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THE INFLUENCE OF A CHILD'S LEARNING DISABILITY ON A PARENT'S  
PSYCHOLOGICAL EXPERIENCE: A COMPARISON OF PARENTS WITH AND  
WITHOUT LEARNING DISABILITIES

by

Alice Varley Mangan

A dissertation submitted to the Graduate Faculty in  
Psychology in partial fulfillment of the requirements for the  
degree of Doctor of Philosophy, The City University of New York

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This manuscript has been read and accepted for the Graduate Faculty in  
Clinical Psychology in satisfaction of the dissertation requirement for the  
degree of Doctor of Philosophy.

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## Abstract

### The Influence of a Child's Learning Disability on a Parent's Psychological Experience: A Comparison of Parents With and Without Learning Disabilities

By

Alice Varley Mangan

Advisor: Professor Denise Hien, Ph.D.

This dissertation examined the psychological experience of parents whose children have been diagnosed with moderate to severe learning disabilities (LD) and compared the impact of a child's learning disability across two groups of parents: one with LD and one without LD. In-depth semi-structured interviews were administered to eleven parents of children with LD, four of whom had LD themselves, and seven of whom did not have LD. Three levels of qualitative data analysis were employed to code the interviews resulting in four theoretical constructs: (1) Diagnosis as a Threat to Parental Narcissism; (2) Parents Engage Containing and Stabilizing Strategies; (3) The Centrality of Schools and Professionals; (4) Striving Toward Acceptance. The findings suggested that those parents with LD and those parents whose early relational experiences were characterized by gross parental misattunement were more vulnerable to narcissistic trauma. The findings revealed similarities and differences in the ways parents with and without LD contained their fears and anxieties and stabilized self-esteem. School personnel and other professionals came to represent "holding" or invalidating entities and were central influences in these parents' experiences. Finally, parents' journeys toward acceptance were complex, characterized by moments of personal transformation and healing along with lack of resolution and ongoing periods of insecurity. Mourning processes and a capacity to achieve

psychological separation from one's child appeared crucial to healing, feats that were more complex for parents with LD. The findings from this study contribute to a greater understanding of the experience of parents of children with LD, and inform recommendations for professionals who work with these parents.

*Key words:* Parents, learning disabilities

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## Chapter 1: Introduction

The diagnosis of a moderate to severe learning disability in a child represents a pivotal moment in the life of a parent, affecting a parent's intrapsychic experience and igniting a cascade of interpersonal, familial, and systemic effects, themselves shaping the parent's internal processes. The parent may experience intense feelings of anger, shame, grief, and guilt, and in turn, engage defensively in denial as a way of warding off the potential for narcissistic injury and rage. When one of the parents also has a learning disability, the impact of this diagnosis can be particularly resonant for this parent. While the presence of a learning disability does produce negative effects, parents with and without learning disabilities may also feel unusual closeness to, identification with and empathy for their child, and can be positively influenced or even transformed through the experience of their child's learning disability. Even more, parents may gain a sense of relief in having their worries and fears confirmed and contained by a diagnosis.

This dissertation will closely examine the intrapsychic<sup>1</sup> experience of parents whose children have been diagnosed with moderate to severe learning disabilities and will compare the impact of a child's learning disability across two groups of parents: one with learning disabilities and one without learning disabilities. Attention will be given to the interpersonal, familial, and systemic effects of a learning disability diagnosis, as these experiences likewise shape the intrapsychic experience of the parents.

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<sup>1</sup> "Intrapsychic experience" is an intentionally general term, encompassing such elements as the nature of identifications, the content of fantasies, parental narcissism, self-esteem, self-concept, and self and child representations.

While the intrapsychic experiences of parents of children with more profound disabilities are represented (e.g., Als & Brazelton, 1984; Crown, 2009; Farjardo, 1987; Gensler, 2009; Solnit & Stark, 1962) and children with learning disabilities are well-studied in the psychoanalytic literature (e.g. Garber, 1988, 1989, 1991, 1992; Migden, 2002; Palombo, 1995; Shane, 1984), learning disabled (LD) and non-learning disabled (non-LD) parents of children with learning disabilities have historically been underrepresented within the psychoanalytic literature. Moreover, when these parents and their children have been the focus of psychoanalytic investigation, the lens through which they are studied and, in turn, represented is generally negative and at times pathological, focusing little if at all on strength, resiliency, adaptation, and health. Rather than capturing an image of the potential diversity of intrapsychic experience within this population, findings are often reduced to generalities that are negative in content and tone. These representations impact the manner in which professionals understand and respond to these parents and their families, and further, influence the ways in which these parents and their children come to view themselves. While a great deal of disabilities research has been done on families of children with learning disabilities, as with the psychoanalytic literature, the disabilities literature historically framed studies about this population from an assumption of negativity. More recently, in response to growing critique of the pessimism that attends this research, researchers within the disabilities field have begun to reframe the questions they ask and greater attention has been paid to adaptive coping, resiliency, the benefits of appropriate social and professional supports, and the positive impacts of learning disabilities in the lives of these families. This dissertation, in part, promises to redress the imbalances described above. Attention will

be given to capturing, understanding and representing not only the troubling intrapsychic experiences of being the parent of a child with a moderate to severe learning disability, but the positive intrapsychic and psychodynamic outcomes as well.

In addition to the limited and, at times, problematic theorizing on parents of children with learning disabilities in general, the existing psychoanalytic and disabilities literature on the particular intrapsychic experience of a parent with a learning disability is scant, at best. The inclusion of parents who themselves have learning disabilities in this study allows for a more in depth understanding of the particular intrapsychic experience of these parents. It is hoped that the findings generated from this dissertation will offer perspectives that begin to address this omission.

As alluded to above, this study is situated at the intersection of the psychoanalytic and disabilities literatures. While the study's emphasis on intrapsychic experience is more squarely psychoanalytic in nature, the study is also concerned with the impact of interpersonal, familial and systemic effects that often accompany the diagnosis of a learning disability on the quality of the parent's intrapsychic phenomenology. In contrast to the emphasis on intrapsychic phenomena within the psychoanalytic literature, the disabilities literature on parents of children with learning disabilities focuses primarily on external factors such as familial, social and professional support and their impact on such things as levels of parent stress and distress, adaptive vs. maladaptive coping, and the quality of relationships within families of children with learning disabilities. However, the disabilities literature generally fails to consider the impact of these external factors on intrapsychic processes in a manner so richly captured within the psychoanalytic tradition. While qualities of the parents' psychological life and history will undoubtedly shape the

intrapsychic impact of having a child with a learning disability, equally important is the influence of external factors related to and effects of having a child with a learning disability. This dissertation aims to weave together these perspectives. As such, a review of the psychoanalytic and disabilities literatures will provide a context for the present study, which, in turn aims to further elaborate and distinguish itself from this literature. It is hoped that the findings generated by this study will add new ways of understanding the experiences of parents of children with learning disabilities to both of these literatures and will positively influence the quality of professional support these families receive.

## **Chapter 2: Literature Review**

### **Introduction**

The review of literature begins with a section on learning disabilities, and includes definitions, causes, manifestations, statistical data on people with learning disabilities, responses to intervention and remediation, the impact of learning disabilities in adulthood, and psychoanalytic perspectives on learning disabilities. The second section presents psychoanalytic conceptualizations of parenthood, including major theoretical perspectives from classical libido theory, Winnicott, self psychology, and ideas emanating from attachment theory and research and considers the connections between these theoretical formulations and the current study. The third section considers the particular experience of parenting a child with a disability. Drawing from psychoanalytic and disabilities literatures, theoretical and empirical ideas about the time leading to evaluation and diagnosis, the experience and effects of evaluation and diagnosis, narcissistic injury, grief and mourning processes, parental stress and distress, the impact of the diagnosis on the relationship between parents, and positive impacts of the learning disability on parents and families are reviewed. The next section addresses particular elements that support parental acceptance, adaptation, and healing in the face of the learning disability. Ideas presented include the psychological experience of “separateness” as an essential ingredient in recovery, elements of and factors that lead to adaptive coping and the impact of interactions and relationships parents have with the many professionals with whom they must interact to support their child. The end of the chapter includes a rationale for the current study framed against the backdrop of the

literature reviewed, and presents an overarching set of research questions that will guide the data collection and analysis for the dissertation.

## **Understanding Learning Disabilities**

### **Definition of Learning Disabilities**

Learning disabilities (LDs) have long been difficult to define, a problem that has had an effect on identification, classification, and intervention processes for school-aged children (Fletcher, Morris, & Lyon 2003; Fletcher, Lyon, Fuchs, & Barnes, 2007). At least part of the struggle to capture the definition of LDs is the “unobservable” nature of the construct that exists only in relation to attempts to measure it (Fletcher et al., 2007). Indeed, LDs generally appear in children of normal intelligence, and as such are hidden, often invisible, and seemingly benign (Dyson, 1993; Faerstein, 1981; Reid, 1988). Moreover, rather than presenting as discrete, well-organized categories, LDs are dimensional and exist on a continuum of severity leading to arbitrary and inaccurate “cut offs” (Fletcher et al., 2007).

Nonetheless, the commonly held and applied definition of LDs focuses on “unexpected” underachievement and intraindividual variability, and excludes other factors that could cause this unexpected underachievement. According to the Individuals with Disabilities Education Act (2004), a specific learning disability is defined as:

...a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such term includes such conditions as perceptual

disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such term does not include a learning problem that is primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage. (20 U.S.C. § 1401 (30))

Researchers in the fields of learning disabilities and special education have criticized this definition (Fletcher et al., 2007 citing Fletcher et al., 2002; Kavale & Forness, 1985; Lyon, 1987; Lyon, et al., 2001; Senf, 1987). Criticism of the definition centers on four primary factors. The definition fails to mention the heterogeneity of LDs, does not include a statement about the persistence and manifestation of LDs in both childhood and adulthood, neglects to note the significance of failures in information processing across all LDs, and does not discuss the possibility of comorbidity of LDs with other disabling conditions such as sensory deficits or mental retardation (Fletcher et al., 2007). The definition drafted in 1990 by The National Joint Committee on Learning Disabilities (NJCLD) addresses many of these limitations. According to NJCLD:

Learning disabilities is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical skills. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the life span. Problems in self-regulatory behaviors, social perception, and social interaction may exist with learning disabilities but do not, by themselves, constitute a learning disability. Although learning disabilities may occur concomitantly with other disabilities

(e.g., sensory impairment, mental retardation, serious emotional disturbance), or with extrinsic influences (such as cultural differences, insufficient or inappropriate instruction), they are not the result of those conditions or influences. (NJCLD, 1990)

Though the federal definition of LDs continues to dominate school procedures for identification of LDs, controversy over the validity and usefulness of these and other commonly used criteria persist. Over the last two decades, research has led to increased skepticism about the focus on discrepancy between IQ and achievement as the basis for identification of LD as opposed to other causes of underachievement (Fletcher, et al., 2002). Recent research has led to the formation of two models for identifying LD. One model focuses squarely on intraindividual variation as the determining factor in identification of LD, and the second model, called the “problem-solving model” focuses primarily on the context in which the child learns (Kavale & Forness, 2000; Reschly, Tilly, & Grimes, 1999). While these models remove the emphasis on discrepancies between IQ and achievement, they each continue to stress discrepancies in different ways. Whereas in the first, the focus is on discrepancies within the child, in the second, the discrepancies are with class, school, or social expectations for achievement and performance (Fletcher et al., 2003). It has been argued that the discrepancy model produces the effect of “waiting to fail” rather than engaging in a proactive and early remediation effort as soon as even mild difficulties are evidenced (Fuchs & Young, 2006). Many researchers endorse defining LDs on the basis of “response-to-intervention” rather than focusing on discrepancies as a determining feature of LDs (Grimes, 2002; Lyon et al., 2001; Fuchs, Fuchs & Compton, 2004). Fletcher and his

colleagues (2003) suggest that LDs should be “conceptualized as ‘unexpected’ largely in the absence of response to adequate instruction, and ‘discrepancy’ a matter of not learning to expectations” (p. 52).

### **Manifestations of Learning Disabilities**

Learning disabilities manifest as a heterogeneous group of impairments resulting from neurological differences and dysfunction that negatively affect the processing, storage and communication of information (Cortellia, 2011; Fletcher et al., 2007). The underlying neurological and cognitive underpinnings of LDs are vast. For example, deficits in executive functions may manifest in problems with attention, organization and problem-solving across a range of academic and social realms (Cutting & Denckla, 2003). Specific language impairments such as poor phonological processing lead to difficulties and delays in word recognition and spelling skills (Siegal, 2003). Procedural deficits may manifest in problems with mathematics (Geary, 2003). Deficits in memory function may negatively impact not only performance in academic tasks such as reading or mathematics, but also cognitive functions, such as problem solving (Swanson & Saez, 2003). While the root causes for these neurological differences that lead to LDs are manifold and LDs can be conceptualized as a benign form of human variation, LDs do tend to run in families and, indeed, heritability is a long-documented characteristic of LD (Cortellia, 2011; Fisher, 1905; Hinshelwood, 1907; Raskind, 2001; Stephenson, 1907; Thomson & Raskind, 2003).

As indicated above, while LDs originate from neurological differences or deficits, they frequently manifest in—though are not limited to—difficulty within the academic

domains of reading, writing, and mathematics, and identification and diagnosis is generally based on these manifest difficulties. Indeed, the DSM IV-TR defines, classifies, and codes LDs according to deficits in specific academic domains, (i.e. “reading disorder”; “disorder of written expression”; “mathematics disorder”) and maintains the emphasis on IQ-achievement discrepancies as a primary inclusionary criterion (American Psychiatric Association, 2000). Reading disabilities include deficits in word recognition, spelling, comprehension, fluency and automaticity (Fletcher et al., 2007). Dyslexia, a specific type of reading disability, is the most common learning disability, and is caused by language deficits rooted in poor phonological processing (Shaywitz, 2003). Math disabilities manifest in problems with computation as well as problem solving and disabilities in written expression are observed in difficulties with handwriting, spelling, and composition (Fletcher et al., 2007). A person with LD may demonstrate struggles within one or across multiple academic domains.

Beyond the realm of achievement, LDs also manifest in deficits in social skills, motor ability, perceptual skills, and oral language (Fletcher et al., 2007), aspects of functioning that may negatively affect the child in all parts of his or her daily life. Non-verbal LDs, a less well-researched and more poorly understood type of LD, are characterized by social, visual-perceptual and mathematical difficulties (Rourke, 1989). Children with LDs are at greater risk than their non-learning disabled peers for social and emotional difficulties (Grolnick & Ryan, 1990) including struggles with self-concept (Chapman, 1988), greater levels of anxiety (Margalit & Zak, 1984), and reduced peer acceptance (Priel & Leshem, 1990; Stone & La Greca, 1990). Moreover, these children exhibit higher levels of behavioral problems stemming from noncompliance at home, in

the community and in school, poor impulse control, distractibility, and problematic and immature social behaviors (e.g., Bloom, 1990; Cordoni, 1990; Dyson, 1993; Mearig, 1992; Silver, 1988). Some children with LD have comorbid diagnoses of ADHD, currently understood as a syndrome manifesting in deficits in self-control (Barkley, 1997a, 1997b) and problems with effectively deploying or distributing attentional resources (Cutting & Denckla, 2003). The complexity of responding to and managing the particular needs of children with learning disabilities impacts parent and family functioning. This will be explored in greater detail in later sections of this chapter.

