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Social emotional assessment of infants at-risk using the Ages and stages questionnaire social emotional (ASQ:SE)

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SOCIAL EMOTIONAL ASSESSMENT OF INFANTS AT-RISK USING THE AGES AND STAGES QUESTIONNAIRE SOCIAL EMOTIONAL (ASQ:SE)

BY

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M.A., Child Development, University of Maryland, 2005

THESIS

Submitted in Partial Fulfillment of the
Requirements for the Degree of

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ABSTRACT

Background and Purpose: With the increased survival rate of pre-term infants, there is also an increased risk for poor developmental outcomes including poor social-emotional competence. The purpose of the current study is to examine relationships between parent completed scores of full term and preterm infants on two standardized questionnaires: 1) Ages and Stages Questionnaire (ASQ) measuring all areas of development and 2) Ages and Stages Questionnaire Social Emotional (ASQ-SE) measuring social-emotional development.

Methods: Participants included parents of 25 preterm infants (less than 36 weeks gestation, corrected age of 3 to 8.5 months, and time spent in the NICU) who were referred to UNMH Special Baby Clinic and 25 term infants (age and gender matched infants who have no history of developmental risk and who were between 3 and 8.5 months adjusted age). Exclusion criteria included being foster parents, parents under the age of 18, and families that were not English speaking. Parents filled out the ASQ and the ASQ:SE as well as a Social History Questionnaire.

Results: Spearman Rho correlations were used to examine the relationship between scores on the ASQ and ASQ:SE for the two groups of infants. No significant correlations were found between individual ASQ domains with the ASQ:SE for separate groups of infants. When groups were combined, scores for ASQ Gross Motor ($r = -.30$: $p = .03$), Personal Social ($r = -.28$: $p = .05$), and Total ($r = -.32$: $p = .02$) reached significance. Between group analyses yielded significant differences on the ASQ:SE ($p = .01$) as well ASQ Personal Social domain ($p = .05$). Trends towards significance were: ASQ Total Scores compared to ASQ:SE scores in the at-risk infants ($r = -0.36$: $p = 0.08$), and the ASQ Communication domain with both groups combined ($r = -0.24$: $p = 0.09$).

Conclusions: Significant differences between groups on the ASQ:SE were found, however the at-risk group was not above the cut off for developmental concerns. Significant but weak correlations were revealed with combined groups on the ASQ Gross Motor, Personal Social and Total scores, indicating that the ASQ:SE and the ASQ have preliminary construct validity in these areas. Additional research with a larger sample size may establish construct validity between the ASQ and the ASQ:SE.

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Chapter 1

Introduction

Early human development is a time of opportunity and also of great vulnerability. The first three years of life are characterized by rapid and dramatic developments in nearly all facets of advancing maturity, including physical, mental, physiological, behavioral, and socio-emotional, among others. These developments are viewed as contributing factors to building the foundation for adult functioning in all aspects of life (Berlin, Brooks-Gunn, McCarton, & McCormick, 1998). With this concept in mind, the importance of early experience emerges as a central theme in helping or hindering developmental trajectories. For the preterm child, the impact of early experience is even greater as their developmental systems are not fully matured and insults to their systems pose greater risks than to the child born at term. Preterm birth has been shown to be a risk factor for poor developmental outcomes, including poor social-emotional competence, decreased self-regulatory skills, decreased cognitive skills, and poor attentional capacity (Crnic Ragozin, Greenberg, Robinson, & Basham, 1983; Davis & Burns, 2001; Taylor, Klein, Minich, & Hack, 2000; Vohr et al, 2000; Gomez, Baird, & Jung, 2004).

The high risk nature of preterm birth is supported by Vohr and colleagues (2000) who found that 49% of 1151 surviving extremely low birth weight infants (ELBW; < 1000g) born between 1993 and 1994 had abnormal neurodevelopmental and/or sensory findings when assessed at 18-22 months adjusted age. These results indicate the essential need of earlier assessment of the neurodevelopmental status of at-risk infants. The discipline of occupational therapy plays a major role in assessing this population of at-

risk infants, and also in providing early intervention strategies for these infants and their families. However, few cost effective tools are available which can asses the developmental competency of at-risk infants at an early age. The current study will examine the use of the Ages and Stages Questionnaire Social-Emotional (ASQ:SE; Squires, Bricker & Twombly, 2002) and its ability to identify significant differences in the social emotional development between infants identified as at-risk and infants with typical development.

Social Emotional Development of Typical Infants

When examining assessments and interventions for the at-risk population of infants, it is important to understand the foundations of typical development that guide these concepts in order to appreciate the occurrence and impact of deficits. Typical development of infants encompasses the ability to regulate attention, form attachment bonds, process sensory information as well as regulate internal states to remain calm and organized (Thomasgard & Metz, 2004). Infant development however is not the sole responsibility of the infant, it occurs in a bi-directional relationship with the parent/s. For example, high levels of attentional control on the part of the infant during interactions have been found to be a protective factor, serving to buffer the adverse effects of negative emotionality. This attentional control is apparent because when infants are able to shift and maintain attentional focus, they are able to modulate their own negative affect by turning their attention away from unpleasant stimuli within the environment (Belsky, Friedman, & Hsieh, 2001). Parents who exhibit behavior in the form of high responsiveness to their infant's social and emotional cues have infants who show greater

stress regulation, as well promoting social, cognitive and emotional development (Haley, & Stansbury, 2003; Malatesta, Grigoryev, Lamb, Albin & Culver, 1986).

The attachment bond with the primary caregiver drives the infant's cycle of engagement, emotional communication, and the development of self regulation during the first postnatal year of life (Bowlby, 1969). The theory of attachment, which was proposed by John Bowlby (1969), is described as the formation of the mother-infant relationship, and has become the dominant model of human social-emotional development. The characteristics of this bond are dynamic and lay the foundation for many of the infant's earliest experiences. The quality of the infant's attachment experiences pave the way for social interactions, in turn affecting regulatory capabilities that are essential to the healthy affective development of the infant (Schore, 2005; Schore 2000).

Overall, infants rapidly develop interactive, regulatory, and attentional competencies that contribute to their social and emotional development over the first several months of life. There are however many individual differences across typically developing infants that can contribute to the range of capacities and emerging abilities that are seen (Thomasgard, & Metz, 2004; Schore, 2005). On the other hand, the at-risk infant displays distinctly diverse patterns of emerging developmental capabilities, outside the range which can be attributed to individual differences alone, and which can contribute to a host of ongoing problems as the infant matures (Smith, 2007; Als, 1986).

Social Emotional Development of At-Risk Infants

Preterm birth has been shown to lead to infants who exhibit developmental delays, difficult temperaments, and cognitive deficits. These infants have also been shown to be less alert, less active, and less responsive than full-term infants during the neonatal period (Crnic Ragozin, Greenberg, Robinson, & Basham, 1983; Davis & Burns, 2001; Taylor, Klein, Minich, & Hack, 2000). Along with cognitive and attentional concerns, preterm infants are also at an increased risk for showing deficits in their self-regulatory skills, linking closely with decrements in social-emotional development, and leading to difficulties in most if not all aspects of daily functioning as the child matures (Vohr et al, 2000; Davis & Burns, 2001; Gomez, Baird, & Jung, 2004). Problems communicating, and difficulties socializing have also been identified as important social precursors to the development of emotional and behavioral disorders (Weiss, & St. John Seed, 2002). Thus, the caregiver-infant-environment interaction becomes *extremely important* as premature birth disrupts the expected course of pregnancy and usually lengthens the hospital stay. This in turn impacts the time and quality of contact between infant and parents which can affect the development of attachment and bonding (VandenBerg, 2007; Olson, & Baltman, 1994).

Environmental stimuli within the Neonatal Intensive Care Unit (NICU) play a large and oftentimes stressful role in the young infant's life. It has become evident that because preterm infants are highly sensitive and vulnerable to their surroundings, the setting can have deleterious long lasting implications (White, 2005). The physical environment includes sound, light, position, touch and other variables. Any or all of these variables have the potential to interfere with the infants body rhythm, stress levels,

sleep states, and/or physiological factors such as oxygenation and blood pressure (Nair, Gupta, & Jatana, 2003; Spencer, & Edwards, 2001; VandenBerg, 2007). Along with these physical hindrances, the typically longer stays in the NICU can delay the contact between caregiver and infant that usually promote positive interaction, and leave the mother with an altered sense of bonding, attachment, and decreased competence as a parent (Keilty, & Freund, 2005).

Developmental Care, introduced in the 1980's, is a broad category of interventions built to diminish the stress of the Neonatal Intensive Care Unit (NICU; Als, 1986). This strategy was created due to the concern that an unfavorable environment might compound the morbidity associated with the immaturity of a preterm babies' organ systems (Als, 1986; Blackwell, 2000). Various strategies such as noise and light reduction, decreased handling, and longer rest periods have been used to modify the environment to decrease stress (Symington, & Pinelli, 2006). The effectiveness of Developmental Care has been studied with mixed results. Symington and Pinelli (2006) conducted a review of the literature and found limited benefits of developmental care interventions overall, however the determination of the effect of any single intervention was difficult because most studies included multiple interventions.

The influence of touch (i.e. light massage, and skin-to skin contact) has received attention as a possible way to help the preterm infant cope better with the stressful NICU environment. Findings in this area are also mixed, with some reporting positive effects on not only the infant, but on the caregiver as well (Blackwell, 2000; Feldman 2004). A review of the literature on massage found some positive outcomes, such as decreased length of stay, however many of the studies reviewed posed methodological concerns,

particularly with respect to selective reporting of outcomes (Vickers, Ohlsson, Lacy, & Horsley, 2004). It is important to point out that although the literature is mixed, no study has found adverse effects to the infant or parent through the implementation of touch therapy (DiMenna, 2006; Vickers, Ohlsson, Lacy, & Horsley, 2004; Symington, & Pinelli, 2006).

