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Maternal stress predicted by characteristics of children with autism spectrum disorder and intellectual disability

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ABSTRACT

To determine maternal stress and child variables predicting maternal stress, 104 mothers of children with autism spectrum disorder (ASD) and intellectual disability (ID) completed the Dutch version of the Parental Stress Index (PSI; De Brock, Vermulst, Gerris, & Abidin, 1992) every six months over a period of two years. The level of maternal stress remained stable over time. Child characteristics predicting maternal stress are behavioral inflexibility toward objects and initiating social interactions. However, these factors do not predict maternal stress when analyzed in combination with children's emotional and behavioral problems measured on the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000). The subscales emotionally reactive behavior, withdrawn behavior and attention problems explain a third of the variance in maternal stress. This study revealed no relation between maternal stress and children's developmental age and IQ, receptive and expressive language, adaptive behavior, severity and subtype of ASD, behavioral flexibility toward the environment and persons, initiating and responding to joint attention, initiating and responding to behavioral requests, responding to social interactions and the other subscales of the CBCL. Findings are discussed in relation to the clinical and non-clinical norm groups of the PSI, the limitations of the study and clinical practice.

1. Introduction

Parenting a child with autism spectrum disorder (ASD) may face parents with unique challenges due to the nature of ASD, as children with ASD are significantly impaired in social interaction and communication and show restricted and stereotyped patterns of behaviors (APA, 2000). Additionally, intellectual disability (ID), anxiety, sleeping and eating disturbances, temper tantrums, self-injury and aggressive behavior, social isolation and difficulties in self-care are frequently seen in children with ASD, causing considerable challenges to parents on a daily basis (e.g., Cotton & Richdale, 2010; Matson & Shoemaker, 2009; Rodrigue, Morgan, & Geffken, 1991; Schreck, Williams, & Smith, 2004; White, Oswald, Ollendick, & Scahill, 2009).

Many parents experience the period in which their child obtains the diagnosis of ASD as additionally stressful, especially when there is a lack of clarity about the diagnosis, the diagnosis is set comparatively late and when there is a delay between the first concerns and the final diagnosis (Brogan & Knussen, 2003; Howlin & Moore, 1997; Moh & Magiati, 2011). Concerns

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about the future of the child, his or her level of cognitive and communicative impairment, physical health and needs and abilities to get accepted in the community, to function independently and to obtain help may even further elevate stress (Baxter, Cummins, & Yiolitis, 2000; Koegel et al., 1992; Konstantareas & Homatidis, 1989; Ogston, Mckintosh, & Myers, 2011). Furthermore, early intervention of a young child with ASD may be very intensive, and selecting, coordinating and advocating treatment can be burdensome (Johnson & Hastings, 2002; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Trudgeon & Carr, 2007). Finally, families are faced with financial issues associated with having a child with ASD due to their child's challenging behavior, therapy costs and lifestyle changes that may cause heightened stress levels (Sharpe & Baker, 2007).

However, while it is known that parenting a child with ASD may cause elevated levels of stress, not all parents with a child with ASD report heightened stress levels (Ornstein Davis & Carter, 2008). Stress in parents of children with ASD seems related to parent characteristics as gender, age and coping style (Dąbrowska & Pisula, 2010; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings & Johnson, 2001; Herring et al., 2006) and (perceived) levels of social and professional support (Bromley, Hare, Davison, & Emerson, 2004; Dąbrowska & Pisula, 2010; Dunn et al., 2001; Hastings & Johnson, 2001). In addition, interrelationships between mothers, fathers and other family members influence parental stress. For example, Hastings (2003) found that child behavioral problems and father's mental health (i.e., anxiety and depression) were associated with mother's stress.

Also, child variables may be linked to increased levels in parental stress. Most studies have focused on the severity of the child's disability and behavioral problems and found that the latter may be a more prominent stressor for parents than the severity of the disability itself (Bromley et al., 2004; Hastings, 2002; Hastings et al., 2005; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006). However, studies on the relationship between maternal stress and other variables related to diagnosis are inconclusive. For example, Mori, Ujiie, Smith, and Howlin (2009) reported no relation between parental stress and IQ and results about the relation between maternal stress and impaired adaptive behavior are mixed (Beck, Hastings, Daley, & Stevenson, 2004; Lecavalier et al., 2006; Tomanik, Harris, & Hawkins, 2004). On the other hand, several studies report that higher parental stress is associated with higher autism symptom scores (Hastings & Johnson, 2001; Konstantareas & Homatidis, 1989; Konstantareas & Papageorgiou, 2006). Other child factors associated with higher parental stress are amongst others lower social skills (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005), less responsiveness to interactions and social relatedness (Ornstein Davis & Carter, 2008; Kasari & Sigman, 1997), temperament (Konstantareas & Papageorgiou, 2006) and repetitive and self-injurious behavior (Konstantareas & Homatidis, 1989).