### **Prevalence of Learning Disabilities**

Given their prevalence, millions of parents and families in the United States are impacted in positive and negative ways by learning disabilities. In 2009, 2.5 million or 5% of all public school students were identified as having LDs and entitled to special education services under IDEA (Cortiella, 2011). Of the total number of students with disabilities in public schools, those with LDs were the majority at 42% (Cortiella, 2011). Reading disability is the most common of the LDs, comprising approximately 80% of all children with LDs (Shaywitz, 2003). During the two decades after the passage of the original IDEA law in the late 1970s, numbers of children diagnosed with LDs rapidly increased—by some estimates, as much as 300% (Cortiella, 2011). Yet in the last decade, these numbers have fallen by as much as 14%. This downward trend represents shifts in funding for special education, an emphasis on early childhood “school readiness” programs as well as identification for earlier remediation, and improvements in reading education (Cortiella, 2011). Disproportionality continues to plague LD

diagnosis. Boys are consistently identified at higher rates than girls, and are thus overrepresented in special education (Cortiella, 2011; Shaywitz, 2003). In racial and ethnic minority populations, African American and Hispanic children are overrepresented in special education, while Asian American populations are underrepresented (Cortiella, 2011).

### **Statistics on Experiences of People with Learning Disabilities**

Statistics on the academic experiences of children with LDs is discouraging and shed light on the many hurdles that parents of these children must face as they work to understand and advocate for their children. In terms of achievement, students with LDs continue to lag behind their non-learning disabled peers. On average, they are more than three years behind in both reading and math, and with each passing year, the gap between these children and their non-learning disabled peers widens at a rapid pace (Cortiella, 2011). Students with LDs are retained more frequently, evidence greater behavioral difficulties and receive more disciplinary intervention in school, and while dropout rates are down nearly 20% in the last ten years, these students continue to drop out at a higher rate than do students without LD (Cortiella, 2011). While more students with LD are graduating from high school, they pursue secondary education at a much lower rate than their non-learning disabled peers, and, when they do pursue college, they tend not to seek supports (Cortiella, 2011). Discrepancies persist into adulthood, with a 55% employment rate among adults with LD compared to 76% of adults without learning disabilities (Cortiella, 2011).

While greater numbers of the general population are more familiar with learning disabilities, agree that people learn in different ways, and appreciate the fact that children with LDs have average to above average intelligence, troubling misconceptions persist and pose negative consequences for children with LDs and their families (Cortiella, 2011). For example, LDs may be seen as a product of poor home environments, are often confused with or incorrectly connected to autism and mental retardation, as well as other disabilities and disorders, and can be misconstrued as resulting from “laziness” (Cortiella, 2011).

### **Response to Intervention and Remediation**

Response to intervention and remediation is uneven and dependent upon a number of variables, including the severity of the LD as well as the quality and appropriateness of the intervention techniques. Some studies have examined the influence of IQ on response to remediation, demonstrating a connection between higher IQ and greater success with remediation (e.g., Beringer et al., 1999; Foorman, Francis, Fletcher, Schatschneider, & Mehta, 1998; Hatcher & Hulme, 1999; O’Connor, Jenkins, Leicester, & Slocum, 1993; Torgesen et al., 2001; Vandenberg & Emery, 2009; Wise, Ring & Olson, 1999), though this conclusion has been questioned by other researchers (e.g., O’Shaughnessy & Swanson, 2000; Schneider, Ennemoser, Roth, & Kuspert, 1999; Vadasy, Jenkins, Antil, Wayne, & O’Connor, 1997; Vellutino, Scanlon & Lyon, 2000). Socioeconomic status (SES) may also influence the success of intervention, and some studies have demonstrated a connection between low SES and higher incidence of LD (Barona & Fayku, 1992) as well as more negative outcomes in general for students who

have LDs and low SES (O'Connor & Spreen, 1998). Age at diagnosis is an essential variable, and findings from research consistently indicate that the earlier the intervention, the more likely the child will have a favorable response to remediation and a better outcome in general (e.g., Francis, Shaywitz, Stuebing, Shaywitz, and Fletcher, 1996; Lyon, 1996; Vandenberg & Emery, 2009).

### **Learning Disabilities in Adulthood**

A good deal of research has been done examining the negative impact and effects of learning disabilities in adulthood. The following themes and findings from these studies may illuminate the potential problems and conflicts as well as strengths and possibilities of parents with learning disabilities. Studies indicate problems with employment (i.e., unemployment, underemployment, and work-place difficulties), struggles with independent living, ongoing self-esteem and emotional problems, and dissatisfaction with life (Blalock, 1981; Hoffman et al., 1987; Rogan & Hartman, 1976, 1990; Sitlington & Frank, 1990; White, Schumaker, Warner, Alley, & Deshler, 1980; Zigmond & Thornton, 1985). Other studies have highlighted the positive effects of learning disabilities on adults and demonstrate the reality that adults with LDs can have fulfilling careers, relationships, and lives (Reiff, Gerber, & Ginsberg, 1997).

In their qualitative study, Shessel and Reiff (1999) conducted multiple ethnographic interviews with 14 adults with learning disabilities to examine the positive and negative impacts and outcomes of living with LDs in adulthood. Mirroring findings from other studies, they highlighted four dominant negative themes as well as several positive themes. The adults in their study had persistent and varied problems with daily

living, including problems with efficiently reading, understanding, and retaining a variety of written information, reliance on others to read or interpret written information (e.g., forms and legal documents), problems with word retrieval which produced frustration and embarrassment, visual-spatial difficulties that negatively impacted directional sense, difficulty following oral directions, and problems with time management which affected work and personal life. Many subjects reported job related difficulties that they attributed to their LD ranging from left/ right confusion to problems with social interaction with colleagues and supervisors in the workplace. Many adults in the study suffered from effects characteristic of the “imposter phenomenon” (Clance & Imes, 1975). These feelings increased insecurity, as the subjects consistently struggled with fears of being exposed as frauds or fakes. Interestingly, those who experienced greater levels of success academically or professionally often experienced higher levels of feeling like an imposter, and tended to view themselves as unworthy of the success they had achieved (Shessel & Reiff, 1999).

Many of the adults in the study noted ongoing problems with social isolation, reportedly beginning in childhood (Shessel & Reiff, 1999). This social isolation appeared to be related to the ever-present feeling of “being different” from others, and the struggle to navigate this feeling of difference. Some adults reported that during college they emphasized studying at the expense of developing social relationships. Thus, social inexperience contributed to an already existing social anxiety that was present for many of the participants. Along these same lines, Rourke and his colleagues (1989) noted the persistence of social withdrawal in populations of people diagnosed with non-verbal learning disabilities.

The emotional health of adults with learning disabilities was frequently compromised by their experience of the LD (Shessel & Reiff, 1999). They reported high levels of stress and anxiety viewed as coming in part from the cost of having to hide, cover or constantly explain the LD. This stress and anxiety had a secondary negative impact on the physical health of these participants. These adults reported having a negative self-concept and high levels of shame, guilt and embarrassment that some participants linked to the devaluation they experienced in the context of school, or within their family of origin. Half of the respondents in this study noted having struggled with depression and reportedly connected this depression to the rejection, negative self-concept and amount of physical and emotional energy required to make it in the world with a learning disability.

While negative impacts and outcomes seem to dominate this and other studies, just under half of the adults interviewed in this study noted the numerous positive impacts and outcomes they experienced as a result of having an LD (Shessel & Reiff, 1999). The presence of positive impacts and outcomes for these participants was likely due to their optimistic outlook on life, a particular bent toward positive explanatory styles, and a capacity for cognitive reframing (Shessel & Reiff, 1999). Positively, these adults felt that the LD helped them to be better people, encouraged them to think creatively, increased their sensitivity to others, improved them professionally, and brought about a desire to help others. Spekman and his colleagues (1993) found that these positive impacts of LDs may serve as a protective factor for people with LDs.

### **Psychodynamic Ideas about Learning Disabilities**

While the learning disabilities literature provides important insight into the causes, manifestations, and outcomes of children and adults with LDs, the psychoanalytic literature has long attempted to account for psychological and psychodynamic causes and effects of learning disabilities. Indeed, psychoanalytic understandings of learning disabilities date back to the early part of the 20<sup>th</sup> century (e.g., Abraham, 1924; Fenichel, 1937; Glover, 1925; M. Klein, 1931; Strachey, 1930). Throughout the 1940s, 1950s, and 1960s, psychodynamic explanations of difficulties in learning were influenced by advances in ego psychology specifically focused on the impact of the drives and superego on particular ego functions (Rothstein & Glenn, 1999). Learning disabilities were largely viewed as having originated from dynamic and drive-oriented conflicts (e.g., Pearson, 1952), with some theorists stressing the influence of interpersonal conflicts in childhood, principally the parents' contribution to the learning disability (e.g. Buxbaum, 1964). Hartmann (1950) introduced the notion that the quality of the child's ego "equipment" likewise influenced his psychological development. With this, Hartmann encouraged an exploration of the neuropsychological contributions to learning problems and the impact on the psychological arena. Hartmann wrote:

So far we have in analysis mainly been dealing with the intervention of conflict in [the autonomous ego apparatus's] development. But it is of considerable interest not only for developmental psychology but also for clinical problems to study the converse influence too: that is, the influences which a child's intelligence, his perceptual and motor equipment, his special gifts, and the development of all these factors have on the timing, intensity and mode of expression of these conflicts. (p. 123)

Beginning in the early 1970s, neuropsychological explanations for learning disabilities and disorders proliferated, and psychoanalytic inquiries and explanations centered exclusively on conflict began to fade (Garber, 1991; Rothstein & Glenn, 1999). Weil (1961, 1970, 1971, 1977, 1978) published widely on the impact of neuropsychological differences and deficits not only on learning but on psychological development and personality organization as well. She argued that the rate and timing of ego maturation affected the development of the psychic structure as well as concepts about objects and the self. Likewise, Watt (1990) developed the connections between neuropsychological and psychoanalytic notions arguing that psychoanalytic concepts about affect, thoughts and behaviors are built upon an understanding of basic brain characteristics and functions. Building on this trend, Rothstein and her colleagues (1988, 1992, 1998, 1999) asserted that neuropsychological impediments must be considered together with psychic conflicts and emphasized the innumerable manifestations coming from the interaction between neuropsychological characteristics and unconscious fantasies, wishes, defenses and the superego. Recent contributions have dispensed with the idea that neuropsychological dysfunction is caused by psychological conflict, but argue that it does indeed become incorporated into fantasy (e.g., Coen, 1986; Cohen, 1985, 1993; Pine, 1991, 1994; Rothstein, 1992, 1998).

A number of psychoanalytic clinicians have written extensive case studies based on treatments with child and adult patients with learning disabilities (e.g., Bucholz, 1987; Garber, 1991; Gensler, 1993; Herman & Lane, 1995; Kafka, 1984; Migden, 1990; Myers, 1989; 1994; Palombo, 1995; Rubovitz-Seitz, 1988; Schwaber, 1992). Importantly, these formulations emanate from work with clinical populations of people with learning

disabilities, and the intrapsychic and behavioral phenomena described are largely interpreted through the lens of psychopathology. Thus, these formulations are limited by virtue of their relatively exclusive focus on pathology rather than health or adaptation. Nonetheless, these rich case studies illuminate potential psychodynamic manifestations of learning disabilities and shed light on trends in personality organization and characteristics of some patients with learning disabilities. Specifically, these clinical case studies point to a lack of self-cohesion (Silbar & Palombo, 1991) and unstable sense of self (Garber, 1991); compromised object constancy which affects object relations and self systems (Archowitz, 2000; Bucholz, 1987); problems with separation-individuation (Archowitz, 2000; Herman & Lane, 1995); narcissistic traits including rage in the face of narcissistic deprivation (Moore, 1995); vulnerability to narcissistic psychopathology linked to the effects of parents' narcissistic injuries (Garber, 1991; Shane, 1984); conflicts with dependency (Gensler, 1993); low self-esteem, self-defeating tendencies, and struggles with compensatory grandiosity (Migden, 1990); a sense of humiliation (Myers, 1989); and elaborate fantasies of defect and damage (Coen, 1986; Garber, 1991) which contribute to separation and castration anxiety (Kafka, 1984).

Psychoanalytic writers have likewise considered the range of ways learning disabilities may influence the social, emotional and behavioral qualities of people with LDs. Garber (1988, 1989, 1991, 1992) has written extensively on the impact of LDs on the development of empathy, and suggested that the absence of certain "cognitive integrative skills" coupled with a preoccupation with their own well-being were at the heart of deficits in empathy for people with LDs (Garber, 1989, p. 633). Palombo (1995, 2001) wrote about the difficulties people with non-verbal LDs have in interpreting

nonverbal and affective communication, and Gabbard (1990) noted the general difficulties in social relatedness among people with LDs. Related to these findings, Garber (1992) noted the loneliness and lack of peer acceptance experienced by many adolescents with LDs, and connected these experiences to deficits in perceiving social signals. Difficulties with the regulation of self-esteem rooted in a sense of defect and a pervasive sense of incompetence have been noted, and influence the social, emotional and behavioral qualities of the person with LD (Aleksandrowicz & Aleksandrowicz, 1987; Burka, 1983; Garber, 1988, 1989, 1991, 1992; Heisler, 1983; Lewis, 1986; Shane, 1984). Garber (1991) found that children with learning disabilities are highly dependent upon others' perceptions, exhibit a labile emotional state and are highly reactive to and dependent upon the environment. Migden (2002) observed that the language deficits of many children with ADHD contribute to difficulties with using language to express thoughts and emotions, and underlies a tendency to, instead, engage through action and respond impulsively.

These theoretical formulations regarding the psychological and psychodynamic contributions and impacts of learning disabilities may resonate in the experiences of some families with people with learning disabilities. However, although these complex and often problematic psychological, social, emotional, and behavioral qualities and dynamics *may* manifest in children and adults with learning disabilities, they also *may not*. There are innumerable variables that impact the psychological development of people with learning disabilities, not the least of which is the quality of parental and school response. This study has the potential to produce findings that confirm, extend or perhaps contradict the psychoanalytic formulations noted in the literature.

### **Becoming a Parent**

The wish to become a successful parent<sup>2</sup> to a thriving child is arguably a common human desire. The massive psychological and, in the case of the mother, physiological transformations, themselves intricately colored by familial, historical, and socio-cultural elements, powerfully impact the processes of pregnancy, childbirth, and parenthood. Indeed, parenthood becomes a fundamental aspect of the parent's personality, mutually shaping and being shaped by the qualities of the person who becomes a parent (Schwartz, 1984).