The quality of early social interactional experiences between the infant and primary caregivers is viewed as a major foundation for the development of the infant's socio-emotional skills (Forcada-Guex, Pierrehumber, Borghini, Moessinger, & Muller-Nix, 2006; Olson, & Baltman 1994). Preterm infants typically have an immature neurological system, leading to decreased organization across their self-regulatory system, as well as heightened sensitivity to stimuli. This physiological immaturity has potentially negative implications for the social interactions between infant and caregiver and may impact the attachment bond (Olson, & Baltman, 1994; VandenBerg, 2007). However, the goal is to help parents in the NICU understand their infant's physiological and behavioral cues so that the parents can appropriately foster an attachment bond and support the development of their infant's self-regulatory capacities to the fullest (Olson, & Baltman, 1994; Smith, 2007).

Assessments to Measure Infant Social Emotional Development

The survival rate for preterm and very preterm infants has increased steadily with advances in the medical world. Data from the Centers for Disease Control released in 2007 indicate a steady rise in preterm births since 1990, currently reporting a preterm birth rate of 12.7% (CDC, 2007). With this increase in survival, it becomes extremely important to accurately assess the developmental status of these at-risk infants earlier.

The profession of occupational therapy plays a major role in assessing this population of at-risk infants, and also providing early intervention strategies for these infants and their families. Routine screenings with an easy to administer tool may aid in the early identification of possible social-emotional and behavioral issues and allow the best opportunity for interventions to be implemented (Keilty, & Freund, 2005). However, limited screening tools exist which are cost effective and which can asses the developmental competence, specifically the social emotional development of at-risk infants sufficiently (Stancin & Palermo, 1997; Bricker, & Squires, 1999).

Purpose of the Study

There remains a need for a tool that can accurately identify delays in social-emotional competence and problems in early infancy and childhood. The Ages and Stages Questionnaire (ASQ: Bricker, & Squires, 1999) and its counterpart, the Ages and Stages Questionnaire: Social-Emotional (ASQ:SE; Squires, Bricker, & Twombly, 2002a) addresses social-emotional and behavior problems from birth to 5 years. Acceptable test-retest reliability and sensitivity in detecting children with developmental delay or social-emotional problems have been reported (Squires, Bricker, & Twombly, 2002b). The purpose of the current study is to examine the use of the ASQ (Bricker, & Squires, 1999) and ASQ:SE (Squires, Bricker, & Twombly, 2002a) and the ability of the ASQ:SE to identify significant differences in the social emotional development between infants identified as at-risk and infants with typical development between the ages of 3 and 8.5 months. Use of these two tools together has not been completed with this subgroup of infants. It is hypothesized that:

a) Social-emotional status of at-risk infants as measured by the ASQ:SE will be above the cut off for normal development (indicating an increase in risk behaviors),

b) There will be a significant difference in the scores on the ASQ and the ASQ:SE between the at-risk infants and the age-matched control infants, and

c) There will be a high correlation between the results of the ASQ and the ASQ:SE of both groups of infants.

Chapter 2

Methods

Participants

Participants: At-risk sample. The parents, natural or adoptive, or the legal guardians of 25 at-risk infants were invited to participate. Inclusion criteria included being born less than 37 weeks gestation, less than two years adjusted age, having spent time in the NICU, and infants at risk for developmental disabilities and delays. The sample came from caregivers who were referred to the Special Baby Clinic at the University of New Mexico Hospital (UNMH) in Albuquerque, New Mexico. The exclusion criteria for this group were infants who were under 3 months, and children who were over 2 years adjusted age. Foster parents, parents under the age of 18, and those families that were not English speaking were also excluded.

Participants: Control Group. Parents, natural or adoptive, or the legal guardians of 25 infants who had no history of developmental risk and who were under two years of age were invited to participate. Infants were matched on age, and gender with infants in the at-risk sample. These participants were recruited using flyers that were placed in child care centers, a children's dance studio, referrals from professionals in the Albuquerque community, and through word of mouth. Exclusion criteria included infants under 3 months, and children who were over 2 years. Infants born less than 37 weeks gestation, infants who had spent time in the NICU, and infants with developmental disabilities or delays were excluded. Foster parents, parents under the age of 18, and those families that could not complete the English version of the questionnaires were excluded.

Procedures

Families of the babies attending the Special Baby Clinic were mailed copies of the Ages and Stages Questionnaire (ASQ) and the Ages and Stages Questionnaire: Social Emotional (ASQ: SE) with their appointment letters. Upon arrival at the clinic, the families were approached by a member of the research team and asked to participate in the study. Consent and HIPPA forms were explained, and caregiver signatures were obtained. Once consent was established, the caregiver was interviewed using the Social History Questionnaire, which was developed for this study. The completed ASQ and ASQ: SE forms which the families brought with them to the clinic were collected and reviewed for completeness.

During the study period, information from the medical records of the infants attending the Special Baby Clinic was utilized. Information that was used included prenatal history and care, labor and delivery information, medical intervention given before, during and after birth, medical treatment provided to the infant during his/her stay in the hospital, social history, and information from follow-up visits to the Special Baby Clinic. This information was used to explore trends between the responses given to the ASQ and the ASQ: SE and the available medical information.

Once families of control babies were recruited, a member of the research team set up an appointment conducive to each families schedule to meet with them. The parents were given brief details about the ASQ, the ASQ: SE, and the Social History Questionnaire and told that everything would take approximately 30 minutes to complete. Consent and HIPPA forms were then explained by a member of the research team and caregiver signatures were obtained. Once consent was established, the caregiver was

interviewed using the Social History Questionnaire, and then asked to complete the ASQ and the ASQ: SE. All forms were collected and reviewed for completeness.

Instruments/Questionnaires

Ages and Stages Questionnaire (ASQ): The ASQ is a measure filled out by the parent, and consists of 19 questionnaires for ages 4 through 48 months. Each one contains 30 developmental items which are divided into five areas: Communication, Gross Motor, Fine Motor, Problem Solving, and Personal-Social. For each item, parents are asked to check *yes* if their child performs the behavior mentioned in the question, *sometimes* if their child performs the behavior occasionally and *not yet* if their child does not yet perform the behavior. To score the questionnaire, the responses of *yes, sometimes, or not yet* are converted to *10, 5, or 0* points respectively, and are totaled for each area. Scores 2 standard deviations below the normative sample mean in any area are indicative of delay in that area of development. The ASQ has been shown to have validity of 83%, test-retest reliability of 90%, and interrater reliability of 90%.

Ages and Stages Questionnaire: Social Emotional (ASQ:SE): The ASQ:SE was designed to supplement the ASQ with a series of eight questionnaires to be completed by the parents to address the emotional and social competence of young children for ages 3 through 65 months. The item content of the questionnaires target seven behavioral areas: self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people. Parents are asked to respond to each item by checking *most of the time*, *sometimes*, or *rarely or never* depending on which they feel most closely matches their child's response to the behavior in question. To score the ASQ:SE,

responses of *most of the time*, *sometimes*, or *rarely or never* are then converted to point values of *0, 5, or 10,* respectively, and yield a total score. A high total score indicates concerns about an infant's social emotional functioning and is cause for further assessment, while a low total score suggests that the parent considers their infant or child to be competent in their social emotional behavior. It is important to keep in mind that this is the opposite scoring pattern of the ASQ, in which low scores (indicative of the absence of skills) indicates further assessment. Internal consistency of the tool ranges from .67 to .91, indicating strong relationships between total scores and individual items. Test-retest reliability measured at 1 to 3 week intervals was 94%. Sensitivity (the ability of the tool to identify children with social-emotional problems) ranged from 71% to 85%. Specificity (the ability of the tool to correctly identify children without social-emotional delays) ranges from 90% to 98%. Both questionnaires derive total scores for each domain of development and place them on a grid, which has a cut-off indicating normal or abnormal development, coinciding with 2 standard deviations below the mean (Squires, Bricker, & Twombly, 2002b).

Data Analysis

Percent agreement was computed between primary interviewers with a 90% or above agreement required prior to data being colleted. Spearman Rho correlations and t-tests were used to assess the relationship between the infant scores on the ASQ sub-scales and the ASQ: SE. Spearman's correlations were used to assess the relationship between the two groups of infants on scores on the ASQ sub-scales and the ASQ: SE.

Chapter 3

Results

Statistical Analysis

Scores for the infants born at-risk and control infants on the five domains of the ASQ and total score on the ASQ: SE were computed and entered into an Excel spreadsheet for analysis. Correlations between the ASQ and ASQ: SE scores of the at-risk group (n=25), the control group (n=25), and all or both groups combined (n = 50) were computed using Spearman's Correlation analysis to measure the relationship between socio-emotional scores (ASQ:SE) and scores for the other areas of development (ASQ). A post hoc visual inspection of the data was completed to identify score trend differences between the infants born at risk and full term control infants by demographics of medical history (birth weight, gestational age at birth, and length of stay in the NICU) and psychosocial factors including maternal education, risk category, and ethnicity.

Demographic data of the parent reports of the 50 infants included in the study are presented in Table 1. In the sample population (n = 50), there were 27 males, and 23 females. There were equal numbers of male and female participants in both the 4 month and 8 month groups, while the 6 month group contained 9 males, and 15 females. Maternal education was similar for both groups of infants across age groups with exception of the 6 month group of preterm infants. The mother's of these infants had the least amount of formal education, with forty percent of mother's in that group having no high school diploma. Comparison of gestational age for both groups of infants indicated that term infants, in all age groups, remained in utero on average 6 weeks longer than the preterm infants. The mean birth weight of the at-risk sample was 1975.3g with a

standard deviation of 257.12, while the mean birth weight of the control sample was 3416.0g with a standard deviation of 189.5 (see Table 1).

