

Running head: PARENTING STRESS AND COMPETENCE

The Effects of a Parent-Focused Intervention for Children with a Recent Diagnosis of  
Autism Spectrum Disorder on Parenting Stress and Competence

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### Abstract

This paper reports on the effects of two types of parent-focused intervention, for parents of children with autism spectrum disorder (ASD) aged 2 to 4 years and within 6 months of diagnosis, on parent's perceptions of stress and competence. Interventions aimed to decrease parenting stress and increase parenting competence by embedding empirically supported parenting strategies within family routines. Families were assigned to a professionally supported intervention that included a workshop and ten home-visits (n = 17) or to a self-directed video based intervention (n = 22). Development in social communication was greater for children of families receiving professional support as measured by a caregiver questionnaire but not on a clinically measured behavior sample. Improvements in adaptive behavior were greater for children in the professionally supported intervention when relatively low adaptive behavior scores had been demonstrated at pre-intervention. The professionally supported intervention resulted in reduced child-related parenting stress and increased parenting self-efficacy relative to the self-directed intervention. The findings support the importance of providing individualized information and professional support around the time of diagnosis for families who have a child with ASD.

**Keywords:** Parenting stress; parenting competence; early intervention

## 1. Introduction

The time of diagnosis and period of waiting for intervention can be one of the most stressful periods for parents of children with an autism spectrum disorder (ASD) especially as most encounter waiting lists for early intervention services (MacDermott, Williams, Ridley, Glasson, & Wray, 2006). There are considerable demands on parents at this time as they learn to adjust to their child's communication and social interaction impairments (Aarons & Gittens, 1992). Social skill delays have been identified as one of the most consistent predictors of parenting stress for both mothers and fathers of children with ASD while mothers are typically more affected by eating, sleeping and emotional dysregulation than fathers, and fathers are typically more affected by a child's externalizing behaviors than mothers (Davis & Carter, 2008). Early parenting programs that are targeted to the specific requirements of families of children with ASD offer a mechanism for addressing and reducing the impact of these parenting related stressors.

Early parenting programs can potentially support the wellbeing and development of both parent and child. There is substantial empirical evidence to indicate that children with and without developmental disabilities benefit from a responsive parenting style whereby the parent follows the child's focus of attention (Siller & Sigman, 2002; Yoder, Warren, McCathren, & Leew, 1998). Children with an autism spectrum disorder (ASD) who had parents with more synchronous or responsive behavior have been reported to achieve superior communication skills at 1, 10, and 16 years when compared with children whose parents showed lower levels of responsivity (Siller & Sigman, 2002). In addition to adult responsivity, the use of augmentative and alternative communication strategies (Charlop-Christy, Carpenter, Le, LeBlanc, & Kellet, 2002; Ganz & Simpson, 2004; Sigafos et al., 2004),

environmental arrangement (Kaiser, Ostrosky, & Alpert, 1993), offering choice (Bambara, Koger, Katzer, & Davenport, 1995; Koegel, Dyer, & Bell, 1987; Moes, 1998), imitation (Garfinkle & Schwartz, 2002; Nadel & Pez , 1993; Schuler & Prizant, 1987) and turn taking (Girolametto, Verbey, & Tannock, 1994) are all strategies that parents may use in their everyday interactions with their children to encourage social and communication development. Parenting programs focusing on enhancing the quality of the parent-child relationship and requiring parents to practice new skills with their own child have demonstrated the largest effects on child behavior and parenting behavior and skills (Kaminski, Valle, Filene, & Boyle, 2008). Parenting programs offer a means for providing children with ASD home environments that enhance communication and social development and simultaneously address the compounding difficulties related to parental experiences around stress and competence.

Parents of children with an ASD generally report significantly higher levels of stress and lower levels of parenting competence than parents of children without disabilities (Hassall, Rose, & McDonald, 2005; Hastings & Johnson, 2001; Tomanik, Harris, & Hawkins, 2004). This increased stress is often chronic and persistent over time (Dyson, 1993). Stress and low self-esteem in mothers have been linked to less than optimal parenting, failure to engage with services, less beneficial outcomes for children in early intervention programs, decisions to seek out-of-home care for their child, impeded child development, and higher rates of child psychopathology and antisocial behavior (Brinker, Seifer, & Sameroff, 1994; Llewellyn, McConnell, Thompson, & Whybrow, 2005; O'Connor, 2002). Access to knowledge on the range of evidence-based strategies for supporting their child around the time of diagnosis may, at least in part, alleviate some of this parenting stress.

Research that focuses on supporting parents in ways that can both reduce the stress related to parenting and increases responsive parenting behaviors for parents of very young children with ASD is in its infancy. There is still much to discover about effective practices for families at the time of diagnosis. Advances in diagnostic practices can result in identification of children with ASD as young as 12 to 18 months (Johnson & Myers, 2007; Kleinman, et al. 2008). These advances have heightened the need for research into parent-focused interventions for families who have children diagnosed with ASD at an early age and the impact of such interventions on child and parent outcomes. Despite this need, a recent review of parent implemented early interventions for children aged between 1 and 6 years with ASD found few published studies that employed adequate research design (McConachie & Diggle, 2007). The authors, while calling for improved research in this area, cited a small number of randomized controlled studies that demonstrated some advantages of parent training in relation to child outcomes (communicative behavior) and parent outcomes (maternal knowledge of ASD, parental responsiveness and maternal depression).

