

# Raising a Child with Autism: A Developmental Perspective on Family Adaptation

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**Abstract** While raising a child with an Autism Spectrum Disorder (ASD) often produces chronic stress and strain in families, positive family outcomes are also evident following an ASD diagnosis. Although the complex and heterogeneous nature of ASD is well documented, a coherent understanding of the apparent differences in family outcomes is lacking. This review focuses on the process of family adaptation, identifying important contextual factors that may influence family experiences through the use of a conceptual model. Due to inconsistencies in research findings to date, the potential risk and protective factors in determining family outcomes remain unclear, with most research only focusing on mothers. Few studies have attempted to understand family processes utilising a conceptual model of family adaptation, accounting for stressors, resources, appraisal, and coping strategies. The role of child age in the adaptation process has also been ignored with investigation of family processes across key developmental periods needed to assist in tailoring supports and services to families in a timely fashion.

**Keywords** Autism · Stress · Adaptation · Autism severity · Problem behaviour · Coping

## Autism and the Family

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by social and communication

impairments, and stereotyped, repetitive behaviours and interests [1]. Approximately one in 68 children have an ASD [2], highlighting the importance of research investigating the impact of these complex disorders on families and carers. Delays in diagnosis, the inevitable changes in family life, the educational needs, and the often limited community support means that raising a child with an ASD increases the risk for negative family outcomes across childhood and adult life [3–6]. Research has focused predominately on the construct of caregiver ‘burden’, with numerous studies highlighting the negative impact of raising a child with an ASD on parents, particularly mother’s physical and psychological wellbeing [e.g. 7, 8, 9, 10].

Parents raising children with ASD have been found to report higher levels of parenting stress, depression and anxiety, and increased general life stress than parents raising children with Down syndrome (DS), cerebral palsy (CP), fragile X syndrome (FXS), intellectual disability (ID), cystic fibrosis (CF) or typically developing (TD) children [e.g. 11–17]. More recently, research identifying the positive aspects of raising a child with a disability has increased, with families identifying both positive and negative outcomes associated with raising children with ASD [e.g. 18], and a focus on resilience in family members [e.g. 19, 20]. These findings reflect a growing awareness of the construct of family adaptation.

Family adaptation refers to a phase of change that results from the restructuring of family processes, such as roles or interactions, in an attempt to accommodate to the consequences of stressors and other life strains [21]. It takes into account the protective factors influencing a family’s ability to cope with their child’s disability, and any subsequent changes in the family unit. Multivariate models have been used to understand the simultaneous impact of risk and protective factors on family adaptation, providing a framework for identifying factors both within and external to the family unit which contribute to family outcomes in the face of major life

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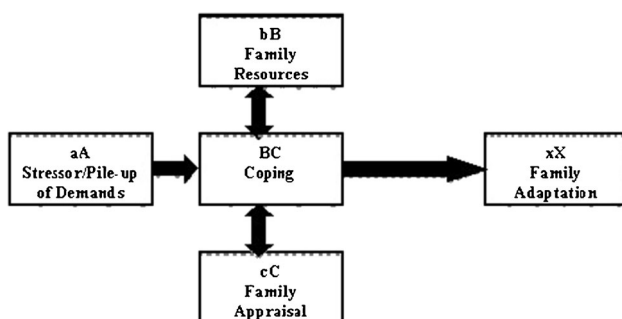
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stress [22]. In doing so, these models tend to focus on parental reports of family life, assessing maternal, paternal or the views of both parents on aspects of the family unit. One model, which has used this approach to examine functioning and adaptation in families of children with ASD, is McCubbin and Patterson's [21] Double ABCX model of adaptation (see Fig. 1).

## Theoretical Framework

The Double ABCX model defines the process of adaptation through identification of key risk and protective factors that may influence family functioning over time. Risk factors are considered as variables that increase the likelihood of adverse or negative outcomes in families [23], such as poorer wellbeing and maladaptation. Alternatively, protective factors act to reduce the impact of risk factors on family outcomes, acting as potential buffers to improve wellbeing, restore homeostasis and support successful adaptation [23].

In McCubbin and Patterson's [21] model, stressors (A) are defined as expected or unexpected life events that cause changes in the family system (e.g. diagnosis of a child). In addition to the initial stressor, the model accounts for a pile-up of demands (e.g. prior strains and expected transitions within the family unit) that may compound the initial stress experienced by families (aA) [6, 21]. Two variables proposed to moderate the impact of stressors on family outcomes are family resources and appraisals. While resources (B) include existing skills and characteristics that the family draw upon to cope with stressors (e.g. the support of individual family members, the family unit, or the community), appraisals (C) consider the family's interpretation and understanding of the stressor and its impact on the family system (e.g. seeing the stressor as a challenge that can be overcome) [6, 21]. The model also accommodates for expanded resources (bB) obtained over time, as families learn to cope with the stressor, and subsequent changes in definitions and meaning (cC) of the overall crisis situation.



**Fig. 1** Double ABCX model of family adaptation. Based on McCubbin and Patterson [21]

In addition to the three variables described, coping (BC) is an important factor that connects family resources and appraisals [6]. Coping is viewed as the ability of family members to seek out and apply resources to manage a stressful event and restore balance within the family unit (e.g. seeking support from the community or one's spiritual beliefs) [21, 24]. Family adaptation (xX) represents the outcome of interactions between the four components of the model. Represented by positive and/or negative outcomes, it symbolises a family's attempt at reaching a new level of homeostasis following upset to the family system [21].

While a number of theoretical models exist for understanding stress and coping in families, including Hill's [25] ABCX family crisis model, Lazarus and Folkman's [26] model of stress and coping, and Luthar and colleagues' [27] resilience theory, the double ABCX model was chosen for a number of reasons. Firstly, unlike previous models, the double ABCX model recognises the fluid process of family adaptation. While capturing the initial processes employed by family members in direct response to the stressful event, the model also acknowledges the phase of adjustment that family members experience as the event unfolds. Thus, the double ABCX model aims to capture the natural progression of additional stressors, the development of resources, changes in appraisals, and the building of coping strategies as the stressor and family develop over time [6, 21]. Second, unlike the limited focus of other models on either positive *or* negative outcomes, the double ABCX model accounts for a variety of experiences of family adaptation. Thus it is possible to examine parental outcomes that are *both* positive and negative in nature. Finally, the utility of the double ABCX model to explain successful adaptation in families of children with ASD has been demonstrated in a number of studies in diverse populations [e.g. 6, 28, 29, 30•]. As such, it was determined that this model provided for a comprehensive understanding of the process of adaptation which is the focus of this review.

Few studies have investigated the trajectory of factors included in the double ABCX model across child development. The current review aimed to clarify the changes in identified risk and protective factors in relation to child age to identify periods in which families require an increase in support and periods in which families appear to demonstrate greater adaptation to raising children with ASD. Due to the limited inclusion of fathers in ASD research [31•], the current findings provide a very one-sided view of family adaptation and the experiences of parents raising children with ASD. The review aimed to overcome such limitations by exploring, where possible, both similarities and differences between mothers and father's experiences to provide an understanding of how to best support successful adaptation in these families.

Peer-reviewed studies investigating factors associated with family adaptation (i.e. identified risk or protective factors in relation to raising children with ASD, positive and/or negative

parent or family outcomes) were included in the current review. Studies were not excluded based on specific criteria, but rather were examined for the following inclusion criteria: (a) contained data from primary caregivers of a child with ASD (i.e. mothers and/or fathers); (b) investigated study outcomes of parental stress, coping, quality of life, or wellbeing (i.e. depression, anxiety, mental health); (c) investigated child ASD symptom severity, child maladaptive/problem behaviour, child adaptive functioning, or general life stress in families; (d) investigated the marital relationship, family functioning, social support, or coping; and (e) assessed the Double ABCX model of family adaptation. Table 1 presents a summary of included studies, which utilise a cross-sectional design. Longitudinal studies included in this review are presented in Table 2.

Journal articles were identified through online searches of PsychINFO, Medline and Proquest Central with a focus of including articles published within the past three decades. Google Scholar search engines were also utilised. In addition, relevant articles, in line with inclusion criteria, were identified through searches in key journals (e.g. Autism, Journal of Autism and Developmental Disorders) and from the reference lists of all papers. Key search terms included: Autism, ASD, adaptation, stress, coping, parents, mother, father and wellbeing.

#### The Double ABCX Model and ASD

A number of researchers have examined the capacity of the double ABCX model to explain the process of raising a child with ASD. Since Bristol's [28] initial study, authors have attempted to expand the applicability of McCubbin and Patterson's model to capture the broadening impact of ASD on the family [4, 6], and the impact of parent gender on family adaptation [30••]. The results from these studies have supported the utility of the double ABCX model in capturing a range of experiences of families raising children with ASD. This includes, but is not limited to, the demonstration of healthy levels of functioning in families, suggesting possible adaptation over time. A summary of methods and key findings are included in Table 1.