Against the backdrop of major psychoanalytic ideas in parental development, the particular intrapsychic experience of a parent with a child with a learning disability may be more fully investigated and analyzed. Thus, in this section, theoretical perspectives on parenthood including major contributions from classical libido theory, Winnicott, self psychology, and ideas emanating from attachment theory and research will be reviewed. These theoretical contributions, while presenting conceptualizations of parenthood from different points of view, each in their own way speak to the reciprocal nature of the psychological development of parent and child, the powerful influence of identification and empathy, and the ubiquity of fantasy. The aim of this extensive review of the

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<sup>2</sup> The words "parent" and "parents" will be used when the content of the sentence is judged to be appropriate for both male and female parents. The word "mother" will be used when the particular issues discussed apply solely to female-bodied parents (i.e., pregnancy) and/or when the literature cited is limited to documenting theories about the particular experience of the "mother" of a child. Pronoun use will be somewhat more flexible, with efforts at trying to include and alternate between both male and female pronouns whenever possible, except when the literature reviewed refers solely to male or female parents, or in the case of experiences that are limited to female-bodied parents (i.e., pregnancy).

psychoanalytic literature on parent development is to develop a theoretical context within which to apprehend both the normative and unique developmental experiences for LD and non-LD parents of children with learning disabilities. To this end, this section will conclude with a presentation of the potential connections that may be drawn between the major ideas coming from this literature and the current study.

### **Perspectives from Classical Theory**

Pregnancy ushers in not only considerable physiological changes but also significant and sweeping psychological changes (Bibring, 1959; Bibring, Dwyer, Huntington, & Valenstein, 1961; Deutsch, 1945). Bibring (1959) linked the psychological experience of pregnancy to other developmental transformations such as puberty and menopause, and viewed pregnancy as a “maturational crisis” characterized by disequilibrium in the personality resulting in a reorganization of the sense of self and identity. During this developmental upheaval (Lester & Notman, 1988), conflicts from earlier developmental periods are reignited, regression to the oral phase is common and supports the mother’s identification with the child, and previously repressed fantasies are activated (Bibring, 1959; Kris & Provence, 1955; Pines, 1972; 1982). Common themes characterize the conflicts and fantasies that attend pregnancy and persist in motherhood including ambivalence, overidentification, regression, hostility and fears of separation (Bibring, 1959; Brazelton & Cramer, 1990; Deutsch, 1945; Kris & Provence, 1955; Lester & Notman, 1988; Trad, 1990, 1991). These feelings are linked to the multiple and simultaneous changes and feared changes that occur with pregnancy and subsequent parenthood: the loss of a particular bond to one’s partner, the need to change work

routines or professional identity, the shift in bodily appearance, fears of parenthood and questions about one's capacity to weather the all-consuming demands inherent in caring for and raising a child (Brazelton & Cramer, 1990; Trad, 1990). A parent's flexibility in the face of the enormous transformations during pregnancy and in parenthood coupled with her capacity to symbolically represent, discharge or repress her ambivalence, regression, separation and hostility supports her ability to successfully parent her child (Trad, 1990).

As a pregnancy progresses, the once "foreign body" becomes an integral part of the mother, fulfilling a desire for "fusion and oneness with another" and creating the ideal space for developing the "fantasy of symbiosis" linking mother with child as well as with her own mother (Bibring et al., 1961; Brazelton and Cramer, 1990). As the mother begins to feel the fetus move, this merger shifts and the fetus becomes for the mother a new object within the self (Bibring, 1959; Brazelton & Cramer, 1990). With the arrival of the latter phases of pregnancy, the mother begins to prepare for the physiological and psychological experience of anatomical separation, but "the child will always remain part of herself, and at the same time will always have to remain an object that is part of the outside world and part of her sexual mate" (Bibring et al., 1961, p. 16).

Therese Benedek's (1959) seminal paper elaborated a classical drive theory of parenthood. In this paper, Benedek introduced parenting as a developmental phase, positing that personality organization continues well beyond adolescence, and that reproduction and parenthood represent significant "drive motivations for further development" (p. 389). Later, Benedek revised her notion of parenting as a developmental phase, instead endorsing the idea of parenting as a developmental process

(Schwartz, 1984, citing Parens, 1975). This distinction, seemingly minor, reflects the notion that while “phase” signifies the development of new psychic structures within a classical theoretical context, “process” does not (Cohen et al., 1984). That is, rather than producing new psychic structures within the adult, parenthood encourages the continued development of existing psychic structures (Schwartz, 1984). Regardless, Benedek’s contribution to a classical libido and conflict theory of parenting influenced countless theorists that followed and remains a valuable perspective through which to understand the intrapsychic experience of parents.

Central to Benedek’s (1959) ideas about parenthood was the notion that the experience of parenting awakens the parent’s past—her unresolved conflicts, her memories of her relationships to her own parents, her unrealized ambitions, her experience in her own infancy and childhood. As the mother is consciously and unconsciously reminded of her own infancy, she “relives with her infant the pleasure and pains of infancy” (Benedek, 1959, p. 395). A parent’s experience of having been an infant coupled with her experience of receiving from her own parents strongly affects her ability to receive from and give to her child in the present (Benedek, 1959). “Her giving, her patience and motherliness are derived from the developmental vicissitudes of primary identifications with her mother” (Benedek, 1959, p. 395). And, the balance of gratification and frustration the parent experiences while parenting her child directly influences the positive and negative aspects of her identification with her child. According to this model of parenthood, the mother’s frustrations with parenting harken back to her own early frustrations with the “bad” mother (Farjardo, 1987).

Beyond infancy, indeed, in each crucial period of the child's development, the parent relives his or her related developmental conflicts (Benedek, 1959; Schwartz, 1984). Ideally, parenting provides the opportunity for parents to rework and possibly resolve these conflicts across past phases of development (Benedek, 1959; Schwartz, 1984). The parent's personality is further developed not only through the awakening of her related developmental conflicts, but also through the satisfactory resolution of these conflicts (Benedek, 1959; Schwartz, 1984). While a favorable outcome results in a new level of integration in the parent's personality, failure to work through the conflict may manifest pathologically (Benedek, 1959). Schwartz (1984) writes, "Where there has been a pathological resolution for the parent, the effect of the child's experience will be to intensify these conflicts with inappropriate interactions by the parent in response to the child" (p. 366). That is, where conflict remains active and unresolved and regression cannot be overcome, a parent may be less able to view the child as a separate entity, operating in a manner akin to the mode of "psychic equivalence" (Fonagy & Target, 1996) and fail to effectively meet the child's needs.

Just as the parent's ongoing development is affected by the experience of parenthood, the child's psychological development is, in turn, affected by the parental response in general and to this reawakening of past conflicts. In this way, the child and parent mutually influence one another's ego development (Benedek, 1959). A parent's ability or inability to satisfy her infant's needs has tremendous effect on both participants as the child's response to the parent's efforts affirms or casts doubt on whether the parent is a good parent. Benedek (1959) writes, "The mother's gratification in satisfying her infant's needs as well as her frustration when she is unable to do so affect her emotional

life and again reciprocally that of the child” (p. 392). Benedek refers to this “spiral of interpersonal processes” as “emotional symbiosis” understood as the “reciprocal interaction between mother and child which, through the process of ‘introjection-identification,’ creates structural change in each of the participants” (p. 392). Through the positive experience of reciprocal gratification, both infants and mothers gain confidence. With this, the mother introjects “good-thriving-infant = good-mother-self” and subsequently integrates these new, positive experiences of self into her personality, further fueling her confidence as a parent (Benedek, 1959, p. 393). Likewise, the infant introjects “good mother,” powerfully transforming this introject into “good self.”

An essential aspect of classical psychoanalytic theory related to parenting is identification—the psychological process in which a person integrates traits, behaviors or qualities of the mind of another into the self (Sadow, 1984). The decision to become a parent is deeply influenced by the range of conscious and unconscious identifications parents have with their own parents (Sadow, 1984; Schwartz, 1984). The effect of intergenerational identifications is powerful. As Terman (1984) writes, “When the parent is confronted by the needs and affects of the child, he/she will process, understand, and react to them, in part, as his/her own parent had responded to similarly expressed needs and affects. Those grandparental responses are as much a part of the parent as the individual’s own creation” (p. 332). These identifications are intertwined with the identifications the parents feel with the child, the child’s phase of development, and the distinct successes, disappointments, and “failures” within the developmental phase for that particular child (Schwartz, 1984). The interactions between parent and child come to reflect the tenor of these identifications, themselves influenced by the family, parenting

partner, siblings, and the sociocultural context in which the child is being raised (Schwartz, 1984). While many of the identifications the parent feels to the child and the child's developmental phase serve to fuel an empathic connection to the child, the parent must work to keep the child's separateness and individualism in mind. Schwartz (1984) citing Kestenberg (1975) writes, "A twofold task of parenthood is the management of a balance between the parent's identification with the child which tends to blur the distinction between the psychic representations of the parent and child on one hand, and on the other to maintain a representation of the child as separate and individualistic" (p. 362).

Freud (1914) wrote, "Parental love, which is so moving and at bottom so childish, is nothing but the parents' narcissism born again...transformed into object-love," (p. 91). The affection shown by parents to their children is evidence of the "revival and reproduction" of the parents' own long forsaken narcissism (p. 90-91). Freud argued that, as a result, parents are inclined to elevate the child to perfection while masking or overlooking all of the child's inadequacies. In this narcissistic reverie, the child shall come to realize all the parents' unattained ambitions and dreams (Freud, 1914). Benedek (1959) echoed Freud's notions, writing, "That which the fond parent projects ahead of him as his ideal in the child is merely a substitute for the lost narcissism of childhood" (p. 399-400). The parent, then, employing projection, fantasy and idealization, comes to "use" the child not only for narcissistic fulfillment, but for "his hope and expectation of self-realization," for development of the self (Benedek, 1959, p. 400). Not only do parents project onto their child their hopes and ambitions, but they also confront the projection of their conflicts (Benedek, 1959). Benedek (1959) writes, "The

child...represents hope and promise for self-realization and at the same time he forewarns that he may expose not one's virtues but one's faults" (p. 415). Each parent then must contend with "the positive as well as the negative revelations of the self in the child" (Benedek, 1959, p. 405). It is through these "unconscious processes of reciprocal introjections and identifications" that parents and children mutually influence each other's development through (Benedek, 1959, p. 400). And, as the parent navigates positive and negative introjects and identifications and gains confidence in her capacity to care for the child, her self-esteem strengthens, leading to the emergence of a new source of secondary narcissism and self-assurance (Benedek, 1959).

The fantasies produced during pregnancy and parenthood serve as essential fuel for the transformation of parental narcissism, establish the parent's first attachment to the unborn child, and support the parents' ability to devote considerable amounts of energy and time to achieve and carry out the complex and demanding role of parenthood (Brazelton & Cramer, 1990; Hugger, 2009; Trad, 1990). A ubiquitous and normal part of the process of parenthood, these fantasies often begin before conception, heighten during pregnancy, and transform throughout the developmental process of parenthood (Brazelton & Cramer, 1990; Trad, 1990). Further, these fantasies are linked to deeply rooted, narcissistically driven motivations and desires to have a child: the wish to achieve one's ideals, to experience a sense of completeness and omnipotence, to see oneself mirrored in another, to fulfill lost opportunities, and to recreate old ties while simultaneously experiencing a more complete separation from one's own parents (Brazelton & Cramer, 1990). Past fears and conflicts are also captured in fantasies (Chessick, 1988; Sherwen, 1981; Trad, 1990). Fantasies have the potential to provide a

space for the resolution of these fears and conflicts, and may support the parent as she works to manage the common anxieties regarding separation that attend pregnancy and parenthood. When this potential is realized, the chance of developing a secure and flexible bond to the child is increased (Lester & Notman, 1988; Trad, 1990).

### **Contributions from Winnicott**

Winnicott's focus on the relationship between the infant and mother, and the kind of maternal care that facilitates or derails healthy development in the infant added an important perspective to psychoanalytic thinking about parenthood. His notion that there is "no such thing as an infant" highlights his focus on the essential role of maternal care within a responsive environment. According to Winnicott, it is through the intricate relationship between the infant and maternal care within a "holding environment" that the infant emerges. Winnicott (1960a) wrote, "... the infant and the maternal care, disentangle and dissociate themselves in health; and health, which means so many things, to some extent means a disentanglement of maternal care from something which we then call the infant or the beginnings of a growing child" (p. 587). Indeed, the infant's emerging psychic structure is built on the manner in which maternal care offers ego-support, enabling "the infant to live and develop in spite of his being not able to control, or to feel responsible for, what is good and bad in the environment" (1960a, p. 586). Maternal empathy in the face of the infant's dependence creates a "reliable" environment that sufficiently provides for the physiological and psychological needs of the infant. Within this "holding environment," the infant, in his dependent state, is ideally protected and cared for in ways that are adapted to his particular needs—the responsive mother is

there when she is needed, and retreats when unneeded. This adaptation by the caregiver allows the infant to have the “illusion” that what he creates really exists; that, for instance, the breast is a part of the infant, and comes into being under the “subjective omnipotence” of the infant. The mother’s state of “primary maternal preoccupation” allows for this illusion.

Winnicott conceptualized the parent-infant relationship in two parts. The first concerns the infant’s journey from dependence to independence, from pleasure principle to reality principle, and from autoeroticism to object relations. About this journey, Winnicott (1971) wrote, “There is no possibility whatever for an infant to proceed from the pleasure principle to the reality principle or towards and beyond primary identification, unless there is a good-enough mother” (p. 13). And so, the second part of the parent-infant relationship focuses on the shifts in the mother, in her ability to orient herself to the particular needs of the developing infant for whom she cares, to allow for separation and independence in the growing infant, to be the “good-enough mother.” Winnicott illuminated the effect of the identification the mother feels to the baby, noting that through identification, she is able to imagine what the infant feels like, and what the infant needs in terms of “holding” and environment. The infant’s development depends on “good-enough” maternal care and in cases where the care is insufficient to the infants’ needs development is negatively altered.

Winnicott (1971) notes that the good-enough mother repeatedly and effectively “meets” and makes sense of the omnipotence of the infant. From this experience with the good-enough mother, a True Self capable of feeling real, creative, and alive emerges in the infant. While at the beginning of the infant’s life, the exactness of the mother’s

adaptation matters more acutely, as the infant grows, he comes to benefit from the experience of frustration “since incomplete adaptation to need makes objects real” (p. 14). This shift, and the infant’s ability to tolerate this shift, is a result of the affirmations he has received and emblematic of his growing sense of process, beginning mental activity, and his ability to remember (Winnicott, 1971). The infant begins to recognize that he is not omnipotent and gains a gradual awareness of the existence of many subjectivities, not simply his own. As the infant begins to recognize the illusion of his omnipotence, he is able to allow it to slowly dissolve and tolerate the intermingling of external reality with his rich capacity for play and imagination. The child’s recognition of the illusory nature of his omnipotence is a product of the development of the True Self and the basis for the development of a symbolic capacity in the child.

About the False Self, Winnicott (1960b) wrote, “Whereas the True Self feels real, the existence of a False Self results in a feeling unreal or a sense of futility” (p. 148). The False Self is a product of the parent’s failure to accurately and repeatedly grasp and meet the child’s needs. Instead, the child must comply with the parent’s reality, and this compliance forms the beginning of the development of False Self in the child.