As stated in Lecavalier et al. (2006) some of the outcomes of instruments used in above studies may be influenced by the child's level of functioning or the presence of behavioral problems and as a result obscure the associations between particular child characteristics and parental stress (e.g., the CARS, which is used to measure autism severity contains items regarding hyperactivity and anxiety). Furthermore, not all studies have used reliable measures for child characteristics of ASD, behavior and developmental age, but relied on reports of the mothers. As longitudinal studies addressing maternal stress are scarce, this study investigates if and how child characteristics influence maternal stress using a longitudinal design. As data was collected on several variables (i.e., cognitive functioning, adaptive behavior, autism subtype and severity, behavioral flexibility, communication and behavioral problems), an attempt was made to provide a comprehensive view of child characteristics and their relative contribution to maternal stress.

We aimed at improving above studies in several ways. To confirm the diagnosis of ID and assess developmental age and IQ the Mullen Scales of Early Learning (MSEL; Mullen, 1995) and the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) were administered in a relatively large sample of children ($n = 104$). As children with lower developmental age and adaptive behavior are more dependent upon their parents to meet their needs, we expect higher maternal stress in mothers of children with lower developmental age and lower levels of adaptive behavior.

Subsequently, the diagnosis of ASD was confirmed by administering the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2006) and the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Rochen Renner, 2007). To further address heterogeneity of ASD, subtypes of social interaction and communication were included in the analyses as these three subtypes (i.e., aloof, passive, and active-but-odd; see, Wing & Gould, 1979) may correspond to distinct subgroups of children with ASD (Beglinger & Smith, 2001). Castelloe and Dawson (1993) suggested that the aloof and active-but-odd subtypes fall at two ends of the continuum with the most autistic children in the aloof group and the least autistic in the active-but-odd group. In concurrence with the literature, we hypothesize that as the severity of autism increases, maternal stress increases and that higher maternal stress is reported by mothers of children with the aloof subtype than in the active-but-odd group with the passive subtype in the middle.

As poor communication skills are related to increased levels of stress (Baxter et al., 2000), data were collected on early social communication skills (i.e., joint attention, behavioral requests and social initiations) and receptive and expressive language. We expect that mothers of children with less communication skills experience more maternal stress than mothers of children who have better communication skills.

Next to impairments in communication and social interaction, the insistence on sameness is one of the core features of ASD and there is accumulating evidence of an increased risk of problems with behavioral flexibility in individuals with ASD (Green et al., 2006; Didden et al., 2008; Peters-Scheffer, Didden, Sigafoos, Green, & Korzilius, submitted for publication). We hypothesize that behavioral inflexibility may be burdensome to the mothers and that mothers of children with more problems regarding behavioral flexibility experience more maternal stress than mothers of children who are more flexible.

Considering the interplay between maternal stress and behavioral problems, data were collected on emotional and behavioral problems as well. We hypothesize that mothers of children with more behavioral problems experience more stress than mothers of children with fewer behavioral problems. Finally, we expect that behavioral problems predict parental stress over time (Lecavalier et al., 2006). A longitudinal design was used and all variables were measured over a period of two years. One hundred and four mothers completed measures on stress, and their child's behavioral problems, behavioral flexibility, severity of autism and adaptive behavior. In addition, data on cognitive functioning, (non-verbal) communication and language were collected in the children. Due to the absence of a control group, outcomes of the children with ASD and ID were compared to those of the clinical and non-clinical norm groups of the Parental Stress Index (PSI; De Brock, Vermulst, Gerris, & Abidin, 1992). Next, predictors of maternal stress were explored.

2. Method

2.1. Participants and setting

Participants were 104 mothers of children with ASD and ID enrolled in longitudinal study on the development of children with ASD and ID in the Netherlands. Over a period of two years, data were collected on maternal stress, and a range of child variables related to cognitive functioning, adaptive behavior, autism severity and subtype, early social communication, language, behavioral flexibility and emotional and behavioral problems.

All children (78 males) had received a clinical diagnosis of ASD (82 autism; 22 Pervasive Developmental Disorders-Not Otherwise Specified [PDD-NOS]) and ID (17 profound ID; 33 severe ID; 33 moderate ID; 19 mild ID; 2 borderline ID) from a child psychiatrist or a multidisciplinary diagnostic clinic independent of the study. In all children the diagnosis of ASD was confirmed by the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2006) and the Childhood Autism Rating Scale (CARS; Schopler et al., 2007) and the diagnoses of ID was confirmed by the Mullen Scales of Early Learning (MSEL; Mullen, 1995) and the Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 1984) administered by the first author at baseline. All children attended a preschool or school for children with ID. Information about the demographic characteristics is presented in Table 1.