However, some limitations are evident. While many applications of the model have explored the combination of child ASD symptomatology and/or behaviour problems with life stress, child adaptive functioning (i.e. daily living skills), a characteristic which Hall and Graff [4] identified as demonstrating strong associations with adaptation in families of children with ASD, has not been investigated as an additional stressor in this model. Further, studies have tended to focus on an individualised view of family adaptation, focusing predominately on mother's reports of their own resources, appraisals, coping, and experiences of raising children with ASD. Consequently, few family-related variables have been

explored in relation to this model resulting in gaps in the understanding of a *family's* process of adjustment to raising a child with ASD. Finally, only one study has focused on both positive and negative outcomes of adaptation in families. This research highlights that there is still much to be understood about the positive impact of raising a child with ASD, with the double ABCX model found to account for only 28 % of the variance in family functioning [6]. Thus, clarity surrounding individual predictors of successful adaptation is required.

#### Predictors of Family Adaptation

Despite knowledge of the complexity of the adaptation process and the utility of a conceptual model to understand families' experiences, the role of potential risk (i.e. stressors), and protective factors (i.e. resources, appraisals, coping) in producing family outcomes (i.e. stress and wellbeing) remains unclear. Like family outcomes, these factors are suggested to vary significantly as children develop through infancy, childhood and adolescence [5]. This review will summarise the findings of risk and protective factors identified in McCubbin and Patterson's model, with a specific focus on how these factors may be impacted across the developmental trajectory.

#### Stressors (aA)

##### Child Problem Behaviour

In addition to the difficulties associated with the core impairments of ASD, many children also experience poor attention, and externalising and internalising behaviours. These behaviours are often referred to as maladaptive or problem behaviours separate from ASD symptomatology and symptom severity. Such behaviours have been found to consistently demonstrate positive associations with stress levels reported by parents raising children with ASD [e.g. 6, 15, 16, 37, 43, 49, 73, 83, 84, 88], with suggestions that child behaviour is the strongest predictor of negative parent outcomes of all child related characteristics (referred to as child behaviour problems for the remainder of this review).

While the relationship between child problem behaviour and negative family outcomes has a strong evidence base, the majority of studies have focused on maternal report, failing to capture the experiences of other family members. In addition, research has not focused on child age restricting an understanding of changes in behavioural concerns over time. This is an important factor to address, with studies indicating that behavioural and emotional problems often decrease as children grow [82].

**Table 1** Cross-sectional studies investigating factors of the double ABCX model

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Allen, Bowles, & Weber (2013) [32]	124 parents (101 mothers, 23 fathers)	Range 2-16	ASD	Examined the impact of child symptomatology (child speech, sociability, cognitive impairment, health, and behaviour) on maternal and paternal stress outcomes.	While poor child sociability was found to predict maternal stress, paternal stress was predicted by poor child sensory/cognitive awareness. Mothers reported higher levels of perceived stress than fathers.
Aliere & von Kluge (2009) [3]	52 parents (26 mothers; 26 fathers)	Range 3-16	ASD	Assessed the impact of family characteristics (adaptability and cohesion) on parental coping.	High levels of cohesion were found to predict greater ratings of social support, along with greater use of positive coping strategies in these families. Consistent ratings on outcome variables were found for both mothers and fathers.
Baker-Ericzen, Brookman-Frazee, & Stahmer (2005) [33]	60 parent dyads	2.3-6 (0.43)	ASD ( <i>n</i> =37) TD ( <i>n</i> =23)	Compared stress levels of ASD and TD parent groups and outcomes post an inclusion child-care program accounting for child characteristics (ASD symptoms, developmental functioning).	Parents of children with ASD reported higher levels of stress than TD parents pre and post program. Mothers of children with ASD also reported a decrease in child-related stress. A negative association was found between child social skills and maternal stress in the ASD cohort. No such association was found for fathers.
Bebko, Konstantareas, & Springer (1987) [34]	20 parent dyads, 20 therapists	Range 6-18	AD	Investigated the impact of child ASD symptoms on parent stress and the accuracy of professionals in perceiving parent stress levels.	No differences in parental stress were found. Despite lower levels of symptomatology reported in older children, fathers of older children reported greater stress (in relation to child symptomatology). Overall parents rated themselves as less stressed in comparison to professional stress ratings.
Benson (2010) [35]	113 mothers	8.60 (1.50) Range 6-9	ASD	Explored the influence of four coping styles (engagement, distraction, disengagement, cognitive reframing) on maternal distress (depression and anger) and wellbeing.	Mothers who reported higher levels of cognitive reframing were found to report greater wellbeing. A positive association was also found between avoidant coping and maternal distress. The severity of child maladaptive behaviours was found to moderate relationships between coping and outcome variables.
Bishop, Richler, Cain, & Lord (2007) [36]	110 mothers	9.23 (1.32)	ASD or PDD-NOS	Measured the influence of child characteristics (repetitive behaviours, adaptive behaviour, IQ) and social support on perceived negative impact in African American and Caucasian mothers.	Lower adaptive behaviour was associated with greater negative impact in mothers. In addition, lower levels of support and higher levels of repetitive behaviours were associated with poorer maternal outcomes. Caucasian mothers reported poorer outcomes than mothers of African American decent.
Blacher & McIntyre (2006) [12]	282 primary caregivers	20.30 (2.60) Range 16-26	ASD ( <i>n</i> =23) DS ( <i>n</i> =59) CP ( <i>n</i> =87) ID ( <i>n</i> =113)	Examined the impact of child diagnosis, behavioural problems, and adaptive behaviour on family wellbeing.	Mothers of young adults with ASD reported greater levels of behavioural problems and poorer wellbeing compared to other diagnostic groups. While behaviour problems predicted multiple outcomes of maternal wellbeing, adaptive behaviour was only associated with negative impact scores.
Bristol (1987) [28]	45 mothers	5.30 (2.02) Range 2-10	AD ( <i>n</i> =27) Non autistic, communication-impaired ( <i>n</i> =18)	Assessed the applicability of the Double ABCX model including symptom severity (A), pile-up of demands (aA), family cohesion (B), social support (bB), self-blame (C), catastrophising (cC), and coping (BC) on maternal depression and marital satisfaction (XX).	Significant predictions between components of the model and outcome variables were found. Family resources and appraisals were found to be better predictors of adaptation than severity of child's diagnosis (stressor). In isolation, family cohesion demonstrated a positive relationship with family adaptation, however the opposite direction was evident in regression analyses.
Brobst, Clopton, & Hendrick (2009) [37]	45 parent dyads	Range 2-12	ASD ( <i>n</i> =25) TD ( <i>n</i> =20)	Compared parental stress, social support, and child behaviour problems between participant groups to assess the impact on relationship quality.	Parents of children with ASD were found to report higher stress, more behavioural concerns, and less social support and satisfaction within their relationships. However, similar levels of spousal support and commitment were found between groups. Gender differences were reported between the ASD parent sample. Maternal stress was negatively associated with satisfaction, commitment, and support within the marriage. Paternal stress was negatively associated with social support.
Cappe, Wolff, Bobet, & Adrien (2011) [38]	160 French parents (41 parent dyads)	Preschool to adult	PDD	Explored measures of perceived stress, control, support and coping on parents' quality of life.	A negative relationship was found between emotion-focused coping and parent quality of life. However, positive perceptions, in particular seeing the experience of raising a child with ASD as a challenge, were associated with a greater sense of fulfillment and use of coping strategies.
Dabrowska & Pisula (2010) [14]	162 parent dyads	Range 2-6	ASD ( <i>n</i> =51) DS ( <i>n</i> =54) TD ( <i>n</i> =57)	Compared the role of coping and parental stress across diagnostic groups.	Parents of children with ASD reported higher levels of stress than comparison groups, with mothers reporting higher stress than fathers. This was a unique relationship to the ASD sample. Emotion-focused coping predicted increased parent stress in the ASD sample.