### **Perspectives from Self Psychology**

Rather than emphasizing conflict or biological instinct, self psychological perspectives offer a different view of parenthood. Kohut (1977) proposed that the healthy adult continuously seeks opportunities to affirm and consolidate the total self, and parenthood can be viewed as one such opportunity. Indeed, for some a primary purpose of parenthood is to gain a sense of self-completeness (Sadow, 1984). The reciprocal

relationship with the child provides the parent with the needed social environment and “selfobjects” within which to engage mirroring and idealizing functions (Farjardo, 1987). As the child comes to serve as a “selfobject” for the parent, the parent engages in processes that lead to a more complete and cohesive sense of self.

Kohut’s perspective on the nature and development of narcissism influenced ideas regarding parental narcissism. Elson (1984) provided a comprehensive account of the transformation of narcissism during parenthood from a self psychological perspective. Contrasting classical and self perspectives on parental narcissism, Elson wrote, “Unlike Freud (1914), Behrens (1954), and Benedek (1959), who viewed the attitude of fond parents toward their children as a revival and reproduction of their own long since abandoned narcissism, Kohut would view it as a reactivation through empathy of that grandiosity which fuels our ambitions, permitting a further transformation of narcissism” (p. 299). Thus, parenthood provides an impetus for the development of mature and adaptive forms of narcissism including increased empathy for the needs of the child, increased wisdom and creativity, and the capacity to view the child as a separate “center of perception and initiative” (Elson, 1984, p. 298). As expectant parents imagine their unborn child, they experience a heightening and transformation of parental narcissism coupled with a growing vulnerability to narcissistic injury (Elson, 1984). Positively perceived characteristics of each parent are “externalized and reinternalized in fantasies of the unborn child” (Elson, 1984, p. 300). Qualities of the self and parenting partner that are negatively viewed are likewise analyzed and are either accepted or sometimes defiantly defended (Elson, 1984).

Mature narcissism grows from a parent's ability to create powerful fantasies about her child, to support her child in accepting mild frustration, and to mirror, affirm and contain her growing child (Elson, 1984). In turn, the interactions between parent and infant support the development of narcissism in the child as the caretaking functions of the parent (selfobject) are transformed into the child's psychic structure (self) (Elson, 1984). As parents offer themselves to the child as antecedents of psychic structure, the child's psychological development is supported. This offering affords parents the opportunity to reconcile or at least manage their own deficits with greater effectiveness (Elson, 1984). Thus, in this "double helix" of reciprocal influence, Elson argued that the developmental *task* of parenthood is the growth of narcissism in the child, while the developmental *process* of parenthood is the transformation of narcissism in the parent.

The child's unique response to the parent's care has the effect of furthering the development of the parent's narcissism, which "quickens, deepens, and expands to include empathic responsiveness to the child's needs" (Elson, 1984, p. 298). Elson (1984) argued that while parents may experience a reawakening of past conflicts and deficits in development through their child, more mature forms of narcissism in the parent allow for an empathic response to the child, unfettered by the parent's own conflicts. Minor breaks in empathy are to be expected, and support the child in developing a capacity to tolerate frustration and anxiety contributing to the development of a "cohesive nuclear self" (Elson, 1984, p. 301). Failures in parental narcissism, so-called "pathological" parental narcissism, may lead the parent to "merge" with the child long after the child requires this merger, derailing not only the development of mature narcissism in the parent, but also healthy narcissism in the child.

### **Perspectives from Attachment Theory and Research**

The evolving research rooted in attachment theory highlights the importance of the quality of relationships between children and their parents, the significance of nonverbal experience, and the relevance of the parents' capacity for attunement, regulation of affect, reflective function and metacognition. These contributions resonate in the context of considering the experience of a parent of a child with a learning disability.

A primary premise of attachment theory is that human beings have a psychobiological motivation borne of evolutionary necessity to formulate strong and enduring attachments to primary caregivers (Bowlby, 1969/1982; Bretherton, 1995). Humans possess an instinctively guided response to threat and insecurity and, as such, are motivated to seek out that which is familiar, maintain proximity to the familiar, and use the familiar as a "secure base" (Ainsworth) to which they might return to refuel, experience pleasure and connection, or seek protection in moments of uncertainty, danger or alarm (Ainsworth, 1989; Bowlby, 1969/1982; Bretherton, 1995; Wallin, 2007). As a biologically based phenomenon, attachment is universal, "despite difference attributable to genetic constitution, cultural influences, and individual experience" (Ainsworth, 1989, p. 709). Patterns of attachment are enduring and continuous; indeed much evidence points to the intergenerational transmission of attachments (Slade and Aber, 1992; van IJzendoorn, 1995).

Ainsworth's major contributions to attachment theory included the notion of malleability in these biologically based attachment relationships (Wallin, 2007). That is, the quality of the infant's attachment is highly dependent upon and influenced by the

behaviors of the parents in the infant's life (Wallin, 2007) as well as the "goodness of fit" (Thomas & Chess, 1977) between the infant's disposition and needs and the offerings of the parents. According to Ainsworth and her colleagues (1978), the security or insecurity of the attachment relationship is determined by the patterns and qualities of non-verbal communication between infant and parent. Given this, Ainsworth's notion of "secure base" grew to encompass not only issues of proximity, but also the child's expectations of the caregiver borne out of repeated communicative experiences with the attachment figure (Wallin, 2007). The quality of this non-verbal communication is key and under the best circumstance, the highly attuned parent's response is both collaborative and contingent upon the infant's state and needs (Ainsworth, 1978). Main and her colleagues (1995) came to find that whereas the parents of secure infants were more highly attuned to the infant's needs and responded in a manner that was contingent, parents of insecurely attached infants were either emotionally and physically unavailable or they were inconsistent and unpredictable in their capacity to respond to their infant. In the worst cases, children whose attachment was disorganized had parents who were frightening, frightened or dissociated (Main & Solomon, 1990).

Following on the notion that a parent's attachment status intimately influences the nature of the attachment that parent will have to his or her child, Main developed the Adult Attachment Inventory (AAI), a semi-clinical interview designed to "prime" the attachment system thus allowing it to be studied (Wallin, 2007). The AAI achieves this aim by asking parents questions about the history of their relationships with their own parents, including painful experiences of loss, rejection and separation, and then assesses the parent's state of mind with regard to attachment (George, Kaplan, & Main, 1984,

1985, 1996; Slade, 2000). Indeed, Main and her colleagues (1985) found that the parents' coherent or incoherent mode of discourse as seen on the AAI strikingly corresponded to the infant's non-verbal behavior during the Strange Situation as well as to the six-year-old child's attachment representations, collected during a separate study. Secure infants had parents who could construct coherent narratives in response to the emotionally charged questions on the AAI. In contrast, insecure infants had parents whose discourse was incoherent, either because of the parent's tendency to minimize and dismiss the importance of attachment relationships or as a result of the parent's preoccupation with the way in which their past relationships invaded their current relationships.

From these findings, Main was able to extend Bowlby's concept of "internal working models," understood as schemata of the self, attachment figures, and the environment constructed from regular, repeated experiences with primary others (Wallin, 2007). The research allowed Main to firmly establish the connection between attachment behaviors and these internal representations. Thus, a parent's internal working models—representations based on the quality of his or her attachment relationships—have tremendous impact on the formation of the child's working models. In turn, these working models affect the infant's thoughts, feelings, and actions throughout her life.

Fonagy, Steele and Steele (1991a) built on Main's findings, and combined with ideas from "theory of mind," emphasized the significance of an adult's capacity to attend to and understand not only the contents of his mind, but also the mental states of others. This notion, termed mentalization, grew from a person's capacity for what Fonagy and his colleagues termed reflective function. Strong mentalizing abilities are evidenced by

not only an awareness of mental states, but also a sense that mental states lay beneath surface behaviors (Wallin, 2007). This finding has tremendous relevance to parenting. In a large-scale study utilizing the AAI and Reflective-Functioning Scale developed by Fonagy and his colleagues, they were able to show that parents with a strong reflective capacity—regardless of their history of attachment—were more likely to have secure children. That is, given a parent with a compromised attachment history, reflective function proved to be an ameliorative factor—indeed, it was viewed as the key to breaking the cycle of intergenerational transmission of insecure attachment (Fonagy et al., 1991b; Fonagy et al., 1995; Fonagy, 2001).

Fonagy and his colleagues (1995; 2002) came to view affect regulation as an essential ingredient in the formation of a secure attachment and the development of a reflective mode of experience. Indeed, the attachment relationship between the infant and parent(s) is secured through—among other elements—regulation of affect, and it is this experience that sets the stage for the “dyadic regulation of emotion” (Carlson & Sroufe, 1995, p. 584). Drawing from Bion’s (1962) notion that the mother is instrumental in shaping and containing the emotional experiences that the infant is unable to handle on his own, Fonagy (2002) explained that infants experience a sense of “felt security” (Sroufe & Waters, 1977) as their parents modulate and contain the overwhelming affects the infant feels. Further, Fonagy and his colleagues (1995) contended that the parents’ effective use of affective communication and corresponding physical care demonstrates to the child that they understand and can cope with the distress the child is feeling, and further, that they appreciate their child’s burgeoning intentional stance (Dennett, 1987). This final feature of containment is emblematic of the

parents' ability to view the child as a separate person, is vital to the formation of a secure attachment and undergirds the emergence of a mentalizing capacity in the child (Fonagy et al., 1995; 2002).

Infants need parents who can provide sufficient affect attunement, a particular form of intersubjectivity that involves mirroring or echoing the subjective feeling state of the infant (Stern, 1985). Fonagy and his colleagues (2002) emphasized the importance of contingent and marked affect mirroring between parent and infant. Namely, affect mirroring is most effective when it corresponds to the child's affect and when the parent's mirroring is experienced as an exaggerated reflection of, rather than identical to, the child's affective experience. Parental affect mirroring is an essential ingredient in developing the child's understanding of self-states, and a precursor to the emergence of a reflective capacity in the child (Fonagy et al., 2002; Slade, 2005). That is, a child's capacity to develop a reflective function grows out of her experience of her parent's mentalizing capacity. When a parent is attuned and able to apprehend her child's feelings, desires and intentions, the child begins to learn about her own internal experience, have a sense of her own subjectivity as distinct and meaningful, gain knowledge of her own affectivity, and learn that her mental states can be recognized and shared (Fonagy et al., 2002; Stern, 1985; Slade, 2005).

Related to affect attunement are experiences of mutual regulation and interactive repair between parent and infant. The parent's ability to effectively "read" the infant's communicative attempts in order to apprehend the infant's needs and respond with appropriate action is vital to the regulation of every system in the infant (Tronick & Weinberg, 1997) and is intimately linked to the parent's attachment history and

metacognitive and reflective capacities. During these regulatory attempts, the parent and infant move in and out of coordinated states and, when mis-coordinated, mutually engage in “interactive repair” (Tronick & Weinberg, 1997, p. 63). Importantly, these moments of repair contribute to the building of a “positive affective core” in the infant (Tronick & Weinberg, 1997, p. 65, citing Emde, Kligman, Reich, & Wade, 1978; Gianino & Tronick, 1988). Repeated experiences of mutual regulation and interactive repair help the infant to build a representation of herself as “effective,” her interactions as “positive and reparable,” and her caretaker as someone to trust and on whom to rely (Tronick & Weinberg, 1997, p. 65-66). These representations result in a coherent, continuous, and agentic sense of self and set the stage for stable and secure relationships (Tronick & Weinberg, 1997, citing Tronick, 1980; Tronick, Cohn, & Shea, 1986). These experiences of interactive repair are crucial. Over time, repeated failure to repair causes the infant to retreat and withdraw from engagement with the other, essentially isolating herself.

While ideal, there are situations in which parent is unable to engage in mutual regulation, struggles to be attuned to the child’s affective experience and exhibits poor reflective capacities. This has significant consequences for the child’s well-being. Inaccurate mentalizing on the part of the parent is a threat to the child’s psychological self (Fonagy et al., 1992). When feeling states are not attuned to, the infant experiences these states in isolation, outside of a comprehensible, intersubjective space (Stern, 1985). Without a caregiver who is able to reflect and respond accurately to the child’s mental state, the child is left to resort to primitive strategies, such as aggression or avoidance (Fonagy et al., 1992). This absence of a person who is able to form consistent and benign representations of and for the child results in a fragile representation of mental life in the

child (Fonagy et al., 1992). Ordinary frustrations experienced by the child are more likely to be felt as potentially destructive and produce intolerable anxiety in the child (Fonagy et al., 1992). The child responds defensively through aggressive acts that cannot be sustained as long-term solutions and ultimately lead to a “pathological fusion of the self structure and the defense (aggression)” (Fonagy et al., 1992, p. 274).

Tronick & Weinberg’s (1997) study of depressed mothers and their infants offers important insight into how the psychological health of a parent has tremendous effects on the developing child. Maternal depression interferes with the ability to engage in mutual regulatory processes and results in an intersubjective impasse (Tronick & Weinberg, 1997). Depressed mothers may be either overly intrusive or withdrawn during interactions with their infant, both of which carry negative consequences for the infant (Tronick & Weinberg, 1997). Infants with caregivers who are depressed and withdrawn tend to initially protest and exhibit distress, but with chronic exposure to maternal withdrawal, these infants become similarly disengaged, and enter into a preemptive and premature self-directed regulatory style (Tronick & Weinberg, 1997). The result is the development of a “negative affective core primarily characterized by sadness and anger” (p. 68). Parental unresponsiveness or inappropriate parenting characteristic of depressed parents dysregulates the infant and contributes to difficulty in social development, increased anger, decreased enjoyment and the development of a sense of helplessness or hopelessness in the infant (Tronick & Weinberg, 1997).

### **Summary of Section and Connections to Current Study**

The psychoanalytic literature on parenthood paints a rich and complex picture of the processes involved in parenthood and provides an important backdrop against which to understand the experiences of LD and non-LD parents of children with learning disabilities. Parenthood is thought to reawaken the parents' past conflicts, ignite fantasies as well as deep fears, and produce strong identifications in parents with their child as well as their own parents. These conflicts, fantasies and identifications both fuel and are fueled by the way the child comes to represent the self of the parent. Moreover, these conflicts, fantasies and identifications increase the empathy a parent feels in the face of the vulnerable young child, in turn, helping the parent weather the many demands of parenting, including parenting a child with a learning disability. For LD and non-LD parents who have a child with a learning disability, these conflicts, fantasies, and identifications along with the empathy that emerges in the context of being a parent are likely shaped in unique ways, influenced by the presence of their child's learning disability.

Because of the deep investments and identifications parents experience, parenthood contributes to a transformation of narcissism, holding the potential for more mature forms of narcissism to emerge while simultaneously increasing the parents' vulnerability to narcissistic injury. This formulation holds particular resonance for LD and non-LD parents of children with learning disabilities, who, by virtue of their child's diagnosis, are generally though not always, even more vulnerable to narcissistic injury. Moreover, for these parents the development of mature forms of narcissism documented in the literature is arguably even more crucial than for a parent of a typically developing child as the parental demands these parents face generally are greater.

The reciprocal influence parents and children have on one another's psychological growth is linked to the explicit and implicit responses each offer to the other. How might these explicit and implicit responses vary for children with learning disabilities, and in what ways does this in turn influence the parents' explicit and implicit responses to their children? Further, how might these differences positively and negatively shift the nature of the reciprocal psychological development in these parent and child dyads?

