Mieke Meirsschaut<sup>a</sup> \*

Herbert Roeyers<sup>a</sup>

Petra Warreyn<sup>a</sup>

<sup>&</sup>lt;sup>a</sup> Research Group Developmental Disorders, Ghent University, H. Dunantlaan 2, B – 9000, Ghent, Belgium

<sup>\*</sup> Corresponding author: Research Group Developmental Disorders, Ghent University, H. Dunantlaan 2, B – 9000, Ghent, Belgium, Mieke.Meirsschaut@Ugent.be, Tel.: +32(0)9-2649414; Fax: +32(0)9-2646489.

#### **Abstract**

The parenting experiences of mothers in a family with a child with autism spectrum disorder (ASD) and a typically developing (TD) child were studied using a qualitative analysis of mothers' perceptions of the impact of autism on family and personal life. An additional quantitative comparison was performed to evaluate the effect of ASD on mothers' parenting cognitions about their other, TD child. Mothers differentiated clearly in parenting cognitions about their child with ASD and about their TD child. Strong associations were found between mothers' symptoms of stress and depression, and their parenting cognitions about both their children. To maximize intervention outcome, family interventionists should consider parenting experiences and should become aware of interfering maternal feelings and cognitions, such as guilt or low parental self-efficacy beliefs.

#### 1. Introduction

Raising a child with autism spectrum disorder (ASD)<sup>2</sup> is uniquely challenging to parents. The children's restricted social, communicative and emotional competencies, their uneven cognitive development, and their maladaptive behaviour place tremendous stress on parents of children with ASD (Davis & Carter, 2008; Hastings & Johnson, 2001). In comparison to mothers of typically developing (TD) children and mothers of children with other disabilities, mothers of children with ASD report elevated stress levels (Eisenhower, Baker, & Blacher, 2005; Estes, et al., 2009; Montes & Halterman, 2007; Rao & Beidel, 2009) and they are at an increased risk for depression (Olsson & Hwang, 2001). Only recently, research has focused on mothers' experience of having a child with ASD. It seems, however, very important to understand what it is like to be a parent of a child with ASD, given the increased involvement of parents in the early intervention of their child (Shields, 2001). Accordingly, several authors recommend to assess mother's well-being before implementing any parenting intervention and to address symptoms of stress and depression, in order to maximize intervention outcome (Kuhn & Carter, 2006; Rao & Beidel, 2009). Otherwise, stress and depressive symptoms may interfere with mother's ability to engage in interventions for her child.

Having a child with ASD does not only affect parents, but it also poses a threat to the well-being of the whole family. Existing research exploring parent's experiences with a child with ASD points to impairments of family functioning such as 'giving up normal family activities and outings', 'lack of spontaneity or flexibility in family life', 'lack of personal social activities', 'stress surrounding the marital relationship', and 'difficulties to maintain employment or to pursue outside activities' (Gray, 1994, 1997; Hutton & Caron, 2005; Montes & Halterman, 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Phelps, McCammon,

-

<sup>&</sup>lt;sup>2</sup> ASD: autism spectrum disorder; TD: typically developing

Wuensch, & Golden, 2009). In these studies, however, only parents (mainly mothers) of children with ASD of a broad age range (between 3 and 35 years of age) and with a mean age of 10 years and older have been interviewed. As children are being diagnosed at younger ages (Barbaro & Dissanayake, 2009), investigating mothers' experiences with their young child with ASD is necessary in order to adapt the early intervention practice to their specific needs (Davis & Carter, 2008). Therefore, the first aim of this study is to investigate how mothers perceive the impact of their young child with ASD on their personal and family life (1).

There are a number of studies revealing that parental stress and depressive symptoms are negatively associated with parenting cognitions such as parental self-efficacy (Coleman & Karraker, 1997; Hassall, Rose, & McDonald, 2005; Jackson & Huang, 2000; Scheel & Rieckmann, 1998), which refers to judgements of one's capability to perform competently and effectively as a parent (Teti & Gelfand, 1991). According to Goodnow (1985), a parent's perception of parenting competency is considerably influenced by the direct feedback from daily interactions with the child. Donovan and colleagues (Donovan, Leavitt, & Walsh, 1990) argue that parents with high self-efficacy beliefs interpret the difficult behaviour of their child as a challenge to their parenting skills, whereas parents with low self-efficacy beliefs are likely to perceive the difficult child as a threat to their limited parenting skills. Moreover, there is evidence that a parent's self-efficacy beliefs operate as a mediator between various psychosocial variables and parental competence (Coleman & Karraker, 1997; Teti & Gelfand, 1991; Teti, O'Connell, & Reiner, 1996). More specifically, maternal depression restricts parental competence indirectly by undermining a mother's self-efficacy beliefs. In a recent study, Kuhn and Carter (2006) examined the associations between maternal selfefficacy and other parenting cognitions among mothers of children with ASD. They found that mothers who reported to be more active in promoting their child's development, i.e., mothers with a high degree of agency, showed higher self-efficacy, whereas mothers who

reported more frequent feelings of guilt about not doing enough for their child with ASD showed lower maternal self-efficacy. Given the behavioural problems and other developmental challenges in ASD, parental self-efficacy may be especially compromised for mothers of a child with ASD.