**Table 1** (continued)

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Davis & Carter (2008) [39]	54 parent dyads	2.24 (0.35)	ASD	Investigated associations between child characteristics (ASD symptoms, developmental skills, social and emotional concerns) and parent outcomes (anxiety, depression, stress) in mothers and fathers of recently diagnosed toddlers.	Mothers and fathers reported similar levels of stress, anxiety, and depressive symptoms. However, differences were observed in relation to predictors of negative parent outcomes. Maternal stress was impacted by poor child self-regulation skills while paternal stress was impacted by externalising child behaviours. For both parents, children's delays in social skills impacted stress outcomes.
Dunn, Burbine, Bowers, Tantleff-Dunn (2001) [40]	58 parents (39 mothers; 19 fathers)	7.47 (3.31) Range 3-15	ASD	Assessed relationships between social support, coping styles, locus of control, and negative outcomes (depression, marital difficulties, social isolation).	High levels of escape-avoidance coping were associated with greater isolation, depression, and problems within the marital relationship in parents. Distancing was also associated with higher levels of depression, while a lack of positive reappraisal and problem-focused coping was associated with greater relationship difficulties.
Ekas & Whitman (2010) [41]	119 mothers	Range 2-18	ASD	Explored the influence of the level, frequency and diversity of child ASD symptomatology on measures of maternal socioemotional functioning (stress, depression, positive and negative affect, life satisfaction, psychological well-being).	Identified positive associations between core autism symptomatology and child-related stress, parenting stress, and negative affect. Despite this finding, behavioural problems were noted as strong predictors of poor maternal outcomes. Higher levels of symptomatology were associated with greater stress levels, with mothers of older children found to report less stress.
Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck (2008) [42]	39 parents	Range 5-12	AspD	Explored the impact of child symptomatology (executive functioning, sensory processing) on parent stress, accounting for parent gender differences.	No significant gender-based differences in stress were found. However, a significant positive association was found between maternal stress and child impairment in sensory and executive domains.
Estes et al. (2009) [16]	74 mothers	3.66 (0.35)	ASD ( <i>n</i> =51) DD ( <i>n</i> =23)	Compared measures of parent stress, psychological distress, child behaviour, diagnosis, and adaptive functioning between groups.	Mothers of children with ASD reported higher levels of stress and distress, which were associated with higher levels of child problem behaviour. While child adaptive behaviour was lower in ASD children, adaptive functioning did not impact negative outcomes in mothers.
Firth & Dryer (2013) [43]	109 parents (mothers or fathers)	7.89 (2.43) Range 4-12	ASD	Assessed the impact of child characteristics (ASD severity, behaviour, social skills, empathy) on parent outcomes (anxiety, depression, stress, parenting-specific stress).	After controlling for child age, child behavioural and emotional concerns demonstrated a positive association with parent distress. The only child characteristic found to predict greater levels of parenting stress was child social impairment.
Gabriels, Cuccaro, Hill, Ivers, & Goldson (2005) [44]	14 parents	10.70	AD or PDD-NOS	Assessed the relationship between child intelligence and associated symptoms on reports of repetitive behaviours and parental stress.	A strong positive correlation was evident between child repetitive behaviours and parent stress.
Gau et al. (2012) [45]	264 families from Taiwan	Range 3-15	AD ( <i>n</i> =151) TD ( <i>n</i> =113)	Compared measures of family functioning, marital satisfaction, and parental distress between mothers and fathers of children with AD and TD.	Parents of children with AD reported more psychopathology and less consensus within their relationship than parents of TD children. However, mothers of children with AD reported lower levels of marital adjustment and family functioning than mothers of TD children. Mothers of children with AD also differed from fathers, reporting greater psychopathology and a poorer marital relationship.
Grill & Harris (1991) [46]	60 mothers	Range 2-18	Autism	Measured the impact of hardness and social support on maternal depression and health.	Greater levels of hardness were found to predict decreased levels of maternal depression and somatic complaints above and beyond reports of perceived social support.
Gray (2003) [47]	53 parents (32 mothers, 21 fathers)	Range 5-26	HEFA	Semi-structured interviews were used to obtain information regarding parent experiences of child diagnosis and symptoms, and their subsequent impact on the family.	Fathers reported little impact of child ASD symptoms on their personal experiences, reporting greater stress in relation to their partner's experience of stress. Mothers reported greater experiences of emotional distress, less employment, greater child involvement, and sense of responsibility for their child's behaviour.
Greeff & van der Walt (2010) [48]	34 families	6.48 (2.16)	ASD	Collected both qualitative and quantitative data to identify factors of resilience in successful adaptation.	Family hardness demonstrated the strongest relationship with family adaptation ( <i>r</i> =-.76). Other protective factors such as the presence of siblings, higher socio-economic status, a higher degree of family cohesion, maintaining a positive outlook, a healthy parental relationship, the mobilisation of community resources, and information seeking were also identified.

**Table 1** (continued)

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Hall & Graff (2011) [4]	75 parents/primary caregivers (50 mothers; 23 fathers; 2 other)	Range 4–12	ASD	Explored associations between self-report measures of child adaptive behaviour (aA), social support (bB), parental stress (cC), and coping behaviours (bC).	A negative relationship between child adaptive functioning and parent stress levels was found. Parents reported partners as their best supports.
Hall & Graff (2012) [49]	70 parents (48 mothers; 22 fathers)	Range 3–21	Autism	Explored the relationship between child maladaptive behaviours, social support, coping and parental stress between mothers and fathers.	Parents reported higher levels of externalising than internalising behaviours in their children with overall behavioural problems accounting for 26% of the variance in parental stress. No significant differences were found in relation to parent gender.
Hartley, Barker, Seltzer, Greenberg, & Floyd (2011) [50]	91 parent dyads	Range 11–46	ASD or ASD and ID (58.2%)	Explored the influence of marital satisfaction on the parent-child relationship and feelings of parental burden.	A negative relationship between marital satisfaction and parental burden in both mothers and fathers was found. Reports of parental burden were found to be consistent across couples. Child age demonstrated a negative association with parent burden for fathers while ASD symptom severity demonstrated a negative association with a close parent-child relationship.
Hartley, Seltzer, Head, & Abbeduto (2012) [51]	240 fathers	Range 10–22	ASD ( <i>n</i> =135) DS ( <i>n</i> =59) FXS ( <i>n</i> =46)	Compared measured of depressive symptoms, pessimism and coping (emotion-focused, problem-focused) among diagnostic groups.	Fathers of children with ASD reported greater depressive symptoms than comparison groups. While no differences between groups were found in relation to coping, children in the ASD sample demonstrated higher levels of behavioural problems.
Hastings (2003) [52]	18 parent dyads	11.80 (2.60) Range 8–17	ASD	Explored the role of partner stress and child behaviour on separate reports of maternal and paternal mental health.	While no differences were found between reports of stress and depression among parents, mothers reported greater levels of anxiety. Paternal mental health and child behaviour were significant predictors of maternal stress only.
Hastings et al. (2005a) [54]	26 mothers and 20 fathers of school-age children; 48 mothers and 41 fathers of preschoolers	Range 2–4 and 8–17	ASD	Compared aspects of coping and parental wellbeing (anxiety, depression and stress) across parent gender and child age.	While mothers demonstrated greater use of avoidance coping strategies, group differences were not found in relation to child age on either coping or wellbeing measures.
Hastings et al. (2005b) [55]	48 parents (41 parent dyads)	3.08 (0.37)	Autism	Explored relationships between child characteristics (problem behaviour, adaptive behaviour, ASD symptom severity) on parent measures (anxiety, depression, stress, positive perceptions).	Mothers and fathers reported similar levels of stress. However, higher levels of depression and positive perceptions were found in mothers. While child problem behaviour demonstrated a positive association with maternal stress this association was not evident for fathers. A positive relationship was found between paternal stress and maternal depression scores.
Hastings & Johnson (2001) [53]	141 primary caregivers	4.98 (1.50)	Autism	Explored the impact of social support, coping strategies and ASD symptoms on parental stress in families involved in a home-based intensive behavioural intervention for their child with ASD.	A positive association was found between ASD symptoms and parental stress. Lower stress levels were associated with greater informal social support and adaptive coping.
Higgins, Bailey, & Pearce (2005) [56]	53 primary caregivers	10.83	ASD	Explored the impact of caring for a child with ASD on family adaptability, cohesion, marital satisfaction, self-esteem, and coping.	Compared with normative data, caregivers of a child with ASD reported less satisfaction within their marriage and lower levels of cohesion and adaptability. While coping strategies did not predict family outcomes, healthy levels of self-esteem were reported among caregivers.
Jones, Totsika, Hastings, & Petalas (2013) [57]	161 parent dyads	10.50 (2.93)	ASD	Explored gender differences in parents on measures of positive and negative psychological wellbeing (anxiety, depression, stress, positive perceptions) and the impact of child characteristics (ASD symptoms, adaptive behaviours, behavioural and emotional concerns) on parent outcomes.	Mothers reported higher levels of both positive and negative experiences than fathers. While child problem behaviour was associated with distress in both mothers and fathers, stronger relationships were found between child behaviour problems, adaptive functioning, and anxiety in mothers.
Kaniel & Siman-Tov (2011) [29]	88 parent dyads	10.30 (3.10) Range 6–16	PDD or PDD-NOS	Compared resources (social support, SOC, locus of control), appraisals (challenge vs threat), and adjustment (mental health, marital quality) of mothers and fathers through path analysis.	For both mothers and fathers, SOC, internal locus of control, and social support were predictors of less parental stress. Marital quality was also a predictor of better mental health for both parents. Mothers reported feeling more threatened than fathers in relation to their appraisal of raising a child with ASD.
Kayfitz, Gragg, & Orr (2010) [58]	23 parent dyads	Range 5–11	ASD	Explored the impact of parent gender on positive perceptions and parenting stress.	A negative association was found for both parents between positive perceptions and parenting stress. However, a greater degree of positive experiences were reported by mothers.

