

**Parental Reaction to a Diagnosis of Autism: How Resolution Relates to Parental  
Reflective Functioning and Parenting Stress**

**By**

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the Requirements of the Degree of Doctor of Psychology  
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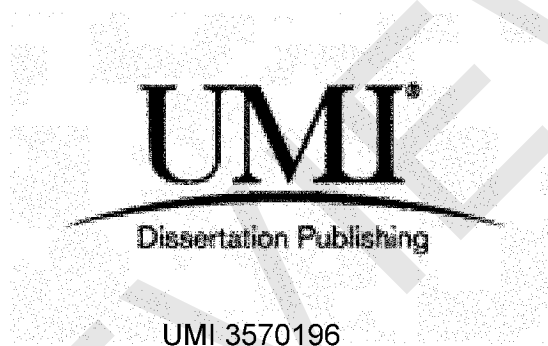
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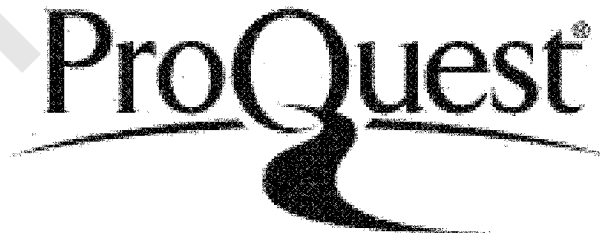


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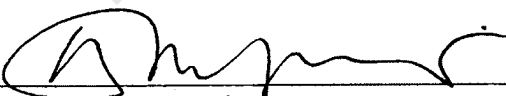
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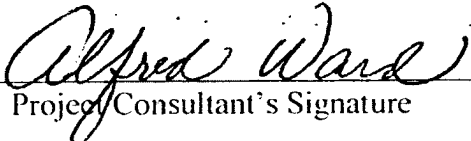
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PREVIEW

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## ABSTRACT

The purpose of the present study is to examine the relationships among a parent's resolution of a diagnosis of autism ascribed to his/her child, parental reflective functioning, as assessed using the Adult Attachment Interview, and total reported parenting stress. Success of the resolution of a diagnosis of a chronic illness or disability has important implications for the parent-child relationship. Prior research suggests that resolution promotes enhancement of the caregiver representational system and fosters more reciprocal and attuned caregiving behaviors, whereas non-resolution impedes these attainments (Pianta, Marvin, & Morog, 1999). Furthermore, the parent's capacity to envision the mental states of her or his own primary caregiving figures is predictive of the infant's security of attachment to each parent (Fonagy, Steele, Moran, Steele, & Higgitt, 1991a). It would follow that Unresolved status and/or a lack of reflectivity evidenced by a parent would call for intervention. In the current study, examination of hypothesized relationships between parental resolution and reflectivity, and between parental resolution and total reported stress related to parenting did not yield significant findings. However, there was a significant relationship between parental reflectivity and total reported stress related to parenting (PSI-Parent). Specifically, a parent feeling greater stress in the parenting role is more likely to show a higher level of reflectivity than a parent feeling less parenting stress. Possible explanations for this finding are discussed.

## **CHAPTER I**

### **INTRODUCTION**

According to the Autism and Developmental Disabilities Monitoring (ADDM) Network, an active surveillance system that estimates the prevalence of autism spectrum disorders (ASDs) and describes other characteristics among children aged 8 years whose parents or guardians reside within 14 ADDM sites in the United States, the current overall prevalence of ASDs is 1 in every 88 children. This prevalence rate of autism is more than double the rate of 10 years ago, and 10-times the estimation of a generation ago (Center for Disease Control, 2012). Furthermore, the 2008 data from the 14 ADDM sites estimated the following:

- ASDs are reported to occur in all racial, ethnic, and socioeconomic groups.
- ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252).
- Studies in Asia, Europe, and North America have identified individuals with an ASD with an average prevalence of about 1%. A recent study in South Korea reported a prevalence of 2.6%.
- About 1 in 6 children in the U.S. had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.