Children with and without learning disabilities benefit in a multitude of ways from having "good enough" parents. They need empathic parents who are sufficiently attuned and able to flexibly respond to their needs, desires and the qualities of their developmental phase as well as developmental variations. They need parents who are capable of supporting them in regulating their affects, and able to engage in reflective and metacognitive processes as well as mutual regulation and interactive repair. While universal claims may be made about what constitutes "good enough," it seems reasonable to speculate that as they work to fulfill these essential aspects of being "good enough," parents of children with learning disabilities must employ unique, creative, and flexible approaches that correspond to the particular needs of their child.

### **Becoming the Parent of a Child with a Disability**

As detailed above, the anticipation of a baby ignites in the parent significant intrapsychic transformations, including shifts in narcissism, the creation of rich and elaborate fantasies alongside potent fears of something going wrong (e.g., Lax, 1972; Solnit & Stark, 1961) and the development of strong identifications to the fetus as well as to one's own parents. With the birth of the child, indeed throughout each phase of the

child's development, the parent must negotiate the inevitable distance between the actual child and the idealized child of the parent's fantasies and repeatedly contend with the realities of the child (e.g., Abrams & Kaslow, 1976; Solnit & Stark, 1961). Citing Condon and Dunn (1988), Trad (1990) writes, "...parents who have invested considerable energy in the representation of a fantasy baby, who personifies the ideal child, may face, in the presence of the neonate, the loss of that imagined and already loved child" (p. 355). In the face of this loss, some parents may experience a sense of disillusionment, enter a period of mourning and regression, and suffer narcissistic injury as they confront the objective reality of the child (Farjardo, 1987; Hugger, 1990; Trad, 1990). In these cases, which are not characteristic of all parental experience, these parents require time to grieve the lost fantasy, resolve the discrepancies and adapt to the reality, and engage a process of separation that will be repeated with every developmental milestone (Abrams & Kaslow, 1976; Trad, 1990).

While these experiences represent a normative process for many parents, for parents of children with disabilities, the process is distinguished by its *intensity* (Farjardo, 1987) and may, in fact, be experienced as a kind of psychic trauma (Abrams & Kaslow, 1976; Als & Brazelton, 1984; Solnit & Stark, 1961). In her deeply moving personal account of being the parent of a daughter diagnosed with autism, Crown (2009) writes, "Just becoming a parent is a profoundly challenging and transformative experience. But absorbing the blow that your child has a disability can be disorganizing, shattering, and devastating" (p. 70). Parents may experience anger, shock, denial, confusion over the cause, guilt, self-blame, isolation, and intense feelings of being cut off from the "normal" world (Abrams & Kaslow, 1976; Crown, 2009; Heiman, 2002). Alternatively or in

addition, the parent may feel relief in having her worries and fears confirmed (Crown, 2009). In addition to these profound intrapsychic experiences, parents must confront and manage myriad other complex interpersonal, familial, and systemic effects of the learning disability, the experience of which likewise colors the intrapsychic life of the parent. Importantly, while the effects described below are largely negative in tone, the literature also points to, while sparsely documented, the positive effects a disability diagnosis can have on the parents and family of a child with a disability.

In this section, psychoanalytic and learning disabilities literature regarding the intrapsychic, interpersonal, familial, and systemic experiences of parents of children with learning disabilities will be reviewed. Building on the previous section on psychoanalytic theories of parent development in general, this literature, with its explicit focus on parents of children with disabilities, provides an important context within which the current study will reside. The section begins with commentary on the time leading to evaluation, and moves on to consider parents' experience of the evaluation and diagnostic process. Particular intrapsychic aspects of parental experience are reviewed including narcissistic injury and trauma, the impact of the diagnosis on self-esteem, and grief and mourning processes. Other effects of having a child with a learning disability are presented including parental stress and distress as well as the impact on the quality of the relationship between parenting partners. Finally, the positive effects of having a child with learning disability will be discussed. While a number of the ideas presented are conceptualized in relation to the birth of a more profoundly disabled child (e.g., autism spectrum disorders; physical disabilities or disorders; mental retardation, etc.), the themes

that emerge from this literature can be useful in considering the potential impact of learning disability diagnosis in the years after birth.

### **Before Evaluation and Diagnosis**

For some parents, the type and extent of the disability at birth makes diagnosis an immediate and sudden event. For others, particularly those who have children with learning disabilities, the years preceding the diagnosis may be unremarkable as the child's idiosyncratic needs or behaviors are seamlessly integrated into the fabric of the family, leaving the parents with no concrete sense of anything potentially amiss. These parents may react in profound shock or dismay when, upon reaching school age, their child exhibits struggles with academic learning (Seligman & Darling, 2007). Still for other parents, there may be an ongoing, unformulated sense that something is "not quite right," a feeling that is diffuse and difficult to describe (e.g., Crown, 2009; Gensler, 2009). Many parents of children with undiagnosed disabilities, including learning disabilities as well as other more profound disabilities such as autism spectrum disorders, develop this tentative sense when their child fails to meet particular developmental milestones or through comparison to other same-age children (e.g., Gensler, 2009). Often, the already existing yet unarticulated sense of something wrong is compounded in the face of these failures and comparisons resulting in the intensification of feelings of dread and uncertainty (e.g., Crown, 2009). In two parent families, one parent may hold the worry, overemphasizing the child's struggles or catastrophizing in the face of these worries, while the other parent may focus on the "hope that the baby will outgrow the problem" (Gensler, 2009, p. 58). Referring to parents of children with as yet diagnosed

autism spectrum disorders, Crown (2009) writes, “Parents try to hide the initial, vague uneasiness from their minds, and yet it revisits, unbidden, in the middle of the night, or in the wake of a casual comment by a stranger” (p. 72). Eventually, as the evidence mounts, concerns for the child generally eclipse the ambiguity and reticence many parents experience and they turn toward evaluation and diagnosis (e.g., Gensler, 2009).

### **The Experience and Effects of Evaluation and Diagnosis**

Neuropsychological and psychoeducational evaluations coupled with informal and formal observations and interviews by professionals are essential tools as parents seek to gain greater clarity on their child’s development and potential developmental variation. While parents generally believe it is important to prepare for and be involved in the assessment process, many parents have little notion of what is entailed, and struggle to know how to talk with their children or others close to them about these processes (Pentyliuk, 2002). The assessment process can be overwhelming, from the potentially large number of professionals involved (particularly if assessment occurs within the public school system, which most do), to the adversarial and defensive feelings that may arise in the context of meetings with professionals, to managing the deluge of highly technical information delivered in a short amount of time (Pentyliuk, 2002). Many parents find themselves feeling unprepared for these encounters, unable to fully understand and clarify the information presented, overwhelmed and confused by the implications of the findings and recommendations, and frustrated by the limited opportunity to offer their own perspectives on their child and have their perspectives honored and validated by professionals (Pentyliuk, 2002). Given this, parents may walk

away from evaluations with little new understanding of their child's difficulties, doubts about how and if they can better support their child, and concerns over whether recommendations will be carried out in school and other settings (Pentyliuk, 2002).

These negative experiences are due in part to some professionals' failures to effectively, sensitively, and plainly communicate with parents about their child's needs (Kroth, 1987). Indeed, the manner in which the evaluation is conducted by the professional and the tenor in which the diagnosis and recommendations are delivered has a tremendous impact on the parents (e.g., Crown, 2009). Professionals may lose touch with just how profound this experience can be for parents, as "the child the parent loves is still there but has been transformed in her eyes by the diagnosis" (Crown, 2009, p. 74). Several studies have repeatedly found considerable difficulties in the relationships between parents and professionals, and often times there are more negative than positive aspects despite good intentions (e.g., Kroth, 1987; Turnbull, 1983, Waggoner & Wilgosh, 1990). Given just how much time parents of children with LDs spend in consultation with professionals and the importance of this consultation, enhancing these relationships is vital. Specific ways to improve these relationships will be discussed in greater detail in a later section of this chapter. It is hoped that this study will contribute to documenting the ways in which professionals can empathically communicate and collaborate with parents of children with learning disabilities.

Beyond the complexities of the evaluation process and collaboration with professionals, the diagnosis and presence of a learning disability triggers particular patterns and dynamics in the relationship between parent and child (Berman, 1979; Rothstein & Glenn, 1999). Intense feelings of anger, guilt, shame and denial may result

in sadomasochistic dynamics as parents act out toward the child in angry and depressive ways in the face of their child's limitations (Rothstein & Glenn, 1999; Solnit & Stark, 1961). In turn, children may respond "with an amalgam of craving for acceptance, a depressive sense of hopelessness to bring this about, feelings of entitlement to repair these (as well as cognitive) injuries, anger that was [*sic*] libidinized, hatred for their attackers, and a pleasure in being attacked" (Rothstein & Glenn, 1999, p. 34). Parents may compensate for their negative reactions, particularly feelings of guilt, by over-indulging or becoming overprotective of and assiduously devoted to the child (Abrams & Kaslow, 1976; Lax, 1972; Solnit & Stark, 1961). The reality is that a child with a learning disability does have greater needs, and a parent must be more heavily involved in most if not all aspects of her child's daily life. The child's weaknesses make every day living that much harder for the parent, and parents may become tired, anxious and angry in the face of their child's needs and dependency (Abrams and Kaslow, 1976). At times, a parent may view herself as the sole ally in her child's corner, assuming a fused and "self-sacrificial devotion" which interferes with differentiation (Abrams & Kaslow, 1976, p. 36). Parents' heavy involvement in the life of their child with a learning disability often inhibits the child's striving for autonomy and the development of his secondary ego functions (Abrams & Kaslow, 1976). This, in turn, reinforces a higher level of dependency as children cling to "wishes for union with potent grown-ups" (Rothstein & Glenn, 1999, p. 33).

Little has been written about the particular experience of a parent with a learning disability when faced with his or her child's learning disability. While Rothstein and Glenn (1999) offer general ideas about the increased intensity of the effect of a learning

disability in the learning disabled parent's child, they don't elaborate. In his article about the connection between self-esteem and depression in adolescents with LD, Migden (2002) offers some insight into the response fathers with LD have to their child with LD. Migden finds that fathers who react more critically to their child's LD often have LDs themselves, and have struggled to "overcome, deny, and otherwise defend against recognition of their own learning problems" (p. 155). This produces a barrier to being able to tolerate weakness of any sort in themselves and other people, especially their children (Migden, 2002). "When, in adulthood, these men are presented with sons who also have a learning disability, they are reminded of their own failures and narcissistic vulnerabilities" (Migden, 2002, p. 155). These reminders spark feelings of anger and acts of criticism toward the child who reignites the memories of their struggles (Migden, 2002). This dynamic is particularly painful for the child who struggles with significant feelings of inadequacy, especially in relation to the parent (Migden, 2002). The results of this dissertation aim in part to contribute to the understudied phenomena of the impact of a child's LD diagnosis on parents who themselves have LD.

### **Narcissistic Injury and Trauma**

Given the normal narcissistic investments inherent in pregnancy, birth and parenthood, the diagnosis of a disability in one's child can be experienced as an "intrapsychic assault" by parents (Als and Brazelton, 1984, p. 578). The child's failure to fulfill the parents' "narcissistic desires for perfection" delivers a powerful narcissistic blow (Rothstein and Glenn, 1999, p. 33). For parents who give birth to a child with a more dire or obvious disability, the "suddenness" of the narcissistic trauma contributes to

a more immediate and, in some instances, extreme response. In these cases, “established libidinal pathways and attachments are abruptly terminated, and at the same time a demand for new libidinal cathexes is made” (Solnit and Stark, 1961, p. 526). Because most children with learning disabilities are not diagnosed until early elementary school, years after birth, parents of these children may only have had an inchoate sense of their child’s disability, if they sensed it at all (Abrams, 1970). While the threat to parental narcissism and self-esteem is delayed, the experience of loss coupled with the need for immediate action is nonetheless quite real for these parents.

Parental reaction to the birth of a child with a disability varies according to the extent and type of disability, the parents’ past relationships, particularly with their parents and siblings, previous trauma, and the origin of the disability (Solnit & Stark, 1961). The extent of the disability may not correspond predictably to the quality of the parents’ response (Lax, 1972). Rather, the parents’ response is dependent on the extent to which the parent is identified with and symbolically linked to the “defect” of the child. That is, the response rests on the whether the child’s “defect” represents or comes to represent the “defective” self of the parent (Lax, 1972). Als and Brazelton (1984) write, “Given the normal narcissistic investment in a child the infant is usually experienced as an extension of the self, but often as a positive part unless disappointment or deviations from expectations occur” (p. 579). When parents themselves have similar learning disabilities, the intensity of the distress and degree of identification they may experience in relation to their child’s learning disability is generally even more acute (Rothstein & Glenn, 1999).

Typically, parents suffer a loss of self-esteem in the face of the narcissistic trauma that attends the recognition of a disability in their child (Abrams and Kaslow, 1976; Als

& Brazelton, 1984; Elson, 1984). Several writers have highlighted the mother's increased vulnerability to narcissistic injury and loss of self-esteem due to the heightened identification the mother may feel to her baby (Abrams & Kaslow, 1976; Lax, 1972). During pregnancy, the mother came to view the growing fetus as an integral part of herself (Bibring, 1959; Bibring et al., 1961) and thus, her "failure" to produce a child who satisfies her and her partner's narcissistic yearnings results in feelings of worthlessness, helplessness, and inferiority and a reduction in positive self-directed feelings (Abrams & Kaslow, 1976; Lax, 1972). Through the nature of her intense identification with the child, her child's "impairment" comes to stand as her own (Als & Brazelton, 1984; Lax, 1972). In the case of a child suspected of having a learning disability, "The fact that the child exhibits no obvious physical defect but merely appears to be 'slow' or 'different' increases the degree of the mother's fear and fantasy, her pride and sense of self-worth are severely threatened" (Abrams & Kaslow, 1976, p. 36).

### **Grief, Mourning, and Depression**

Freud (1917) wrote, "Mourning is regularly the reaction to the loss of a loved person, or to the loss of some abstraction" (p. 243). The mourning response is reality-based as "the loved object no longer exists" and necessitates a withdrawal of libido from the lost object (p. 244). Freud distinguished mourning from melancholia, noting the absence of a "lowering of self-regarding feelings" (p. 244) in mourning, a feature present in melancholia. Whereas in mourning the world has lost its value, in melancholia, the ego itself has become "poor and empty" (p. 246). Freud considered this evidence of a "pathological disposition" inherent in melancholia (p. 244). Mourning does, however,

carry with it many of the same features of melancholia—intense pain, decreased investment in the outside world, a struggle to feel love for any new object, and incessant thoughts of the lost object (Freud, 1917). The person in mourning resists the withdrawal of libido, “clinging to the object through the medium of a hallucinatory wishful psychosis” (p. 244). Gradually, “respect for reality gains the day” (p. 244) and with the work of mourning complete, the ego can once again be “free and uninhibited” (p. 245).