**Table 1** (continued)

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Lee (2009) [59]	37 parent dyads	Range 6–13	HFA ( <i>n</i> =48) TD ( <i>n</i> =26)	Compared coping strategies and adjustment (depression, anxiety, marital adjustment) between parents of children with and without HFA.	Parents of children with HFA reported higher levels of stress, mental health concerns, lower marital adjustment, and less adaptive coping than the TD sample. Mothers reported using more adaptive coping strategies, and higher levels of depression and anxiety than fathers in the HFA group.
Little (2002) [60]	103 parent dyads	10.57 (3.74) Range 3–21	AspD and Nonverbal Learning Disorders	Assessed differences in maternal and paternal stress and coping.	Mothers reported greater stress and were more likely to be pessimistic, take medication for depressive symptoms, and seek professional help than their partners.
Lyons, Leon, Phelps, & Dunleavy (2010) [61]	77 primary caregivers	8.33 (4.20) Range 2–22	ASD	Assessed the relationship between ASD severity and coping strategies (task-oriented, emotion-oriented, distraction, social diversion) on four domains of parent stress (physical incapacity, pessimism, parent and family problems, child characteristics).	ASD symptom severity was the strongest predictor of parental stress across all domains. Emotion-oriented coping and distraction coping were found to moderate associations between ASD severity and parent outcomes.
MacMullin, Tint & Weiss (2011) [62]	132 mothers	Range 4–21	ASD	Explored the influence of professional support (e.g., therapists, services, doctors, respite) on mothers' perceptions of positive gain (benefits of raising a child).	Professional support demonstrated a positive association with maternal positive gain with a greater number of supports predicting an increase in reported gains.
Mak, Ho, & Law (2007) [63]	157 mothers	Range 2–28	ASD	Assessed the impact of ASD symptom severity and SOC on parenting stress.	SOC appeared to moderate the effect of ASD symptom severity on parent stress levels. Higher levels of SOC were associated with less parenting stress.
Manning, Wainwright, & Bennett (2011) [64]	195 primary caregivers	8.80 (2.10) Range 6–12	Autism or PDD	Assessed the impact of child problem behaviour (a), pile-up of demands (aA), family support (bB), reframing (cC), and coping strategies (BC) on family environment and stress (xx).	Mothers reported healthy levels of functioning despite high levels of parental stress. Child problem behaviour, social support, and parent positive perceptions were identified as strong predictors of family functioning and stress levels.
McStay, Dissanayake, Scheeren, Koot, & Begeer (2013) [64]	207 parents	Range 6–19	ASD ( <i>n</i> =153) TD ( <i>n</i> =54)	Compared parenting stress in parents of TD children and children with ASD and the impact of child characteristics (age, autism severity, quality of life, problem behaviour) on parent outcomes.	Parents of children with ASD reported higher levels of parenting stress than parents of TD children. Child problem behaviour (hyperactivity) significantly predicted greater parenting stress in the ASD sample above other child characteristics.
Orr, Cameron, Dobson, & Day (1993) [65]	112 mothers	Range 2–5 ( <i>n</i> =37) Range 6–12 ( <i>n</i> =40) Range 13–18 ( <i>n</i> =33)	DD	Investigated the relationship between child age and family adaptation, assessing age-related changes in maternal stress.	Mothers of children aged 6 to 12 years reported significantly higher levels of stress in both child and parent domains of the Parenting Stress Index than mothers of children aged 2 to 5 years and 13 to 18 years.
Pakenham, Samios, & Sofronoff (2005) [24]	47 mothers	Range 10–12	AspD	Assessed components of the Double ABCX model including child behaviour problems, pile-up of demands, social support, appraisal, and coping on maternal depression, social adjustment and health.	Accumulation of family demands accounted for 20% of the variance in maternal anxiety and 19% of the variance in maternal physical health. The association with maternal depression was not significant.
Paynter, Riley, Beamish, Davies, & Milford (2013) [66]	43 parents (25 mothers; 18 fathers)	4.04 (0.82) Range 2.5–6	ASD	Examined the utility of the Double ABCX model including symptom severity, pile-up of demands, internal and external resources, family appraisals, and coping on parenting stress, depression, anxiety and stress, marital satisfaction, and family psychological distress.	Child challenging behaviour, negative appraisals, and active avoidance coping demonstrated positive correlations with parenting stress while social support demonstrated a negative association. Similar findings were evident in relation to predictors of family distress whereas greater use of positive appraisals and social support were associated with greater relationship quality between parents.
Pisula & Kossakowska (2010) [67]	55 parent dyads	Range 3–7	ASD ( <i>n</i> =26) TD ( <i>n</i> =29)	Compared reports of SOC and coping strategies between parents of children with ASD and TD. Comparisons were also made between mothers and fathers.	Parents of children with ASD were found to report lower SOC than parents of TD children, with negative associations found between SOC levels and the use of negative coping strategies. Similar levels of SOC were reported between mothers and fathers.
Pozo, Sarría, & Brioso (2013) [30••]	118 parents (59 mothers; 59 fathers)	Range 4–38	ASD	Examined the severity of ASD and behaviour problems (aA), social support (bB), sense of coherence (cC), and coping strategies (BC) on FQoL and psychological wellbeing (xx).	Separate models of adaptation were identified for mothers and fathers within the same family unit. Both mother and father models indicated a positive relationship between SOC, social support, and FQoL. For mothers, ASD severity demonstrated a negative association with FQoL while the opposite relationship was found for fathers. Differences in coping strategies were also identified, with mothers aided by problem-focused coping (i.e. seeking support, reframing the situation in a positive light, planning) and fathers benefiting from active avoidance (i.e. self-blame, distraction, denial).

**Table 1** (continued)

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Rivard, Terroux, Parente-Boursier, & Mercier (2014) [68]	118 families (118 mothers; 118 fathers)	Range 2-5	ASD	Explored predictors of stress for mothers and fathers prior to the receipt of specialised services. Compared stress levels between parents.	Fathers were found to report greater stress than mothers. While ASD severity and child gender predicted paternal stress levels, child age, IQ and adaptive behaviour were associated with maternal and paternal stress.
Rodrigue, Morgan, & Geffken (1990) [69]	60 mothers	10.71	ASD ( <i>n</i> =20) DS ( <i>n</i> =20) TD ( <i>n</i> =20)	Compared the psychological functioning of mothers between diagnostic groups on measures of parenting sense of competence, coping, marital adjustment, family functioning, mother-child relationship, and social support.	In comparison to other groups, mothers of children with ASD reported greater use of maladaptive coping strategies (self-blame, wish-fulfilling fantasy), greater information seeking, less marital satisfaction, sense of competence and family adaptability, and higher family cohesion. No differences in social support were found.
Siman-Tov & Kaniel (2011) [70]	88 parent dyads	10.30 (3.10) Range 6-16	PDD	Assessed parent-reports of SOC, locus of control, social support, mental health, marriage quality, and ASD symptoms on parental stress.	High SOC was associated with better mental health, and marital quality in parents, and less distress in mothers. Greater social support was also found to be associated with less stress.
Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter (2008) [9]	153 mothers of toddlers; 201 mothers of adolescents	Range 1.50-2.80 Range 10-21	ASD	Participants completed measures of wellbeing (positive and negative) and coping. Child core ASD symptoms were independently assessed.	Higher problem-focused coping and lower emotion-focused coping was associated with better adaptation in all mothers. However, the benefits of maternal coping strategies appeared to be stronger for mothers of adolescents. A greater use of disengagement was also found in mothers of adolescents than mothers of younger children.
Tehee, Honan, & Hevey (2009) [71]	42 parents (23 mothers; 19 fathers)	3-6 ( <i>n</i> =14) 7-10 ( <i>n</i> =9) 11-14 ( <i>n</i> =12) 15-18 ( <i>n</i> =7)	ASD	Assessed measures of general stress, parenting stress, the provision of information/education on ASD, and support (both in informal/formal).	Parents of children aged 11 to 14 years reported better support than parents of children aged 3 to 6 years and 15 to 18 years. Parents of 3 to 6, and 11 to 14 year old children also reported receiving more information about ASD than parents of children aged 15 to 18 years. Mothers reported greater levels of stress and coping than fathers, in addition to greater involvement with their child.
Tobing & Glenwick (2007) [72]	97 mothers	Range 2-18	PDD	Investigated predictors and moderators of psychological distress including ASD symptoms, social support, parenting sense of competence, and coping strategies.	Poorer child functioning was associated with greater stress. No moderating effects for this relationship were found. While satisfaction of social support demonstrated a negative relationship with maternal outcomes, the amount of supports or coping strategies employed by mothers did not impact reported levels of distress.
Tomanik, Harris, & Hawkins (2004) [73]	60 mothers	Range 2-7	PDD	Assessed the impact of child behaviour and adaptive functioning on maternal stress.	Child behaviour and adaptive functioning predicted 32% of the variance in maternal stress, with adaptive functioning accounting for 16% of unique variance in maternal outcomes.
Weiss (2002) [74]	120 mothers	Range 2-7	ASD ( <i>n</i> =40) ID ( <i>n</i> =40) TD ( <i>n</i> =40)	Assessed the impact of hardness and social support on maternal stress.	While mothers of children with an ASD had the lowest hardness scores, hardness was found to predict decreases in depression, anxiety, and depersonalisation within the ASD sample.
Zablotsky, Anderson, & Law (2012) [75]	1,110 mothers	8.90 (3.97)	ASD	Measured the association between ASD symptoms, maternal quality of life and risk of depression in an internet-based registry of families of children with ASD collected in 2007.	High ASD symptomatology was associated with greater risk for maternal depression and poorer quality of life. The same relationship was also evident for children with greater levels of comorbid conditions.
Zablotsky, Bradshaw, & Stuart (2013) [10]	1,014 mothers	Range 3-17	ASD	Assessed stress levels, psychological wellbeing, and associated coping strategies in an internet-based registry of families of children with ASD collected in 2007.	Families with greater income, more than two children, who engaged in effective coping, emotional support, and neighbourhood support, appeared to have better psychological outcomes. Higher levels of child co-morbidity were associated with greater stress and poor mental health in mothers.