Table 1: Demographics of study population

	4 Months *(Range = 3 - 4.5)*		6 Months *(Range = 5 - 6.5)*		8 Months *(Range = 7 - 8.5)*	
	n= 9 (%)	n= 9 (%)	n= 12 (%)	n= 12 (%)	n= 4 (%)	n= 4 (%)
	At Risk	Control	At Risk	Control	At Risk	Control
Gender Distribution:						
Male	7 (78%)	7 (78%)	5 (42%)	4 (33%)	2 (50%)	2 (50%)
Female	2 (22%)	2 (22%)	7 (58%)	8 (67%)	2 (50%)	2 (50%)
Ethnicity						
Hispanic	2 (22%)	3 (33%)	7 (58%)	6 (50%)	2	2 (50%)
Anglo	2 (22%)	5 (56%)	--	1 (8%)	(50%)	2 (50%)
African Am	2 (22%)	--	1 (8%)	--	2	--
Native AM	1 (11%)	--	2 (17%)	2 (17%)	(50%)	--
Other	2 (22%)	1 (11%)	2 (17%)	3 (25%)	--	--
					--	
					--	
Maternal Education						
Secondary-incomplete	--	--	4 (40%)	1 (8%)	1 (25%)	--
Secondary-completed	1 (11%)	1 (11%)	--	5 (42%)	--	2 (50%)
Tertiary-incomplete	3 (33%)	1 (11%)	2 (20%)	4 (33%)	2 (50%)	--
Tertiary-completed	3 (33%)	5 (56%)	1 (10%)	2 (17%)	1 (25%)	2 (50%)
Tertiary +further education	2 (22%)	2 (22%)	--	--	--	--
Risk Category						
1B	1 (11%)	--	--	--	--	--
2A	2 (22%)	--	2 (17%)	--	--	--
2B	5 (56%)	--	7 (58%)	--	3 (75%)	--
2C	--	--	1 (8%)	--	--	--
Missing	1 (11%)		2 (17%)		1 (25%)	
Gestational Age (weeks)						
Mean						
(SD)	31.2	39.8	32.6	39.6	33.7	39.0
	(3.2)	(1.4)	(3.8)	(1.7)	(2.9)	(0)
Chronological Age (weeks)						
Mean	5.8	4.0	7.3	5.7	9.5	8.2
(SD)	(0.8)	(0)	(1.1)	(0.5)	(0.6)	(0.5)
Birth Weight (g)	n = 8	n = 8	n = 10	n = 12	n = 4	n = 3
Mean	1716.1	3371.5	1979.4	3253.1	2230.3	3624.01
(SD)	(668.4)	(545.3)	(802.6)	(300.8)	(858.6)	(227.0)

NICU Days Mean (SD)	32.1 (24.8)	--	25.1 (18.3)	--	26.5 (27.9)	--

NICU = Neonatal Intensive Care Unit

Hypothesis 1: *Social-emotional status of at-risk infants as measured by the ASQ:SE will be above the cut off for normal development (indicating an increase in risk behaviors).*

Tables 2 and 3 summarize the results of group comparisons on the ASQ:SE and ASQ domains relative to cutoff values. Scores for the ASQ:SE or all domains of the ASQ failed to reach significance for the standardized cut off scores of infants at risk for developmental delays. Specifically in relation the above hypothesis, ASQ:SE scores, in which scores above the cutoff are considered reason for further testing, 92% of the at-risk group of infants fell below the cut-off, while 100% of the control sample fell below the cutoff, with no significant difference between the groups (p = .49). The domain of ASQ Personal Social was the only domain that indicated a trend towards significance (p =.19), but did not reach significance (Table 3).

Table 2: Comparison of ASQ: SE and ASQ domain scores: High Risk vs. Control vs. Normative Sample Cut-off Scores

	ASQ:SE *mean* *(SD)*	ASQ C *mean* *(SD)*	ASQ GM *mean* *(SD)*	ASQ FM *mean* *(SD)*	ASQ P Sol *mean* *(SD)*	ASQ P Social *mean* *(SD)*
<u>High Risk</u>						
4 Months (n=9)	28.3 (34.8)	47.2 (12.0)	51.7 (10.3)	40.6 (21.4)	46.1 (17.8)	44.4 (20.1)
6 months (n=12)	23.3 (9.6)	51.7 (7.8)	33.8 (15.8)	46.2 (14.8)	45.0 (12.2)	39.2 (15.5)
8 months (n=4)	20.0 (13.5)	41.2 (11.1)	31.2 (20.6)	50.0 (16.8)	42.5 (16.6)	43.8 (12.5)
<u>Control</u>						
4 Months (n= 9)	8.3 (5.0)	52.8 (7.9)	56.7 (5.6)	51.7 (9.4)	57.8 (3.6)	56.7 (4.3)

6 months (n= 12)	16.2 (11.5)	48.8 (6.4)	39.2 (9.0)	43.8 (10.9)	45.4 (11.2)	47.9 (11.6)
8 months (n= 4)	6.2 (7.5)	57.5 (2.9)	40.0 (23.1)	41.2 (13.1)	48.8 (19.3)	41.2 (19.3)

	ASQ:SE Cut-off (<2SD)	ASQ C Cut-off (<2SD)	ASQ GM Cut-off (<2SD)	ASQ FM Cut-off (<2SD)	ASQ P Sol Cut-off (<2SD)	ASQ P Social Cut-off (<2SD)
Normative						
4 Months	45	33.3	40.1	27.5	35	33
6 months	45	20	20	20	20	20
8 months	45	36.7	24.3	36.8	32.3	30.5

ASQ: SE = Ages and Stages Questionnaire: Social Emotional; ASQ = Ages and Stages Questionnaire; C= Communication; GM = Gross Motor; FM = Fine Motor; P Sol = Problem Solving; P Social = Personal Social

Table 3: Comparison of ASQ:SE, ASQ subtests, and ASQ total scores to cutoff values for high-risk infants with control infants

	Control N=25 N (%)	High Risk N=25 N (%)	p-value[b]
ASQ: Social Emotional			0.49
Less than cutoff	25 (100%)	23 (92%)	
Greater than or = cutoff	0 (0%)	2 (8%)	
ASQ Communication			0.49
Less than or = cutoff	0 (0%)	2 (8%)	
Greater than cutoff	25 (100%)	23 (92%)	
ASQ Gross Motor			0.42
Less than or = cutoff	2 (8%)	5 (20%)	
Greater than cutoff	23 (92%)	20 (80%)	
ASQ Fine Motor			0.42
Less than or = cutoff	2 (8%)	5 (20%)	
Greater than cutoff	23 (92%)	20 (80%)	
ASQ Problem Solving			0.42
Less than or = cutoff	2 (8%)	5 (20%)	
Greater than cutoff	23 (92%)	20 (80%)	
ASQ Personal Social			0.19
Less than or = cutoff	1 (4%)	5 (20%)	
Greater than cutoff	24 (96%)	20 (80%)	

[b] Exact p-value

Hypothesis 2: *There will be a significant difference in the scores on the ASQ and the ASQ:SE between the at-risk infants and the age-matched control infants*

T-tests were used to compare the raw score means on the ASQ:SE, ASQ domains, and ASQ total scores between groups. Scores on the ASQ:SE between groups reached significance (p =.01), with the mean for the at-risk group being significantly higher than the control group, indicative of social and emotional problems when compared to the control group. The ASQ domain of Personal Social also reached significance (p =.05), with the mean for the high-risk group being significantly lower than the control group, and as the two tools have opposite scoring patters, this again is indicative of problems associated with the personal social domain (Table 4). It is noteworthy that scores between groups on the ASQ:SE and ASQ Personal Social domain reached significance, however when compared to cutoff values for each tool, there were no significant differences between groups. When Spearman's Correlations were used to compare individual ASQ domains with the ASQ:SE, no correlations for scores of at-risk infants (n = 25; Table 5), or scores of the control infants (n =25; Table 6) reached statistical significance (p =.05). A trend toward significance was identified in the ASQ Total scores compared to the ASQ:SE in the at-risk infant group (r = -.36: p =.08) as shown in table 5.

Table 4: Comparison of ASQ:SE, ASQ domains, and ASQ total scores for at-risk infants with control infants

	Control N=25 Mean (SD)	High Risk N=25 Mean (SD)	p-value[a]
ASQ:Social Emotional	11.8 (9.8)	24.6 (21.9)	**0.01***
ASQ Communication	51.6 (7.2)	48.4 (10.3)	0.21
ASQ Gross Motor	45.6 (13.6)	39.8 (16.9)	0.19
ASQ Fine Motor	46.2 (11.1)	44.8 (17.3)	0.74
ASQ Problem Solving	50.4 (11.9)	45 (14.5)	0.16
ASQ Personal Social	50 (12.1)	41.8 (16.4)	**0.05***
ASQ TOTAL	243.8 (42.2)	219.8 (58.5)	0.10

***significant (*p*=.05)**
[a] t-test p-value

Table 5: Spearman's Correlations between ASQ:SE and ASQ Domains: At Risk Infants

ASQ Domain	N	Spearman's Correlation Coefficient	Spearman's Coefficient *p* value
Communication	25	-0.24	p=0.26
Gross Motor	25	-0.23	p=0.27
Fine Motor	25	-0.13	p=0.54
Problem Solving	25	-.24	p=0.25
Personal Social	25	-0.25	p=0.22
TOTAL	25	-0.36	**p=0.08***

*** = trend**

Table 6: Spearman's Correlations between ASQ:SE and ASQ Domains: Control Infants

ASQ Domain	N	Spearman's Correlation Coefficient	Spearman's Coefficient *p* value
Communication	25	-0.13	p=0.52
Gross Motor	25	-0.21	p=0.31
Fine Motor	25	-0.12	p=0.57
Problem Solving	25	0.03	p=0.87
Personal Social	25	-0.01	p=0.98
TOTAL	25	-0.10	p=0.64

Hypothesis 3: *There will be a high correlation between the results of the ASQ and the ASQ:SE of both groups of infants.*

Spearman's Correlations were used to compare individual ASQ domains with the ASQ:SE in both groups of infants combined (N=50). The ASQ domain of Gross Motor (r = -.30: p = .03), Personal Social (r = -.28: p = .05), and Total scores (r = -.32: p = .02) reached statistical significance, indicating a correlation with the total score on the ASQ:SE (Table 7). Frequency of the top five concerns reported on the ASQ:SE was also examined, are reported in Table 8, and will be expanded upon in the discussion.