The evidence of more parenting stress, depressive feelings and impaired functioning in families of a child with ASD and the negative association between parenting cognitions and parenting stress and depression, as found in several studies, have contributed significantly to the understanding of mothers' experiences with a child with ASD. However, in these attempts to clear out mother's perspectives on the impact of having a child with ASD, an important factor has been neglected. The parenting experiences of mothers are not restricted to their child with ASD if they also have one or more typically developing children. Given the elevated levels of stress and depressive symptoms, the negatively associated parenting cognitions and the impaired family functioning, one should investigate whether this autismrelated stress also affects a parent's cognitions about another, typically developing child. Surprisingly, little is known about how parenting cognitions about a child with ASD may affect the cognitions a mother has concerning her other child(ren). A better understanding of this association is, however, important for the development of more supportive interventions that enhance maternal and family well-being. Therefore, the second aim of this study is to compare parenting cognitions of mothers towards their child with ASD and towards their TD child (2). The particular aspects of parenting cognitions to be studied are parental selfefficacy, feelings of guilt, agency and three factors for parenting stress and depression, i.e., parenting incompetence, role restriction and symptoms of depression. Based on previous findings, the following specific hypotheses were therefore examined: 1) Mothers will report lower sense of self-efficacy towards their child with ASD than towards their TD child. 2) Mothers will report more feelings of guilt, more stress concerning incompetency and role

restriction and more symptoms of depression towards their child with ASD than towards their TD child. 3) Mothers will not differ significantly in degree of agency in the development of their child with ASD versus of their TD child.

Thirdly, associations between the parenting cognitions about a child with ASD and about a TD child will be explored (3). Specific hypotheses for these associations are difficult to formulate due to lack of published studies in this area.

#### 2. Method

# 2.1 Participants

Seventeen mothers with a child with ASD and with a TD child participated in this study. The families were recruited through local rehabilitation centres. The children with ASD ranged in age from 46 to 84 months (M(sd) = 68.94 (11.76)). Their younger, typically developing siblings ranged in age from 29 to 83 months (M(sd) = 50(15.23)). We chose to include only families where the TD sibling was the younger one of the two children, in order to have comparable developmental levels between both children and thus to have homogeneity in the collected data. The TD child was on average 19 months younger than the ASD sibling (sd= 8.23). One dizygotic twin was included in the study. There was a predominance of boys in our sample, with 7 'brother-brother' dyads (ASD – TD), 7 'brothersister' dyads, 2 'sister-brother' dyads and one 'sister-sister' dyad. A chi-square analysis showed no significant difference in sex ratio between the ASD and the TD group  $(\chi^2(1))$ 1.21, p = ns). Both the children with ASD and the TD children were pre-screened for ASD with the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003; Dutch translation by Warreyn, Raymaekers, & Roeyers, 2004). For families to be included in the study the SCQ scores of the child with ASD and of the TD sibling had to differ with at least 5 points. The use of the SCQ permitted to examine whether the mothers reported significantly

more ASD symptoms in their child with ASD than in their TD child, according to their child's diagnostic status. All the children with ASD had received a clinical diagnosis of ASD after an extensive diagnostic procedure from an experienced multidisciplinary team, prior to the study. If there was any doubt about the diagnostic status of a sibling, e.g., because of a sub-threshold score on the SCQ (n=4) or because of concerns by the parent (n=1), an additional Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi, 1999) was performed. Accordingly, two families were excluded from the initial study group (n=19) because of a sub-threshold score of the sibling on the ADOS. Mean total SCQ scores, standard deviations and difference scores are presented in Table 1. The nonverbal intellectual functioning of each child was assessed with a short form of the Snijders-Oomen Niet-verbale Intelligentietest  $2^{1/2}$ -7 (SON-R; Tellegen, Winkel, Wijnberg-Williams, Laros, 1998). Word comprehension was measured with the Peabody Picture Vocabulary Test-III-NL (PPVT-III-NL; Dunn, & Dunn, 2005). See Table 1 for details of the results.

A one-way analysis of variance (ANOVA) revealed no significant differences in word comprehension between children with ASD and their TD siblings. Children with ASD, however, showed a significantly lower non-verbal IQ. Mothers ranged in age from 27 to 47 years old (M(sd) = 34 (4.77). Their mean social status ranged from 27 to 53 (M(sd) = 42, (7.89) (Hollingshead, 1975). All but two families were two-parent households.

#### 2.2 Procedure

[insert Table 1 about here]

This study is part of a larger observational study on the mother-child interaction in families with a child with ASD and a TD child. For this study, a mother and her both children were invited for an observation of the mother-child interaction. The results of this observational study are reported elsewhere. All mothers were interviewed by the first author.