*Note.* AD=Autistic disorder; ASD=Autism spectrum disorders; AspD=Asperger's disorder; CP=Cerebral palsy; DD=Developmental disorder; DS=Down syndrome; FQoL=Family quality of life; FXS=Fragile X syndrome; HFA=High-functioning Autism; ID=Intellectual disability; PDD=Pervasive developmental disorder; PDD-NOS=Pervasive developmental disorder-Not otherwise specified; SOC=Sense of coherence; TD=Typically developing



**Table 2** Longitudinal studies investigating factors of the double ABCX model

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Anderson, Oti, Lord, & Welch (2009) [76]	192 parents	2.40 (5.17) on entry	Autism ( <i>n</i> =93) PDD-NOS ( <i>n</i> =51) DD ( <i>n</i> =46) ASD	Assessed the developmental trajectory of adaptive social skills across 5 age points (2, 3, 5, 9 and 13 years). Assessed the developmental trajectory of adaptive behaviour over a 10-year period.	A positive relationship between adaptive behaviour and child age was found with improvements in social deficits across child development. Demonstrated improvement in children's daily living skills over time. Improvements in socialization and communication were also seen in children with lower autism severity and greater language and cognitive abilities at preschool age.
Baghdadi et al. (2012) [77]	152 parents	4.90 (1.30) on entry	ASD	Assessed the developmental trajectory of adaptive behaviour over a 10-year period.	Demonstrated improvement in children's daily living skills over time. Improvements in socialization and communication were also seen in children with lower autism severity and greater language and cognitive abilities at preschool age.
Barker et al. (2011) [7]	379 mothers	21.91 (9.40) Range 10-52	ASD	Investigated the trajectory of maternal emotional wellbeing (i.e. separate measures of anxiety and depression) in relation to child variables (i.e. ASD symptoms and problem behaviour) at 18-month intervals across a ten-year period.	Stable trajectories of maternal depression and a decline in anxiety were found over time. While noted increases in child behaviour problems were associated with an increase in maternal depression and anxiety scores, behaviour problems were reported to be relatively stable over time.
Benson & Karlof (2009) [78]	90 parents (84 mothers, 6 fathers)	Range 3-7 on entry	ASD	Assessed measures of child symptomatology, stress proliferation, social support, and parent anger on parent depression over a 2-year period.	Found a positive association between stress proliferation and depressed mood, with stress proliferation suggested to mediate the relationship between ASD symptoms and parent outcomes (8.2% of explained variance). A negative relationship was also found between informal support and depressed mood over time. ASD severity accounted for 6.2% of the variance in depression scores.
Benson & Kersh (2011) [79]	96 mothers	8.70 (1.50)	ASD	Assessed the impact of marital quality, child behaviour, life stress, and social support on depressed mood, psychological wellbeing, and parenting self-efficacy at two time points over a 2-year period.	Cross-sectional results indicated a negative association between marital quality and life stress. Longitudinal results demonstrated that high levels of marital quality predicted lower levels of depression and greater psychological wellbeing in mothers.
Chadwick, Cuddy, Kusel, & Taylor (2005) [80]	82 parents	Range 4-11 on entry	ASD ( <i>n</i> =16) CP ( <i>n</i> =17) ID ( <i>n</i> =43)	Assessed child adaptive and problem behaviours over a 5-year period (4-11 years and 11-17 years).	Improvements in adaptive behaviour (i.e. daily living skills and communication) was found to predict less behaviour problems, and parental stress over time.
Eisenhower, Baker, & Blacher (2005) [15]	215 mothers	2.94 (0.26)	TD ( <i>n</i> =136) UDD ( <i>n</i> =43) DS ( <i>n</i> =12) ASD ( <i>n</i> =14) CP ( <i>n</i> =10)	Assessed the trajectory of behavioural problems and parenting stress over a period of 2 years.	At time 1 mothers of children with ASD reported more stress and higher levels of behavioural problems in their children compared to other groups. However, mothers of children with ASD reported a decrease in behavioural problems at time 3 impacting maternal stress levels.
Gray (2002) [81]	26 families (25 mothers; 10 fathers)	Range 4-19	Mild-severe autism	Interviewed parents about concerns surrounding their child's diagnosis and subsequent effects on parent wellbeing. Parents were interviewed upon entry into the study and after a period of 8-10 years.	Child behaviour problems mediated parental outcomes, with less adaptation reported by parents of children who displayed aggressive behaviour. However, two-thirds of parents reported increased adaptation, describing improvements in social experiences, stress and wellbeing across the years.
Gray et al. (2012) [82]	119 families	8.70 (4.30) Range 2-20 on entry	AD	Assessed the trajectory of child emotional and behavioural problems, and ASD symptomatology across a period of 18 years.	Small improvements in emotional and behavioural problems were observed in 61.8% of the sample, with 22.5% indicating no change and 15.7% reporting higher levels of symptomatology. No changes in social impairments were observed despite an improvement in ASD symptoms over time.
Hayes & Watson (2013) [84]	Parents	Varied	ASD vs comparison groups (TD, ID, DS)	Meta-analysis of 15 studies comparing reports of parenting stress in parents of children with and without ASD.	Parents of children with ASD reported higher levels of stress than parents of children without ASD (TD or other DD). Core deficits of ASD were suggested to strong predictors of stress in parents.
Herring et al. (2006) [83]	123 parents (117 mothers; 106 fathers)	3.15 (0.59)	PDD ( <i>n</i> =84) Non PDD ( <i>n</i> =39)	Explored associations between child adaptive behaviour, language, intelligence, behavioural, and emotional problems on parent mental health, stress and family functioning over a period of 2 years.	Child behavioural and emotional problems were the greatest predictor of negative parent outcomes over time. Mothers reported significantly higher levels of stress than fathers. No associations were found between partner mental health and maternal or paternal stress.
Lecavaller, Leone, & Wiltz (2006) [84]	293 parents/teachers	9 (3.40) Range 3-18	ASD	Assessed the impact of child behaviour problems and adaptive functioning on parental stress over a 2-year period.	Child behaviour problems were the strongest predictor of maternal stress with similar reports found on parent and teacher ratings. Stability was evident in both child behaviour and parent stress measures over time.