Table 7. Spearman's Correlations between ASQ:SE and ASQ Domains: Both At-Risk Infants and Control Infants

ASQ Domain	N	Spearman's Correlation Coefficient	Spearman's Coefficient *p* value
Communication	50	-0.24	p=0.09
Gross Motor	50	-0.30	**p=0.03***
Fine Motor	50	-0.13	p=0.39
Problem Solving	50	-0.23	p=0.11
Personal Social	50	-0.28	**p=0.05***
TOTAL	50	-0.32	**p=0.02***

*** Significant (*p* = .05)**

Table 8. Frequency of top 5 Concerns on ASQ:SE Reported by Caregivers

Concern (Item #)	Description	Number of Responding (*'most of the time or sometimes')*	
		Preterm Group	**Control Group**
(#4)	Baby stiffens and arches back when picked up	13	13
(#8)	Baby is able to calm himself	9	6
(#10)	Baby's body is relaxed	9 *rarely or never*	1 *rarely or never*
(#12)	Takes longer than 30 min to feed baby	7	1
(#14)	Problems during feeding (e.g. gagging or vomiting)	7	2

Chapter 4

Discussion

This study is the first to examine the use of the ASQ (Bricker, & Squires, 1999) and ASQ:SE (Squires, Bricker, & Twombly, 2002a) and the ability of the ASQ:SE to identify significant differences in the social emotional development between infants identified as at-risk and infants with typical development between the ages of 3 and 8.5 months. Use of these two tools together has not been completed with this subgroup of infants.

Participants included parents of 25 at-risk infants, and parents of 25 control infants. Inclusion criteria for the at-risk group included gestation less than 36 weeks, corrected age of 3-8.5 months, time spent in the Neonatal Intensive Care Unit, and referral to the UNMH Special Baby Clinic. The control sample included 25 age and gender matched infants who were carried to term, had no history of developmental risk, and were between 3-8.5 months.

Spearman's correlations and t-tests were used to examine the relationship between scores on the ASQ and ASQ:SE for the two groups of infants. When raw scores were used to compare ASQ:SE, ASQ domains, and ASQ total scores for at-risk infants with control infants, the ASQ:SE score between groups was significant, as was the ASQ Personal Social domain. No significant correlations were found between individual ASQ domains with the ASQ:SE for separate groups of infants. When the groups were combined, ASQ Gross Motor scores, Personal Social scores, and Total scores reached significance, while the Communication domain neared significance. Another trend

towards significance included the ASQ Total Scores compared to ASQ:SE scores in the at-risk infants group.

The significant correlation between the ASQ:SE and the ASQ Personal Social, Gross Motor, and Total scores, as well as a trend towards significance for the Communication score for the combined group of infants is consistent with the concept that an infant's ability to self regulate is directly related to their ability to engage in interactions with their caregiver and immediate environment (Schore, 2005). An infant's ability to self regulate their nervous system impacts their overall social-emotional development which can influence attachment with caregiver, levels of alertness, activity, and responsive behaviors that are exhibited during the neonatal period, all concepts that directly relate to the significant domains (Crnic, Ragozin, Greenberg, Robinson, & Basham, 1983; Davis & Burns, 2001; Taylor, Klein, Minich, & Hack, 2000).

The significant, although weak correlations of the ASQ:SE to the ASQ domains of Personal Social, Gross Motor and Total scores as well as the trend towards significance of the ASQ Communication domain supports our third hypothesis and indicate that for these domains, the ASQ:SE and ASQ are demonstrating preliminary construct validity. One explanation as to why the other domains are not significantly correlated is that the areas of Fine Motor and Problem Solving may not overlap between the two tools enough to result in high correlations. Another explanation is that the parameters measured by the two instruments differ. While the ASQ measures general development, the ASQ:SE measures specific behaviors of self regulation and interaction which may not be directly related to the general development of fine motor and problem solving as defined by the ASQ.

A high score on the ASQ:SE is considered poor or at-risk for social emotional development, while low scores on the ASQ are considered poor or at-risk for general development, leading to an expectation of negative correlations between the two tools, which was indicated by the results. Those who scored lower on the ASQ:SE also scored higher on the Gross Motor, Personal Social and Total areas on the ASQ, and those whose scores were lower in those domains also tended to be those whose scores were higher on the ASQ:SE. However for both tools, the at-risk group did not reach the cut off for developmental concern. The raw score comparisons did indicate significant differences between the two groups on the ASQ:SE as well as ASQ Personal Social domain, however these were not indicated when compared to cut off values.

This may be related to the at-risk group having elevated scores on the ASQ:SE but not elevated enough to be above the cutoff. If raw score differences are proving to be significant, but not in relation to the cutoff, it may warrant further discussion about the appropriateness of lowering the cutoff score. Another point of contention when considering the above results is that although the control group scored lower on the ASQ:SE and higher on the ASQ than the at-risk group, their scores were not as robust as would be expected developmentally for infants their age. This may be due to the small number of infants in each group, and that with a larger sample size more significant differences may be revealed. This may also be why significant differences evolved when examining the whole group which had a larger sample size as compared to when each group was examined separately.

When examining the frequency of the top five concerns as reported by caregivers on the ASQ:SE, both groups of infants had caregivers who indicated the highest response

of ‘most of the time or sometimes’ to the question of “Does your baby stiffen and arch her back when picked up.” The top five areas of concern for both groups could be characterized in relation to the parents’ concern with their infant’s emotional state and ability to feed; however the parents of the infants in the at-risk group had a much higher rate of frequency of those concerns. It is of interest that a much larger number of parents (9 out of 25) of infants in the at-risk group reported their infant’s body as being ‘rarely or never’ relaxed as opposed to only 1 out of 25 parents of infants in the control sample reporting the same thing.

These results are supported by the statistically significant correlation between the ASQ:SE scores and the combined group ASQ Total scores. The parents of the at-risk group reported increased concerns with their infants’ ability to demonstrated self-regulatory behaviors as compared to the frequency of concerns identified by the parents of the control infants. These results are supported by the literature that describes pre-term infants as having a limited capacity to self-regulate, as demonstrated by difficulties in being consoled, decreased social interactions with caregivers, and decreased coping abilities (VandenBerg, 2007; Schore, 2005; Davis & Burns, 2001).

One interesting finding was that there were equal numbers of affirmative responses across both the at-risk and control groups demonstrating concern that their infant “stiffens and arches back when picked up.” This may indicate that the question is not specific enough, and that parents of both at-risk and control infants perceive their infants “stiffening” as a positive response to the action of being picked up. Parents may misinterpret the cue and the question and they may be unaware or unable to determine

between an appropriate amount of increased muscle tone in preparation of being picked up and what the question terms “stiffens.”

A follow up study conducted by Skellern, Rogers, and O’Callaghan (2001) examined the test characteristics of the ASQ compared to three formal psychometric assessments in a population of preterm infants with a corrected age of 12-48 months. Results indicated that the ASQ over referred 20% of children and under referred 1% of children, demonstrating that it has a high negative predictive value. Results of the current study did not indicate this, as there were no significant correlations between the ASQ:SE and the individual domains of the ASQ for the at-risk group (Table 5). In light of the current results, it is important to consider in more detail the population of our at-risk infants and possible reasons why our results differ from Skellern and colleagues (2001). The at-risk sample was drawn from attendees of the Special Baby Clinic at the University of New Mexico Children’s Hospital, which follows a Development Care approach. This approach places a strong emphasis on developmental care which was created to diminish the stress of the Neonatal Intensive Care Unit (NICU) on the medical, physiological, and social-emotional status of the infant (Als, 1986). Various strategies to modify the environmental stress are utilized such as noise and light reduction, decreased handling, longer rest periods, as well as encouragement and support for family participation in the daily care of the infant (Symington, & Pinelli, 2006).

The current results may mirror the impact of the developmental care approach as there were no significant differences between groups in relation to the ASQ:SE and the individual scores of the ASQ (see Tables 5 and 6). The mean scores of the ASQ:SE and the ASQ Personal Social domain for the at-risk group were significantly different than

the control group, but did not reach significance in relation to the cut off scores. This indicates that the overall social-emotional status of the at-risk infants in the current study fell within normal ranges when using cut off values (see Table 2 and 3). Research on the benefits of the developmental care approach are consistent with the currently reported results, suggesting that this type of individualized developmental care can influence the self regulatory abilities of at-risk infants as well as promote positive changes in brain function and structure (Als, et al., 2004; Mouradian, & Als, 1994). It may be that the developmental care approach utilized in the NICU at UNMH positively impacted the population of at-risk infants enough to fall below the cutoff for the ASQ:SE and above the cut off for the ASQ. What is concerning is that these infants are still demonstrating problem behaviors as indicated by the significant differences between groups on the raw scores, however because they do not meet the cut off values, these infants would not be referred for services.

Als (1986) theory of synactive development identifies five interactive systems that contribute to the infant's ability to modulate behavior and are the prominent parameters of an infant's individuality and personal uniqueness. The systems are the autonomic system, the motor system, the state organizational system, the attention and interacting system, and the self-regulatory balancing system. These subsystems are interdependent, and mature sequentially, and the loss or predominance of any one of the five subsystems, which function synactively, influence the organization of the others in response to environmental demand. In developmental care, many techniques are utilized which target stabilization of the autonomic system and aim to help the infant regulate that system (Mouradian, & Als, 1994). As such, the subsequent developing motor and state

systems can begin to be regulated. The social-emotional component of behavior is dependent on autonomic stability and regulation of attention, motoric capacities, interaction with environment, and the infant's state.

In light of the current results, developmental care practices may result in less immediate impact on social-emotional behavior as this is a complex construct depending on the development and regulation of all five subsystems identified by Als, and that is in continued development when the infant leaves the NICU. The highly structured, supportive environment quickly changes as the infant and family transition to the family and home environment. The significant difference between groups on the ASQ:SE substantiates the claim that differences in social emotional development exist in our samples between the ages of 3 and 9 months, however it would be beneficial to have a large enough sample to examine each specific age group in relation to differences on the ASQ:SE, which this sample did not provide.

A study conducted by Weiss and St. John Seed (2002) examined infant characteristics and early family environment to the incidence of emotional and behavioral problems for low birth weight children. They found that 48% of the variance in the incidence of emotional-behavioral problems was accounted for by inadequate family income, trouble with family cohesion and adaptability, and an infant's insecure attachment to the mother. Developmental care practices can set the stage for continued development in a positive trajectory; however it is within the home environment that continued development takes place. A subsequent limitation to the current study was that although data was collected on level of education completed, no data were collected on the context of the family, or family income levels, so few references to contextual

influences can be made. Further analyses of the current data in relation to caregiver presence in the household may reveal some interesting information in relation to present findings.