About the impact of reality on the resolution of the mourning process, Freud wrote:

Each single one of the memories and situations of expectancy which demonstrate the libido's attachment to the lost object is met by the verdict of reality that the object no longer exists; and the ego, confronted as it were with the question whether it shall share this fate, is persuaded by the sum of the narcissistic satisfactions it derives from being alive to sever its attachment to the object that has been abolished. (p. 255)

Freud's investigation of mourning and melancholia in relation to object loss bears relevance to the parents' experience of the loss of the longed-for fantasied child. In a process that is lengthy and circular, parents must experience the longing for the lost “normal child” and gradually release this fantasy (Solnit & Stark, 1961). This, in turn, frees the parents to adapt to reality and they can begin to engage in meaningful and potentially fulfilling ways with the actual child in front of them (Solnit & Stark, 1961). Thus, mourning can be viewed as key to eventual adaptation and recovery (Abrams and Kaslow, 1976) as parents move “...from the initial phase of numbness and disbelief; to the dawning awareness of the disappointment and feeling of loss with the accompanying affective and physical symptoms; to the last phase of the grief reaction in which intense

re-experiencing of the memories and expectations gradually reduce the hypercathexis of the wish for the idealized child” (Solnit & Stark, 1961, p. 526). Importantly, Als and Brazelton (1984) found that in order for parents to engage a mourning process, they first needed to see the baby as a separate entity rather than a damaged aspect of the self. They wrote, “Continued rejection, withdrawal, avoidance, or overprotection suggest that the parent is not yet experiencing the infant as a separate individual” and thus, the grieving process will not be possible (p. 582). If family does not mourn, the “ghost of the desired, expected healthy child” will haunt the family, impeding with the family’s ability to adapt to reality (Solnit and Stark, 1961, p. 532). Crown (2009) speaks to the complexity of this grief process contrasting it to “less ambiguous losses” (p. 74, citing Boss, 1999) in which “a space is created for the bereaved person to pause, to mark the loss, often to be taken care of by others, and to grieve” (p. 74). This stands in sharp contrast to the grief process for parents of children with learning or other disabilities who must immediately mobilize in order to advocate for their child’s needs leaving little time to grieve and mourn their loss.

From a self psychological perspective, Farjardo (1987) wrote that the healthy child is a “happily appreciated, selfobject for the parent” who represents the “fulfillment of an important ambition” while the child with a disability is a “massively disappointing selfobject” representing “an injury to the self” (p. 26). Mourning in the face of this injury and loss occurs at birth and across the years, as the child moves through each developmental phase (Farjardo, 1987). Depression or “obsessional mourning” (Freud, 1917) is understood as coming from this experience of injury, an experience that likewise results in rage “caused by repeated disappointment with the child (a selfobject)”

(Farjardo, 1987, p. 26). Chronic forms of depression and rage in the face of having given birth to a child with a disability represents the parent's psychic experience of repeatedly suffering an "empathic breach between her self and selfobject" represented by the child (p. 34). Farjardo (1987) argues that the process of parenthood offers an opportunity—for parents of normal and disabled children alike—to work toward resolution of conflict and further self-consolidation. In contrast, parenthood can also be "a precipitant for regressions and disruption of self-cohesion" (p. 26).

### **Parental Stress and Distress**

Numerous studies within the disabilities literature have repeatedly found that parents of children with learning and other types of disabilities are at increased risk for emotional, social and physical stress and distress (e.g., Brannon, Heflinger, & Bickman, 1997; Dyson, 1993, 1996, 2010; Egan & Walsh, 2001; Fuller & Rankin, 1994; Hassall, Rose, & McDonald, 2005; Lardieri, Blacher, & Swanson, 2000; Margalit & Heiman, 1986; McGilloway, Donnelly, & Mays, 1995; Saloviita, Italinna, & Leinonen, 2003; Shearn & Todd, 2000; Spratt, Saylor, & Macias, 2007). In a recent qualitative study, Dyson (2010) identified a number of sources that contributed to parent stress in families with a child with a learning disability. Differences between parenting partners in terms of style, approach and expectations for the child with LD produced increased tension and stress. Parents suffered from unsupportive reactions from family members, including blame, detachment, refusal to accept the child's disability and comparisons between the child with LD and non-disabled family members. While some parents indicated positive interactions with schools, most school interactions were also reportedly a source of

difficulty for parents, with parents and children enduring sub-par assessments, insufficient or disorganized delivery of services, conflicts over labeling of the child, and unrealistic expectations of the child.

Echoing some of Dyson's (2010) findings, Johnson and his colleagues (2006) found that parents' stress levels and capacities to cope were weakened by "secondary stressors" such as social and emotional isolation, tension with the parenting partner or other family members, and conflicts with professionals. These and other secondary stressors were likewise detailed in additional studies. Pearlin and colleagues (1990) noted the pressure of family conflict, financial strain and limited social contact. Redmond & Richardson (2003) revealed the negative impact of limited access to necessary services. Egan and Walsh (2001) focused on the consequences of reduced or limited informal and formal social supports. A number of other studies also detailed the anxiety parents feel in the face of uncertainty about the course of their child's future (e.g., Todd et al, 1993; Waggoner & Wilgosh, 1990; Walsh et al, 1993). Waggoner and Wilgosh (1990) detailed the stress parents experience in the face of the many roles they play in their child's education, from "teacher" to advocate. They reported that parents in their study frequently felt frustrated with their interactions with school personnel, and noted, "Most negative experiences occurred when teachers either did not accept the learning disability or made no apparent effort to understand it and adapt their tuition to the needs of the child" (Waggoner & Wilgosh, 1990, p. 98). They also noted the strain parents experienced as they spent extra time supporting the child with homework, in social interactions, and with emotional concerns.

In a study assessing parenting stress and distress in samples of children with special needs, including LD and ADHD as well as children with more pervasive developmental and cognitive disorders and health problems, Spratt and her colleagues (2007) found that “parents who have no reason to anticipate developmental or behavioral problems are even more distressed” (p. 445) when these issues emerge in their child. This suggests that parents of children who are born with more severe and obvious impairments may be better able to cope or adapt than parents whose children receive less severe diagnoses later in life, such as children with learning disabilities.

Several studies have found that parents of children with LD who demonstrate comorbid behavioral problems experienced higher levels of stress in the face of having to manage the behavioral needs alongside the other needs of their child (Baker, Blacher, Crnic, & Edelbrock, 2002; Johnson, O’Reilly, & Vostanis, 2006; Johnston et al., 2003; Ong, Chandran, & Boo, 2001; Raina et al., 2005; Spratt, Saylor, & Macias, 2007). The parents’ experience was exacerbated in the absence of support services and resources. These parents also frequently felt guilty about the quality of their interactions and communication with the child with behavioral difficulties, contributing to feelings of distress.

### **Effects on Relationship between Parenting Partners**

A good deal of literature exists that suggests the presence of a child with a disability in a family leads to strain on the spousal relationship. Some studies found that these families had higher rates of divorce and lower marital satisfaction (Breslau & Davis, 1986; Bristol, Gallagher, & Schopler, 1988; Cappelli, 1990; Floyd & Zmich,

1991; Friedrich & Friedrich, 1981; Gath, 1977; Hodapp & Krasner, 1995; Kazak, 1987; Martin, 1975; Roesel & Lawlis, 1983; Singhi et al., 1990; Tew, Laurence, Payne, & Rawnsley, 1977; Tew, Payne, Laurence, 1974; Witt, Riley, & Coiro, 2003). Yet, other studies suggest that there are no significant differences in rates of separation, divorce and marital satisfaction (Guess, 1998; Mullen, 1997; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Spaulding & Morgan, 1986). Moreover, some studies also demonstrate higher rates of marital satisfaction and lower rates of divorce and separation in some of these families (Kazak, 1987; Kazak & Clark, 1986; Roesel & Lawlis, 1983). Risdal and Singer (2004) conducted a historical review and meta-analysis of literature pertaining to the question of the impact of a child with a disability on the marital relationship. While they were able to detect a negative effect on marital adjustment, this effect was considerably smaller than might be concluded given a more cursory review of the research or by the presence of the many studies suggesting otherwise. While they contended that their findings contradict previous findings of consistently severe strain on these families, they also noted that the slightly higher level of divorce, separation and marital dissatisfaction suggests the need for more effective interventions and ways of supporting these families.

### **Positive Effects**

In their critique of the tide of negativism in literature about children with learning disabilities and their families, Risdal and Singer (2004) highlight the manner in which the work of the social sciences is embedded in historical and cultural contexts. They note shifting ideas of “disability” in light of advances in Disability Studies, an emerging field

that has developed the idea that conceptions of and responses to both “ability” and “disability” are constructed and naturalized against the backdrop of particular assumptions embedded within the historical and sociocultural landscape (e.g., Davis, 1997; McRuer, 2006; Siebers, 2008). Recent shifts in the discourse surrounding “disability” have influenced contemporary perspectives on children with disabilities and their families. Increasingly, literature on these children and their families focuses on variability, adaptation, and resilience (e.g., Ferguson, 2001; Seltzer et al., 2001; Singer & Irvin, 1991; Turnbull et al., 2000) as opposed to the long-standing and pervasive narratives of trauma, tragedy, grief, and stress. These shifts together with rising parent advocacy and activism (e.g., Kalyunpur & Harry, 1999) have influenced researchers to begin asking new questions and raising new theoretical notions about children with learning disabilities and their families. These questions and notions focus on positive adaptation, quality of life, and the benefits of having a child with a disability to the family (e.g., Behr, Murphy, & Summers, 1992; Hastings & Taunt, 2002; Nachshen, Andersen, & Jamieson, 2001; Poston et al., 2003). As noted above, this study likewise aims to capture a more balanced view of the experiences of parents of children with learning disabilities.

Numerous studies point to the positive and rewarding aspects of parenting a child with a learning disability (e.g., Kenny & McGilloway, 2007; Lardieri et al., 2000; Wagonner & Wilgosh, 1990). Siblings of children with learning disabilities may demonstrate a greater ability to manage responsibility, higher levels of patience and empathy, greater advocacy abilities as well as deeper understanding and tolerance of others who are different from them (Burke & Montgomery, 2000; Dyson, 1993, 2010; Lobato, Faust, & Spirito, 1990; Wagonner & Wilgosh, 1990). Likewise, parents report

that the experience of parenting their child with LD has deepened their ability to value and honor differences in general, built their capacity for advocacy, and increased their compassion and sensitivity not only toward their child, but also toward themselves and others (Wagonner & Wilgosh, 1990).

### **Acceptance, Adaptation and Healing**

Psychoanalytic and disabilities literatures point to a number of factors that support parents' abilities to accept, adapt to and heal from the pain and stress brought on by their child's disability. In the psychoanalytic literature, it has been argued that when parents can achieve a sense of psychological "separateness" from the child, adaptation and healing are more assured. The disabilities literature documents many examples of adaptive coping and points to the underlying aspects that lead to successful coping. Both psychoanalytic and disabilities literatures highlight the significance of the working relationship between parents and professionals noting that these relationships can, though don't always, lead the parent to experience greater levels of acceptance, adaptation and healing.

### **Separateness**

As documented in the section above, the psychoanalytic literature identifies grief and mourning processes as crucial to the parent's ability to accept and eventually heal the psychic wound of having a child with a disability (e.g., Abrams and Kaslow, 1976; Lax, 1972; Solnit and Stark, 1961). Abrams and Kaslow (1976) wrote:

Only when the remnants of the wished for child can be buried and mourned can the real, defective child be allowed to live and develop to his fullest with encouragement and even love, from his parents. The acceptance of the child as he is and for what he can become within the boundaries of his own potential is essential before parents and child can make progress. (p. 36)

With sufficient mourning, the parent can engage a process of “letting-go” (Shabad, 2001), and become better able to view the child as a separate entity. From a psychoanalytic perspective, the achievement of a sense of separateness in the face of this “narcissistic mortification” is a key ingredient to healing (Lax, 1972, p. 342). With sufficient separateness, the parent is better able to support the child in achieving higher functioning, which in turn becomes a source of self-esteem for the parent (Lax, 1972).

Als and Brazelton (1984) likewise viewed parental self-esteem as linked to the parent’s ability to view the infant as a separate person and to find aspects of the infant that are “personal and individual.” About the parents in their study who had given birth to infants with more profound disabilities they wrote:

The turning point in the restoration process of parental self-esteem was when the parents experienced their infants as separate persons and found aspects of the infants which they could identify as personal and individual. The parents' experiences with the infant, which provided feedback from the infant, helped to focus their attention on such positive qualities as compelling eyes, cuddliness, and suck, so that they could enjoy both their child and being the child's parent. (p. 581)

### **Adaptive Coping**

While families with children with learning disabilities struggle under the weight of multiple and simultaneous stressors that result not just from daily family life, but from caring for a child with a learning disability, many of these families also demonstrate impressive resilience and coping capacities. Corroborating findings in other studies, (e.g., Christenson, 1990; Parker, Hill, & Goodnow, 1989), Dyson (1996) found that the families in her study have “positive and cohesive family relationship[s] and use rules for operating the family routine” (p. 285). Indeed, in the face of frequently higher levels of stress in families with children with disabilities, many of these families also demonstrate good levels of adaptation (McDonald, et al., 1999).

There are a number of studies that have discussed key elements that contribute to adaptive coping in families with children with learning and other disabilities. These factors included “...a belief that they can adjust, change or resolve the situation” (Johnson et al., 2006) or a sense of self-efficacy (Bandura, 1986), and a capacity to establish and maintain positive frames of reference (Harris and McHale, 1989). Other factors linked to adaptive coping included maternal health (Sharpley, Bitsika, & Efremidis, 1997), flexibility and an ability to adjust in multiple ways to the disability (Quine and Pahl, 1991), the ameliorating effects of religious beliefs and religious communities (Rogers-Dulan, 1998) and the influence of socio-economic status (Quine and Pahl, 1991). Several studies pointed to the influence of the parents’ ability to successfully seek and gather necessary information to understand and advocate for their child’s needs across contexts (Kenny & McGilloway, 2007; Pain, 1999).

Many studies focused on the role of socio-ecological factors in adaptive coping such as the extent of felt partner support (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989), the quality of family relationships (Dyson, 1993), the presence of extended family support (Sharpley et al., 1997), experiences of peer support (Stallard and Lenton, 1992), ability to access and utilize community resources (Dyson, 2010) and the existence of professional support (White & Hastings, 2004). Relatedly, from a systems perspective, family adaptation and coping is situated within and emerges from the quality of relationships between family members themselves as well as the interactions the family system has with other social systems such as schools, religious institutions, medical systems, evaluators, doctors, and psychologists (Pentyliuk, 2002).

### **Interactions with Professionals**

Psychoanalytic and learning disabilities literatures both discuss the influence of the many interactions that parents have with professionals. These literatures offer recommendations for building effective, positive, flexible and enduring relationships.

Solnit and Stark (1961) elucidated the complex dynamics that often emerge between families and professionals (i.e., psychologists, psychiatrists, and other medical doctors). Noting the tendency of parents to initially “distort” the information about their child’s disability delivered to them by these professionals, Solnit and Stark suggested that the problem frequently lies with professionals’ lack of follow up in the face of this phenomenon. The mistake that these professionals often make is thinking that the work is complete at the initial discussion of the child’s diagnosis (Solnit & Stark, 1961). Solnit and Stark clarified, “The main reason for this misconception by the physician is that he

has not understood the repetitive aspect of the mourning process in the mother's reaction" (p. 530). They recommended a "continuing process" that is "gradual and repetitive" and consistently mindful of the particular position of the parents (p. 530). They argue that these qualities secure the development of trust and confidence in the parents' view of the professional. Within this experience of trust and confidence, the parent will gradually confront the reality of the child's disability, and begin to express her fears and questions. Solnit and Stark advocated a "dynamic interpretation of reality" (p. 532) wherein professionals clarify a parent's questions and fears as they emerge but cautioned against the use of interpretation of unconscious conflicts due to the narcissistic vulnerability during the mourning period.