Table 2 (continued)

Authors	Participants	Child's age in years <i>M</i> ( <i>SD</i> )	ASD symptom severity	Method	Findings
Lounds, Seltzer, Greenberg, & Shattuck (2007) [85]	140 mothers	16.90 (2.40) Range 13-22	ASD	Assessed maternal (i.e. depression, anxiety and pessimism) and child (i.e. ASD symptoms, behaviour, and physical health) measures over a period of 4.5 years.	Decreases in child behavioural problems with age predicted a subsequent decline in maternal reports of depression and anxiety.
McGovern & Sigman (2005) [86]	48 parents	Range 2-5 on entry	ASD	Completed assessments of child adaptive functioning, social interaction, and repetitive behaviours upon entry to the study and at two later time points (i.e. when children were 12-13 and 19-20 years of age).	Highlighted significant increases in child socialization and daily living skills between middle-childhood and adolescence. Greater improvement in high-functioning individuals was observed.
Osborne & Reed (2009) [87]	65 parents	3.40 (0.75)	ASD	Assessed the relationship and directionality of dynamics between parent stress and child characteristics (adaptive behaviour, problem behaviour, ASD severity) over a 10-month period.	After controlling for the impact of other child characteristics, a strong relationship was found between child behaviour problems and parent stress. However, this relationship was only found for parents of older children, with ASD severity demonstrating a stronger relationship with parenting stress in younger children.
Peters-Scheffer, Didden, & Korzilius (2012) [88]	104 mothers	Range 2-9	ASD and ID	Collected maternal reports of parenting stress, child adaptive behaviour, ASD severity, and problem behaviours over a 2-year period.	Emotional and behavioural problems accounted for one third of the variance in reports of maternal stress, with other child characteristics demonstrating no association with maternal outcomes.
Pottie & Ingram (2008) [89]	93 parents (60 mothers, 33 fathers)	7.30 (2.08)	ASD	Explored the relationship between daily stress, coping, and mood in parents over a 12-week period.	Seeking support, positive reframing, emotional regulation, compromise and problem-focused coping were associated with an increase in parental positive mood. Escape, withdrawal, blaming, and helplessness were associated with a decrease in parental positive mood. Alternatively, distraction and emotional regulation predicted lower levels of negative mood in parents, with problem-focused coping, blaming, worrying, and withdrawal associated with higher levels of negative mood. ASD symptoms did not impact parents' daily mood reports.
Shattuck et al. (2007) [90]	241 mothers	22 (9.20) Range 10-52	ASD	Measured changes in ASD symptoms and maladaptive behaviours across a 4.5-year period.	A significant negative association between child age and repetitive behaviours and interests was found. While this change was noted predominately in older participants, a steady improvement in social and communication impairments was also observed over time.
Shattuck, Wagner, Narendorf, Stierzing, & Hensley (2011) [91]	680 parents	Range 19-23	ASD	Examined the prevalence and correlates of the use of formal support services in children post high school.	Lower rates of formal service use were reported for children post-high school compared to rates in earlier years. Findings indicate a declining use and engagement in formal support over time.
Smith, Greenberg, & Seltzer (2012) [92]	269 mothers	23.15 (9.82) Range 11-50	ASD	Assessed the quantity (i.e. number of supports) and valence (i.e. positive and negative supports) of supports on participant reports of depressive symptoms and positive/negative affect across a period of 18 months.	A negative relationship between the quantity of support identified by mothers and their depressive symptoms was found. Further, a positive relationship was identified between the quantity of support and positive affect over time. Negative support (i.e. criticism and demands) was associated with less positive affect, higher levels of depression and negative affect.
Taylor & Seltzer (2010) [93]	242 mothers	16.30 (3.10) on entry	ASD	Collected measures of autism symptomatology across 5 time points over a period of 10 years.	An overall improvement in ASD symptoms and behavioural concerns over time was found. However, rate of improvement decreased as child age increased.
Totsika et al. (2013) [94]	132 mothers	5.22	ASD	Collected reports of child behaviour and measures of maternal wellbeing (psychological, physical, life satisfaction) across 3 time points (9 months, 3 years, 5 years) using population-based sampling across the UK.	While child problem behaviours did not affect maternal outcomes across time, poor physical health and distress in mothers was associated with later behaviour problems in children with ASD (age 5).

Note. UDD=Undifferentiated developmental delay

To date, those studies that have attempted to address the longitudinal impact of child behaviour problems on parent outcomes [e.g. 7, 15, 81, 85] suggest that child behaviour may mediate the degree of adaptation in mothers raising a child with ASD over time, with mothers of older children reporting greater wellbeing. While this research indicates that a decrease in risk factors may improve positive outcomes in parents, and vice versa, it is difficult to ascertain this trajectory across development due to current methodological limitations. A recent investigation of bidirectional relationships between child behaviour and maternal wellbeing in ASD, for example, has indicated that child behaviour problems had no effect on maternal reports of psychological distress, physical health and life satisfaction over a period of 2 years [94]. As this study employed population-defined sampling, a method in which participants were randomly selected from the population, it was suggested that the lack of findings may be due to the lower incidence of clinical levels of behavioural problems and maternal distress in the sample. This raises a question about the use of convenience sampling and other sampling biases that may impact study findings. Self-referral and the use of clinical populations is prominent in the ASD literature, with it being difficult to minimise such biases in research.

The use of distinct age ranges to assess the impact of child behaviour on maternal outcomes also limits the generalisability of findings. For example, some studies [e.g. 7, 85] have focused solely on adolescent participants, where a longer period of time has lapsed between diagnosis and reports of current family functioning. In contrast, participants in Eisenhower et al.'s [15] research included parents of preschool children, limiting the generalisation of findings to parents of older school-age children with ASD. While Gray [81] addressed such limitations with his 10-year longitudinal study of both mothers and fathers, additional concerns are raised with initial data collected approximately two decades ago when the conceptualisation of autism was different to our current view. Consequently, further research addressing these concerns is needed to confirm the role of child age on behavioural outcomes. As research has also demonstrated that the impact of child problem behaviour on parental stress differs between mothers and fathers [39, 52], studies that address the role of parental gender in family adaptation are required.

### Autism Symptomatology

Like child behaviour problems, the majority of studies examining carer and family outcomes indicate a positive association between the severity of a child's ASD symptoms and the stress experienced by family members [e.g. 8, 33, 41, 44, 53, 61, 72, 75]. However, it appears that this relationship may only be true when ASD symptom severity is measured in the absence of parental reports of additional child behaviour problems.

Research supports the view that child behaviour problems may override associations between ASD severity, or 'core symptoms', and family outcomes when included in the same analyses [e.g. 5, 6, 16, 64, 83, 88]. Thus it remains unclear which child characteristics most impact parent stress, supporting the need for specific and accurate measures of both child behaviour and core ASD symptoms to be included in studies [43]. Another consideration includes the development of ASD symptoms over time with improvement evident for older children with ASD [90, 93]. While it is suggested that child ASD symptom severity may have a stronger impact on parental stress when children are of preschool age [87], the trajectory of ASD symptoms across childhood and their influence on mothers and father's wellbeing remains unclear.

### Adaptive Behaviour

Studies investigating the impact of child adaptive functioning on families have yielded mixed results [e.g. 12, 36]. When measured in isolation, adaptive behaviour has been found to produce strong associations with family outcomes [e.g. 4]. However, like symptom severity, the relationship between adaptive behaviour and maternal outcomes may be masked by the inclusion of child problem behaviours [e.g. 55, 88]. To date, these three child characteristics have not been examined together within the double ABCX model of family adaptation. Thus, the impact of each of these variables as potential stressors and their collective influence on both positive and negative family outcomes is unknown.

Like ASD symptomatology, evidence suggests that in children with ASD, adaptive behaviour improves as children age [76, 77, 86]. Only one study to date has investigated this relationship in relation to parental outcomes, emphasising the complex dynamic between child characteristics and parenting stress over time [80]. However, the small sample of children with ASD ( $n=16$ ) and the potential mediating role of child behaviour problems, limit the generalisability of findings. Despite knowledge of changes in child characteristics across child development, more information is required about subsequent adjustment in the family unit. Controlling the possible interaction of child characteristics may provide a clearer understanding of the role of each variable in predicting positive and negative family outcomes.

### Pile-up of Demands

While child characteristics are identified as major stressors in the double ABCX model, additional stressors such as the pile-up of family demands also impact families. Pile-up of demands refers to factors that may be indirectly related or unrelated to difficulties experienced as part of raising a child with ASD [21]. These may include financial hardships, emotional relationships between family members and modifications in

family functioning. Such factors have been found to play an important role in family adaptation, significantly predicting maternal outcomes within the double ABCX model [28] and accounting for unique proportions of variance in negative family outcomes [24, 78]. However, once again, the majority of research has focused on the pile-up of demands on reports of maternal depression, limiting an understanding of the subsequent impact on fathers, parenting stress and family quality of life (FQoL).

Like child characteristics, secondary demands placed on families raising children with ASD are likely to change over time in relation to the child's particular developmental stage. To date, it appears that the pile-up of family demands may be greater in parents of children in middle childhood [24]; however further research is required to understand this trajectory and its implication of raising children in early adolescence. In addition, the extent to which family demands trigger a crisis in the family unit largely depends on the family's resources and appraisal of the event, with certain family environments (i.e. supportive and open) promoting more effective coping in families raising children with ASD [22].