Through an in-depth-interview, mother's perspectives on parenting a child with ASD were gathered. In two open-ended questions mothers were asked whether their child with ASD had an impact on their family life and whether their child with ASD had an impact on their personal life, respectively. Additionally, information on mother's parenting cognitions was collected with several parenting cognitions questionnaires. For both their child with ASD and their TD child separately, mothers were asked to answer questions from the Maternal efficacy scale (Teti & Gelfand, 1991), the Maternal agency questionnaire (Kuhn & Carter, 2006) and the Maternal guilt questionnaire (Kuhn & Carter, 2006). In addition, they completed three scales of the Nijmeegse Ouderlijke Stress Index (NOSI; De Brock, Vermulst, Gerris, & Abidin, 1992): parental incompetence, role restriction and depression. Half of the mothers first talked about their child with ASD and next about their TD child. For the other half of the mothers the sequence was reversed. Mothers also completed an informed consent and a sociodemographic form prior to being interviewed.

# 2.3 Measures for parenting cognition, stress and depression

# 2.3.1 The maternal efficacy scale (Teti & Gelfand, 1991)

This 10-items scale is developed to assess mother's feelings of efficacy in relation to specific domains of infant care (e.g., soothing the baby, understanding what the baby wants, amusing the baby, etc.) and her global feelings of efficacy in mothering. Items are scored on a 4-point scale (1 = not good at all, 2 = not good enough, 3 = good enough, 4 = very good). This instrument has a satisfactory internal consistency, with a Cronbach's alpha of 0.79. With permission of the authors, we translated this scale into Dutch for this study.

# 2.3.2 The maternal agency questionnaire (Kuhn & Carter, 2006)

This questionnaire is developed to assess mother's feelings of agency, or the extent to which a mother assumes an active role in promoting her child's development. The

questionnaire consists of 20 items beginning with 'how often do you' (discipline your child, read books on autism, tell your child in words how to play with toys, etc.) that are rated on a 5-point scale (1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = almost always). With permission of the authors, we translated this scale into Dutch. To make it applicable to TD children, only the non-autism-specific items<sup>3</sup> (n=12) have been included in the questionnaire. This scale has a good internal consistency of 0.79.

## 2.3.3 The maternal guilt questionnaire (Kuhn & Carter, 2006)

This questionnaire is developed to measure mother's feelings of guilt about not doing enough for her child with ASD. Additionally, mothers are asked how often and in which situations these guilt feelings occur and if those interfere with their parenting competency. Mother's answers are rated on a 5-point guilt frequency scale (1 = never, 2 = less than monthly, 3 = monthly, 4 = weekly, 5 = everyday or almost everyday). With permission of the authors, we translated this scale into Dutch and made it also applicable to TD children.

2.3.4 Nijmeegse Ouderlijke Stress index (De Brock, Vermulst, Gerris, & Abidin, 1992)

The NOSI is the Dutch version of the Parenting Stress Index (Abidin, 1983) that measures perceived stress in the parenting role on three domains, a parent domain, a child domain and a life events scale. For this study three constructs of the parent domain have been selected: Parenting incompetence, role restriction and depression. Parenting incompetence<sup>4</sup> indicates to what extent a parent feels incompetent in parenting this child. Related feelings are negative self-image, lower self-esteem, lack of self-confidence and an external locus of control. Role restriction<sup>5</sup> indicates to what extent the parenting role is experienced as a restriction of freedom and self-identity. Parents reporting high scores on this scale feel dominated by the needs and demands of the child. Ambivalent feelings towards the child,

-

<sup>&</sup>lt;sup>3</sup> Maternal Agency Questionnaire: included items were: 1. 2. 4. 5. 6. 8. 14. 15.17.18.19.20

<sup>&</sup>lt;sup>4</sup> Maternal incompetence: included items were: 4.7.14.16.19.23.30.31.36.43.58.59.61

<sup>&</sup>lt;sup>5</sup> Maternal role restriction: included items were: 26.33.38.41.56.57.62

such as anger and guilt often co-occur with feelings of role restriction. Depression<sup>6</sup> is an indication of feelings of dissatisfaction with the self and conditions of life. Parents scoring high on depression fail to mobilize physical and mental energy. The parent is unhappy, withdraws and feels guilty.

#### 3. Results

The results are organized in two sections. The first section includes the qualitative investigation of mothers' perceptions of the impact of a young child with ASD on the personal and family life and the second section is concerned with the quantitative analysis of mother's parenting cognitions about her child with ASD and her TD child.

### 3.1 Qualitative results

For the first aim of this study, mothers' reactions to the questions about the impact of ASD on family and personal life were analysed through an interactive process of coding and categorizing, according to established methods of qualitative research (Erlandson, Harris, Skipper, & Allen, 1993; Miles & Huberman, 1984). The interviews were transcribed and the transcripts were reviewed repeatedly for the selection of significant statements. Similar statements were then classified together. From this classification meaningful themes emerged. Below is a description of mother's perspectives, sorted in essential themes.

# 3.1.1 It affects our whole life

'It affects our whole life' is the essence of mothers' reports on the impact of having a child with ASD. Mothers told us how hard it is to have 'everything structured and planned in life' and 'to live on the schedule of their child with autism'.