High correlations between a child's emotional regulation abilities and later social-emotional development, cognitive processing skills, and attentional capabilities have been demonstrated (Davis, & Burns; Vohr et al., 2000; Lowe, Papile, & Woodward, 2005). Based on these findings, an inexpensive and reliable tool for the early identification of overall development and social-emotional delays is imperative. If children who have a pattern of behaviors that indicate the possibility of their developing future social or emotional difficulties could be identified early in an infant's development, appropriate services and preventive interventions could be implemented to improve their social and emotional competence. Building a strong foundation in these domains will support the child's ability to develop interactive, regulatory, and attentional competencies that will contribute to future productivity in school, social interactions, and daily functioning (Lowe, Papile, & Woodward, 2005; Vohr et al., 2000).

Limitations

It may have proven beneficial to compare not only the ASQ and ASQ:SE, but to include a third tool that has established reliability, validity and higher sensitivity in relation to identifying social-emotional concerns. A more sensitive measure may have consistently identified areas of concern in the at-risk population and would have allowed comparison to results of the ASQ and ASQ:SE. Further data analyses into the significant findings between groups on the ASQ:SE is warranted in relation to proximity of the

individual scores to cut off values. Use of a third tool may have given some insight into why the differences were not significant in relation to the cut off values for the ASQ:SE.

Additional limitations include the inability to match ethnicity in each age sub-sample between the at-risk group and control group which led to the inability to make comparisons based on ethnicity. The at-risk group was obtained to adhere with the broader ethnic distribution in New Mexico, however although attempts were made to match the control group to the at-risk group on ethnicity, it was not possible to obtain a perfect match.

A further limitation includes the short term nature of the study in that it was designed only to examine responses at one point in time. It would be beneficial for future studies to examine outcomes at multiple time points to investigate if any of the significant findings or trends towards significance would be substantiated or refuted when subjects were tested at a later age. It would also be helpful to follow up with the participants whose scores were significantly different than the control sample but did not reach the cut off for identification of problems or further referral.

The fact that the at-risk group did receive developmental care may have influenced our results in that some of the problems the infants may have presented with at birth may have been attenuated by the comprehensive model of care. Examining a population of infants who did not receive developmental care in comparison to a control group may yield more consistent and robust findings.

Birth weight of the at risk sample was between 1716g and 2230g which makes this a low birth weight (LBW; <2,500g) sample at risk based on weight and gestational age which averaged between 31.6 and 33.7. The percentage of infants born at low birth

weight (LBW; < 2,500g) has been rising steadily since the mid-1980's from 6.7% to the current 8.2% (CDC). The findings of the current study may indicate that with the trend in more infants being born LBW there is also an advancement in referral to early intervention.

The state of New Mexico considers the *presence* of risk factors enough to establish the eligibility of early intervention services. The developmental care guidelines (UNM Developmental Care, 1986) were used to indicate biomedical and psychosocial environment risk and sort infants in the current study into a risk category (see Appendix A for further information). The majority of the participants in the at-risk group (60%) fell in the high biomedical/high risk psychosocial environment category. Based on risk, all participants qualified for early intervention services, and were receiving follow-up at the Special Baby Clinic at UNMH. Because they were receiving these services, this may have affected the outcomes of the current study, impacting the infants overall function in a positive manner. This is supported in the literature with the finding that early intervention services improve cognitive and motor outcomes up to 5 years old (Spittle, Orton , Doyle, & Boyd, 2007). A limitation to the current study is that it is unknown the extent that the at-risk infants were receiving services beyond those provided by the Special Baby Clinic, which makes it difficult to come to any substantiated conclusions.

Conclusions

Results of the current study provide preliminary evidence of construct validity between the ASQ and the ASQ:SE in relation to the ASQ domains of Gross Motor, Personal Social and Total scores, however the lack of significant findings across all

domains point to the need for further research. Research utilizing a larger sample size may provide more robust findings as to the construct validity of these two tools. The fact that the at-risk group did not meet the cut off values for either tool in relation to identifying concerns for typical development raises several areas of exploration. Further research might examine in detail the appropriateness of the cutoff values in appropriately identifying areas of concern in this population. Discussion is also warranted surrounding the at-risk population in the study and exploring how and in what capacity the developmental care approach of the NICU at UNMH impacted the global functioning of the sample. Obtaining further contextual information pertaining to the home and care giving environment would aid in determining how and in what capacity those factors impacted the at-risk sample by possibly attenuating or aggravating developmental concerns. The current study demonstrated significant but weak correlations between the ASQ and ASQ:SE on several domains, as well as several significant between group differences on the ASQ:SE. These results point to the need for further research with a sample that is larger in size, encompasses a wider demographic range, and targets a larger geographic range in order to establish more conclusive evidence of the construct validity of these two tools.

Appendix A

Extended Review of the Literature

Social Emotional Development of Typical Infants

When examining assessments and interventions for the at-risk population of infants, it is important to understand the foundations of typical development that guide these concepts in order to appreciate the occurrence and impact of deficits. Thomasgard and Metz (2004) reviewed Greenspan's conceptual framework of early social-emotional growth called the Developmental level, Individual differences, and Relationship-based model of intervention (DIR). This model elucidates several developmental stages. The first stage is from birth to 4 months and examines the individuals' ability to attend and feel secure. It encompasses the ability to regulate attention, process sensory information and remain calm. Attentional control is thought to be a core process which aids in the regulation of negative emotion. Infants who are able to shift and maintain attentional focus, witnessed in most typically developing infants continuing into childhood and as adults, have been found to be able to modulate their negative affect by turning their attention away from stimuli which generate these negative feelings. High levels of attentional control have also been found to serve as a protective factor, buffering the anticipated adverse effect of high levels of negative emotionality on social functioning (Belsky, Friedman, & Hsieh, 2001).

The second developmental stage mentioned by Thomasgard and Metz (2004) takes place around 4-6 months, and involves the ability of the infant to feel close to and engage with others. Once infants can successfully adapt to changes in the environment, it is increasingly possible to remain calm and organized. When internal states can be

successfully regulated, it enhances the capacity to develop and maintain external relationships. Parental behavior plays a large role in the development of this internal regulation. For typically developing infants, highly responsive parents (those that responded more contingently to their infant's social and emotional cues) have infants who show greater evidence of stress regulation. Highly responsive parents are also thought to instill a sense of self-efficacy in the infant, and promote social, cognitive and emotional development (Haley, & Stansbury, 2003). Mothers of typically developing infants also appear to engage in emotional socialization during face-to face play when the infant is in an alert and attentive state. Furthermore, mothers appear to time their expressive behavior to periods when their infant has an engaged gaze, as well as to encourage their infant's eye contact (Malatesta, Grigoryev, Lamb, Albin & Culver, 1986).

Driving this mother-infant cycle of engagement and emotional communication during the first postnatal year of life is the attachment bond with the primary caregiver, which aids in the development of self regulation. Attachment theory, proposed by John Bowlby (Bowlby, 1969), is described as the formation of the mother-infant relationship, and has become the dominant model of human social-emotional development. Integrating psychology and psychiatry with behavioral biology, Bowlby surmised that the attachment system would be located in specific areas of the brain, and is an evolutionary mechanism common to both humans and animals. He emphasized the idea that developmental progressions are the result of the interaction of the infant's genes with a particular environment, and the infant's emerging social, psychological, and biological capabilities need to be understood in the context of the relationship with the mother. He

also posits that the attachment relationship is a dynamic interchange, with both the mother and the infant attending to emotional cues from one another, leading to an attachment bond of varying qualities dependant upon the features of the interactions (Bowlby, 1969; Schore, 2000).

In the infant's earliest attachment experiences, they use their maturing capacities in the motor and sensory areas, specifically smell, taste, and touch, to interact with the others in their social environment. During times of mutual gaze, the mother and infant engage in spontaneous facial, gestural, and vocal communications, which expose the infant to high levels of social and cognitive information. During these face-to-face interactions, the mother assists in the information processing the infant is experiencing by regulating the amount, mode, variability and timing of stimulation to meet the infant's unique capacities. In turn, the infant's regulatory capabilities are promoted by the orchestrated interactions of the mother and are essential to the healthy affective development of the infant (Schore, 2005).

Drawing from previous literature on attachment and mother infant interactions, it also becomes important to understand the infant's neurodevelopmental capacities. Als (1984) proposed a Synactive Theory of Development that views the infant's functioning within a model of constant intraorganism subsystem interaction. The organism is also viewed as being in continuous interaction with its environment. This model identifies the degree of differentiation of behavior and the capability of the infant to modulate and organize his/her own behavior. Als identified five interactive systems that contribute to the infant's ability to modulate behavior and are the prominent parameters of an infant's individuality and personal uniqueness. The systems are the autonomic system (i.e.

respiration, and color changes); the motor system (i.e. posture, tone); the state organizational system (i.e. ranges of states of consciousness, patterns of state transitions); the attention and interacting system (i.e. ability to come to an alert attentive state and take in and use information from the environment); and the self-regulatory balancing system (i.e. observable strategies the infant uses to maintain or return to a stable state of subsystem integration). The subsystems of the term infant are usually able to function smoothly and enhance each other, resulting in neurobehavioral organization and smooth interactions with the environment and individuals in the environment. Autonomic stability, digestive functioning, and smoothness of movements are restabilized relatively quickly after birth in the healthy term infant. State organization in terms of ranges and transitions between states also appear to follow this same pattern (Als, 1984; VandenBerg, 2007).

Overall, infants rapidly develop interactive, regulatory, and attentional competencies that contribute to their social and emotional development over the first several months of life. There are however many individual differences contributing to the range of capacities and emerging abilities seen in a typically developing infant. On the other hand, the at-risk infant displays distinctly different patterns of emerging developmental capabilities, outside the range which can be attributed to individual differences alone, and which can contribute to a host of ongoing problems as the infant matures.