In one study, a social communication intervention for children with ASD that employed a number of the strategies mentioned earlier led to increased synchronous and decreased asynchronous interactions of parents in the intervention group (Aldred, Green, & Adams, 2004). A significant increase in expressive vocabulary as rated by parents was also achieved through the intervention but not according to vocabulary subdomain scores of the ADOS and Vineland. In another study, Mahoney and Perales (2005) compared outcomes for children with either a developmental disorder (DD) or pervasive developmental disorder (PDD) who participated in an intervention that aimed to increase parental use of responsive teaching strategies to encourage certain

pivotal developmental behaviors in their children. The intervention increased maternal responsivity which was also related to increases in the child's pivotal developmental behaviors. The role of maturation in the child's development, however, was masked due to the absence of a control group,

Parent interventions can be delivered in different modes with advantages and disadvantages attached to each. Comparisons of parent interventions specific to children with ASD that are delivered face to face or through self-directed modalities are not available, however, parent training programs addressing children 'at risk' or with challenging behaviors have been assessed across multiple modes of delivery (Brookman-Frazer, 2004; Morawska & Sanders, 2006a; Peterson, Luze, Eshbaugh, Jeon, & Kantz, 2007; ). Self-delivered training in which parents follow a manual or video format at a pace and intensity they independently determine (Morawska & Sanders, 2006a), contrasts with professional partnership modes of delivery that may include scheduled workshops and home-visits. Self-delivered parent interventions can also vary in structure with some following strict schedules in combination with regular phone consultations (see for example Morawska & Sanders, 2006b). Morawska and Sanders (2006a) found that self-directed programs both with and without telephone consultations were associated with positive changes in parent reported child behaviors and parenting style and confidence relative to waiting list families.

Education programs for parents can reduce parenting stress and increase parental self-efficacy (Sanders & Woolley, 2005) but most studies have focused on children with disabilities other than ASD. One study that involved parents of children newly diagnosed with ASD and aged 2.5-5 years old, evaluated a 20-week parent education and behavior management intervention (Tonge, Brereton, Kiomal,

Mackinnon, King, & Rinehart, 2006). Parents in this study showed greater improvement in their mental health (specifically anxiety, insomnia, and somatic symptoms and family dysfunction) relative to a comparison group of parents who received a parent education and counseling intervention.

The aim of the present study was to reduce parenting stress and increase parenting competence for families of children within 6 months of receiving an ASD diagnosis. The effects of two programs were compared, a professionally supported parent focused intervention and a self-directed video based intervention. Both programs aimed to encourage parent responsivity and to assist parents to integrate increased communication supports into daily family routines. Unlike the intervention developed by Tonge et al., these interventions focused on parental responsivity and use of strategies to promote social communication within family routines. We predicted that parents who participated in the professionally supported early intervention program would report a reduced level of parenting stress and increased parenting competence following the intervention greater than would be reported by parents in the self-directed intervention. Significant improvements in child behaviors were not anticipated due to the brief nature of the intervention.

## **2. Method**

This study used a pre-post test quasi-experimental design to investigate outcomes for children (social communication and adaptive behavior) and their parents (parenting stress and sense of competence) following participation in either a professionally supported or self-directed, self-paced parenting intervention.

### *2.1 Participants*

Participants were 39 families who had a child aged between two and four years with a clinical diagnosis of ASD based on the diagnostic criteria specified in the Diagnostic and Statistical Manual (DSM-IV) (American Psychiatric Association, 1994) received within six months prior to their participation in the study. Diagnosis was confirmed by the Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore, & Risi, 2001) administered by a trained member of the research team. Children met the cut-off for autistic disorder ( $n = 30$ ) or autism spectrum disorder ( $n = 9$ ) on the ADOS. Recruitment of participants through paediatricians, community health, hospital and education-based, early intervention services, and ASD parent support groups occurred continuously over the period of the study. It was not feasible to fully randomize the assignment of families to each intervention as the professionally supported group received home-visits made by a trained facilitator. Thus due to travel distances, only those families within a 10km radius of the researchers' University base were allocated to the professionally supported group. The self-directed group consisted of 22 families and the professionally supported group of 17 families. Demographic details for the two groups are presented in Table 1 and include the following child measures.

## *2.2 Child measures*

### *2.2.1 Scales of Independent Behavior Revised- Early Development Form (SIB-R)* (Bruininks, Woodcock, Weatherman, & Hill, 1996).

The SIB-R is administered via parent interview and provides a measure of adaptive and problem behaviors of children and adults aged from 3 months to 90 years. Scores from the SIB-R include a Broad independence (BIW) score based on adaptive behaviors as well as a maladaptive index which is based on three domain scores, internalizing behavior, externalizing behavior, and asocial behavior. A support



score is derived from a combination of the BIW and the general maladaptive index, while a standard score is derived from the child's age and BIW score at the time of assessment. BIW is used in the present analyses as it provides the finest discrimination for change in adaptive behavior.

### *2.2.2 Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP) (Wetherby & Prizant, 2002).*

The CSBS-DP is a standardized assessment which evaluates the communication and symbolic abilities of children whose functional communication age is between 6 months and 2 years. The CSBS-DP consists of a caregiver questionnaire which is used to obtain parents' perceptions of their child's communicative and symbolic behavior and a 30 minute behavior sample administered and scored by an independent assessor. The CSBS-DP provides domain scores in social communication, speech and symbolic behavior. The assessment has a high degree of internal consistency and test-retest reliability.

### *2.2.3 Mullen Scales of Early Learning (Mullen, 1995).*

The Mullen Scales assess language, motor, and perceptual abilities of children aged from birth to 68 months. T-scores, percentile ranks, and age equivalent scores can be calculated for scales in gross motor, visual perception, fine motor, expressive and receptive language together with an early learning composite. The Mullen has proved a useful instrument for assessing a range of skills in children with autism (Akshoomoff, 2006).

Between-group differences on these variables were analyzed using independent t-tests. No significant differences were indicated for child age ( $t_{37} = -$

0.29;  $p = 0.77$ ), adaptive functioning ( $t_{37} = -1.30$ ;  $p = 0.20$ ), developmental level ( $t_{37} = -0.08$ ;  $p = 0.94$ ) or communication skills ( $t_{37} = 0.59$ ;  $p = 0.56$ ). Differences in parents' education levels were assessed using the Mann-Whitney test. No significant difference in education was indicated for mothers ( $Z = -1.32$ ;  $p = 0.19$ ) or fathers ( $Z = -0.34$ ;  $p = 0.74$ ). Chi-squared tests similarly indicated no significant differences between groups on child gender ( $\chi_1^2 = 1.41$ ;  $p = 0.23$ ).