## Resources (bB)

Family resources are one factor suggested by the double ABCX model to influence the interaction between stressors and family adaptation. Family resources may make the family less vulnerable to stress and more resistant to the strains associated with raising a child with a disability. As resources are comprised of internal and external capabilities present within individuals, the family and the wider community [21], four key resources suggested to support families raising children with ASD include family hardiness, the family environment, marital support and social support. While resources pertaining to individual capabilities have been the focus of much past research, there is much to be said about the potential protective factors of aspects of the family unit, as discussed below.

### Family Hardiness

Family hardiness is a term used to define the durability of the family unit, its sense of commitment, ability to see stressors as a challenge, and its sense of control [48]. This factor may also assist families in coping with raising children with ASD. Greeff and van der Walt [48] highlighted the importance of family hardiness on successful adaptation with strong positive associations found between hardiness and family attachment and changeability. However, caution must be exercised when interpreting these findings, with the majority of outcomes relying on correlational analyses in a small sample consisting of both dual and single parent families.

Only two other studies have investigated the impact of hardiness on mothers raising children with ASD. While hardiness was found to be associated with better mental health and stress outcomes, these studies capture hardiness in individuals rather than hardiness within the family unit [46, 74]. Moreover, no study to date has investigated the association between child age, family hardiness and family outcomes leaving many questions unanswered about the role of family hardiness as a coping resource across key stages in child development.

### Family Environment

The family environment is defined as the extent to which family members support each other, are open and express their feelings towards one another [95]. The majority of studies have investigated the family environment as an outcome variable in families raising children with ASD [6, 48, 56, 83]. Only one study has considered the family environment as a protective factor, assisting coping within families. Bristol [96] reported high levels of cohesion and expressiveness among parents of children with ASD to be associated with greater competence and acceptance of the child, and greater marital happiness, respectively. However, no research has investigated the influence of the family environment on stress and FQoL.

Evidence suggests that cohesion may be a particularly important resource within the family environment. This factor captures the support family members provide one another in raising a child with ASD, and can be described on a continuum of enmeshment and disengagement [3]. Although moderate levels of cohesion are suggested to be beneficial to families raising children with a disability [97], findings indicate that higher levels of cohesion (i.e. families who are excessively involved with the lives of their children and very protective) may be beneficial for adaptation in families of children with ASD [3, 48, 69].

What remains unclear, however, is whether different levels of cohesion are beneficial at different stages of a child's life. High levels of cohesion, for example, may be a positive resource for families during times of dramatic change, such as initial diagnosis or transition to school, where children need extra support around developing skills and adapting to change. Such high levels may be less helpful in other stages of development (e.g. middle childhood) when the family may have settled and children have the opportunity to develop more independence and growth [3]. The ambiguity surrounding optimum levels of cohesion in families of children with an ASD highlight the need to understand the family environment across periods of child development, a factor unaccounted for in studies to date.

### Marital Relationship

In addition to resources associated with the family environment and the strength of relationships between family



members, the strength of the marital relationship is an important form of support to families. Evidence suggests that spousal support is associated with fewer depressive symptoms, higher relationship quality and greater child acceptance in families raising children with ASD [96]. In addition, spouses have been rated as the most important support system in these families [4, 70]. Two studies to date have investigated the role of the marital relationship at different stages of child development, demonstrating the continued importance of spousal support over time [50, 79] with higher levels of satisfaction within the marital relationship associated with less stress and burden among parents. Once again, one major limitation of these studies was the large age ranges of children included in the samples. This may confound study outcomes in relation to determining the trajectory of marital adjustment over time. Although addressing the experiences of parents of adolescents and adults with ASD, the findings cannot be generalised to parents of preschoolers or school-aged children.

Like the family environment, many studies have focused on the marital relationship as an outcome variable of family adaptation, indicating less marital satisfaction in mothers of children with ASD in comparison to mothers of children with other disorders [56, 69], and less positive expression within the marital relationship [45]. While current findings suggest spousal support plays a mediating role in family adaptation, greater understanding of the importance of the marital relationship in families of young children with ASD are needed, including its potential as a protective factor, in successful adaptation.

### Social Support

Numerous studies have highlighted the positive impact of a supportive environment for families raising children with ASD. These studies suggest that social support may act as a buffer against the negative impact of stressors, with social support found to be associated with lower maternal distress, depression, negative affect, and stress, and greater use of positive coping strategies and adjustment [6, 29, 30••, 38, 53, 70, 72, 78]. The type and number of supports available have also been shown to impact study findings [92], with a greater number of positive supports found to improve family outcomes.

While the positive impact of informal support networks (i.e. family and friends) has been well established, limited research has investigated the role of formal support services (i.e. professionals, other services) [5]. This gap is surprising considering the suggested reduction in the number of formal supports available to families over time [81, 91] and the reported association between professional support and positive outcomes in mothers of children with ASD aged 4 to 21 years [62].

The stage of the child's development may influence the impact of support perceived by the family. Middle childhood is a stage where parents have reported feeling most supported

by friends and services [71]. However, few studies have investigated the variable of child age on support networks. Due to the limitations of Tehee et al.'s [71] study (i.e. small sample, lack of relationship between child age, support, and stress measures and unknown impact of child characteristics such as problem behaviour or ASD severity on study outcomes), research that builds on these initial findings is required. Thus, more detailed analysis into the benefits of formal support and the role of social support over time is important to understand the global impact of social support and its apparent protective status to families raising children with ASD.

### Appraisal (cC)

Appraisals encapsulate the manner in which families perceive and interpret the stressor event (e.g. in a negative or positive light), incorporating a family's view about their ability to address the stressor and whether it is something worth overcoming [6]. Many variables have been investigated as a form of appraisal in previous studies examining the double ABCX model in families of children with ASD. These include self-blame and catastrophising [28]; challenge and threat [29]; reframing [6]; parental stress [4, 24, 49, 70]; the implications of raising a child with ASD [66]; and sense of coherence (SOC) [30].

While high SOC has been associated with positive outcomes in families [29, 30••, 70] and has been suggested to mediate relationships between stressors and family outcomes [63], parents of children with ASD have been found to report lower levels of SOC than other families [67]. However, once again, these studies fail to account for changes in appraisals across different stages of a child's development. In addition, they do not assess 'family' appraisals in their measures of SOC. In order to understand this perception of family life a measure of family SOC is required.

Family sense of coherence (FSOC) extends the definition of SOC to encapsulate a family's assumptions of the family unit and the outside world, including the resources available to it and the ability to manage stressful situations (i.e. that they are manageable, meaningful and comprehensive) [98]. By viewing the challenges associated with their child's diagnoses in a positive light, families may attribute meaning to their situation, thereby facilitating the selection of appropriate coping styles and subsequent adaptation [24, 70, 98].

Findings from the wider disability literature indicate that higher levels of FSOC are related to greater adaptation and a higher level of reorganisation following crises [98]. In addition, FSOC has demonstrated strong associations with FQoL and acted as a significant mediator between illness stress and quality of life [99]. Further, FSOC has been found to account for up to 35 % of the variance in family adaptation [100]. Despite these outcomes, no study has explored the impact of

FSOC on families raising children with ASD, or investigated possible changes in the impact of FSOC over time, or its relationship with other variables in the double ABCX model.

### Coping (BC)

Coping is the factor in the double ABCX model that connects resources, appraisals and behavioural strategies to restore a balance in family functioning [6, 24]. This may involve reducing demands, seeking new or maintaining useful resources, or changing the meaning of the stressor event [21]. Coping has been widely studied in the ASD literature with both quantitative and qualitative research attempting to define the most beneficial strategies to assist families in raising children with ASD. To date, these strategies remain unclear, determined by a number of contextual factors [61]. However, there is evidence to suggest that problem-focused coping (i.e. actions which aim to solve problematic situations) and positive reframing (i.e. reinterpreting a problem in a positive light) are associated with reports of greater parental wellbeing in families of children with ASD [e.g. 6, 35, 38, 40, 55, 59, 61, 89].

Studies have also investigated parental coping over time with mixed findings. Despite some studies indicating no age affects [54], Smith et al. [9] provide valuable information about differences in maternal coping at specific stages of child development. In their study, mothers of older children engaged in greater detachment from stressors, and reported higher levels of anger compared to mothers of toddlers. However, it is unclear whether differences in sample cohorts may have contributed to study outcomes (e.g. mothers of younger children were more likely to be married and receive higher incomes). In addition, the findings may not be able to be generalized to parents of children aged between 4 and 10 years of age, and, possible differences in parental coping are unknown with data collected solely from maternal caregivers. Such restrictions limit the generalisability of study outcomes. In particular, little remains known about the critical stage when many children are entering the school system.