Social Emotional Development of At-Risk Infants

In New Mexico, approximately 850 infants are discharged per year from the University of New Mexico Hospital Special Care Nurseries. In order to clarify what exactly is meant by 'at-risk', these Nurseries implement a System of Risk Triage (SORT; UNM Developmental Care 1986) to assign infants who enter this system a developmental risk group. This decision is based on child biomedical risk factors as well as family environmental factors and is used to appropriate available professional resources to the families and infants. The Biomedical risk groups are as follows:

1. Increased Risk (5-15%) where infants are at higher risk for developmental problems than the general population, however they will most likely follow a typical developmental trajectory.
2. High Risk (80-95%), in which their condition places them at high risk for developmental delays. Recovery is prolonged due to persistent medical problems. Some risk factors included in this category are a birth weight less than 1250grams, gestational age below 36 weeks, low APGAR score (<6) at 5 minutes, identified central nervous system injury, surgery with prolonged hospitalization, ventilator assistance longer than ten days, or positive prenatal exposure to illicit substances.
3. Established Risk (3%), in which an infant's physical or neuro-biological diagnosis is associated with developmental delay and/or disability. Typically, service needs can be established from birth or within the newborn period, and usually begin shortly after birth to promote the best trajectory of development. Infants in this category include those with congenital physical anomalies and syndromes present

at birth that are known to be linked with developmental delays or disabilities, or those infants with severe sensory loss.

Following are the Psychosocial Environment Categories:

1. Adequate psychosocial environment (19%), which is identified as risk equal to the general population.
2. High Risk psychosocial environment (80%), identified as risk greater than the general population. The family will most likely need help in identifying resources to support their infant's growth, development and well-being.
3. Professionally identified concerns (< 1%), in which the family's psychosocial environmental circumstances are unstable and the infant's future safety is in question.

The preceding categories are used to identify at-risk infants in the state of New Mexico, and lead to eligibility for Early Intervention services which work to promote the infant's most optimal development. For purposes of the current study, being born less than 36 weeks gestation (i.e. preterm, and therefore spending time in the NICU) was one of the inclusion criteria for the 'at-risk' group of infants.

Preterm birth has been shown to lead to infants who exhibit developmental delays, difficult temperaments, and cognitive deficits. These infants have also been shown to be less alert, less active, and less responsive than full-term infants during the neonatal period (Crnic Ragozin, Greenberg, Robinson, & Basham, 1983; Davis & Burns, 2001; Taylor, Klein, Minich, & Hack, 2000). Along with cognitive and attentional concerns, preterm infants are also at an increased risk for showing deficits in their self-regulatory skills, linking closely with decrements in social-emotional development, and

leading to difficulties in most if not all aspects of daily functioning as the child matures (Vohr et al, 2000; Davis & Burns, 2001; Gomez, Baird, & Jung, 2004). Thus, the caregiver-infant-environment interaction becomes *extremely important* as premature birth disrupts the expected course of pregnancy and usually lengthens the hospital stay. This in turn impacts the time and quality of contact between infant and parents for their development of attachment and bonding.

In order to support and encourage the infant's development, it is imperative to understand the infant's behavioral cues and how to respond appropriately to these cues. In Als's (1982) model of synactive development, she recognized various characteristics that can be observed to identify whether an infant is in an *organized* or *disorganized* state. An infant who is termed *organized* can maintain stable respiration, even pink skin color, and steady digestion, while also maintaining smooth movement, tone and posture, and at the same time manage waking and sleep. The *organized* newborn is additionally able to self-calm by using self-regulation strategies such as finger sucking, leg bracing, foot clasping, and grasping (Als, 1982; VandenBerg, 2007). The stressed newborn displays variations in their capability to handle environmental stimuli. The preterm infant frequently expresses reactions to stimuli physiologically rather than interactionally (Gorski, 1991). Changes in very subtle behaviors in the infant's physiologic patterns such as variations in breathing, hiccoughing, pale mottled color, finger spreading, or floppy posture, can follow in response to the environment or of being handled and can be indicative of the appropriateness of the stimulation. This information can then be used by caregivers to effectively support the infant to regulate autonomic function in combination

with maintenance of motor systems to work towards an organized state (Als, 1982; VandenBerg, 2007).

A recent study conducted by Dudek-Shriber (2004) examined parental stress in the Neonatal Intensive Care Unit. It was found that parents reported their greatest stress to be in the relationship with their baby and their parental role, and the second highest degree of stress to result from how their baby looks and behaves. This finding reinforces the importance of helping parents to observe, interpret, understand, and respond to their infant's subtle cues, behaviors, appearance, and state changes. This information will support the parent/s in understanding that their infant's behavior has a physiological basis, and that their infant cannot always regulate their own systems concurrently, leading to a better understanding of how to respond and interact with their infant appropriately (Dudek-Shriber, 2004).

It follows that observation of the infant's various states and subtle behavior changes needs to be placed in the context of their immediate environment. The global physical environment of the preterm infant is the Neonatal Intensive Care Unit (NICU), which has transitioned into recognizing that environmental stimuli play a large and oftentimes stressful role in the young infant's life. It has become evident that because preterm infants are highly sensitive and vulnerable to their surroundings, the setting can have deleterious long lasting implications (White, 2005). The impact of the NICU environment needs to be taken into consideration when examining the challenges of the infant who is expected to form a secure bond to its mother as well as grow and mature (Spencer, & Edwards, 2001). For example, vision is the last physical sense to develop, so minimizing visual stimuli, such as light, prior to 28 weeks gestation, while the other

senses are developing is important so there is no interference during the critical periods of sensory development (White, 2005). Constant light may agitate body rhythm, and bright light may not allow the infant to open their eyes and look around. It has been found that preterm infants in nurseries with a dimmed nightlight progress more quickly in their natural sleep-wake cycles (Nair, Gupta, & Jatana, 2003).

The auditory environment in the NICU is also of concern. The preterm infant suddenly begins receiving auditory stimuli through the air instead of the muffled liquid medium found *in utero*. The auditory system starts to develop between 3 and 6 weeks gestation, and by 25 weeks gestation, all major fetal ear structures are in place for the physiologic effects of sound to produce effects. For adults, the range of comfortable sound levels is from 60-80dB, the recommended sound levels for preterm infants in the NICU is below 55dB. Sound levels in NICU's usually range from 50-80dB, with spikes of over 100dB, which clearly exceed recommended levels (Neal & Lindeke, 2008; Krueger, Wall, Parker, & Nealis, 2005).

This excessive noise is stressful for babies, and as early as 1980, noise in the NICU was shown to increase intracranial pressure, decrease oxygen saturation, contribute to episodes of apnea and bradycardia, as well as cause sudden fluctuations in blood pressure (Krueger, Wall, Parker, & Nealis, 2005; White, 2005). It is also likely that excessive sound may interfere with the infant attuning to their mother's voice, delaying the development of the interactions between infant and parent. Additional effects include neural damage to the developing auditory structures, leading to later language or auditory processing disorders (Neal & Lindeke, 2008). However, noise is also a fundamental byproduct of monitor alarms and caregiver communication, which even the newest

NICU's still find as a challenge. Although they have made significant alterations to dampen the acoustic environment, it appears that sound levels are still elevated in NICU's (Kreuger, Wall, Parker, & Nealis, 2005; Philbin, & Evans, 2006; White, 2005). The best sound quality is most likely achieved through close contact with parents who sing or talk to their infant in an individualized manner, and recognizing that the need still remains for quiet speech as well as thoughtful action when in the space of preterm infants (Gray & Philbin, 2004).

There are several ways that the negative environmental impacts can manifest themselves in the preterm infant. Physiologically, stress markers typically include increased heart rate and decreased oxygen saturation. Very subtle changes in the infants physiologic behavior patterns, such as skin color, fluctuations in heart rate or respirations, or the presence of startle or tremors are all clues to how the environment and stimuli are affecting the infant (VandenBerg, 2007). Increased energy expenditure during routine care can lead to decreased growth. The adverse effects of the environment might also affect the infant's immune system, delaying recovery from typical illnesses. The infant's quickly developing brain is especially susceptible to stress, which can also have many implications for neurobehavioral development (Symington, & Pinelli, 2006).

Along with these physical impacts, the typically longer stays in the NICU can also delay the contact between caregiver and infant that usually promotes positive interaction, and leave the mother with an altered sense of bonding, attachment, and decreased competence as a parent (Keilty, & Freund, 2005; Olson, & Baltman, 1994). Developmental care, introduced in the 1980's, is a broad category of interventions built to diminish some of the aforementioned stressors of the NICU (Als, 1986). This strategy

was created due to the concern that an unfavorable environment might compound the morbidity associated with the immaturity of a preterm infants' organ systems (Als, 1992; Blackwell, 2000). Along with formal observation and regular assessment of infant behavior, developmental care guidelines include environmental modifications to control external stimuli (vestibular, tactile, auditory, visual), minimizing disorganized responses, altering care-giving and handling to promote stability in physiologic function, motor system, and state system function. These interventions are designed to promote optimal neurodevelopment of the infant, and may be integrated into an individualized approach known as the Neonatal Individualized Developmental Care and Assessment Program (NIDCAP; Sizun, & Westrup, 2004).

A review examining developmental care for the promotion of development and the prevention of mortality in preterm infants was conducted by Symington and Pinelli (2006). The authors found and examined 36 studies which fit their criteria and found a wide range of outcomes. An estimate of overall effectiveness could not be determined due to the difference between individual interventions across studies. There was evidence of limited benefits; however there were a large number of outcomes that showed no effects or conflicting effects. Examination of individual studies revealed six trials which modified external stimuli and demonstrated clinically important outcomes. Tactile stimulation resulted in shorter length of stay and improved short-term growth outcomes. Vestibular, auditory, visual and tactile stimulation resulted in improved transition to nipple feeding and shorter length of stay. Due to conflicting results, it will be necessary to demonstrate consistent effects of developmental care interventions on outcomes through sound methodological studies. Although Symington and Pinelli (2006)

found no harmful effects of interventions, individual institutions should consider the economic impact of the application and upkeep of developmental practices prior to implementing them.