(Insert Table 1 about here)

### 2.3 Parent Measures

Parents in both groups completed the following self-report measures.

#### 2.3.1 Parenting Stress Index (PSI) (Abidin, 1995).

The PSI is a 101-item assessment that consists of two factors: (1) stress resulting from parental perceptions of the child's contribution to the parent-child relationship (child stress), and (2) the impact of the parental role on the parent with respect to psychological well-being, health, marital and other relationships (parental stress). A 5-point Likert scale is used to measure these items, where higher scores indicate greater levels of stress.

#### 2.3.2 Parenting Sense of Competence (PSOC) (Johnston & Mash, 1989).

The PSOC is a 16-item scale measuring parental satisfaction and efficacy and was administered both as a pre- and post-intervention measure. Each item is measured on a 6-point Likert scale ranging from strongly agree (1) to strongly disagree (6). Higher scores indicate greater levels of competency.

### 2.4 Procedure

Ethical approval to conduct the study was obtained from the University [removed for blind review] and participants were provided with an information sheet and consent form explaining the purpose and requirements of the study.

#### *2.4.1 Timeline of assessments.*

An initial telephone interview was conducted with families who consented to participate. In addition to checking eligibility based on participant criteria, the M-CHAT (Robins, Fein, Barton, & Green, (2001) was used to ensure the child was experiencing social communication difficulties. To be included in the study, families had to receive no more than 20 hours per week of services for their child and were not to be enrolled in an intensive behavioral intervention. Eligible families were then assigned to the professionally supported intervention if they lived within a 10 km radius of [Removed for blind review] University or to the self-directed intervention if the family lived further from the University. Dates for pre-intervention assessments were booked after screening at which time all parents completed the PSOC and PSI, while mothers only completed the SIB-R and CSBS-DP caregiver questionnaire. A trained assessor, who was blind to the group status of the children, administered the CSBS-DP behavior sample, the ADOS and the Mullen. Parents then participated in one of two interventions over the following 6 weeks as described below. Follow-up assessments were conducted three months after the intervention was completed. At this assessment parents repeated the 4 questionnaires given at pre-intervention; the PSOC and PSI completed by mothers and fathers and the SIB-R and CSBS completed by mothers. A trained assessor administered the CSBS behavior sample.

#### *2.4.2 Intervention groups.*

The professionally supported intervention consisted of a two day parent group workshop and a series of 10 home-based consultations with a facilitator. While both parents were encouraged to participate, one mother and 3 fathers were unable to attend the workshop with their spouse. Home-based facilitation was primarily attended and followed through by mothers. The workshop provided information and parent education on the following topics: autism; social; communication; play; sensory; behavior; strategies to improve social interaction and communication; embedding strategies within daily routines; using a balanced approach; and selecting a child-focused early intervention program. Each topic followed a prescribed format and content that was delivered through a series of powerpoint slides. The following strategies were presented to encourage parental sensitivity and responsivity: following the child's focus of attention, getting down to the child's level, augmentative and alternative communication approaches, offering choice, environmental arrangement, imitation and turn-taking. A number of structured interactive group activities were also employed to promote parent-to-parent interaction and opportunities to individualize the information and strategies to particular children and families. For example, on the first day, parents used family photos to describe who was in their family and the strengths and interests of their child with ASD. A maximum of five families participated in each workshop.

Immediately following the workshop, facilitators trained in the assessments and strategies used in the program, made 10 x 1 hour home-visits which occurred twice-weekly over 5 to 6 weeks. Facilitators were doctoral students experienced in working with families of young children with ASD. Weekly meetings were held between facilitators and one of the authors to ensure compliance with program goals. Home-visits aimed to: support parents to identify early intervention goals for their

child using the Canadian Occupational Performance Measure (COPM) (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 1998) (see Rodger, Braithwaite, & Keen, 2004 for information about parent goal setting), select strategies from the workshop to achieve those goals, and provide parents with an opportunity to ask questions and receive feedback on how workshop strategies could be embedded into their daily life to meet their goals. Diaries completed by parents each week indicated different levels of program implementation outside consultation visits. Time spent implementing program strategies were reported as ranging from half an hour to thirteen and a quarter hours in a single week.

Parents in the self-directed parent intervention received a copy of the interactive, instructional DVD 'Being Responsive: You and Your Child with Autism' produced by Braithwaite, Keen, and Rodger (2004). The DVD provided information about the strategies presented in the two day workshop attended by the intervention group. The DVD gave real-life examples of how parents could use these strategies in daily routines to enhance communication and social interaction in the home. Video based examples were supported by activity sheets modeled on the interactive activities used in the workshop and designed to help parents individualize the information presented on the DVD for their family and incorporate the strategies within their daily routines. Participants were advised to work through the DVD over the ensuing six weeks. Use of the DVD was evaluated for each family using a self-report questionnaire. Families were asked how many sections of the DVD they watched, the number of days over which they used the DVD, the number of times they watched the DVD and the number of activity sheets they used from the DVD workbook. Of the 22 families in this group, one family did not use the DVD, 17 (77%) watched all 13 sections, and 4 families watched between 1 and 12 sections of the DVD. The activity

sheets were used to varying degrees by 8 (36%) families and not used by the other 14 (64%) families.