The DSM-IV-TR (American Psychiatric Association, 2000) describes a triad of deficits in individuals with autism that include primary disruptions in communication and relatedness, and restriction of personal interests. However, the DSM-5 proposed revisions combine these three domains to two: social/communication deficits and fixated interests and repetitive behaviors. Furthermore, the DSM-5 Neurodevelopmental Disorders Work Group is proposing that Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified be subsumed under Autistic Disorder (American Psychiatric Association, 2012). ASDs can sometimes be detected at 18 months or younger (Kleinman et al., 2007), and by age 2, a diagnosis by an experienced professional can be considered very reliable and stable (Lord, Risi, DiLavore, Shulman, Thurm & Pickles, 2006). Thus, children diagnosed with ASDs often require intensive intervention that spans school, home, family treatment, peer groups, sibling interventions, and the larger community. With the incidence of children diagnosed with ASDs consistently on the rise worldwide, including children of all ages, classes, and ethnic backgrounds (Al-Farsi et al., 2011; Parner et al., 2011), programs that help children with autism forge meaningful emotional connections is vital.

There are many forms of educational, medical, and clinical interventions available for children and families who are seeking treatment for ASDs. Applied Behavioral Analysis (ABA) has received funding as a primary intervention modality due to its history as an empirically derived, evidence-based approach (Jensen & Sinclair, 2002). However, other intervention methods, such as the Developmental, Individual-Difference, Relationship-based (DIR) model of intervention (Greenspan & Wieder 2006; Greenspan & Wieder, 2004; ICDL.com), while less researched to date, have much support for

children and families with autism. The literature has demonstrated the efficacy of interventions that incorporate a developmental approach, strengthen parent-child interaction and relationships, are tailored to the children's individual abilities, and focus more on joint attention, social engagement and reciprocity, and symbolic play, all of which are core deficits in ASDs (Gulsrud, Jahromi, & Kasari, 2010; Kasari, Paparella, Freeman, & Jahromi, 2008; Mahoney & Perales, 2005). The process of coordinating representations of self and other, which is thought to underlie the sharing of affect, attention, and higher order beliefs, plays a role in the development of reflective abilities (Gergely & Watson, 1996; Target & Fonagy, 1996).

Success of the resolution of a diagnosis of a chronic illness or disability has important implications for the parent-child relationship. It is suggested that resolution promotes enhancement of the caregiver representational system and fosters more reciprocal and attuned caregiving behaviors, whereas non-resolution impedes these attainments (Pianta, Marvin, & Morog, 1999). A lack of parental resolution of a diagnosis may result in inconsistent or limited caregiving behaviors toward the child as well as in a distorted representation of one's child and his/her symptomatic behaviors. Subsequently, an Unresolved reaction to diagnosis disrupts the fluidity, sensitivity, warmth, and creativity of parent-child interactions, with long term implications for a child's secure attachment to his/her primary caregiver.

A serious diagnosis of autism represents a "crisis to the caregiving system," which can translate into distorted and distressing representations of the child and conflicted caregiving behaviors (Gombosi, 1998; Marvin & Pianta, 1996; Infantino, 1994; Bowlby, 1980). Parents of children diagnosed with ASDs are profoundly impacted

by the extraordinary demands and stress of providing guidance and support to their children, including the enormous economic costs associated with caring for a special needs child. According to the ADDM, individuals with an ASD had average medical expenditures that exceeded those without an ASD by \$4,110–\$6,200 per year. In addition to medical costs, intensive behavioral interventions for children with ASDs cost \$40,000 to \$60,000 per child per year (Centers for Disease Control, 2012). Life and economic stress factors, such as these, were found to be predictive of higher levels of parenting stress (Smith, Oliver, & Innocenti, 2001).

Parents draw on their own dispositions and histories when responding to the many emotional and practical demands placed on them. Fraiberg's reference to "ghosts in the nursery," is a well-known clinical metaphor that suggests that past unresolved elements of a mother's primary relationships influence the developing relationship with her infant (Fraiberg, Adelson, & Shapiro, 1975). Studies have consistently found empirical links between the caregiver's current state of mind with regard to early attachment experiences in the family of origin, and infant-parent attachment from one generation to the next (Main, Kaplan, & Cassidy, 1985). Furthermore, the parent's capacity to envision the mental states of her or his own primary caregiving figures is predictive of the infant's security of attachment to each parent (Fonagy, Steele, Moran, Steele, & Higgitt, 1991a).

This information can be used to understand the implications of parental resolution to a diagnosis of autism ascribed to his/her child, parental level of reflective functioning and parenting stress as they relate to the parent-child dyad. It would be useful for clinicians to understand the complex ways in which parental attachment histories, specifically parental level of reflective functioning, heighten or diminish the resources

they are later asked to call upon when confronted with the realities of raising a child with a developmental disability. The present study seeks to examine how a parent's resolution of a diagnosis of autism in his/her child relates to parental reflective functioning and parental stress.