\_

<sup>&</sup>lt;sup>6</sup> Maternal depression: included items were: 6.9.10.17.21.27.34.39.44.46.50.52

They reported how difficult it is to do **normal family activities** such as going to a playground with the children, going on vacation, visiting friends, etc. Their family life is **less spontaneous or flexible** compared to 'normal families' life'. In order to make life livable for the child with ASD, every outing is minutely planned: 'Where are we going to? When will we come back? Can we have dinner over there? How crowded will it be?' Some parents even have given up normal family activities: 'Going to a store to buy clothes for Marie is not possible. She has to try them on at home.' 'We did not have a party for Bram's first Communion, because he didn't want to and because my husband did not want to do that to him ....' Sometimes, 'family meetings are avoided because of the negative impact on Thomas afterwards'.

Mothers also spoke of the **job and career adjustments** they made to care for their child. A major part of the mothers expressed that it was impossible to combine a full-time job with the care for their child with ASD: 'My work life has changed completely since Lisa's diagnosis. I used to work full-time, now I am full-time at home for the children.' Some mothers referred specifically to the time they spent with transporting the child to and from therapy or a special school: 'My day consists of taking Lisa from here to there. For many mothers leisure time is restricted because 'it is hard to find someone to look after my child'. A mother explains: 'In the past 5 years we (my partner and I) have not been on a date together. Victor does not want to stay with his granny. And we can't enjoy going out if Victor is not happy at that time. But sometimes I really want to go out, that's something I really need!' A small but notable number of mothers also mentioned a **positive impact**: 'We definitely do not want to change Loïc for a Loïc without autism. Having a child like him is also enriching for our family. This way, we realize that everyone is different. We are happy that our children, this way, learn to be considerate of each other...'

# 3.1.2 Lack of understanding

In many of the interviews mothers mentioned how their family suffers from the lack of understanding from the environment of what ASD is and what consequences it has for a family. For example, mothers told how their parenting competency is constantly under heavy criticism: 'It is difficult to go somewhere with Victor. The environment is quick to criticize, and that is very hard. I think it's stupid if people judge to fast 'this must be a bad child'.' One mother expressed how hard it is to deal with the denial and disbelief of people about her daughters' diagnosis of Asperger syndrome: 'This justifying and substantiating is endless'. Another mother agreed: 'We avoid social contacts because of the people saying that they don't see anything about Lander. But that's just typical about the autism of Lander: He is a model child with other people, but afterwards the bomb bursts'. For some families, a lack of understanding for the ASD of their child resulted in an **isolation from their relatives**: 'It has a large impact on our contact with the extended family. Acceptance of the diagnosis is very hard. For this reason, we hardly ever see my husband's parents.' Sometimes, mothers reported **marital strain** because of conflicts about their child's upbringing. One mother told: 'It has been 2 months since we've split up. I'm not saying that Brecht is the main cause of this, but...'.

# 3.1.3 Inaccessible caregiving system

Some mothers expressed feeling on their own with their questions and concerns about raising a child with ASD: 'We have struggled with many doubts and questions, also after diagnosis. You have to find it yourself, and if at first you don't succeed, try, try, and try again. It would be much more helpful to have someone at your house after diagnosis, someone who explains what you can do and what you can't do. ... We had to find it out all by ourselves.' Long waiting lists for care **restrict the accessibility of the care giving system**.

3.1.4 Coping strategies

To deal with the challenges of raising a child with ASD, and to deal with the lack of understanding and with the inaccessible system, mothers have developed several coping strategies. Most importantly, mothers do everything they can for their child with ASD: 'I put much time and energy into Tom'. 'For certain occasions I have to make a countdown calendar, otherwise it is unbearable for Brecht.' In order to realise an optimal development for their child with ASD, parents become 'super' parents. They try to learn everything about autism in order to be prepared for everything and in order to adjust their life to the needs of their child: 'My husband and I even have been thinking of building a chalet in our garden for Robin. This way he can partly live on his own,... but still under our supervision.' Mothers reported, however, how they constantly have to balance between doing everything for their child with ASD and being a normal family: 'It's so hard to keep things balanced. Sometimes I really become a maniac in planning.' – 'We are constantly seeking for the right balance between 'being normal' and doing something which is also nice for Robin.'

# 3.1.5 Concerns and questions

Mothers also spoke of their **concerns** about the future of their child with ASD and about their parenting. 'There are lots of question marks, we have to take many difficult decisions, we are never free of worries. We also have lots of questions about his future and other things.' A very frequent theme in mother's responses was their concern about the **impact on their other children**: 'Neither is it easy for Laila (sibling). Sam claims all attention. Sam and Laila also fight a lot.' – 'We also have to live according to his scheme. His sisters have to adjust themselves to him all the time. That's hard for them, it's even hard for us, parents, thus...' – 'Marius has been confronted very soon with the pressure of autism.'

# 3.2 Quantitative results

# 3.2.1 Comparison of parenting cognitions

To compare a mother's cognitions about her child with ASD and about her TD child, several repeated measures ANOVA's have been conducted with child as within-subjects factor. All the variables were found to be normally distributed according to a one-sample Kolmogorov-Smirnoff test. A chi-square analysis was conducted to compare the occurrence of guilt feelings with parenting competence.