Farjardo (1987) emphasized the importance of distinguishing between mourning and chronic depression brought on through the experience of the narcissistic trauma when considering how to intervene therapeutically with the parent. Arguing for "soothing and restorative" (p. 41) intervention and echoing Solnit and Stark's recommendations, Farjardo called for the judicious use of interpretation with neurotically organized parents in mourning, but cautioned against such technique in work with parents who are more vulnerable psychologically, namely those with narcissistic or borderline organization.

In their study of parents of infants born with significant disabilities, Als and Brazelton (1984) noted the ameliorative effects of the collaboration these parents engaged in with the researchers on this study. They argued that the parents' collaboration in the research process developed the parents' confidence and "provided an emotional bridge for the parents by viewing infant and parents as dyad and triad" (p. 584). Als and Brazelton found that ongoing clinical support was necessary because of the reoccurring

vulnerability parents experience over time. The focus of their support was on building parental self-esteem and securing a positive relationship to the infant. In terms of the qualities of intervention with these families, Als and Brazelton wrote, “If one assumes imbalance and injury to parental self-worth when deviations from expectations occur, then a parent-infant approach which stresses the infant's strengths, views the infant as separate, and improves the parents' self-esteem is indicated” (p. 587).

The disabilities literature likewise points to the importance of the relationships between parents of children with learning disabilities and the many professionals with whom they come into contact. Indeed, the extent to which parents are able to access a range of appropriate supports, including professional supports, correlates to how well these parents will be able to adapt and cope (e.g., Dyson, 2010; Kenny & McGilloway, 2007; Pain, 1999; Stoll Switzer, 1985, 1990). Importantly, Qureshi (1993) notes that professionals should be sensitive to the coping strategies used by parents and not expressly undermining of them. When parents' coping strategies are undermined, this becomes yet another source of stress for parent.

Spratt and her colleagues (2007) point out that while children with special needs may receive support in school or in the community, it is less likely that appropriate family support will be given directly to families. In the face of this gap in services, she advocates for screening and support services for families, alongside the already existing services children receive in schools and community settings (Spratt et al., 2007). Dyson (2010) advocates for the development of public and community programs that help parents manage daily stressors, build skills to flexibly respond to the needs of their child with LD, learn to successfully navigate interactions with schools, and provide support

groups for siblings. She argues that focus needs to be placed on improving communication between parents and school staff members involved in education of the child. This essential element will encourage the development and delivery of appropriate services for children with LD at schools (Dyson, 2010). Children with LDs often receive numerous services and interact with multiple service providers throughout the week. Dyson (2010) highlights the need for better coordination of these services alongside more efficient and effective means of communicating information among service providers and with parents. A number of studies point to the usefulness of involving parents in the assessment and evaluation process (e.g. Turnbull, 1983; Wilchesky & Reynolds, 1986). Pentyluk (2002) suggests that parental participation in evaluations will produce a more reliable diagnosis, increase the chances that parents will better understand and accept the disability, and ultimately feel more able to support the child more effectively at home.

### **Summary of Section**

The diagnosis of a disability in a child has a profound effect on the parents' intrapsychic experience, leading to a variety of troubling and intense affective experiences and complex narcissistic wounds. Moreover, the interpersonal, familial and systemic effects of parenting a child with a learning disability are immense. Parents experience higher levels of stress and distress, frequently exacerbated by a lack of social, community, and professional supports. Importantly, many families who have children with learning disabilities experience numerous positive effects as a result of the learning disability. Likewise, many families are able to engage in adaptive coping in the face of the heavy demands of having a child with a learning disability. Parents who themselves

have learning disabilities may have a more intensified experience of their child's learning disability, may feel more exposed, responsible for the child's struggles, and identified with the child. The degree to which a parent is able to experience psychological separateness from his or her child impacts acceptance, adaptation, and healing.

Importantly, the interactions parents have with professionals are key to these processes of acceptance, adaptation, and healing. Professionals must engage parents in collaborative and continuous interactions over time, highlight the child's strengths along with the parents' abilities to support the child, and be ever-sensitive to the position of the parents.

### **Rationale for the Current Study**

This dissertation will investigate the intrapsychic and psychodynamic experience of parents who have children diagnosed with moderate to severe learning disabilities, and will compare the experiences of parents with and without learning disabilities. The interpersonal, familial, and systemic effects of a learning disability diagnosis will also be considered as these experiences likewise influence the parents' intrapsychic process.

Given the focus, this study is positioned at the intersection of the psychoanalytic and disabilities literatures, and aims to address the gaps detailed herein that exist within each of these literatures. Firstly, while the intrapsychic experiences of parents of children with more profound disabilities are represented and the psychodynamic qualities of children and adolescents with LDs have been well-studied in the psychoanalytic literature, little has been written about the intrapsychic experiences of either LD or non-LD parents of children with learning disabilities. Secondly, the effects of learning disabilities on families is well-represented in the disabilities literature, yet the focus is

primarily on external factors and their impact on family and parent functioning adding little to a deeper understanding of the manner in which external factors influence the internal experience of these parents. Thirdly, the particular experience of learning-disabled parents of children with learning disabilities is underrepresented in both the psychoanalytic and disabilities literatures. By including this population alongside non-LD parents within the sample, this study promises to produce potentially helpful findings about the ways in which the intrapsychic experiences within and across these groups are similar and distinct. Lastly, this study aims to balance the tendency toward primarily negative frames in the psychoanalytic and, to a lesser degree, disabilities research on parents of children with disabilities by leading with the assumption that the effects of a child's learning disability on parents' intrapsychic process are diverse and extend from positive, to neutral, to negative in quality. Specifically, this study will focus on capturing and representing the range of experiences parents of children with learning disabilities have, illuminating both the difficult intrapsychic impacts of the diagnosis and their effects as well as the positive and, at times, transformative influence of the child's learning disability on the parent's intrapsychic process.

The overarching intention of this study is to present a deeper and more nuanced understanding and representation of the intrapsychic influences of a child's learning disability on his or her parents, including the manner in which interpersonal, familial and systemic effects of the learning disability likewise shape the parents' internal experience. The hope is that this understanding will lead to specific recommendations for how professionals may sensitively conceptualize, interact with, and intervene to support these parents and their children, balancing a tendency toward focusing on deficit, or in some

cases, pathology, to include visions of strength, resilience, and adaptation. Professionals play crucial roles in the lives of these parents and their children, and the manner in which they understand and respond to these families has considerable resonance. When parents are understood and responded to in empathic, supportive and constructive ways—even in the context of tremendous struggle—they are, in turn, generally better able to respond sensitively to their child. Not only are the parents the beneficiaries of professionals' appropriate intervention, but, by extension, the children are as well.

### **Research Questions**

The following research questions that guide this study are embedded within the context of the theoretical and empirical assumptions about learning disabilities, parenthood and parenting a child with a learning disability presented in detail above. These theoretical and empirical assumptions will also serve as a loose guide during the analysis of the data that emerges as the study unfolds. It is expected that the data will come to both exemplify and challenge these assumptions, leading to emerging hypotheses about the experience of LD and non-LD parents of children with learning disabilities that will inform important recommendations for how professionals understand and respond to these parents.

1. Given the powerful internal processes involved in parenthood, how does a child's moderate to severe learning disability affect a parent's intrapsychic experience?

2. How do external variables<sup>3</sup> influence the intrapsychic experience of parents of children with learning disabilities?
3. In what ways are the intrapsychic experiences of parents with learning disabilities similar and distinct compared to each other, and compared to parents without learning disabilities?

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<sup>3</sup> The term “external variables” encompasses such factors as social support vs. isolation, adaptive vs. maladaptive coping strategies, access to appropriate services, the effect of financial means vs. financial strain, quality of relationships between parenting partners, and with family members, community/ religious organizations, schools, professionals, etc.

## **Chapter 3: Methodology**

### **Introduction**

The methodology for this study is rooted in qualitative principles and methods for research and will employ grounded theory (Glaser & Strauss, 1965, 1967) as the primary method of data analysis. Grounded theory is based on the notion that theories can be derived through the systematic collection and analysis of data; data creates the concepts that in turn produce theory (Charmaz, 2006; Strauss & Corbin, 1998). Strauss and Corbin (1998) argued that grounded theories “offer insight, enhance understanding, and provide a meaningful guide to action” (p. 12). It is hoped that the theoretical conceptions emerging from this study will expand on and elaborate existing psychoanalytic theory about the intrapsychic experience of parents of children with learning disabilities and contribute new ideas to the disabilities literature on the experiences of parents of children with learning disabilities. The greater aim of this research is to more deeply understand the experiences of parents of children with learning disabilities in order to increase professional sensitivity to this population and propose more effective professional supports and interventions for these parents and their children.

This chapter will review several aspects of methodology including sources for participant recruitment, criteria for participant selection, instruments to be used for data collection, and procedures for the collection and analysis of data.

### **Participants**

The participants in this study included 11 parents of children with moderate to severe learning disabilities. Efforts were made to include a balanced number of parents

representing each group (learning disabled group and non-learning disabled group). In addition, attempts were made to balance the sample in terms of the proportion of specific birth orders (first born, second born, etc.) as well as the proportion of single children to children with siblings. The researcher recruited participants who fit the inclusion criteria stated below using a “convenience sample” approach, drawing on already established contacts with neuropsychological testers, child psychologists and school personnel in schools where children with moderate to severe learning disabilities are in attendance. After initial participants were interviewed, the researcher increased the participant pool utilizing a “snowball sample” method.

The criteria for selection of parents with and without learning disabilities included the following: (a) at least one of the parents in a two (or multiple) parent family must be biologically related<sup>4</sup> to the child with the moderate to severe LD, (b) the child was born full term<sup>5</sup>, (c) the primary language of the parent(s) is English, and the child is being raised as a monolingual English speaker<sup>6</sup>, (d) the child was diagnosed with a learning

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<sup>4</sup> The intention was to ensure the examination of the psychological impact of the biological root of many LDs as well as the experience of being biologically connected to a child with an LD. The underlying assumption is that biological connections may produce particular intrapsychic effects on parents. It is understood that for some limited number of families, there are no known hereditary precursors and the LD is viewed as an anomaly of sorts within the family. It is further understood that parents who have non-biologically related children with LDs may share in the same or similar intrapsychic experiences and face the same or similar interpersonal, familial, and systemic effects of having a child with an LD as those parents who are biologically related to their children.

<sup>5</sup> The inclusion of children born full term was intended to eliminate the possibility of LDs arising from premature birth as opposed to LDs that may have some genetic origin. Further, a parent with a premature baby arguably faces significant hurdles from the very beginning of the child’s life, the experience of which likely influences the parent’s intrapsychic experience and interpretation of this experience, thus potentially confounding the data that emerges in the research.

<sup>6</sup> The intention was to eliminate simultaneous and/or successive bi/ multi-lingual language acquisition as a confounding variable in the diagnosis of a learning disability.

disability as documented by a neuropsychological or psychoeducational evaluation performed or supervised by a licensed and qualified professional, and is currently school-age, (e) the child was found to have at least low average intelligence (Full Scale IQ of 80 or higher) as measured by the Wechsler Intelligence Scale for Children IV- Fourth Edition (WISC-IV) or an earlier version of the WISC, and was found to have academic weakness(es) (at or below 25<sup>th</sup> %ile or at least 2 years below grade/ age expectancy on an academic measure such as the Woodcock-Johnson Tests of Achievement or the Wechsler Individual Achievement Test (WIAT), (f) the child's diagnosis did not include Pervasive Developmental Disorders, Tic Disorders, Mental Retardation or other Axis II disorders<sup>7</sup>, but may include Learning Disorders along with any of the following: Motor Skills Disorder, Communication Disorder, Attention-Deficit and Disruptive Behavior Disorders, Adjustment Disorders, Mood Disorders, and Anxiety Disorders (DSM IV-TR, American Psychiatric Association, 2000), (g) the child, siblings of the child, and/or parent(s) were not suffering from a comorbid severe or life-threatening medical issue or

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Because of the widespread misunderstanding of dual and multiple language acquisition, many children who are second language learners or bi/ multi-lingual are mistakenly diagnosed as LD. Further, the researcher's primary language is English, and she possesses weak skills in other languages, severely limiting her ability to conduct research in a language other than English. This is a limitation in this study that will inherently reduce and homogenize the sample.

<sup>7</sup> These diagnoses, while they may co-exist with LDs, generally manifest in different and/or more complex and severe dysfunction across a range of aspects of daily life. The intention was to narrow the variables so as to focus more exclusively on LDs and, in certain cases, more typical and/or less severe co-existing struggles (e.g., motor dysfunction, speech and language disorders, ADHD, or social/ emotional and behavioral difficulties not due to pervasive developmental disorders, tic disorders, mental retardation or personality disorders).

health condition<sup>8</sup>, (h) recommendations in the child's report included some type of special education service (i.e., resource room support, speech/ language therapy, occupational therapy) and/or modifications and adaptations for learning, or include a recommendation for placement in a special education classroom or school. Parental learning disability was determined by the presence of a diagnosis or by anecdotal evidence of a history of significant struggles in academic and/or social arenas<sup>9</sup>.

### **Instruments**

A semi-structured interview served as the primary instrument for data collection (see Appendix A). The semi-structured nature of the interview allowed the researcher to flexibly follow emerging themes during the interview process. The interview took approximately one and a half to two hours to complete, and took place during one session in a private location to be determined with each interview. All interviews were tape-recorded and saved in a secure location.

The interview contained 29 open-ended questions designed to correspond to the overarching research questions for the study. As such, the questions elicited details about the parents' intrapsychic experience, as well as the interpersonal, familial and systemic effects of having a child with an LD and the manner in which these effects color the

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<sup>8</sup> The presence of a severe or life-threatening medical issue would likely confound the findings, given that severe or life-threatening medical problems generally produce significant amounts of stress and burden in families, and can impact intrapsychic process.

<sup>9</sup> Depending on the age of the parent along with other variables such as geographic location during childhood, school system attended while growing up, and socio-economic status of family of origin, etc., testing for learning disabilities may not have been possible and thus, an LD diagnosis would not have been given. In fact, many parents come to "discover" their LD with their child's diagnosis. Because of these factors, anecdotal evidence of a learning disability will suffice in the absence of an official LD diagnosis in the parent.

intrapsychic experience. The influence of the parents' own history of learning and schooling, including experiences of struggling and succeeding with learning as well as parent/ teacher responses to these successes and struggles, were elicited through these open-ended questions and were meant in part to draw for similarities and differences between parents with and without learning disabilities. Some of the interview questions were based on Charmaz's (2006) sample of grounded theory interview questions about a life change. In addition to this interview, participants were asked to complete a demographic questionnaire covering such topics as age, sex, marital status, racial and ethnic background, language, education, occupation, socioeconomic status, learning disability status, and details about the identified child's learning disability and schooling (see Appendix B).