PREVIEW

## CHAPTER II

### LITERATURE REVIEW

*Endurance is only the beginning. There must be acceptance and the knowledge that sorrow fully accepted brings its own gifts. For there is an alchemy in sorrow. It can be transmuted into wisdom, which, if it does not bring joy, can yet bring happiness.*

(Buck, 1950, p. 25)

#### **Parental Reflectivity and the Caregiver/Child Attachment System**

The term reflective function (RF) refers to the psychological processes underlying the capacity to mentalize, a concept that has been described in both the psychoanalytic (Fonagy & Target, 1997) and cognitive psychology literatures (e.g., Morton & Frith, 1995). The emergence and full development of the RF depends upon the caregiver's capacity to consider his/her child's intentions, emotions, desires, and beliefs (Fonagy & Target, 1997). RF involves both a self-reflective and an interpersonal component that ideally provides the individual with a well-developed capacity to distinguish inner from outer reality, pretend from 'real' modes of functioning, intra-personal mental and emotional processes from interpersonal communications (Fonagy & Target, 1997). The concept of RF emerged out of attempts to refine understanding of the rating and classification of the Adult Attachment Interview (AAI). The construct of reflective functioning refers to a parent's (most often, a mother's) mentalization capacity in the context of her attachment style (Fonagy, Gergely, Jurish & Target, 2002). The more a mother is able to reflect upon the motivational roots of her own or her parent's behavior, the higher her



reflective functioning (Steele & Steele, 2008). Additionally, the quality of mother-infant affective communication strongly predicts the level of maternal reflective functioning and infant attachment (Grienenberger, Kelly, & Slade, 2005).

With regard to attachment, Bowlby (1958, 1988, 1991) utilized an evolutionary perspective. He suggested that all primates, including humans, are predisposed to create a strong attachment to their caregiver. Bowlby (1969) proposed two complimentary attachment systems in operation between mother and child. For the child, Bowlby described the “attachment system” as an innate system that alerts the child to seek and maintain proximity to the caregiver in times of threat. For the parent, Bowlby portrayed a complimentary system called the “caregiving system.” The attachment system and the caregiving system work in synchrony, evolving from the biological need to protect one’s young from danger. In theory, these two systems function as a self-regulating dyadic system to keep the child safe from harm and to promote optimal growth (Beebe, Jaffe, & Lachmann, 1993).

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behaviors. Within both the attachment and the caregiving systems, two further subsystems are operating: internal representations held by each of the partners in the relationship and patterns of behaviors (e.g., Bowlby, 1969; Bretherton, 1990; Main, Kaplan, & Cassidy, 1985). The representational subsystems include attitudes, goals, plans, inferences, feelings, and defenses that organize and regulate the fluidity of the behavioral subsystems. Therefore, the way the mother represents her child in her mind will influence how she behaves toward her child, and vice versa.

Easterbrooks and Abeles (2000b) found that secure attachment patterns were positively related to the extent to which a child was able to be open and reflective about their strengths and weaknesses at age eight. Thus, the authors indicate that emotional security in the relationship with the parent, facilitated by the parent's own emotional availability, was positively related to personal openness in the child and increased emotional availability in the parent-child dyad. Cohn, Cowan, Cowan, and Pearson (1992) applied the AAI measure to both parents and found that parents classified as insecure were less warm and provided less structure in interactions with their children than did parents classified as secure. Furthermore, Fonagy, Steele, Moran, Steele, and Higgitt (1991a) found that ratings of the quality of the reflective function of each caregiver independently predicted the child's security of attachment in the London Parent-Child Project. A recent study by Jessee (2012) was the first to investigate the relationship between RF and coparenting quality for mothers and fathers. Maternal RF significantly predicted paternal dyadic sensitivity and coparenting quality, and marginally predicted maternal dyadic and paternal triadic sensitivity. Paternal RF did not predict parenting quality. These findings highlight the bidirectionality of the relationship

between secure attachment and the capacity for reflective function.