As hypothesized, mothers reported a significantly lower sense of self-efficacy about parenting their child with ASD (M(sd)= 29 (4.83)) than about parenting their TD child (M(sd)= 32.29 (3.79) (F(1,16)= 11.2, p < .01). Mothers' perceived self-efficacy differed significantly between their ASD and their TD child for the following items: 'how good are you at getting your child to pay attention to you?', 'how good are you at getting your child to have fun with you?', and 'how good do you feel you are at feeding, changing and bathing your child?'.

Contrary to the expectations, the chi-square analysis revealed a trend for mothers feeling more frequently guilty towards their TD child (n = 13) than towards their child with ASD (n = 8) ( $\chi^2$  (1) = 3.11, p <.10). If mothers were asked whether this guilt feeling ever interfered with their parenting competency, they answered yes in half of the cases for their child with ASD (n = 4/8) and in 15% of the cases for their TD child (n = 2/13).

As expected, mothers reported significantly higher levels of stress and depressive symptoms concerning their child with ASD than concerning their TD child. We found significantly more stress related to parenting incompetence towards their child with ASD  $(M(sd)=32.31\ (10.36))$  than towards their TD child  $(M(sd)=28.06\ (8.36))\ (F(1,15)=4.58,\ p<0.05)$ . Compared to mothers out of the normal population, the mothers in our study scored 'on average' for incompetency stress towards their TD child and 'above average' towards their child with ASD (De Brock et al., 1992). Mothers also felt significantly more role restrictions

from parenting their child with ASD (M(sd)= 21.44 (9.2)) than from parenting their TD child (M(sd)= 17.19 (6.79)) (F(1,15)=6.13, p<.05). Mothers' scores on role restriction were classified 'highly' stressful for their child with ASD and 'above average' stressful for their TD child (De Brock et al., 1992).

Mothers' feelings of depression for both children were classified as 'average' in comparison to a normal population (De Brock et al., 1992), but they were significantly higher concerning their child with ASD (M(sd)= 29.31 (9.85)) than those reported concerning their TD child (M(sd)= 25.31) (F(1,15)= 10.38, p < 0.01).

In line with the expectations, mothers reported a comparable degree of agency in the development of their ASD child (M(sd) = 44.06 (3.68)) and of their TD child (M(sd) = 43.12 (5.68) (F(1,16)= .59, p = ns).

# 3.2.2 Associations between parenting cognitions

To examine the associations between mothers' cognitions about her child with ASD and about her TD child, Pearson's correlational analyses have been used.

The correlations in the diagonal of Table 2 show that maternal cognitions about self-efficacy, agency, incompetence, role restriction and depression related to parenting a child with ASD and a TD child were significantly positively associated. By contrast, no significant associations were found between mothers' feelings of guilt towards their child with ASD and towards their TD child and additionally no significant associations between guilt and other parenting cognitions were obtained.

Mothers' self-efficacy concerning their child with ASD was significantly negatively correlated with their feelings of incompetence about their TD child. The beliefs of self-efficacy related to parenting their TD child were negatively correlated to their depressed

feelings about their child with ASD. For the degree of mother's agency in the development of their child with ASD and of their TD child no significant correlations with other maternal cognitions about the other child were found.

Incompetence, role restriction and depression about the child with ASD and about the TD child, i.e., the three factors contributing our measure for parenting stress and depression, showed to be highly intercorrelated.

Table 2 shows that ASD depression has the most significant associations with TD parenting cognitions. Remarkably, for three of these four significant associations between ASD depression and TD parenting cognitions there exists a reversed significant or nearly significant association between TD parenting cognitions and ASD self-efficacy (See the italized correlations in Table 2). Therefore, it is interesting to explore these associations more in detail. To sort out the size of the unique relation between ASD depression and TD self-efficacy, between ASD depression and TD incompetence stress and between ASD depression and TD depression, three partial correlations were conducted while controlling for the effect of ASD self-efficacy. This first-order correlations indicate that the association between ASD depression and TD self-efficacy is greatly reduced (r = -.52,  $p < .05 \Rightarrow r = -.36$ , p = ns) and no longer significant, when ASD self-efficacy is controlled. After controlling for ASD self-efficacy, the associations between ASD depression and TD incompetence stress (r = .72,  $p \le .001 \Rightarrow r = .66$ ,  $p \le .01$ ) and between ASD depression and TD depression (r = .87,  $p \le .001 \Rightarrow r = .84$ ,  $p \le .001$ ) remain significant.

### 4. Discussion

In this study we gathered mothers' parenting experiences in a family with a child with ASD and a TD child by a qualitative investigation of mothers' perceptions of the impact of ASD on family and personal life and by a quantitative exploration of (the associations

between) mother's parenting cognitions about both her child with ASD and her TD child. A better understanding of what it is like to be a parent of a child with ASD is necessary for the development of more supportive interventions that enhance maternal and family well-being.