Table 1
Characteristics of the participants and Pearson's correlations with maternal stress at baseline.

Child variables	Descriptives			Maternal stress	
	n	*M*	*SD*	*r*	*p*
Cognitive functioning					
Developmental age in months	104	23.13	7.85	.09	.39
IQ	104	35.71	15.20	−.02	.87
Non-verbal IQ	104	40.41	15.76	−.03	.77
Adaptive behavior in months					
Composite	104	19.70	5.50	.12	.22
Communication	104	24.85	9.64	.02	.85
Daily Living Skills	104	22.24	7.92	.16	.11
Socialization	104	22.15	6.18	.05	.65
Behavioral flexibility					
Behavioral flexibility (total)	102	10.18	6.48	.34	<.001
Behavioral flexibility: objects	102	6.37	3.81	.37	<.001
Behavioral flexibility: environment	102	2.19	2.02	.23	.02
Behavioral flexibility: persons	102	0.70	0.96	.15	.15
Emotional and behavioral problems					
CBCL total	102	66.22	25.47	.55	<.001
Internalizing	102	21.46	9.46	.51	<.001
Externalizing	102	24.05	10.84	.49	<.001
Autism					
ADOS total	104	15.13	4.09	.01	.93
ADOS communication	104	5.79	1.85	−.04	.70
ADOS social interaction	104	9.50	2.88	.02	.84
CARS	104	40.71	5.88	.18	.06
Early Social Communication Scales					
Initiating joint attention	88	7.16	8.52	−.07	.52
Responding to joint attention	88	94.15	66.49	−.04	.69
Initiating behavioral requests	88	23.30	6.83	−.02	.47
Responding to behavioral requests	88	67.69	31.41	.07	.87
Initiating social initiations	88	2.52	1.79	.24	.03
Responding to social initiations	88	6.80	3.28	−.00	.97
Language					
Receptive language	104	25.11	4.53	.07	.46
Expressive language	101	20.13	8.39	−.07	.50

2.2. Variables and measures

All measures were selected for their good psychometric properties and their applicability to children with ASD and/or ID.

2.2.1. Parental stress

Parental stress was measured by the Dutch version of the Parental Stress Index, short form: the Nijmeegse Opvoedingsstress Index (PSI; De Brock et al., 1992). Using a six-point Likert-type scale, caregivers rated 25 items regarding the upbringing of their child. In the manual of the PSI a non-clinical and a clinical norm group are described and due to the absence of a control group outcomes of the present study are compared to these norm groups. In general, mothers seem to experience more stress than fathers (Dąbrowska & Pisula, 2010), complicating between-subject comparison due to the gender effect of the parent. To avoid the confounding effect of the gender of the parent, only mothers – as primary caregivers – were asked to complete the PSI.

2.2.2. Developmental level

The Mullen Scales of Early Learning (MSEL; Mullen, 1995) is a standardized measure to assess the developmental level of children from birth to 68 months of age. A developmental age was calculated averaging age equivalent scores on the visual reception, fine motor, receptive language and expressive language scales. Since most children were typically too old and/or too low functioning to determine standardized scores, a ratio IQ was calculated using the following formula: developmental age divided by chronological age and multiplied by 100.

2.2.3. Autism

The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2006) is a semi-structured observation to assess social and communicative functioning in individuals suspected of having an ASD. The Childhood Autism Rating Scale (CARS; Schopler et al., 2007) was administered as a measure of symptom severity. The Wing Subgroups Questionnaire (WSQ; Castelloe & Dawson, 1993) is a questionnaire with 13 behavioral domains (e.g., communication, social approach, play, imitation, motor behavior, resistance to change) on which parents rate their child's behavior. A summary score is calculated for each subtype (i.e., aloof, passive and active-but-odd) and the highest summary score is considered to indicate the subtype.

2.2.4. Adaptive behavior

The Dutch version of the Vineland Adaptive Behavior Scale – survey form (VABS; Sparrow et al., 1984) was used to measure adaptive behavior across three domains: Socialization, Communication and Daily Living Skills. Based on the subscales a composite score was derived.

2.2.5. Emotional and behavioral problems

The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000) is a well-known and widely used questionnaire with 100 items on various problem behaviors grouped into seven syndrome scales: emotional reactive, anxiety, somatic complaints, withdrawn, sleep problems, aggressive behavior and attention deficits. In addition, scores on internalizing, externalizing and total scales were calculated. Based on the developmental and chronological age of the participants the CBCL 1.5–5 years was used.