The coping literature demonstrates the importance of contextual factors such as parent gender [e.g. 30••] and child age in the process of successful family adaptation. However, like other factors in the double ABCX model, gaps still exist regarding the use of paternal reports and an understanding of coping as children develop.

### Family Adaptation (xX)

Both positive and negative outcomes co-occur in families raising children with an ASD. Predicted by different factors, it is important to distinguish both outcomes as separate measures of family adaptation [18, 101]. To date, family adaptation has been conceptualised by measures of the family environment [e.g. 6], parental stress [e.g. 6, 65], maternal depression [e.g. 28], marital

adjustment [e.g. 28, 56], quality of parenting [e.g. 28] and family attachment and changeability [e.g. 48]. Thus, the definition and operationalisation of family adaptation varies from study to study. Mothers and father's experiences of adaptation are also unclear with some studies suggesting higher levels of both negative (e.g. stress and depression) and positive outcomes (e.g. positive perceptions/experiences) in mothers [14, 55, 58], and others suggesting no reported differences [e.g. 39, 52].

Unlike other constructs used to measure family adaptation, FQoL is a recent measure developed to capture the importance and satisfaction of different aspects of family life from the perspective of family members. Family quality of life has been associated with child behaviour problems, social support, SOC and psychological wellbeing in parents of children with ASD. It is conceptualised as a positive outcome variable and has been shown to relate to different predictors of mother and father adaptation [30••]. While preliminary evidence suggests an association between child age and family adaptation, no research to date has explored FQoL across child development.

Stress is a measure of family adaptation which has received more attention (than FQoL). However, results to date have been inconsistent, with some studies suggesting higher stress in parents of younger children [e.g. 7, 81, 85], some studies indicating no age-related effects [e.g. 54, 84, 88], and other studies suggesting differences in parent gender and child age [e.g. 34]. One study investigated the trajectory of maternal stress, focusing on mothers of children in preschool, middle childhood, and adolescence [65]. While the findings indicated a variable pattern of maternal stress across child development, participants included mothers of children with developmental disorders where data was not available for all age cohorts (i.e. behaviour problems in children aged 2 to 5 years).

By charting the change in stressors, resources, appraisals and positive outcomes over time, information regarding potential risk and protective factors for successful adaptation, captured by FQoL measures, can be explored. However, to date, the majority of studies have employed designs focused on a range of different predictors of the outcomes of one family member. The recent findings of gender differences in parental experiences of adaptation prompt greater exploration into the role of mothers *and* fathers in raising children with ASD.

### The Role of Parent Gender

Like mothers, fathers of children with ASD have been found to demonstrate higher levels of stress than fathers of children without ASD [8•, 14, 33, 37, 51]. However, in a recent review investigating the involvement of fathers in ASD, Braunstein and colleagues [31•] concluded that despite child age, journal type, or publication date, fathers were rarely included in studies assessing the impact of raising a child with ASD on parents.

The limited studies that have included both parents in investigations of family outcomes demonstrate mixed results.

The majority of studies indicate that mothers experience greater stress levels than fathers [14, 47, 57, 60, 71, 83], which may be the result of greater involvement with the child [71]. Nonetheless, some research has also suggested similar experiences of stress between parents [39, 52, 55]. While in some studies fathers have been found to report no direct impact of child characteristics on their subsequent wellbeing [47], in others, fathers report higher levels of stress than mothers [68]. This suggests that there is still much to be explained about the experiences of parents raising children with ASD. Parental roles within the family, for example, may influence the experiences of mothers and fathers, with differences in occupation and time spent with the child found to impact parent outcomes in families raising children with ASD [47, 71].

In addition to differences in the experience of stress, maternal and paternal outcomes have been shown to be affected by different predictors. Maternal stress, for example, has been attributed to a number of child characteristics including greater emotional dysregulation [39], poor social skills [32, 33], executive dysfunction and sensory difficulties [42] and increases in behaviour problems [52, 55, 57]. Relationship factors including lower levels of relationship satisfaction and spousal support [37] have also been identified as sources of stress in mothers. Alternatively, fathers report higher levels of stress in relation to child externalising behaviours [39, 57], ASD symptoms [68], poor child sensory and cognitive awareness [32] and less social support [37]. Together, both parents have been found to demonstrate positive relationships between child social deficits [39], partner mental health [47, 52, 55] and parent stress.

Parents also report disparities in the strategies employed to cope with raising a child with ASD. Specifically, mothers have been found to report more positive experiences in relation to raising their child than fathers [58], and a greater use of positive and problem-focused coping [59]. Greater reports of avoidance coping [54] and feeling threatened by the challenge of raising a child with ASD have also been found [29] for mothers. Fathers, on the other hand, report engaging more frequently in active avoidance coping [30••]. While this research highlights the different experiences of mothers and fathers in raising children with ASD, few studies have compared parental reports of family adaptation through the use of the double ABCX model [e.g. 4, 29, 30••]. In turn, these studies have investigated different stressors, appraisals and outcomes of adaptation, making it difficult to compare and interpret study findings.

## Summary and Conclusions

The heightened stress and strain placed on families raising a child with ASD has been consistently highlighted in studies comparing families of children with ASD to control groups.

Research has demonstrated that families have to manage competing child related stressors such as increased maladaptive behaviour and impairments in communication, social skills and adaptive functioning. In addition, they may be equipped with less personal and family resources (e.g. lower marital satisfaction and social support), a lower propensity to view their situation as meaningful, manageable and comprehensive, and demonstrate greater use of maladaptive coping strategies. Each of these aspects appear to impact the success of a family in adapting to raising a child with ASD, and play a role in protecting against or increasing the risk of negative family outcomes.

Despite this evidence, families have demonstrated resilience and adaptation in the face of identified stressors. These findings raise a number of questions about the breadth of family experiences and key contributing factors for positive family outcomes. However, there are a number of methodological limitations that confound the generalisability of the findings to date, in particular the conceptualisation and measurement of family experiences. This is an important factor to consider when referencing the double ABCX model and considering the overlap of variables included in analyses. As previously noted, the need for separate and distinct tools to differentiate core ASD symptoms from measures of maladaptive and adaptive behaviour may provide clarity to the current overlap between child characteristics and their influence on family outcomes. Also, measurement of family experiences often provides similar conceptual overlap between family resources, appraisals, coping strategies and adaptation. Further, the definition of adaptation is variable in individual studies with a number of predictor variables often defined as outcomes of adaptation and vice versa. As a result, further clarification of the rationale for and validity of constructs used in this area is required to determine potential risk and protective factors for families in order to develop appropriate support and intervention resources.

Limited longitudinal research has demonstrated the fluid nature of child and family experiences over time. Generally, child characteristics have been shown to improve as children develop, with some evidence of a positive impact on parental outcomes. However, this evidence is sparse and more research is needed to capture changes in family resources, appraisals and positive experiences over phases of child development. Although, a number of studies have attempted to address the impact of child age on family outcomes, findings are generally focused on specific (e.g. adolescence) or global (e.g. children aged 2 to 18 years) stages of development. This limits interpretation of the trajectory of family experiences over time, especially considering the use of multiple constructs, designs, and samples used in current research.

A recently acknowledged and growing area of focus is the impact of raising a child with ASD on the family system, broadening the understanding of experiences to other family

members, in particular, fathers. The importance of this shift in parent report is demonstrated by findings of significant gender related differences in parent's perceptions, resources, identified stressors, and coping strategies in raising a child with ASD. Information from both parents is essential for developing programs to support parents, and can highlight the need to consider different models of support for mothers and fathers. However, these findings remain unclear particularly in regards to the double ABCX model.

In order to address the question of how to better support families raising children with ASD, further understanding of family experiences are required in a number of critical domains. Specifically, 1) a greater focus on factors that promote resiliency in individual family members and the family unit; 2) specific measurement of stressors, resources, appraisals, coping and adaptation; 3) research examining positive and negative experiences of mothers and fathers with a focus on the specific predictors of each outcome; and 4) measurement across the developmental trajectory.

Due to the fluidity of family needs, particular resources and coping strategies may be beneficial to families at different stages of child development within different family members. Thus utilising a theoretical framework that incorporates both the challenges and rewards of raising children with ASD will assist in the development of appropriate support services to be implemented at these time points. While no model will account for the myriad of experience of individual families, the results from this more holistic approach have the potential to determine effective coping strategies, and inform stakeholders and policy makers about risk and protective factors. Further information about how to improve family outcomes may also serve to reduce the long-term economic costs of education and care for families of children with an ASD.

#### Compliance with Ethics Guidelines

**Conflict of Interest** Rebecca L. McStay, David Trembath and Cheryl Dissanayake declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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