## *2.5 Analytic Methods*

Analysis of co-variance (ANCOVA) was used to compare intervention outcomes for child's adaptive behavior (SIB-R) and communication (CSBS). Because mother and father responses on the parent questionnaires (PSI and PSOC domains) are non-independent, multilevel regression was used to compare these outcome measures (see Kenny, Kashy, & Cook, 2006). Both the ANCOVA analyses and the multilevel regression analyses assessed for post-intervention effects after covarying baseline scores. This technique is generally considered to have the greatest power for a pre- post assessment design (Rausch, Maxwell, & Kelly, 2003).

### *2.5.1 Multilevel analysis considerations.*

The effects of a parent intervention for mothers and fathers in the same family will be determined both by factors that are specific to an individual parent and also by factors that the mother/father pair share. In multilevel analysis this is accommodated using a dyadic structure (Kenny et al., 2006) where variation at the level of the individual parent is nested within variation at the level of the dyad or family grouping. Independent variables included in a model can explain within-dyad variance, for example parent role, with father's role differing from the mother's role. Independent variables may alternatively explain between dyad variance for example 'intervention condition' because mothers and fathers in the same family were allocated to the same intervention. Some independent variables such as baseline scores can explain variance at both the level of the individual and the dyad because while baseline scores differ for individuals they may also be considered as high or low for a specific family.

While multilevel regression works the same as traditional regression, the variation in parent scores is partitioned to allow individual level influences and family level influences to be accounted for in a simultaneous process.

If dependencies within parent dyads were ignored standard errors would tend to be too small and spurious intervention effects could occur (Nash, Kupper, and Fraser, 2004). If mothers' and the fathers' data were treated as two independent samples differences between genders would be assumed rather than tested. Kenny et al. (2006) have described such traditional approaches as "less than optimal" (pp. 46-48) for data with a dyadic structure and promote multilevel regression as superior. *MLwiN*, a multilevel statistical package (Rasbash, Steele, Browne, & Prosser, 2005), was used to analyze these data. Use of multilevel analysis permits a relaxation of many of the assumptions related to dependencies that are required for OLS regression.

Parameter estimation in multilevel modelling is typically an iterative process where a high speed computer program generates parameter estimates until the estimate maximises the probability of producing the observed sample scores given the model specified by the researcher (Hox, 2002). This is called maximum likelihood (ML) estimation and is most frequently used when estimating parameters in multilevel regression. ML estimation, however, is most accurate for large-samples and least effective when the number of groups (i.e. families in the present study) is small (Hox, 2002). Hox recommends using Markov chain Monte Carlo (MCMC) estimation when group numbers are small. MCMC estimation does not generate a single best estimate from sample scores, instead the process generates upwards of tens of thousands of estimates for each parameter based on the study sample and a prior probability distribution. Without prior information about the probability distribution, a flat or diffuse distribution is selected because it has minimal influence on parameter

estimates (Hox, 2002). The mode of the generated distribution of estimates becomes the point estimate (or parameter estimate), and the 2.5th and 97.5th percentiles of this distribution sets the limits of a 95% central interval. Central Intervals (CIs) are interpreted in the same way as confidence intervals in OLS regression in that they indicate the uncertainty surrounding the parameter estimate and indicate whether the estimate is significantly different to zero. When 95% CIs do not overlap with zero the parameter estimate is considered 'significant'. MCMC estimation was implemented using the *MLwiN* package (Browne, Rasbash, & Ng, 2005).

The multivariate structure of the PSI, which comprises two variables (child stress and parental stress), and the PSOC scale, which also comprises two variables (parent satisfaction and parent self-efficacy) required the use of multivariate analysis for each assessment. Within the multilevel framework, multiple variables are analyzed by creating an additional level in the hierarchical structure below the level of the individual (Hox, 2002). For each analysis the two measures are "nested" within parents, who in turn are nested within families.

For each of the two variables for PSI and PSOC, the regression models tested for main effects for Group and Gender, and for interactions between Group and baseline and between parent gender and baseline. For instance, the Group main effect asks whether or not the regression lines through the follow-up versus baseline scatterplots for the two groups are separated (i.e., is there an effect at follow-up for group after controlling for baseline). The Group by baseline interaction allows the regression lines to vary on the basis of both group and pre-intervention score (i.e., does the main effect need to be qualified according to baseline scores).

### **3. Results**



Means and standard deviations for mothers and fathers PSI and PSOC scores at baseline and follow-up are provided in Table 2. Preliminary analyses were performed to assess for correlation between follow-up measures and also to assess for multilevel effects in the dataset. Bayesian Deviance Information Criterion (DIC) statistics were calculated for models with and without correlated follow-up measures, and with and without a multilevel structure. Smaller DICs indicate a better fitting model with five or more DIC points considered substantial (Stevens, n.d.). For example, to test whether follow-up PSI measures were correlated, the DIC for a model allowing the correlation to be estimated (DIC = 1233.3) was compared with the DIC for a model in which correlation was constrained to be zero (DIC = 1252.3). The difference is large enough to indicate that the follow-up PSI measures were correlated. Similarly, DICs were used to determine whether the multilevel model was a better fit to the data than the single level model. The multilevel model for follow-up PSI measures (DIC = 1195.3) was a better fit to the data than the single-level model (DIC = 1233.3). Intraclass correlation for child related stress ( $\rho = 0.51$ ) indicates that just over half the variance in child related stress is attributable to family-level differences while less than a quarter of the variance for parent related stress is attributable to family level differences ( $\rho = 0.23$ ). DICs also indicate that the follow-up scores on the PSOC are correlated. The model permitting estimation of a correlation ( DIC = 853.6) is a better fit to the data than the model with the correlation constrained to be zero (DIC = 873.7). For the PSOC data, however, the multilevel model (DIC = 851.8) is not a better fit to the data than the single level model (DIC = 853.6) and thus the single level model is retained.