2.2.6. Behavioral flexibility

The Behavioral Flexibility Rating Scale – revised (BFRS-R; Green et al., 2006, 2007) is a scale for assessing behavioral flexibility in individuals with developmental disabilities. Using a three-point Likert-type scale, ranging from 0 ('not a problem at all') to 2 ('the situation causes severe problems'), caregivers rated the severity of challenging behavior as a result to specific and unexpected events and changed routines that could be problematic to the individual. The BFRS-R comprises three factors: (1) flexibility toward objects, (2) flexibility toward the environment and (3) flexibility toward persons (Peters-Scheffer et al., 2008).

2.2.7. Early communication

The Early Social Communication Scales (ESCS; Mundy et al., 2003) are designed to assess nonverbal communication behavior (e.g., joint attention, behavioral requests and social initiations) in young children during a videotaped semi-structured observation. The first author administered the ESCS and videotapes were scored by four raters, unaware of the exact aim of the study and other scores of the participants. Interrater reliability was assessed using videotaped data from 29% of the children and intraclass correlation coefficients between the paired ratings of the six subscales ranged from .66 to .73 suggesting good reliability (Cicchetti, 1994).

2.2.8. Language

Receptive language was measured by the Peabody Picture Vocabulary Test (PPVT; Dunn & Dunn, 1997), while expressive language was measured by the vocabulary test of the Schlichting Test for language production (Schlichting, van Eldik, Lutje Spelberg, van der Meulen, &van der Meulen, 1995).

2.3. Procedure

The children were identified by local preschools and schools for children with ID in The Netherlands. The (pre)schools distributed letters to the parents of children who met the following inclusion criteria: (1) chronological age from 2 to 9 years; (2) a documented diagnosis of ID and ASD (i.e., autism or PDD-NOS) set by a psychiatrist or a psychologist supported by psychometrically reliable and valid measures; (3) children lived at home at the start of study; (4) absence of medical conditions which could interfere with data collection (e.g., severe epilepsy, visual impairment); (5) written consent of the parents.

Once participants were selected, the first author scheduled an in-home interview with the parents to administer the VABS and the CARS. Six, 12, 18 and 24 months later the questionnaires were administered to the parents during an interview by phone. A week before the interview, the CBCL, BFRS-r, WSQ and the PSI were sent out by mail to the parents along with an information letter and a prepaid and addressed return envelope. The information letter provided contact details and the first time instructions about completing the questionnaires. If the parents had not returned the questionnaires within 4–6 weeks, the researcher sent a reminder. Families did not receive any honoraria for their participation.

In the same month as the first interview was held the first author assessed the MSEL, ADOS, ESCS and the language tests to the child at the preschool or school and the same tests, except for the ADOS, were administered after 12 and 24 months. The ADOS was only administered after 24 months.

3. Results

3.1. Maternal stress

Scores of maternal stress over two years are displayed in Table 2. Scores remained relatively stable over time and ANOVA repeated measures indicated no significant differences between the five assessments over time (F (3.15,327.78) = 1.37, p = .25). One sample t-tests were used to compare the means to the norms of the clinical group of the PSI and no significant differences were found between the mean of the clinical norm group (M = 85.9; SD = 24.3) and the five assessments in the ASD and ID group (M = 80.65–85.00; SD = 25.97–29.16), all p's $>$ 05. However, means of the five assessments of the ASD and ID group were considerably higher than the mean reported of the mothers of the non-clinical norm group of the PSI (M = 54.4; SD = 19.3), all p's $<$ .001. Between 36 and 45% of the mothers in the ASD and ID group scored at or above the 95th percentile of the stress scores reported by the non-clinical norm group. Hence, mothers of children with ASD and ID experience more stress than mothers of the PSI norm group consisting of typically developing children, but no differences were found between the maternal stress experienced by mothers of the ASD and ID group and the clinical norm group of the PSI.

3.2. Child variables associated with maternal stress

Pearson correlations were calculated to explore which variables are associated with maternal stress. These analyses showed that there were associations with small to moderate effects between maternal stress and the initiation of social initiations, a moderate effect on behavioral flexibility and large effects on emotional and behavioral problems. Further, a trend was found between maternal stress and autism severity as measured by the CARS. No associations were found between maternal stress and children's level of cognitive functioning, adaptive behavior, language, responding to and initiating behavioral requests and joint attention.

The results of these analyses are shown in Table 1. As associations between maternal stress and the other variables after 6, 12, 18 and 24 months were not substantial different from the associations of the baseline, only the baseline results are reported in Table 1.

