviour problems across three time points.

Note. T1= baseline; T2= 6 months; T3 = 12 months; Dotted lines represent non-significant associations; \*  $p < .05$ .

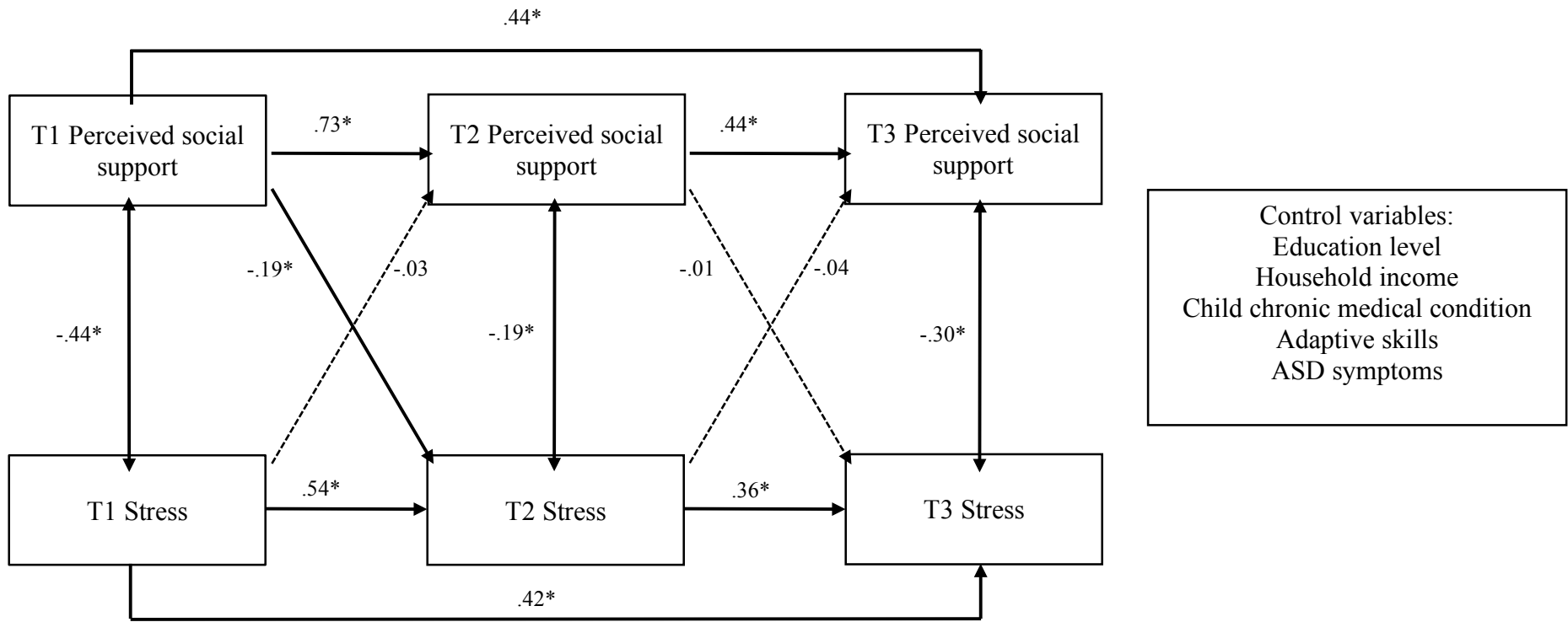


Figure 3. Standardized coefficients of the relationships between perceived social support and stress across three time points. Note. T1= baseline; T2= 6 months; T3 = 12 months; Dotted lines represent non-significant associations; \*  $p < .05$ .