'It affects our whole life' defines the essence of mother's perceptions of the impact of having a child with ASD. Similar to the extant literature (Gray, 1994, 1997; Hutton & Caron, 2005, Montes & Halterman, 2007; Phelps, et al., 2009), the parents of young children with ASD in our study reported impaired family functioning in several ways. For example, mothers spoke of how difficult it is to do normal or spontaneous family activities, because family life with a child with ASD has to be very structured and planned. A very frequently mentioned topic was the job and career adjustments mothers made to care for their child. Furthermore, mothers reported that there was little time left for personal activities or outings. In many of the interviews mothers complained about the lack of understanding of ASD from the environment. Some families even were isolated from their relatives because of denial or disbelief about their child's diagnosis. Sometimes mothers also reported marital strain because of conflicts about their child's upbringing. In line with the evidence of parents' strengths and resilience in coping with the diagnosis of ASD, as found in past studies (Bayat, 2007; Davis & Carter, 2008; Phelps et al., 2009), the mothers in our study also have shown to do 'all they can' for their child with ASD. However, in spite of this, many of mothers' questions and concerns remained unanswered. In fact, a very frequent theme in mother's responses was their concern about the impact of their child with ASD on their other children. Previous sibling-studies also have suggested that a non-disabled sibling may encounter several negative consequences of having a disabled brother or sister, such as less parental attention, less 'normal' family outings, embarrassment because of siblings' deviant behaviour, limited companionship with the sibling, etc. (Fisman, Wolf, Ellison, & Freeman, 2000;

Moyson & Roeyers, submitted; Myers et al., 2009). Hutton and Caron (2005) offered some strategies for parents to deal with this negative impact, for instance by educating the sibling about the consequences of autism, by organizing activities exclusively for the sibling, or by involving the sibling whenever possible in activities with the child with autism.

Like in many studies, our results have verified the tremendous impact of a young child with ASD on family and personal life. At first sight, the younger mean age of the children in our study does not seem to make parents' experiences qualitatively different from what parents of older children have been reporting. Therefore, these results suggest that the strategies used in supporting parents of older children and adolescents with ASD also can be applied with parents of newly diagnosed children. Nevertheless, it would be very interesting to assess mothers' experiences again some years later to determine whether they change over time as families adapt to the demands of parenting a child with ASD.

To gain a more comprehensive view of what it is like to have a child with ASD, the second aim of this study was to explore a mother's beliefs and perceptions about parenting, i.e., the parenting cognitions and to compare parenting cognitions about a child with ASD and about a TD sibling. Accordingly, this study aim assumes that mothers are able to differentiate in their parenting cognitions between their children. In TD families, differentiation in parent's cognitions about their sibling children has been firmly established (e.g., Deater-Deckard, Smith, Ivy, & Petril, 2005), but to our knowledge this has not yet been tested in families with a child with ASD.

In line with our first hypothesis, mothers reported significantly higher levels of stress related to parenting incompetence and role restrictions and more symptoms of depression concerning their child with ASD, compared to their TD sibling. Consistent with the evidence of a negative relation between parental stress, depressive symptoms and parental self-efficacy

(Coleman & Karraker, 1997; Hassall, et al., 2005; Jackson & Huang, 2000; Scheel & Rieckmann, 1998) we also found a significantly lower sense of self-efficacy of the mothers in our study about parenting their child with ASD than about their TD child. Although mothers expressed being equally active in stimulating the development of both their children, they felt more guilty about 'not doing enough' for their TD child than for their child with ASD. This guilt feeling has also been confirmed in the interviews. Many of the mothers were concerned about the negative consequences for their TD child and they worried, for instance, about not having enough time and attention for their TD child. This frequently mentioned guilt feeling seems to be important to consider for professionals supporting the well-being of mothers with a child with ASD and one or more TD children. Altogether, these findings show that mothers have different parenting cognitions about their child with ASD and about their TD child. At the same time, this means that mothers are capable of differentiating in their parenting cognitions. It is, however, not clear whether these specific differences in parenting cognitions are the result of the impact of a child with ASD or whether these differences also exist in families with TD children only. In general parenting research there is evidence of differential parental treatment and differentiation in parenting cognitions within families (e.g., Deater-Deckard et al., 2005; Dunn, Plomin, & Daniels, 1986; Rivers & Stoneman, 2008), but no studies have explicitly focused on mother's differentiation in parenting cognitions within ASD families nor on variation in the degree of parental differentiation between ASD and TD families.

The third aim of this study was an examination of associations between mother's cognitions about both her children. Strong positive correlations were found between symptoms of stress and depression about one child and those about the other child. One interpretation of this finding is that maternal stress and depression generalize over children. In other words, the symptoms of stress and depression evoked by the challenges of raising a

child with ASD –of which we found evidence in the ANOVA comparisons- also affect mother's symptoms of stress and depression about her TD child. This finding has important clinical implications and adds valuable information to what previous studies already suggested (Kuhn & Carter, 2006; Rao & Beidel, 2009), i.e., that autism interventionists should not only address autism related symptoms of stress and depression in mothers with a child with ASD, but they should also be aware of the impact of these negative symptoms on mothers' symptoms of stress and depression related to their other, TD child(ren). An alternative interpretation of these significant stress- and depression-correlations is that the questionnaire we used is perhaps not suitable to differentiate in mother's depressed feelings about her different children. Indeed, inspection of the questionnaire shows that some of the items can be interpreted as general rather than child specific. The significant differences we found in stress and depressive symptoms related to both children, however, suggest that mothers did differentiate in their reports.