3.2.1. Developmental age and adaptive behavior

Although correlations revealed no significant associations between maternal stress and developmental age or IQ, a one-way ANOVA was performed with maternal stress as dependent variable and six categories of developmental age as independent variable (i.e., 9–14, 15–20, 21–26, 27–32, 33–38 and 39–44 months). There was no significant difference on

Table 2
Maternal stress during baseline and after 6, 12, 18 and 24 months. Percentages of scores representing respectively very low, low, below average, average, above average, high and very high compared to the norms of the clinical group of the PSI are displayed.

	n	*M*	*SD*	Range	Very low	Low	Below average	Average	Above average	High	Very high
Baseline	104	81.64	26.73	26–144	16.3	5.8	9.6	40.4	15.4	6.7	5.8
After 6 months	96	85.00	29.16	25–150	11.5	9.4	14.6	27.1	16.7	11.5	9.4
After 12 months	95	80.65	25.97	25–142	12.8	9.6	12.8	38.3	14.9	7.4	4.3
After 18 months	75	83.09	27.75	28–142	10.7	6.7	20.0	32.0	14.7	5.3	10.7
After 24 months	79	84.99	28.09	27–143	10.3	6.4	14.1	38.5	10.3	7.7	12.8

maternal stress between the categories of developmental age (F (5,97) = 1.37, p = .24), nor on the categories of severity of ID (i.e., borderline, mild, moderate, severe, profound; F(4,99) = 0.73, p = .57). Furthermore, there was no significant difference in maternal stress between the categories of adaptive behavior (i.e., 9–14, 15–20, 21–26, 27–32, 33–38 and 39–44 months; F (5,98) = 0.56, p = .73).

3.2.2. Autism severity and subtype

As children with ASD are a heterogeneous group, several analyses were conducted to explore within-group differences related to ASD. First, an independent t-test was conducted to explore differences in maternal stress between mothers of children with PDD-NOS (n = 22; M = 81.36, SD = 24.06) and those of children with autism (n = 82; M = 81.72; SD = 27.54). On average, mothers of children with PDD-NOS experienced comparable levels of stress to mothers of children with autism, t(102) = −.06, p = .96. Based on percentile scores on the CARS, participants were divided into four subgroups and a one-way ANOVA was conducted with autism severity as independent variable and maternal stress as dependent variable. Results did not reveal a significant effect of autism severity on maternal stress (F (3,100) = 1.56, p = .20).

As the subtypes may refer to distinct subgroups, a one-way ANOVA was performed with Wing's subtypes (i.e., aloof, active-but-odd and passive) as independent and maternal stress as dependent variable. There were no significant differences in maternal stress between subgroups, (F (2,101) = 0.61, p = .55).

3.2.3. Emotional and behavioral problems

To assess whether emotional and behavioral problems predict maternal stress a simple regression analysis between emotional and behavioral problems as independent variable and maternal stress as dependent variable was performed. Emotional and behavioral problems accounted for 30.1% of the variance in maternal stress (B = .57; $SE\ B$ = .09; β = .55; $p < .001$, F (1,100) = 43.06, $p < .001$).

Subsequently, a regression analysis was conducted to determine which subscales contributed significantly to maternal stress. A stepwise method was used whereby maternal stress was entered as the dependent variable and the raw scores of the subscales emotionally reactive, anxiety/depressed, somatic complaints, withdrawn, sleep problems, aggressive behavior and attention problems as independent variables. Table 3 displays the unstandardized regression coefficient (B) the standard error of the unstandardized regression coefficient ($SE\ B$) and the standardized regression coefficient (β) at each step.

R^2 was significantly different from zero at the end of each step. All three models significantly improved the ability to predict maternal stress, with the first model the best, (model 1: F(1,100) = 32.65, $p < .001$; model 2: F(2,99) = 21.81, $p < .001$; model 3: F (3,98) = 16.95, $p < .001$).

As the predictors sleep problems (t = −0.38, p = .71), anxiety/depressed (t = −0.61, p = .54), somatic complaints (t = −0.12, p = .90) and aggressive behavior (t = 1.27, p = .21) did not contribute significantly to the models (results reported for model 3), they were excluded from the analyses. After step 3, in which emotionally reactive, withdrawn and attention problems were included, 34.2% of the variance in maternal stress was accounted for.

3.2.4. Behavioral flexibility

As behavioral flexibility correlated significantly with maternal stress, a stepwise multiple regression analysis with the subscales of behavioral flexibility as independent variables and maternal stress as dependent variable was conducted to determine which subscales contributed significantly to maternal stress. Only behavioral flexibility toward objects contributed significantly to maternal stress (B = 2.56; $SE\ B$ = 0.65; β = .37; $p < .001$) with 13.6% of the variance in maternal stress accounted for. This model significantly predicted maternal stress (F (1,100) = 15.75, $p < .001$). As behavioral flexibility toward the environment (t = −0.31, p = .76), and behavioral flexibility toward persons (t = −0.24, p = .81) did not contributed significantly to the model, these were excluded from the analysis.

3.2.5. Early social communication and language

As children's poor communication skills may increase maternal stress, a regression analysis was conducted including the domains of early social communication (i.e., initiating and responding to joint attention, behavioral requests and social interactions), receptive and expressive language and maternal stress. Only initiating social interaction significantly

Table 3
Multiple regression to predict maternal stress from emotional and behavioral problems for children with ASD and ID (n = 102).