### **Neurological Deficits of Autism**

Autistic spectrum disorder (ASD) is a heterogeneous syndrome characterized by impairment in social skills, verbal and nonverbal communication and restricted and repetitive behaviors (DSM-IV-TR 2000). Autism affects a variety of nervous structures, from the cerebral cortex to the cerebellum and brainstem (Minshew & Williams, 2007). Mundy (2003) postulated that the dorsal medial-frontal cortex (DMFC) and the anterior cingulate (AC) might play a role in the basic disturbance in social orienting in autism. More specifically, disturbance in the DMFC/AC system may contribute to the atypical development of intersubjectivity, joint attention and social cognition characteristically found in people with autism. A number of hypotheses have been presented concerning the primary causes of autism, ranging from global deficits, such as a missing drive for global coherence (Frith, 1989), to specialized modular deficits, such as a missing theory of mind module (Baron-Cohen, 1995), a deficient eye-tracking module (Leekam, Baron-Cohen, Perrett, Milders, & Brown, 1997), a deficient attention-switching mechanism (Courchesne et al., 1994), an executive-function deficit (Ozonoff, Pennington, & Rogers, 1991), or a deficient imitation mechanism (Meltzoff & Gopnik, 1993). However, Williams, Whiten, Suddendorf, and Perrett (2001) hypothesized that in the context of a broader neurodevelopmental deficit, a set of ASD symptoms (impairment in communication, language, and the capacity to understand others) appears to match functions mediated by the mirror mechanism, and therefore, might depend on an impairment of the mirror mechanism.

**Broken mirror hypothesis and autism.** Evidence from EEG, TMS, brain imaging and behavioral studies support the “broken mirror” hypothesis, indicating that children with autism process the actions done by others in a manner different from that of typically developing children (Rizzolatti & Fabbri-Destro, 2010; Depretto et al., 2006; Cattaneo et al., 2007). Studies have shown that children with ASD were unable to represent the entire action to be executed as an organized motor chain (grasping for eating), but only as a simple sequence of unrelated single motor acts (reaching, grasping, and bringing-to-the-mouth). While children with ASD do not have difficulty in recognizing an observed action and describing it (picking up a pen), they are only able to report on the why of the action if it is in a context that conveys a “univocal piece of information” (Sinigaglia, 2008).

However, Southgate, Gergely, and Csibra (2009) proposed that the deficits seen in imitation in individuals with ASD reflect a lack of sensitivity to those cues that would help them identify what to imitate, rather than a dysfunctional mirror neuron system. Gergely and Watson (1999) proposed that infants are innately equipped with a “contingency detection module” that is sensitive to the contingent relationships between their responses and consequent stimulus events. The contingency model assumes that after three months of age the typically developing infant prefers “highly but imperfectly contingent,” “nearly, but clearly not, like me” imitative displays over perfectly contingent, “just like me” displays. This shift functions as the basis for the infant’s emerging orientation toward and exploration of the social environment and forms the basis for the establishment of the representations of relationships with primary attachment figures.

According to Gergely and Watson (1999), the normal shift of the contingency detection module does not take place in autistic children and therefore, they continue to invest in perfect contingencies. Gergely (2001) articulated this further, suggesting that this devotion to lifelong perfection-seeking underlies a wide range of the symptoms characteristic of childhood autism, including, stereotyped behavior, executive function problems, aversion to social objects, inattention to faces, lack of social responsivity and lack of social understanding. A study by Cattaneo et al. (2007) revealed that the chained motor act organization is impaired in autism. Specifically, data indicates that ASD children are unable to organize their motor acts into a unitary action characterized by a specific intention (Rizzolatti & Fabbri-Destro, 2010). Subsequent findings suggest that children with autism have a deficit in the “chained organization of motor acts” and, as a result, they are unable to activate it during action observation. Without this internal “replica” of the actions of others, they cannot grasp directly, without cognitive inferences, the intention of others. The contingency detection module is hypothesized as central to both autism (as a function of neurodevelopmental characteristics of the child) and of disorganized attachment (as a function of the parenting/caregiving environment).