'Feelings of guilt about not doing enough for one of your children' was in no way significantly associated with parenting cognitions about the other child, probably because the range of this measure was limited. By contrast, mothers' beliefs of self-efficacy and agency about parenting one of their children were significantly correlated with the beliefs about her other child. This finding is very important, given the lower self-efficacy beliefs we detected in mothers towards their child with ASD, and thus the possible negative impact on mothers' beliefs towards their TD child. Furthermore, depressive feelings about the child with ASD were also negatively associated with mothers' self-efficacy beliefs about parenting their TD child, but this association appears to be mediated by maternal self-efficacy beliefs about the child with ASD. These results extend the previous conclusion of several researchers (Coleman & Karraker, 1997; Teti & Gelfand, 1991; Teti et al., 1996) on the mediational role of parental self-efficacy. It shows that the mediating effect of self-efficacy exceeds the mother-child

dyad, and that it also operates across different mother-child dyads. The latter results strongly recommend addressing also mothers' self-efficacy beliefs about parenting their child with ASD and their TD child in autism interventions. We totally agree with Kuhn and Carter (2006) who recommend interventions to promote mothers' self-efficacy in order to minimize the effects of depression on the mother-child interaction. Furthermore, it is clear that TD siblings may also benefit because empowerment of maternal self-efficacy about a child with ASD will automatically result in improved self-efficacy about the TD sibling and thus in a reduction of the negative effect of maternal depression.

Limitations of the current study include the small sample size, composed of only mothers. It was, however, difficult to find families meeting the criteria of having both a young child with ASD and a younger TD child with a maximum age difference of 30 months. To make the data comparable with previous research, only mothers were included in this study. However, results might have been different with fathers, since different psychosocial outcomes were found when comparing mothers and fathers on their parenting experience (Hastings et al., 2005). Furthermore, this small sample may have resulted in limited power to detect differences in mothers' cognitions.

A second limitation is the lack of a control group of mothers with only typically developing children. Therefore, we can not conclude whether these results are unique for families with a child with autism. Further research with a larger and more representative sample and with a TD control group is required to clarify the generalizability of these results.

In conclusion, the present study confirmed that a young child with ASD impacts largely on family and personal life. Additionally, this study provided clear evidence of strong associations between mothers' symptoms of stress and depression, and their parenting

cognitions about their child with ASD and about their TD child. These findings highlight the need for family interventions to take into consideration the ways in which mothers experience parenting in a family with a child with ASD and other TD child(ren). To maximize intervention outcome and to enhance the child's, maternal and family well-being, interventionists should become aware of interfering maternal feelings and cognitions, such as guilt or low self-efficacy beliefs. This study also has proven that mothers are able to differentiate in their parenting cognitions about their child with ASD and about their TD child and that this differentiation yields relevant cues for intervention.

#### References

- Abidin, R.R. (1983). Parenting Stress Index. Virginia: Paediatric Psychology. Press.
- Barbaro, J. & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood:

  A review of the evidence on early signs, early identification tools and early diagnosis.

  Journal of Developmental and Behavioral Pediatrics, 30, 447-459.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual and Disability Research*, 51, 702-714.
- Coleman, P.K., & Karraker, K.H. (1997). Self-efficacy and parenting quality: Findings and future applications. *Developmental Review*, 18, 47-85.
- Davis, N.O., & Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Research*, 38, 1278-1291.
- Deater-Deckard, K., Smith, J., Ivy, L., & Petril, S.A. (2005). Differential perceptions of and feelings about sibling children: Implications for research on parenting stress. *Infant and Child Development*, 14, 211-225.
- De Brock, A.J.L.L., Vermulst, A.A., Gerris, J.R.M., & Abidin, R.R. (1992). *Nijmeegse Ouderlijke Stress Index*, Swets en Zeitlinger B.V., Lisse.
- Donovan, W. L., Leavitt, L.A., & Walsh, R.O. (1990) Maternal self-efficacy: Illusory control and its effect on susceptibility to learned helplessness. *Child Development*, *61*, 1638-1647.
- Dunn, L.M., & Dunn, L.M. (2005). *Peabody Picture Vocabulary Test-III-NL*, Nederlandse versie Liebeth Schlichting, Harcourt Assessment B.V., Amsterdam.
- Dunn, J.F., Plomin, R., & Daniels, D. (1986). Consistency and change in mothers' behaviour toward young siblings. *Child Development*, *57*, 348-356.

- Eisenhower, A.S., Baker, B.L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being.