	Step 1			Step 2			Step 3		
	B	$SE\ B$	β	B	$SE\ B$	β	B	$SE\ B$	β
Constant	58.76	4.54		46.11	6.16		39.50	6.67	
Emotionally reactive	3.40	0.59	.50**	2.66	0.63	.39**	2.18	0.65	.32**
Withdrawn				2.25	0.77	.27**	2.09	0.76	.25**
Attention problems							1.89	0.82	.21*

Note: R^2 = .25 for step 1; ΔR^2 = .06 for step 2; ΔR^2 = .04 for step 3.
* $p < 05$.
** $p < 01$.

Table 4
Multiple regression to predict maternal stress from emotional and behavioral problems (i.e., emotionally reactive behavior, withdrawn behavior and attention problems, behavioral flexibility toward objects and initiating social interaction for children with ASD and ID ($n = 88$).

	Step 1			Step 2			Step 3		
	B	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Constant	38.16	7.31		36.99	7.63		35.75	7.77	
Emotionally reactive	2.19	0.73	.32**	1.89	0.91	.27*	2.05	0.92	.30*
Withdrawn	2.52	0.86	.29**	2.58	0.87	.30**	2.57	0.87	.30**
Attention problems	1.39	0.97	.15	1.33	0.97	.14	1.12	1.00	.12
Behavioral flexibility toward objects				0.47	0.84	.07	0.15	0.91	.02
Initiating social interaction							1.40	1.55	.09

Note: $R^2 = .35$ for step 1; $\Delta R^2 = .00$ for step 2; $\Delta R^2 = .01$ for step 3.
* $p < 05$.
** $p < 01$.

predicted maternal stress ($B = 3.55$; *SE B* = 1.62; $\beta = .24$; $p = .03$) with 5.5% of the variance accounted for (F (1,83) = 4.84, $p = .03$). As initiating ($t = -1.03$, $p = .31$) and responding to joint attention ($t = -0.62$, $p = .54$), initiating ($t = -0.15$, $p = .88$) and responding to behavioral requests ($t = -0.34$, $p = 74$), responding to social interaction ($t = -0.82$, $p = .42$), receptive ($t = -0.25$, $p = .81$) and expressive language ($t = -1.22$, $p = .23$) did not contributed significantly to the model they were excluded from the analysis.

3.2.6. Relative contribution of child characteristics to maternal stress

To assess for relative contributions of the child's characteristics to maternal stress a hierarchical regression was employed. As emotional and behavioral problems seem a consistent predictor of maternal stress, the subscales emotionally reactive, withdrawn and attention problems were entered in the first step and behavioral flexibility toward objects in the second step. In the third step, initiating social interaction was entered. Table 4 displays the relevant statistics.

R^2 was significantly different from zero at the end of each step, with the first model the best in predicting maternal stress (model 1: F (3,82) = 14.70, $p < .001$; model 2: F (4,81) = 11.01, $p < .001$; model 3: F (5,80) = 8.95, $p < .001$). F-change was not significant between model 1 and 2 (F (1,81) = 0.31, $p = .58$) and between model 2 and 3 (F (1,80) = 0.81, $p = .37$). The first model, which included emotionally reactive behavior, withdrawn behavior and attention problems, accounted for 35% of the variance in maternal stress.

3.3. Maternal stress and child's emotional and behavioral problems over time

As the child's emotional and behavioral problems seem to be the most important predictor for maternal stress, the stability of emotional and behavioral problems and maternal stress over time was examined using Mplus. A cross-lagged model that specified within-time correlations between maternal stress and behavioral problems (e.g., maternal stress at baseline with behavioral problems at baseline), stability effects for each variable (e.g., maternal stress at 12 months predicted by maternal stress at baseline) and cross-legged effects (e.g., behavioral problems at baseline predict stress at 12 months). The overall fit of the model was evaluated by the CFI (Bentler, 1990), TLI (Tucker & Lewis, 1973), SRMR (Hu & Bentler, 1999) and RMSEA (Steiger & Lind, 1980) indexes. Values of the TLI and CFI ≥ 0.95 and the RMSEA ≤ 0.05 are considered excellent fit, while a SRMR $< .08$ is generally considered a good fit (Hu & Bentler, 1999). The proposed model is displayed in Fig. 1 and consistent with the data, $\chi^2(4) = 7.19$, relative $\chi^2 = 1.80$, TLI = .95 CFI = 99, SRMR = 03. Yet, the RMSEA of 0.11 indicates poor fit. However, the RMSEA can be misleading when degrees of freedom are small and the sample size is not large. Significant within-time correlations and standardized parameter estimates were found between maternal stress and emotional and behavioral problems and stability effects for maternal stress and emotional and behavioral problems