Preliminary analyses were also conducted on the PSI and PSOC baseline measures to determine whether group differences existed prior to intervention. The

model estimating group effects (DIC = 1323.1) did not differ substantially from the model without group effects (DIC = 1321.0). For PSOC, the two DICs were 970.0 and 967.5 indicating that the two models do not differ substantially. In both cases, the 95% CIs for group spanned zero. Taken together, the results of these preliminary analyses indicate no differences at baseline between the self-directed group and the professionally supported group for either PSOC or PSI scores.

(Insert Table 2 about here)

Of the 39 families included in the study, two fathers did not complete the baseline PSI (one in the professionally supported group and one in the self-directed group) and one did not complete the PSOC (self-directed group). In addition one mother (self-directed group) and four fathers (self-directed group) did not complete the follow-up PSI and these same four fathers did not complete the follow-up PSOC. Thus there were 39 families across both analyses; but only 38 mothers and 33 fathers for the analysis of the PSI data, and 39 mothers and 34 fathers for the analysis of the PSOC data.

Issues of missing data were addressed through multiple imputation. This was to ensure that data for every parent in the study is represented in all analyses. Ten complete datasets with imputed data were used for these analyses. Parameter estimates are the average of the estimates produced by the multiple datasets. Standard errors were constructed from the average standard error across the ten imputed datasets and from variation between the datasets. That is, multiple imputation uses the inconsistency of the multiply imputed values as additional information to produce unbiased standard errors.

Because non-significant interaction terms were included in models, collinearity could have been an issue. To address this possibility, models were subsequently run without the non-significant interaction terms and estimates for the remaining terms did not substantially change.

### *3.1 Child and parent-related stress.*

Parameter estimates for parent stress ratings are provided in Table 3. As expected, baseline measures for both child-related stress and parent-related stress are associated with their counterpart measures at follow-up. Both intervention type and parent gender had a significant influence on child-related stress, after controlling for the baseline measure. No significant interaction effects for child-related stress were detected.

(Insert Table 3 about here)

The PSI ratings for child-related stress are on average 7.8 points lower for parents in the professionally supported intervention than for parents in the self-directed intervention (see, in Table 3, the estimate for Group). Fathers' ratings are however 6.2 points higher (see, in Table 3, the estimate for Gender) than mothers' ratings of child-related stress. In summary, fathers experienced higher levels of child-related stress than mothers, but the professionally supported intervention reduced child-related stress relative to the self-directed intervention for both mothers and fathers.

For parent-related stress at follow-up, no main effects are indicated (see, in Table 3, that CIs for the Group and Gender effects overlap with zero). There is however an interaction of parent gender with baseline measures of parent stress (see

in Table 3 the estimate for GenderXBaseline). The interaction is illustrated in Figure 1a. At average baseline scores there is little separation between mothers and fathers (i.e., there is no gender main effect), but at lower baseline scores and at higher baseline scores, the lines for mother and fathers separate. Overall there is a relationship between follow-up scores and baseline scores, but the relationship is stronger for mothers than for fathers (i.e., the line for mothers is steeper than the line for fathers).

(Insert Figure 1 about here)

### *3.2 Parenting satisfaction and efficacy.*

Parameter estimates for PSOC ratings are provided in Table 4. Again satisfaction and self-efficacy scores at follow-up are strongly associated with the corresponding baseline scores. No group or gender effects are indicated for follow-up satisfaction scores (see, in Table 4, that CIs for the group and gender effects overlap with zero) indicating that neither intervention type nor parent gender had an overall effect on satisfaction scores at follow-up.

(Insert Table 4 about here)

For self-efficacy there is an interaction for intervention group by baseline score (see, in Table 4, the estimate for GroupXBaseline). The interaction is illustrated in Figure 1b. At average baseline scores ( $M = 25.6$ ) there is little separation between the two intervention groups (i.e., there is no group main effect), but at lower baseline scores and at higher baseline scores, the lines for the two groups separate so that the relationship between follow-up scores and baseline scores is stronger for the self-directed group than for the professionally supported group. Parents in the

professionally supported group with high scores at baseline demonstrated relatively lower self-efficacy scores than parents in the self-directed group who were high in self-efficacy at baseline. Conversely, parents low in self-efficacy at baseline demonstrated relatively higher levels of self-efficacy if they received the professionally supported intervention than if they received the self-directed intervention.

### *3.3 Child measures*

#### *3.3.1 Adaptive behavior*

Mean BIW scores on the SIB-R moved from 451.6 (SD = 8.12) at baseline to 457.0 (SD = 7.62) at follow-up for the professionally supported group, and 448.1 (SD = 9.25) to 452.1 (SD = 11.02) for the self-directed intervention group. The difference between the two follow-up means is small, and indeed, an analysis of covariance indicates that there is no difference after controlling for baseline measure (see, in Table 5, that the 95% CI for the group effect spans zero). However, the ANCOVA indicates that the interaction between baseline scores and group membership is approaching significance (see, Table 5, that the lower limit of the 95% CI for the interaction is very close to zero). Children in families receiving the professionally supported intervention who scored the lowest BIW scores at baseline demonstrated the greatest increases at follow-up, while children scoring higher on the SIB-R at baseline were not advantaged in relation to adaptive behavior by home facilitation.

(Insert Table 5 about here)

#### *3.3.2 Communication*

Mean raw scores on the CSBS-DP (Caregiver Questionnaire) moved from 69.10 (SD = 24.16) at baseline to 91.67 (SD = 28.80) at follow-up for the professionally supported group, and 62.82 (SD = 28.01) to 80.83 (SD = 27.68) for the self-directed intervention group. On the CSBS-DP (Behavior Sample) mean raw scores changed from 56.36 (SD = 31.84) at baseline to 75.84 (SD = 39.73) at follow-up for the professionally supported group, and 55.57 (SD = 38.24) to 73.57 (SD = 48.92) for the self-directed intervention group. ANCOVA indicates a significant effect of group on follow-up scores for the CSBS Caregiver Questionnaire. The professionally supported group demonstrate significantly greater improvement on social communication at follow-up than the self-directed group, regardless of score values at baseline. No significant effect of group and no interaction with baseline scores are indicated for the CSBS Behavior Scale. Behavior sample scores at follow-up are not affected by group condition (see Table 5).