Als and colleagues (2004) specifically examined the effects of early experience on brain structure and function through testing the neurodevelopmental effectiveness of NIDCAP with preterm infants between 28 and 33 weeks gestational age at birth. Neurobehavioral data were collected using the Assessment of Preterm Infants' Behavior (APIB) as well as the Prechtl Neurologic Examination of the Fullterm Newborn Infant (Prechtl). Neurophysiologic data was collected through EEG monitoring, and neurostructural data were collected through MRI. Results indicated that the intervention group showed significant improvement in neurobehavioral outcomes, positive changes in functional connectivity between brain regions, and structural changes in the internal capsules and frontal white matter. These results demonstrate that brain development may be significantly influenced by the quality of experience prior to term. The NIDCAP model views the infant as an active participant who seeks support from their caregivers as well as the developmental care team. Results of this study indicate that this individualized model promotes cortical development by providing an extrauterine environment which supports more stable regulation of the immature autonomic system, thus aiding the infant's developmental progression (Als et. al, 2004).

The influence of touch, in the form of light massage, and skin-to-skin contact (Kangaroo Care), has received a lot of attention as possible techniques to help the preterm infant cope better with the adverse effects of the NICU environment. Gentle human touch (GHT) was developed for nurses and parents to stimulate and soothe

physiologically fragile infants within the first three postnatal weeks (Harrison, Olivet, Cunningham, Bodin, & Hicks, 1996). GHT involves placing a caregiver's hands on the head and abdomen of the infant for 10-15 minutes 3 or 4 times per day. This method is more passive in that it does not involve stroking, but soothes the infants through decreased behavioral stress and motor activity. GHT can be effectively used with fragile infants and is a nice precursor to infant massage and Kangaroo Care, which are both more stimulating techniques (Blackwell, 2000).

Kangaroo Care (KC) is generally considered the method of holding the infant directly against a parent's bare chest, with the head turned so that their ear is over the parent's heart, with the arms and legs flexed close to the baby's body. They will remain in this position for 1-3 hours, depending on how stable the infant is and the comfort of the parent (DiMenna, 2006). Overall, the premise is that tactile stimulation is related to healthy social and emotional development, regulating adaptive social behaviors, and establishing secure attachment to the parent. Skin-to-skin contact specifically has been suggested to contribute to stability and maturation in each of the 5 neuro-behavioral systems that are affected by preterm birth: autonomic, motor, state, attention-interaction, and self-regulation (Feldman, 2004). This is surmised to be accomplished through the activation of hormones that are significant for physical growth, health, neurological development, and stress regulation (Blackwell, 2000).

Although the literature is growing in the number of the studies conducted specifically with KC, many have had inconsistent results, with some finding KC to be beneficial, and others finding no difference. With mixed study results, it is important to point out that no study has found adverse effects to the infant or parent (DiMenna, 2006).

Recently Hake-Brooks and Anderson (2008) specifically looked at the effects of KC and breastfeeding status in preterm infants. They found that mother-infant dyads who participated in KC breastfed more exclusively (100% breast milk), and breastfed significantly longer (in months) than the control dyads. These results suggest that KC is an effective way to facilitate the duration and exclusivity of breastfeeding (Hake-Brooks, & Anderson, 2008). Research has also shown that KC promotes infant warmth, stable vital signs, adequate, oxygen saturation, deeper sleep, less crying, fewer days in incubators, greater weight gain, and earlier discharge (Blackwell, 2000; Smith, 2007). Furthermore, research supports the positive effects of KC on the mother's well being, highlighting the intervention as a natural, cost free intervention, which does not require extensive training, and carries a significant benefit to the infant-mother dyad (Feldman, 2004).

A classic study by Field and colleagues (1986) examined the effects of massage on 40 infants with an average birth weight of 1,280g, and average gestation of 31 weeks. The infants received three 15-min. sessions per day for 10 days, which included massage and kinesthetic stimulation that included passive limb flexing while in supine position. Results indicated the infants that were stimulated had an average of 47% greater weight gain per day, and were more alert and active during sleep/wake behavior observations than control infants. The massaged infants were also discharged 6 days sooner on average than control infants, indicating that massage may be a cost effective way to facilitate growth and behavioral organization in preterm infants.

A recent review (Vickers, Ohlsson, Lacy, & Horsley, 2004) of neonate massage suggests that massage may improve weight gain in preterm and low birth weight infants

and does provide some indication for an effect on length of stay in the hospital. On average, the review also indicated that massaged infants had slightly better scores on developmental tests and had slightly fewer postnatal complications. However, many of the studies reviewed posed methodological issues including small sample sizes, unexplained differences in standard deviations between trials, as well as selective reporting. These issues do not lead to a strong base of evidence in regards to infant massage; however, again, the authors mention that no adverse effects of massage were reported in any study. The results of massage studies as well as KC trials point out the need for more sound evidence based research to be conducted with appropriate sample sizes and follow up (Vickers, Ohlsson, Lacy, & Horsley, 2004).

Blackwell (2000) has pointed out that although touch therapies and other interventions are an important part of neonatal care, its maximal benefits come about when provided in a developmentally focused environment that distinguishes and supports each infant's limitations and strengths as well as promotes family involvement. It is also imperative to observe the behavioral and physiological responses of the infant and adjust stimulation so that it is neurologically tolerable to the infant (Smith, 2007). Although some of these techniques may not be cost-effective for hospital staff to administer, parents can perform them without extensive training. When parents are guided in implementing touch therapy techniques, attachment and bonding behaviors may be increased, leading to an enhanced sense of efficacy in the parent and emotional well-being in the infant that could endure well after leaving the hospital (Blackwell, 2000). Proponents of touch therapies also point out that that the techniques are non-invasive,

they do not require specialist equipment, and they can be employed without disrupting routine care procedures (Vickers, Ohlsson, Lacy, & Horsley, 2004).

The quality of early social interactional experiences between the infant and primary caregivers is recognized as a major foundation for the infant's socioemotional skills. Forcada-Guex, Pierrehumber, Borghini, Moessinger, and Muller-Nix (2006) attempted to identify at 6 months the specific dyadic mother-infant patterns of interaction in preterm and term infants, as well as the impact the patterns might have on the infant's behavioral and developmental outcomes at 18 months. They found that two patterns emerged in the dyads: a "cooperative pattern" (sensitive mother and cooperative-responsive infant), and a "controlling pattern" (controlling mother and a compulsive-compliant infant). Preterm infants of the controlling dyads were found to have more global behavioral symptoms, specifically more eating problems as well as lower personal social and hearing-speech abilities. However, no differences were found between the preterm infants of cooperative pattern dads and term dyads. When assessed at 18 months using the Griffiths Developmental Scales, differences were found for the personal-social subscale and hearing-speech scale between preterm infants and term infants. Specifically, the infants who experienced cooperative patterns of interaction showed greater skills in social communication and greater interest or abilities to communicate with their environment. These results allude to the significant role maternal sensitivity and responsiveness can play in the infants' development of later language and social competencies.

The study by these researchers also supports the need for early individualized family based intervention not only during hospitalization, but also during the transition

home. These early interventions have been shown to reduce maternal stress and depression and to improve positive early parent-preterm infant interactions (Forcada-Guex, et al., 2006). Within the intervention, it is imperative to promote positive interactional styles between the mother and the infant in order to foster parental feelings of self-confidence and competence in caring for their preterm infant (Forcada-Guex, et al., 2006; Olson, & Baltman, 1994). A large part of caring for an infant is reading and responding appropriately to the infant's cues, however, premature infants communicate and attempt to interact in a much more subtle, or different way than term infants, necessitating parental attentiveness and extreme observation until they can read their infant's cues appropriately (Olson, & Baltman, 1994).

Mothers of preterm infants have been described as more active, stimulating, and intrusive during a dyadic interaction, whereas the premature infants are less alert, attentive, active, and responsive than term infants, which lead to a less fulfilling interaction on the part of both dyad partners (Forcada-Guex, et al., 2006; Crnic, et al., 1983). For example, Crnic and colleagues (1983) found that premature infants vocalized and smiled less frequently, averted their gaze and bodies more often, and showed less positive general affective tone than term infants. However the mothers do not appear to adjust their emotional involvement and instead keep their activity levels the same and may increase their stimulation in an attempt to engage their infants, leading to decreased enjoyment (Crnic, et al., 1983). It would appear that this greater maternal activity in counterproductive and leads to overstimulation of the preterm infant as opposed to the greater responsiveness that is sought. In light of interventions which teach parents appropriate interactional skills, these findings are extremely important in regards to the

premature infant. As Haley and Stansbury (2003) found that typically developing infants of more responsive, interactive parents displayed greater regulation than less responsive parents, it is important to understand the greater sensitivity of preterm infants to parent responsiveness and to adjust interventions which target this population appropriately.

Many of the problems exhibited by children who were born preterm, such as behavior problems, social-emotional problems, inattentiveness, failure to follow directions, difficulty adjusting in school and poor school performance can be viewed as issues in self-regulatory functioning (Davis, & Burns, 2001). Self-regulation refers to the ability to regulate emotional state and to organize a behavioral response to the experience (Gomez, Baird, & Jung, 2004). It has been suggested by Davis and Burns (2001) that a physical environment that is organized, along with a nurturing social environment may aid the development of self-regulatory abilities, and more specifically, attentional capacities. These same factors, considered as fundamental to social development, may be directly and indirectly linked to cognitive development, as much early learning occurs in a social context. It would then follow that problems across all domains may result from defects in the development of the self-regulatory system (Davis, & Burns, 2001).

It has been posited that early deficits in joint attention development could lead to later problems in social skill development, and these early social skills may be antecedents for the development of skills in other domains of functioning (Davis, & Burns, 2001). Taylor, Klein, Minich, and Hack (2000) conducted a study following a cohort of children with birth weight <750g (classified as extremely low birth weight; ELBW) to middle school age using several neurobehavioral outcome measures. It was found that consequences of an ELBW earlier in childhood continue to be present at

middle school age. Changes in outcome between the first assessment and 4 years later were less positive in the ELBW group than in term controls for measures of global cognitive ability, word recognition, teacher ratings of academic performance, and parent ratings of behavior and attention problems. They also found that the ELBW group of infants displayed lower IQ, lower academic achievement, higher incidence of AHDH, lower adaptive behavior, speech or language impairment, and more developmental impairment than the group of term infants. It appears that children born preterm have a greater risk for issues linked to the development of joint attention abilities, stemming from a poor self-regulatory system, which leads to a heightened risk in other domains which may be directly or indirectly influenced by these deficits (Taylor, Klein, Minich, & Hack, 2000).