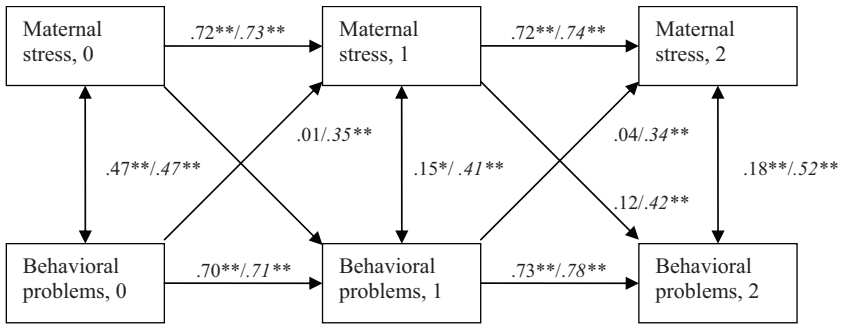

Fig. 1. Model on maternal stress and behavioral problems with standardized parameter estimates (StdXY) and correlations (italicized) at baseline (0), after 12 months (1) and after 24 months (2); *$p < .05$; **$p < .01$.

Table 5
Estimates, standard errors (SE) and standardized coefficients (StdXY) of the model on maternal stress and behavioral problems at baseline (0), after 12 months (1) and after 24 months (2).

	Estimates	SE	Est./SE	StdXY
Maternal stress 1 on maternal stress 0	0.72	0.09	8.05	0.72
Maternal stress 1 on behavioral problems 0	0.01	0.11	0.06	0.01
Maternal stress 2 on maternal stress 1	0.82	0.10	7.95	0.72
Maternal stress 2 on behavioral problems 1	0.06	0.12	0.49	0.04
Behavioral problems 1 on behavioral problems 0	0.59	0.08	7.59	0.70
Behavioral problems 1 on maternal stress 0	0.03	0.08	0.32	0.03
Behavioral problems 2 on behavioral problems 1	0.90	0.09	10.15	0.73
Behavioral problems 2 on maternal stress1	0.13	0.09	1.40	0.12
Maternal stress 0 with behavioral problems 0	270.15	85.01	3.18	0.47
Maternal stress 1 with behavioral problems 1	71.43	30.03	2.38	0.15
Maternal stress 2 with behavioral problems 2	125.56	34.55	3.63	0.18

were also significant. However, no significant relations were found for the cross-legged effects. Table 5 displays the estimates, standard errors and the standardized coefficients for the model.

4. Discussion

This study investigates maternal stress in 104 mothers of children with ASD and ID who were between 2 and 9 years old. Data were collected over a period of two years. Level of maternal stress was compared to that of two norm groups. Besides, child characteristics predicting maternal stress were explored. When compared to the norms of the Dutch version of the PSI, mothers of children with ASD and ID experience more stress than mothers of typically developing children, but no differences in stress were found between mothers of children with ASD and ID and the clinical norm group of the PSI. The latter finding seems deviant from findings of other studies in which parents of children with ASD present greater levels of stress than those of children with other disabilities (e.g., Dąbrowska & Pisula, 2010; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Griffith, Hasting, Nash, & Hill, 2010).

While most studies used control groups of children with mixed etiology ID/developmental disabilities (e.g., Estes et al., 2009; Griffith et al., 2010), Down syndrome (e.g., Dąbrowska & Pisula, 2010; Eisenhower et al., 2005; Griffith et al., 2010), or typically developing children (Eisenhower et al., 2005), this study compared the scores of the children with ASD and ID to the non-clinical and clinical norm group of the PSI. According to the PSI manual, the clinical group of the PSI is comprised of families recruited through professionals of mental health care institutions in two regions of the Netherlands, but additional background information on child or family characteristics (e.g., SES, income, IQ, diagnosis) is lacking (De Brock et al., 1992). As a substantial subset of clients of the mental health care institutions has a diagnosis of ASD, this may cloud comparisons and explain why no significant differences were found between the experimental group and the clinical norm group of the PSI. Most families in the clinical norm group were waiting for treatment. In accordance with a study of Schieve, Blumberg, Rice, Visser, and Boyle (2007) in which parents with special services needs indicated enhanced stress levels compared to parents without special care needs, parents of the clinical group may have experienced increased stress levels in this period before treatment onset. This may also explain why no significant differences were found between the clinical norm group and the children with ASD and ID in our study.