  \*Journal of Intellectual Disability Research, 49, 657-671.
- Erlandson, D.A., Harris, E.L., Skipper, B.L., & Allen, S.D. (1993). *Doing naturalistic inquiry*. Sage, Newbury Park, CA.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*, 375-387.
- Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *The Canadian Journal of Psychiatry*, 45, 369-375.
- Goodnow, J.J. (1985). Change and variation in ideas about childhood and parenting. In I.E. Sigel (Ed.), *Parental belief systems: The psychological consequences for children*. Hills-dale, NJ: Erlbaum.
- Gray, D.E. (1994). Coping with autism stresses and strategies. *Sociology of Health & Illness*, *16*, 275-300.
- Gray, D.E. (1997). High functioning autistic children and the construction of 'normal family life'. *Social Science & Medicine*, 44, 1097-1106.
- Hassal, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49, 405-418.
- Hastings, R.P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism. *Journal of Autism and Developmental Disorders*, 31, 327-336.

- Hastings, R.P., Kovshoff, H., Ward, N.J., Espinosa, F.D., Brown, T., & Remington, B.
  (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35, 635-644.
- Hollingshead, A.B. (1975). *Four factor index of social status*. Unpublished manuscript, Yale University, NewHaven, CT.
- Hutton, A.M., & Caron, S.L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, 20, 180-189.
- Jackson, A.P., & Huang, C.C. (2000). Parenting stress and behaviour among single mothers of preschoolers: The mediating role of self-efficacy. *Journal of Social Service*\*Research\*, 26, 29-42.
- Kuhn, J.C., & Carter, A.S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76, 564-575.
- Lord, C., Rutter, M., Dilavore, P., & Risi, S. (1999). *Autism Diagnostic Observation Schedule, Manual*, Los Angeles, CA: Western Psychological Services.
- Miles, M., & Huberman, A. (1984). *Qualitative data analysis: A sourcebook of new methods*.

  Beverly Hills, CA: Sage publications.
- Montes, G., & Halterman, J.S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, *119*, e1040-e1046.
- Moyson, T. & Roeyers, H. (submitted). "The overall quality of my life as a sibling is all right, but of course, it could always be better." Quality of Life of Siblings of Children with an Intellectual Disability: the siblings' perspectives. *Journal of Intellectual Disability Research*.

- Myers, B.J., Mackintosh, V.H., & Goin-Kochel, R.P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670-684.
- Olsson, M.B., & Hwang, C.P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535-543.
- Phelps, K.W., McCammon, S.L., Wuensch, K.L., & Golden, J.A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 34, 133-141.
- Rao, P.A., & Beidel, D.C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment and family functioning. *Behaviour Modification*, *33*, 437-451.
- Rivers, J.W., & Stoneman, Z. (2008). Child temperaments, differential parenting, and the sibling relationships of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 38, 1740-1750.
- Scheel, M.J., & Rieckmann, T. (1998). An empirically derivde description of self-efficacy and empowerment for parents of children identified as psychologically disordered.

  \*American Journal of Family Therapy, 26, 15-27.
- Shields, J. (2001). The NAS earlybird programme Partnership with parents in early intervention. *Autism*, *5*, 49-56.
- Tellegen, P. Winkel, M., Wijnberg-Williams, B., & Laros, J. (1998). *Snijders-Oomen Niet-verbale Intelligentietest, SON-R* 2½-7. Swets & Zeitlinger, B.V., Lisse, The Netherlands.

- Teti, D.M. & Gelfand, D.M. (1991). Behavioral competence among mothers of infants in the first year: The mediational role of maternal self-efficacy. *Child Development*, 62, 918-929.
- Teti, D.M., O'Connell, M.A., & Reiner, C.D. (1996). Parenting sensitivity, parental depression and child health: The mediational role of parental self-efficacy. *Early Development and Parenting*, 5, 237-250.
- Warreyn, P., Raymaekers, R., & Roeyers, H. (2004). *Handleiding Vragenlijst Sociale Communicatie*. Destelbergen: SIG vzw.

Table 1

Participant characteristics

	ASD (n = 17)	TD (n = 17)			
Sex ratio (M:F)	(13:4)	(10:7)			
Total SCQ					
M(sd)	18.7 (6.23)	4.31 (3.25)			
Range	10-29	1-10			
SCQ difference score					
M(sd)	14.23 (7.03)				
Range	6-28				
Word comprehension			F(1,32)=2.57		
M(sd)	37.76 (37.01)	55.59 (27.04)			
Range	1-99	5-98			
Non-verbal IQ			F(1,32)=8.26**		
M(sd)	89.47 (19.93)	105.88 (12.52)			
Range	50-124	81-130			

Note. SCQ: Social Communication Questionnaire, \*  $p \le 0.05$ , \*\*  $p \le 0.01$ , \*\*\*  $p \le 0.001$ .

Table 2

Associations between parenting cognitions

TD	1	2	3	4	5	6
ASD						
1. Guilt	.10	12	.02	.30	.12	.37
2. Self-efficacy	48	.58*	.44	49*	20	43
3. Agency	27	.44	.48*	45	26	33
4. Incompetence stress	.33	44	31	.66**	.44	.59**
5. Role restriction stress	.15	35	26	.52*	.67**	.57*
6. Depression	.18	52*	20	.72***	.57*	.87***

Note. \*  $p \le .05$ . \*\*  $p \le .01$ . \*\*\*  $p \le .001$ .