### **Greenspan and the DIR Model**

Greenspan and colleagues (Greenspan & Wieder, 2006; Greenspan & Wieder 2004; Greenspan, 2002; Greenspan, DeGangi, & Wieder, 2001; Greenspan & Wieder 2000; Greenspan, 2000; Greenspan & Wieder, 1999; Greenspan, 1992) developed the Developmental, Individual-Difference, Relationship-Based (DIR) model of intervention, which utilizes a developmental framework for conceptualizing treatment and considers all of the elements of a comprehensive, developmental approach. The theoretical

rationale for this intervention is that the child's symptoms are often secondary to underlying biologically based processing difficulties, including auditory, motor planning and sensory modulation processing difficulties (Greenspan, 1992a; Greenspan & Wieder, 1998). Relationships and affective interactions become derailed secondarily. Thus, the first goal of the intervention is to help the child try to work around the processing difficulties in order to reestablish affective contact with primary caregivers and to begin the process of mastering the “presymbolic stages” that serve as a basis for language and other higher level symbolic capacities. Greenspan has attempted to capture the depth of parent-child relationships in his Functional Emotional Assessment Scale (FEAS), which will be discussed in more detail in Chapter III.

Greenspan (2002) argues that the focus on relationships and affect, developmental level, individual differences, and comprehensiveness, serves as the unique feature separating this intervention model from other models, such as the behavioral approaches (Lovaas, 1987) or the TEACCH program (Schopler, Mesibov, & Hearsey, 1995). More specifically, the critical difference is the degree to which early disruptions in development are observed and worked with in a reciprocal way, such that the “me” communicates a wish or intention, and the “other” or “you” communicates back some confirmation, acknowledgement, or elaboration on that wish or intention. This exchange takes place using verbal and non-verbal spontaneous communication. It is a “dance” that occurs between the adult and the child: such that the therapeutic and emotionally responsive adult “woos” the child into a more intimate pattern of relating (Greenspan, 2002).

Greenspan and Wieder's (2006) overarching theory states that as the child becomes exposed to an engaged, empathic, available adult, he/she will be driven toward more joyful and communicative relationships. In turn, withdrawal and self-stimulation behavior will subside when the adult helps the child meet his/her fundamental needs for acknowledgement, relatedness, and purposeful communication. Unfortunately, quantitative research is still limited regarding the utility of the DIR treatment modality for the autism spectrum disorders population. However, the research that does exist, as in the examples that follow, supports the efficacy of a DIR-based approach to treating children with autistic spectrum disorders.

Solomon, Necheles, Ferch, and Bruckman (2007) conducted a study of the PLAY home project (Play and Language for Autistic Youngsters) where psychologists provide and model DIR intervention techniques for parents of young children with autism. 68 parent-child dyads who had completed an 8-12 month program participated in the study, and the authors found that 45.5% of children made "good to very good" functional developmental progress in their levels of emotional availability as assessed by the Functional Emotional Assessment Scales (FEAS).

Bartels (2004) found increases in emotional availability and decreased autistic symptomatology after a one-year DIR intervention with autistic youth. Olszyk (2005) conducted a follow up study to Bartels and found that preschoolers with autism who were treated within a DIR model of intervention for one year demonstrated significant decreases in autistic symptomatology, stereotypic behavior, and sensory seeking behaviors, and increases in adaptive behavior and emotional availability. Olszyk (2005)

contended that as self-regulation, external interest in the world, and two-way purposeful communication increased, while sensory-seeking behaviors significantly decreased.

Finally, a recent study by Seskin et al. (2010) extended the age-range of the FEAS to study children between the ages of 4 and 16. The authors found that children of parents demonstrating secure attachment representations performed at higher functional and relational levels than did those of parents with insecure attachment representations. Furthermore, parents demonstrating secure attachment representations showed a greater capacity for facilitating the development of their child's reflective functions and symbolic play as measured by the FEAS Representational Capacity (Elaboration) Caregiver subscale.

### **Parenting the Autistic Child**

**Parent-child interaction.** It is important to consider the impact that having a child with ASD can have upon parent-child interactions. A mutual sharing of attention and affect during face-to-face interactions characterizes the earliest social exchanges. Through the face-to-face exchanges of affective signals between infant and caregiver between birth and 5 months of age, the child begins to develop representation of affect (Beebe, Lachmann, & Jaffe, 1993). Attuned interactions and parental affect mirroring are instrumental in fostering the capacity for affect regulation (Fonagy, Target, Steele, & Steele, 1998).

However, children with ASD demonstrate core impairment in such joint attention behaviors. Research with children with ASD suggests that these children rarely integrate gaze, gestures, and affective displays to communicate social intention (Kasari, Sigman, Mundy, & Yirmiya, 1990). Yet, the use of such behaviors is less impaired when they are