Although, stability effects for maternal stress and emotional and behavioral problems over time and within-time associations between maternal stress and behavioral problems were found, maternal stress did not predict emotional and behavioral problems one year later, nor did emotional and behavioral problems predict maternal stress one year later. Either this suggest the absence of a longitudinal relation between both variables, or problems with the power. As the sample size of the present study was relatively small and the interval between measures relatively long, further research should investigate the longitudinal relation between maternal stress and emotional and behavioral problems using a larger sample size and smaller intervals between assessments.

No significant effect for developmental age, severity of ID or adaptive behavior on maternal stress was found. Furthermore, diagnosis (i.e., PDD-NOS vs. autism), subtype (i.e., aloof, passive, active-but-odd) or severity of ASD did not influence maternal stress. However, emotional and behavioral problems accounted for a third of the maternal stress, mostly caused by emotionally reactive behavior, withdrawn behavior and attention problems. This study clearly indicates that behavioral problems are more associated with maternal stress than any other child characteristic and that both variables remain relatively stable over a period of two years. The latter results are in accordance with other studies that consistently found that behavioral problems of children with ASD predict maternal stress (e.g., Bromley et al., 2004; Estes et al., 2009; Hastings, 2003; Hastings et al., 2005).

The absence of an effect of developmental age, adaptive behavior and autism severity on maternal stress, however, was in contrast to our expectations and might be explained by a lack of variation in scores within our sample. As all children had ASD and ID, the prognosis for most children was poor (Billstedt, Gillberg, & Gillberg, 2005) and since daily living skills were severely affected in all children, all participants required greater assistance during most basic activities during the day than

typically developing children. In contrast to our study some studies did find a relation between maternal stress and cognitive functioning (e.g., Konstantareas & Homatidis, 1989; Konstantareas & Papageorgiou, 2006), adaptive behavior (e.g., Tomanik et al., 2004) and autism severity (e.g., Hastings & Johnson, 2001; Konstantareas & Homatidis, 1989; Konstantareas & Papageorgiou, 2006). However, as already stated by others (e.g., Lecavalier et al., 2006) these relations might be clouded by other variables as behavioral problems. For example, the CARS, which is used to measure autism severity contains items regarding hyperactivity and anxiety.

As children with ASD and ID require intensive care and treatment, parents must contribute substantially to the development of their children and are frequently and actively involved in their child's therapy. Early intervention based on applied behavior analysis (EIBI) is currently recognized the treatment of choice for children with ASD and results in increased cognitive, social and communication skills and reductions in challenging behavior (Eldevik et al., 2009; Peters-Scheffer et al., 2011; Rogers & Vismara, 2008). Moreover, although EIBI seems to decrease parental stress in the long term (Birnbrauer & Leach, 1993), an important concern of EIBI programs is parental and child stress, especially because parental stress is related to the outcome of EIBI programs (Osborne, McHugh, Saunders, & Reed, 2007). Research implies that parental stress associated with caring for a child with ASD is open to psycho educational treatment (Bristol, Gallagher, & Holt, 1993) and it seems important that parents reduce their stress levels before commencing EIBI since parents who experience stress are less able to contribute to their child's treatment. As indicated by the present study, emotional and behavioral problems contribute significantly more to parental stress than ID or (severity of) ASD, and therefore need to be identified and addressed with priority in EIBI programs.

The current study has some limitations in the sample and method that should be considered in interpreting its results. Parents of the children with ASD were selected through public (pre)schools from most regions in the Netherlands and seem to comprise a representative sample of parents of children with ASD and ID in the Netherlands. However, as involvement in an extensive longitudinal study is time-consuming, parents with the highest levels of stress may decline participation and caution is needed when generalizing these results to the population of children with ASD. As parents had restricted time available, we were limited in our data collection and were therefore not able to collect additional background information on parental and family functioning and data on both parents. As fathers are typically less involved in the daily care of children (Bristol, Gallagher, & Schopler, 1988), we decided to collect data in the mothers. However, it is uncertain if effects found in mothers hold for both parents. As a child functions in a family, family functioning may directly and indirectly through the child's behavior and functioning affect maternal stress (Harris, 1994).

Maternal stress and emotional and behavioral problems were measured using only one data source, i.e. maternal report on the PSI and the CBCL and thereby possible generating common method variance. Although subjective, parents can report information about several situations and behavior, which might not be observed in a short assessment by a clinician. However, in vivo assessment of parental stress and behavioral problems in the home or school setting and multiple informants completing multiple questionnaires would strengthen the study.

Results of this study mark the importance of addressing emotional and behavioral problems in children with ASD and ID as these problems cause more parental stress than children's diagnosis, developmental delay or gender (see also Herring et al., 2006) and parental stress has a negative impact on treatment outcome (Osborne et al., 2007). Therefore, emotionally reactive behavior, withdrawn behavior and attention problems are crucial intervention targets in (early) intervention in children with ASD and ID and optimizing those skills may reduce parental stress and directly and indirectly improve children's functioning.

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