#### **4. Discussion**

The main finding from this study was that a relatively brief parent-focused intervention for parents with a child newly diagnosed with ASD was effective in reducing child-related parenting stress. This intervention was also more effective in increasing self-efficacy when parents were scoring low in self-efficacy prior to intervention. Parents receiving similar information via a self-directed DVD and activity sheet package were not similarly advantaged. High child-related stress scores indicated that children with ASD displayed qualities that parents found challenging and unacceptable, such as distractibility, negativity and demanding behaviors (Abidin, 1995). While child-related stress scores at baseline were in the normal range for a small number of parents in this study (range of 84, 20<sup>th</sup> percentile to 114, 80<sup>th</sup> percentile) the majority of parents in the study had “high scores” with parents scoring

above the 85<sup>th</sup> percentile (scores > 116). The average score at baseline was 144 (98<sup>th</sup> percentile), indicating that, on average, parents in this group were experiencing very high child-related stress. While the 8 point difference between groups, following intervention, is not sufficient to move a parent attaining the average score at baseline out of the 'high' stress ranking, the difference is enough to accomplish this for parents with scores at the 90<sup>th</sup> percentile (a child-related stress score of 122).

Parent related stress was related to perceptions of the parenting role including, management skills, feelings of isolation, support, health and frustration. Unlike child-related stress, the average rating for parent-related stress at baseline (a score of 141) was within the normal range (80<sup>th</sup> percentile).

Professional support appears to have been most effective in assisting parents to understand and reframe their child's behavior to be viewed more positively rather than changing parent perceptions around the parenting role. Professional support at the time of diagnosis appears essential if parents are to successfully apply ASD related information to supporting and accurately interpreting characteristics specific to their own child.

It is well established that the provision of information at the time of diagnosis is important for families who have a child with a disability (Hasnat & Graves, 2000; Sloper & Turner, 1993). The results from the current study suggest, however, that families who received information through an interactive DVD did not experience the same advantages as parents who received a brief face-to-face intervention. Although not identical, the content of the DVD was modeled on the parent group workshop so that both intervention and comparison groups were exposed to similar material. While these results suggest that professional support is necessary to assist families to

understand and make use of the information provided to them, the design of the study did not preclude the possibility that the gains made by parents resulted from non-specific professional contact. Inclusion of a control group receiving professional contact is recommended in future research of this nature.

It is important to note that, similar to Aldred et al (2004), child outcome measures were only found on parent report measures. Greater gains for social communication were indicated for the professionally supported group when the parent questionnaire of the CSBS was the measure of interest but not when the more objective behavior samples, completed by a clinician blind to the intervention, were used for analysis. While adaptive behavior scores on the SIB-R did not differ significantly between the two conditions from baseline to follow-up, an interaction effect indicated that professional support favored children with low adaptive behavior scores at baseline. Given the short duration of the present study, expectations of medium or large changes on child behavior is unrealistic, however the small effect indicated for adaptive behavior is promising. Longitudinal studies are necessary to determine longer term benefits of such early intervention programs with sustained supports across development an essential consideration. The period around diagnosis, however, is critical for both supporting parent well-being as well as establishing a solid foundation for the child's development. The present study raises additional questions around differentiated intervention requirements of families at this time.

Engagement of families to the different intervention types and the determination of families to embed intervention strategies into family routines differed from family to family. A regular visit from a professional appeared sufficient to keep most families engaged with the intervention. For families using the DVD however, the majority had difficulty setting aside time to do the activity sheets and



some indicated difficulty finding time to sit down as a couple and watch the DVD within the 6 week period. There were a few families who reported high motivation in response to the DVD and activity sheets and viewed sections repeatedly for clarification, but these families were in the minority. Family engagement is an important aspect of intervention (Lundahl, Risser, & Lovejoy, 2006). The large number of parents who had difficulty engaging and following through with the DVD intervention is an important consideration and the data of families with low level engagement were included in analyses for this study because they are likely to be representative of families at the time of diagnosis. All families, irrespective of engagement in intervention activities were included in data collection with data therefore reflecting the complexity of family situations at the time of diagnosis. All families had been eager to receive information however; there was considerable diversity in the resources of families to fully use the intervention provided.

The professionally supported intervention did not demonstrate the same range of compliance issues as the self-directed intervention. All families attended the workshops and all had the 10 home-visits. Compliance issues for this group were with respect to the participation of both partners. Three fathers and one mother did not attend the parent workshop with their partner and it was the norm for only one parent to remain involved during home-visits. Families in the professionally supported group also varied greatly in the amount of time they spent during the week implementing intervention strategies. Home diaries indicated families spent between half an hour and thirteen and a quarter hours extra each week implementing the strategies they were learning. Studies with larger numbers of families are required to capture the effect of family characteristics on compliance and to identify the continuum of methods and choices required to maximize intervention effects for different families.

Self-efficacy scores for both groups, tended toward the mean ( $M = 25.60$ ) from pre to post intervention. Mean self-efficacy scores found for this study reflect mean scores for the normative sample of Johnston and Mash (1989). High initial self-efficacy scores tended to fall post intervention and very low initial scores tended to rise. The professionally supported intervention was associated with significantly greater increases in parent self-efficacy when self-efficacy scores at baseline were low. For parents high in self-efficacy at baseline, however, scores of parents who were self-directed showed less decline than scores of parents in the professionally supported group.