If developmental outcome is examined from the point of attention regulation, the poor social development witnessed in children born preterm is better understood. If children display difficulties with shifting attention from one person or object to another, and selectively attending to the environment, then they may not be picking up the necessary environmental cues required for proper social development (Davis & Burns, 2001). Social interactions provide children with the opportunity to learn to organize their environment, and as preterm infants are less responsive to their environment, and have difficulty demonstrating interactive capabilities, they are at greater risk for developing deficits in attention regulation in infancy (VandenBerg, 2007; Davis & Burns, 2001).

Once an infant is born, they begin to use their developing coping abilities to interact with the social environment. Specifically, during the first postnatal year, the infant's primary goals are to create an attachment bond of emotional communication with

the primary caregiver and the development of self-regulation (Schore, 2005). This is accomplished through the face-to-face emotional transactions between the mother and the infant and the facilitation and regulation of cues in a reciprocal exchange. However, misattunement within the dyad, or in the case of preterm infants, lack of positive, lengthy interactions (due to the fragility of the preterm infant, and the simple capacity to be in an alert state) can impact the attachment bond. (VandenBerg, 2007; Schore 2005)

Sajaniemi and colleagues (2001) examined the effects of an early occupational therapy intervention on the cognitive development and attachment patterns in a group of 48 extremely low birth weight infants (ELBW, < 1000 g). The intervention was aimed at supporting parent-child interaction and enhancing motor control and coordination. Attachment to the primary caregiver was assessed with the Preschool Assessment of Attachment (PAA) at 2 and 4 years of age. They found that within the sample of ELBW infants used, the distribution of attachment patterns differed greatly from the normal population with 41% showing atypical patterns. When assessed at 4 years of age, the findings indicated a slight increase in normative attachment patterns in the intervention group as compared to the control group. The findings indicate that there seems to be an overall higher level of attachment difficulties in children born preterm, but that there may be positive effects of early interventions, perhaps changing the parent child interaction to result in cumulative effects on long term development. Another important aspect of the present study is that it brings to light the necessity to enhance the parent's capacity to read their infant's cues and to respond adequately, thus promoting optimal attachment bonds and development.

Assessments to Measure Infant Social Emotional Development

The survival rate for preterm and very preterm infants has increased steadily with advances in the medical world. In 2001, more than 22,000 infants were born extremely premature. From 1995-2001, the mortality rate of these infants decreased 15.4% for those born between 750 and 999g, and 9.7% for those born between 500 and 749g (Matthews, Menacker, & MacDorman, 2003). The Centers for Disease Control reported in 2007 that preterm births have been steadily rising since 1990, currently reporting the preterm birth rate to be 12.7% of all births (CDC, 2007). With this increase in survival, it becomes extremely important to accurately assess the developmental status of these at-risk infants earlier. The profession of occupational therapy plays a major role in assessing this population of at-risk infants, and also providing early intervention strategies for these infants and their families. The early identification of developmental problems would allow the best opportunity for intervention strategies to be implemented and also assessed in a long-term manner. It would also allow the identification of developmental delays and disabilities earlier, aiding to increase the eligibility of families for early intervention programs (Keilty, & Freund, 2005).

Routine screenings with a simple, easy to administer tool, as well as regular child visits may aid in the identification of possible social-emotional and behavioral issues by the physician and help to increase communication between parents and their primary care provider. However, limited screening tools exist which are cost effective and which can asses the developmental competence, specifically the social emotional development of at-risk infants sufficiently (Stancin & Palermo, 1997; Bricker, & Squires, 1999). The tools which do exist to identify these issues, such as the CBCL/1.5-5 (Achenbach & Rescorla,

2000) and the Infant-Toddler Social and Emotional Assessment (ITSEA; Carter & Briggs-Gowan, 2000) are too long to use in screening and do not apply to infants under 1 year of age. The Sensorimotor History Questionnaire for Preschoolers (DeGangi & Balzer-Martin, 1999), which prescreens 3-4 year olds at risk for problems with sensory integration and self-regulation, and the Child Behavior Inventory (Eyberg, 1980), which examines conduct problems in 2-11 year olds, do have a focus on social-emotional issues, however they also do not apply to infants under 1 year of age.

The Ages and Stages Questionnaire (ASQ: Bricker, & Squires, 1999) and its supplement, the Ages and Stages Questionnaire: Social-Emotional (ASQ:SE; Squires, Bricker, & Twombly, 2002a) are two promising tools that address social-emotional and behavior problems from birth to 5 years of age. Acceptable test-retest reliability and sensitivity in detecting children with developmental delay or social-emotional problems have been reported (Squires, Bricker, & Twombly, 2002b). The purpose of the current study is to examine the use of the ASQ (Bricker, & Squires, 1999) and ASQ:SE (Squires, Bricker, & Twombly, 2002a) and the ability of the ASQ:SE to identify significant differences in the social emotional development between infants identified as at-risk and infants with typical development between the ages of 3 and 9 months. Use of these two tools together has not been completed with this subgroup of infants.

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Appendix B

Consent and HRRC Forms

UNIVERSITY OF NEW MEXICO HEALTH SCIENCES CENTER

CONSENT TO PARTICIPATE IN RESEARCH

"Social Emotional Assessment of Infants At-Risk Using the Ages and Stages Questionnaire Social-Emotional (ASQ-SE)"

PURPOSE AND BACKGROUND

Patricia A. Burtner Ph.D., OTR/L, who is the Principal Investigator, and Nancie Furgang MS, OTR/L, Co-Principal Investigator, both from the Department of Pediatrics, are conducting a research study. The purpose of the study is to find out the answers that parents give to questions about their infant's development. We are interested in your answers to questions about your infant's social, emotional, motor and communication development using the Ages and Stages Questionnaire(ASQ) and the Ages and Stages-Social Emotional Questionnaire(ASQ:SE). The ASQ: SE is a new questionnaire. We will also be exploring the relationship between the results of the ASQ: SE and the ASQ and the relationship between the results of the two questionnaires for infants who are at risk and those who may be at a significantly lower risk for developmental delays. Babies who are premature similar to your baby have increased risk of having problems with their development. For this reason, your baby and others at risk are routinely evaluated for their development. However, we know little about the social emotional development of babies who are high risk. We hope this study will provide us with this information.

You are being asked to participate in this study because your baby has had a high risk birth history with scheduled follow-up appointments in the Special Baby Clinic or you have an infant with no history of developmental risk. We are asking approximately 60 parents of infants to participate in the study.

PROCEDURES

If you volunteer to participate in this study, the following things will happen:
During your baby's visit to the Special Baby Clinic, you will be asked to turn in the questionnaires sent to you in the mail with questions about how your baby moves, plays and talks. The second questionnaire asks for information about how your baby calms when crying, how he or she looks at you and other people, eats and sleeps. If you have forgotten to bring the forms, we will ask you to fill out the questionnaires in clinic or give you others to mail to us.

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You will also be interviewed by a member of our research team and asked questions on the Social History Interview so you can tell us more about your family. The entire interview will take about 30 minutes or less. You can refuse to answer any question at any time; however the questionnaire will not be valid unless you answer all of the questions.

In addition, information will be abstracted from your baby's medical records. The information that may be used includes prenatal history and care, labor and delivery information, medical intervention given before, during and after birth, medical treatment provided to the baby during his/her stay in the hospital, social history, and information from follow-up visits to the Special Baby Clinic. The information will be used to explore any trends among the medical information and the responses given to the ASQ and ASQ: SE questionnaire.

Your answers to the questionnaire and any medical information will be recorded with a study number to insure that the information cannot be linked to you or your baby. The information will be stored in a locked cabinet that is accessible only to the investigators. The information will be used to compare your answers regarding your baby's development to other babies who had no reported difficulties at birth. If you wish, we will also share your answers to the questionnaire with your baby's primary health care provider. The information you provide us will be shredded and discarded in December of 2008.

RISKS AND DISCOMFORTS

There may be some unforeseeable risks of research, which may include emotional distress, stress, inconvenience, loss of privacy, etc.

B**ENEFITS**

There may not be any direct benefit to you from this study. However, by participating in this study, your awareness of your baby's development will be increased. We also hope to increase societal awareness of the benefits inherent in following the socio-emotional development of infants who are at high risk as well as the motor and communication development of infants who are at high risk.

ALTERNATIVES TO PARTICIPATION

You do not have to participate in this study for your infant to receive care at the Special Baby Clinic. The only alternative is not to participate.

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CONFIDENTIALITY

Participation in research will involve a loss of privacy, but information about you will be handled as confidentially as possible. Representatives from the University of New Mexico Health Sciences Center Human Research Review Committee that oversees human subject research will be permitted access to your records. Also, your participation in the study and information in your study records may be disclosed as otherwise provided by law. However, your name will not be used in any published reports about this study.

PAYMENT FOR PARTICIPATION

Participants will be given a $10 gift certificate for the time required for their participation.

WITHDRAWAL

Your participation in this study is strictly voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without prejudice to your future health care or other services to which you are otherwise entitled.

QUESTIONS

If you have any questions at any time about the research study, Patricia A. Burtner Ph.D., OTR/L or her associates will be glad to answer them at (505) 272-1753 during the day (i.e., Monday Through Friday 8:00am – 5:00 pm). For emergencies after hours, please call the University of New Mexico Hospital Operator at 272-2111 and ask for the faculty physician on call for the department of Pediatrics. For research-related injuries or emergencies that arise after hours or on weekends, you should call 272-2127 and ask for the pediatrician on call. If you have questions about your legal rights as a research subject, you may call the UNMHSC Human Research Review Committee at 272-1129.

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CONSENT

You will be given a copy of this consent form to keep. By signing this consent form, you are not waiving any of your legal rights, claims, or remedies. If you have questions about your legal rights as a research subject, you may call the UNMHSC HRRC at 272-1129.

I have read (or someone has read to me) the information in this consent form. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. By signing this consent form, I willingly agree to participate in this study.

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Name of Subject (type or print)

_____ _____

Signature of Subject Date

I have explained the research to the subject or his/her legal representative, and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

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Name of Investigator/Research Team Member (type or print)

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(Signature of Investigator/Research Team Member) Date