Mothers and fathers demonstrated differences in stress ratings at follow-up. It is now well documented that sources of stress for mothers and fathers differ (Hastings & Brown, 2002; Hastings et al., 2005; Saloviita, Italinna, & Leinonen, 2003; Shin, Nhan, Crittenden, Flory, & Ladinsky, 2006). A finding from this study was that fathers' follow-up scores on the child domain of the PSI were higher relative to mothers' scores for both the professionally supported group and the self-directed group. A 6 point difference is not large, but could move someone rated on the border of the 'high' stress range (85<sup>th</sup> percentile) to the border of an average stress rating (80<sup>th</sup> percentile). Higher stress for fathers relative to mothers following intervention may be due to an increased awareness of their child and associated difficulties or to the greater role they were being encouraged to adopt through both interventions.

In respect to stress related to the parenting role, mothers' scores appeared to remain relatively constant from baseline to follow-up while fathers' scores tended toward average scores at follow-up. Fathers' parent related stress appears to have been affected in unintended ways by their participation in an intervention, some demonstrating an increase and others a decrease on the parent stress measure. While

mothers' ratings remained relatively stable, fathers' follow-up ratings of stress related to their parenting role would be more difficult to predict based on pre-intervention ratings. The effects of parent based interventions on fathers in particular require further investigation.

The interaction effects found in this study for parent related stress, parenting efficacy and adaptive behaviors from baseline to follow-up suggest that there may be subsets of parents who would most benefit from a professionally supported intervention relative to a self-directed intervention. Parents who, at the time of their child's diagnosis, are high in self-efficacy and low in child-related stress may be served well with self-directed information at this time.

Caution is needed in interpreting the results from this study due to the relatively small group sizes and the lack of randomized assignment of participants to the professionally supported intervention and the self-directed condition. Although there were no differences between groups on critical child and parent variables at baseline, the professionally supported group differed from the self-directed group in terms of their geographic location. All participants, however, were residents of the greater Brisbane area and lived close enough to attend pre and post assessment sessions at the University-based clinic. The participants were, overall, well educated and may not be representative of the wider population of parents who have a child with ASD. Replication of the study drawing on a larger and more representative sample of parents would help to determine the generalisability of the results from this study.

## **5. Conclusion**

This study provides preliminary evidence regarding the impact of provision of intervention to families at or shortly after the time of an ASD diagnosis. The mode in which intervention was provided appears important with benefits for mothers and fathers in parenting stress and competence linked to professional input and individualization of information. Provision of information about ASD and strategies for enhancing social communication via DVD alone does not impact on parenting stress levels or perceptions of parenting competence at the level that can be achieved through parent-focused professional support. Furthermore, fathers and mothers differ in their response to participation in early intervention with respect to parenting stress and competence. These differences may help to inform the future provision and efficacy of parent-focused interventions around the time of diagnosis.

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Table 1

*Demographic Characteristics of Intervention and Comparison Group Families.*

	<b>Professionally supported</b>		<b>Self-directed</b>	
	(N = 17 mothers/16 fathers)		(N = 22 mothers/21 fathers)	
	M	SD	M	SD
Mean child age (in months)	36.38	7.54	35.71	6.92
SIB-R standard score	52.29	23.14	43.18	20.57
Mullen score (DQ)	53.06	9.06	52.86	6.53
CSBS-DP Behavior Sample	56.36	31.84	55.57	38.24
Social (raw scores)	27.34	10.91	25.07	12.10
Speech (raw scores)	17.56	14.78	15.95	16.51
Symbolic (raw scores)	11.47	10.04	14.55	12.55
	N	%	N	%
Parent education (mother)				
9 <sup>th</sup> -12 <sup>th</sup> grade	6	35.3	2	9.1
Vocational	4	23.5	5	22.7
College graduate	0	0	5	22.7
University graduate	7	41.2	10	45.5
Parent education (father)				
9 <sup>th</sup> -12 <sup>th</sup> grade	6	35.3	5	22.7
Vocational	1	5.9	6	27.3
College graduate	0	0	2	9.1
University graduate	10	58.8	9	40.9
Child gender [male]	15	88.2	16	72.7

Table 2

*Baseline and Follow-up Descriptive Statistics for PSI and PSOC: Means (standard deviations)*

Parent	Group	PSI - Baseline			PSI - Follow-up		
		N	Child	Parent	N	Child	Parent
Mother	Self-directed	22	146 (18.6)	146 (18.0)	21	141 (19.1)	143 (16.7)
	Professionally supported	17	147 (23.3)	141 (21.2)	17	132 (21.3)	133 (23.9)
Father	Self-directed	21	145 (17.8)	137 (21.6)	17	144 (16.2)	138 (15.4)
	Professionally supported	16	140 (23.2)	141 (29.2)	16	137 (21.8)	141 (20.6)

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Parent	Group	PSOC - Baseline			PSOC - Follow-up		
		N	Satisfaction	Efficacy	N	Satisfaction	Efficacy
Mother	Self-directed	22	32.8 (7.22)	27.0 (5.86)	21	34.5 (7.53)	28.8 (5.21)
	Professionally supported	17	33.6 (5.27)	24.8 (4.70)	16	37.5 (5.82)	29.6 (4.32)
Father	Self-directed	21	36.1 (6.58)	25.4 (4.98)	18	36.9 (5.61)	28.4 (4.97)
	Professionally supported	17	34.4 (4.89)	24.8 (4.23)	15	35.9 (6.10)	29.1 (3.33)

Table 3

*Estimates for Random Intercepts Model for Group and Gender Effects on PSI*

Parameters	Child		Parent	
	Estimate	95% CI	Estimate	95% CI
<i>Fixed</i>				
Intercept	139.58	(134.16, 145.00)	138.74	(133.23, 144.25)
Baseline	0.78	(0.53, 1.02)	0.70	(0.48, 0.92)
Group	-7.76	(-15.09, -0.43)	-3.32	(-10.68, 4.04)
Gender	6.17	(0.41, 11.93)	3.77	(-2.11, 9.64)
Group X Baseline	-0.002	(-0.27, 0.26)	0.02	(-0.22, 0.26)
Gender X Baseline	-0.18	(-0.42, 0.06)	-0.28	(-0.51, -0.07)
<i>Random</i>				
Family level				
Variances	43.88		45.25	
Covariance	23.20			
Individual level				
Variances	129.20		135.80	
Covariance	78.85			

Estimates are calculated from 10 imputed datasets (MCMC estimation with Gibbs sampler; burn-in period set to 500 iterations; imputations based on successive 10,000 iterations after applying a thinning factor of 10 to 100,000 iterations; model of interest was used to impute the 10 datasets).

Model of interest:

MCMC estimation with Gibbs sampler; burn-in period set to 5,000 iterations; 50,000 iterations stored after calculating 10,000,000 iterations and applying a thinning factor of 200.

Priors set to *MLwiN*'s default uninformative priors.

PSI Child Baseline was centred on its grand mean of 144.3; PSI Parent Baseline was centred on its grand mean of 141.3;

Group was coded as 0 = self-directed, 1 = professionally supported.

Gender was coded as 0 = mother, 1 = father.



Table 4

*Estimates for Random Intercepts Model for Group and Gender Effects on PSOC*

Parameters	Satisfaction		Efficacy	
	Estimate	95% CI	Estimate	95% CI
<i>Fixed</i>				
Intercept	36.35	(33.84, 38.86)	28.00	(26.51, 29.50)
Baseline	0.73	(0.47, 0.98)	0.64	(0.39, 0.89)
Group	1.24	(-0.88, 3.35)	1.34	(-0.48, 3.15)
Gender	-1.53	(-3.65, 0.60)	0.39	(-1.41, 2.18)
Group X Baseline	-0.06	(-0.42, 0.29)	-0.37	(-0.73, -0.02)
Gender X Baseline	0.01	(-0.33, 0.35)	-0.02	(-0.37, 0.34)
<i>Random</i>				
Individual level				
Variations	20.58		14.31	
Covariance	5.70			

Estimates are calculated from 10 imputed datasets (MCMC estimation with Gibbs sampler; burn-in period set to 500 iterations; imputations based on successive 10,000 iterations after applying a thinning factor of 10 to 100,000 iterations; model of interest was used to impute the 10 datasets).

Model of interest:

MCMC estimation with Gibbs sampler; burn-in period set to 5,000 iterations; 50,000 iterations stored after calculating 10,000,000 iterations and applying a thinning factor of 200.

Priors set to *MLwiN*'s default uninformative priors.

PSOC Satisfaction Baseline is centred on its grand mean of 34.21; PSOC Efficacy Baseline is centred on its grand mean of 25.60.

Group coded as 0 = self-directed, 1 = professionally supported.

Gender coded as 0 = mother, 1 = father.

Table 5

*Analysis of covariance on the effect of professional support on SIB-R BIW scores, CSBS-DP caregiver questionnaire, and CSBS-DP behavior sample total raw scores.*

Parameter	B	SE	95% CI
<b>SIB-R (BIW)</b>			
Intercept	453.8	1.03	451.78, 455.82
Baseline (centred)	1.10	0.113	1.32, 0.88
Professional support	1.77	1.531	4.77, -1.23
Baseline X Professional support	-0.35	0.179	0.0008, -0.70
<b>CSBS-DP Caregiver Questionnaire (CQ)</b>			
Intercept	81.2	2.88	75.56, 86.84
Baseline (centred)	0.92	0.11	0.70, 1.14
Professional support	11.51	4.61	2.47, 20.55
Baseline X Professional support	0.08	0.18	0.43, -0.27
<b>CSBS-DP Behaviour Sample (BS)</b>			
Intercept	74.0	5.39	63.44, 84.56
Baseline (centred)	1.19	0.14	0.92, 1.46
Professional support	1.51	8.16	17.50, -14.48
Baseline X Professional support	0.37	0.24	0.84, -0.104

Baseline centred on its grand mean of 449.7 for SIB-R (BIW), 65.36 for CSBS-DP (CQ) and 59.92 for CSBS-DP (BS)

Adj R<sup>2</sup> SIB-R (BIW) = 0.786, F(3, 33) = 45.0, p < 0.001

Adj R<sup>2</sup> CSBS-DP (CQ) = 0.801, F(3, 29) = 43.8, p < 0.001

Adj R<sup>2</sup> CSBS-DP (BS) = 0.687, F(3, 35) = 28.8, p < 0.001

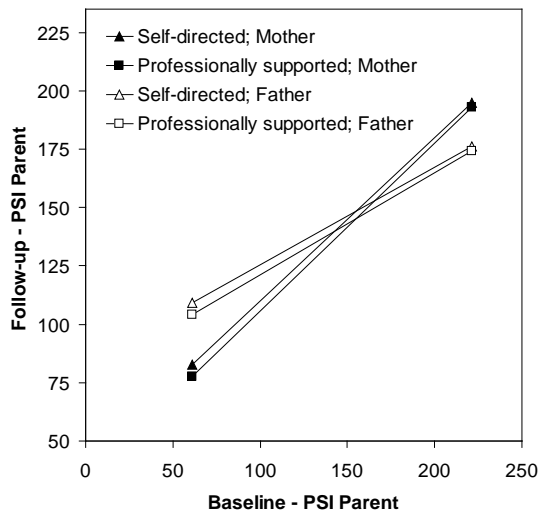
CI = confidence interval

## Figure Captions

*Figure 1.* Regression lines showing interaction for (a) PSI ratings (parent related stress) and (b) PSOC ratings (parent efficacy) at follow-up for parent gender (mother/father) and condition (professionally supported/self-directed). Demonstrating the interaction of (a) gender x baseline parent related stress measure (b) group x baseline parent efficacy measure.

Figure 1 top

a) PSI ratings



b) PSOC ratings