### **Procedures**

Participants who met criteria for selection were contacted by phone to set up an individual interview in a private location. Prior to the interview, the participants were informed of the purpose of and procedures for the study, and any questions were answered. At the interview, the participants were given a consent form to review and sign if they felt comfortable participating in the research. Those participants who signed the consent were then asked to complete a demographic questionnaire in advance of interview questions. After the demographic questionnaire was completed, the interview commenced. The interview was tape recorded in full. The interview included 29 open-ended questions designed to elicit information about the impact of the child's LD diagnosis on the parent's intrapsychic experience as well as interpersonal, familial and

systemic effects of this diagnosis. The semi-structured nature of the interview allowed the researcher to flexibly respond and follow up on ideas during the interview.

After the interview was completed, the participant was again asked to confirm consent to have this interview data used in the study, and if the participant withdrew consent, interview data and demographic information was immediately destroyed in the presence of the participant. All data, including demographic information and interview data, was stored in a secure location.

After the interviews were transcribed, the researcher coded and categorized the data applying a “constant comparative method of analysis” (Glaser & Strauss, 1967). The researcher employed an iterative process of coding, moving from low-level text-based codes, to mid-level “sensitizing concepts” or themes and finally to higher-level theoretical constructs (Auberbach & Silverstein, 2003).

## **Chapter 4: Results**

### **Introduction**

Three levels of data analysis were employed to code eleven interviews resulting in a total of 36 low-level text based categories, ten mid-level themes, and four theoretical constructs. Table 1 illustrates the clustering of text-based categories within themes and presents the frequencies of each text-based category for the entire sample, the four parents who self-identified as LD, and the 7 parents self-identifying as non-LD. The themes are further clustered into overarching theoretical constructs also shown in Table 1. These theoretical constructs will form the basis of the discussion chapter. In this chapter, themes will be presented and text-based categories will be incorporated to more fully elaborate the meanings of each theme. Samples of representative data will be used to enliven each theme.

### **Demographics**

The research participants were 11 parents (9 women and 2 men; 10 White, 1 Latino) of children with learning disabilities. Recruitment ceased after the existing 11 participants were recruited because of recruitment challenges and time frame. The parents in the study ranged in age from 39-52 ( $M= 46.09$ ;  $SD= 3.833$ ); nine parents were married (7 women and 2 men) and two parents were divorced (2 women); and each parent had between one and three children, with two parents having one child (18.2%), seven parents having two children (63.6%) and two parents having three children (18.2%). Seven of the mothers did not have LD (63.6%), while two mothers and both fathers had LD (36.4%). Seven of the parents indicated that another family member

(other than themselves or their spouse) also had an LD (63.6%). Of these seven parents who indicated the presence of LD in their family of origin, three of them were parents with LD and four of them were parents without LD. Nine of the parents (81.8%) reported yearly household income of over \$150,000. All nine were married; three had LD and six did not have LD. One divorced mother without LD reported household income between \$50,000 and \$75,000. One divorced mother with LD reported household income of under \$20,000. Eight of the parents held both undergraduate and graduate or professional degrees (72.7%; 1 LD parent; 7 non-LD parents), while three of the parents held undergraduate degrees only (27.3%; 3 LD parents). Two parents sent their children to public schools (18.2%) and nine parents sent their child to a private school (81.8%). Of those nine private school settings, four were special education private schools (44.4% special education schools). Five of the parents (45.5%) indicated that they had changed their child's school as a result of their child's LD. Demographic information is summarized in Table 2.

### **Themes and Corresponding Text-Based Categories**

#### **Theme A: Emotional Responses to Diagnoses**

All parents explicitly and/or implicitly articulated emotional responses as they reckoned with their child's learning disability. These emotional responses were grouped into the following text-based categories: (1) Fear and anxiety; (2) Traumatic re-experiencing through child's diagnosis; (3) Guilt; (4) Disconnect between fantasy and reality; and (5) Desire to protect child.

All participants expressed feeling fearful and anxious in the face of their child's learning disability. Some parents referred to visceral and bodily experiences of fear. One parent without LD shared, "I came home crying so hard that I hyperventilated" (P10). Another parent without LD recalled, "When I first found out, my issues starting piling on feeling, you know, like someone had just ripped my heart out, you know. I occasionally still feel like that. Sometimes I feel so scared for him" (P11). Other parents noted the anxiety that attended the uncertainty they were experiencing in the face of their child's diagnosis. "When you find anything out that your kid's not where they're supposed to be, you know, whether it's like a health issue or a brain issue like you're concerned. And because you don't know what is that going to mean in the future. Like how severe is this. So there's a lot of that feeling of like concern and uncertainty and worry" (P2).

Half of the parents with LD described a traumatic re-experiencing of their own struggles with learning as children. This phenomenon was not present in any of the transcripts of parents without learning disabilities. One father shared, "It destroyed me, you know, and like I said all those emotions, all that stuff from my childhood, everything was flashing before my eyes" (P3). Another mother stated, "It's like, it -- it really is like-like I'm having flashbacks of that experience" (P6).

All of the parents with LD and 86% of the parents without LD expressed feeling guilt in the wake of discovering their child's learning disability. Parents felt responsible for the learning disability, either because of genetics or a belief that they had done something wrong earlier in the child's life or while the child was in utero. For example, one mother without LD shared, "...that was the clincher, that I took the Zoloft while I was pregnant with him" (P1). Another parent with LD recalled, "I thought it was my

fault...I felt so responsible and so guilty” (P3). Some parents felt that the diagnosis revealed a deficiency in them as parents or people. One parent without an LD shared, “Like any parent feels when...something is brought up about their child that it's like a reflection on you. You know, like it's my fault. Like I didn't do something. I didn't give him enough tummy time when he was a baby. You know, like somehow it was my -- like I did something” (P8). Finally, one parent without an LD expressed guilt for feeling that she was not more “unconditionally loving” toward her son.

Nearly three-quarters of the total sample (50% LD; 86% Non-LD) reported a disconnect between the fantasy they held of their child and parenting experience and the reality they were coming to face through their child’s LD. One parent without LD shared, “It never occurred to me that my child would have difficulties learning to read or write. It never occurred to me that my child might have a learning disability” (P2). Another parent without LD talked about losing the fantasy of a particular connection with her son. She stated, “We went -- we went to the darkest places...We both thought, ‘Oh my God, he'll never go to college.’ That was the first thing... Then I remember crying one day, saying, ‘Oh my God. He's never going to be able to enjoy the theater. He's never going to get satire or irony’” (P10).

91% of the total sample (100% LD; 86% Non-LD) reported strong feelings of wanting to protect their child, either from what they experienced as children with LDs or from feeling unhappy. One father with an LD recalled, “All I kept thinking about is how do I protect him from feeling the way that I feel and the ways that I felt” (P3). A parent without an LD shared, “When he says ‘why does it have to be me?’ I don't want him to feel that way, because he's such a great kid. And could I be doing something differently

so that he's not feeling that way?" (P8). Another parent without an LD recognized the paramount importance of protecting her son's sense of self. She shared, "And forgetting even about my interest in his academic success, he was just unhappy. And in the end, that's all you have to give your child is like, you know, a feeling -- a sense of self and --- and, you know, you're a good person and that you can be successful and feel good about yourself and it just wasn't working" (P9).

### **Theme B: Enduring Influence of the Relational Past**

Parents' past relational experiences were present throughout all of the interviews. This theme included four text-based categories: (1) Negative experiences as a student; (2) Supportive responses from one's parents; (3) Negative responses from one's parents; and (4) "We're not new to this."

Nearly three-quarters of the sample reported having had negative experiences as a student. While all of the parents with LD recounted negative experiences as students, just over half of all parents without LD shared negative experiences. The parents with LD described their experience in strong terms. When asked to describe his experience, one parent with an LD stated, "Horrible. Disinterested. Bored. It was torturous. School was torturous for me" (P3). Similarly, a mother with LD shared, "Oh God. Do I have to? I was shy. I was timid. I was overly self-conscious. I was insecure. I was often not present, you know, I was off creating in my mind and not very present to what was happening-- around me. I -- I had trouble reading" (P6). All parents with LD and many of the parents without LD who had negative experiences as students expressed anxiety about their intelligence. One mother without LD stated, "I think as a student I sometimes felt like I

wasn't very smart. I mean, I would -- I, you know, I always thought, well I'm not, you know, I'm not good at math. You know, there's something wrong with me. I can't get through this, you know" (P8). A father with LD shared, "It was too hard and I just was totally unmotivated to do it...I thought of myself as not being highly, you know, as being dumb" (P5).

Just over a quarter of the total sample described the support they experienced from their own parents when they struggled as students. LD and Non-LD participants were represented in nearly equal percentages (25% LD; 29% Non-LD). One mother with LD shared the way in which her parents believed in and supported her as a student and the lessons she learned from their response to her struggles. She shared, "This I got from my mother and my father for sure... You have the power to build that child up and you have the power to bring them down and if you can't build them up then the world won't build them up. You know, you have to really believe in your child and just support them" (P7). Another mother without an LD recounted her parents' support, sharing, "They always helped. They never pressured me. I didn't need that extra pressure I put a lot of pressure on myself and they recognized that" (P4).

Nearly half of the total sample reported having had negative responses from their parents to difficulties they experienced with learning. However, there was a striking difference in frequency between the two groups of parents with 75% of parents with LD and only 29% of parents without LD reporting negative responses from parents to their struggles with learning. One mother without LD referred to her parents' disappointment in her academic performance, recalling "It was a -- a huge disappointment to my parents and -- and to me... I couldn't function at the level or sort of the perfectionistic level, so I

just sort of forfeited the whole thing...” (P1). Parents with LD recounted significant distress as a result of their parents’ responses to their difficulties. One father shared,

“It’s one of the things like I really whitewash. I don’t have many childhood memories. My childhood was incredibly traumatic because of my parents being so focused on education and that was the measure of good and bad and if you didn’t do well in school you were bad. It didn’t matter if you had a good personality or if you were any of the creative or athletic, all of the things I was good at. It didn’t matter” (P3).

Another father with LD recalled,

“She [my mother] and I had like a very contentious relationship. We always used to fight because I think a lot came from the fact that the academics were very important for her and my mother felt that I was just not, you know, putting forth the effort commensurate with my abilities or my intelligence” (P5).

A mother with LD referred to the way in which she internalized her father’s response to her difficulties. She shared, “My dad was very overbearing on every level...It was horrible. Yeah, I mean, I just -- I never felt good about myself. And -- and so then I internalized that” (P6).

While an outlier, one mother with LD shared her sense that her family’s history with LD was a protective factor in her experience of managing her child’s LD. She shared,

“We’re not new to this world...I can just imagine a parent with no learning issues, both parents with no learning issues and then they have a child that has learning issues, I feel like that is probably so much more devastating than for me, which is

still devastating but, you know, it's like I get strength from my family 'cause I know that, you know, my brother was a huge support system for [my son]" (P7).

### **Theme C: The Space Between Parent and Child Collapses**

Parents of children with learning disabilities demonstrated varying degrees of struggle and comfort with the psychological process of separation. Three text-based categories elaborate this theme: (1) Child's vulnerability exposes parent to threat and shame; (2) Moments of merger with child; and (3) Envy of what the child gets.

Just over half of the parents directly or indirectly referred to the ways in which their child's weaknesses threatened them and/ or exposed shameful parts of themselves. While parents with LD were more likely to report this phenomenon (75%), over half of the parents without LD (57%) also experienced these feelings. Many parents referred to deep concerns about their own intelligence and/ or (dis)abilities. One mother without LD revealed her fear that questions about her and her husband's intelligence would be raised by virtue of her son's LD diagnosis. "We would be exposed... it just brought up so many anxieties about intelligence. If somebody is smart it just like sort of elevates their status in the world so much. And that was so deeply ingrained in me" (P1). Other parents referred to the widespread faulty assumption that LD is equivalent to intellectual dullness, merely hinting at the way in which this exposed their own vulnerabilities. One mother without an LD reflected, "Learning is harder for your kid and if learning is harder then I think then the idea is that your kid isn't, it's just that [he] doesn't come across as smart maybe or – Your kid's not as fast or as not as quick... Yeah, your kid doesn't come across as bright, right?" (P2). One mother without LD suggested that her son's LD called

into question her capacity as a mother, expressing her sense that if her child were “mainstream” it would “validate” her “good mothering” (P10). A mother with LD talked explicitly about how her struggles were exposed in the process of navigating the bureaucracy of the educational system on behalf of her daughter. “This whole process is really showing me my attention issues, my reading issues, my like, ‘start something don’t finish it’ issues. This is the kind of stuff that totally freaks me out” (P6).

Three-quarters of the parents with LD and only 14% of the parents without LD made statements that suggested moments of merger with their child. One father with LD discussed how his son’s testing results validated *his* intelligence. He shared,

“Oh, I mean I guess it [my son’s testing] was useful for me, too, to be like-- You know the whole thing [son’s testing] for me was like kind of a validation that I was intelligent in general and that a lot of this had nothing to do with my—you know, but by the same token my mother would argue that I don’t have these things so like for me it’s unresolved in my mind it’s pretty clear but my mother would say that’s not the case. And so therefore hearing that he’s intelligent and that his IQ score doesn’t reflect how high his IQ probably is. And even though it’s invalid it still comes out average to slightly above average and who knows maybe he actually is more than that.” (P5)

A mother with LD seemingly unconsciously alternated between “I” and “she” in parts of her interview, making it unclear who she was actually referring to: herself or her daughter. For example, she shared,

“Well I worry about what I experienced. Which was -- was disconnecting further from, like making it feel like the goal is even harder to achieve. And -- and -- and

it becoming so overwhelming, the feeling that I, or she will never catch up. And that challenges that come in because of the reading or because of any -- anything then becomes it's too hard; I'm not going to do it...So that -- that she ends up letting herself down because of this disability" (P6).

This same mother also reflected on the ways in which she struggles to separate out her experience from her daughter's. She reflected,

"I'm as hard as her as I was on myself. And it's, I mean that's where I've had to sort of like, really step back and just look at this in a different perspective because I -- I realize that the way I've treated myself and -- and like, felt -- you know, often felt like a failure, is because that's how I felt in that situation as a kid. And so, it's been very difficult for me not to duplicate that behavior on her" (P6).

Half of the parents with LD, both fathers, poignantly expressed some measure of envy over the remediation of and responses to their sons' LDs. This phenomenon was not present in any of the interviews with parents without LD or within the interviews of the two mothers with LD. One father reflected on how he felt after his son's evaluation stating,

"... I was in a way sad because I wished that, you know, had a lot of these things been diagnosed or whatever, had I been told these types of things early on in my life it would have probably made it a lot easier for me... And there are things I might have attempted. I might have chosen different things and done different things in life. You know? If I had an understanding of how my brain works and that I was intelligent and you know I would have made vastly different decisions is my guess. And I didn't have that self-awareness to know that. And so even if

my mother had told me that I had average to high IQ or whatever, you know, I think that would have you know, it would have been helpful” (P5).

The second father stated,

“[My son] has a different kind of thing. We caught it very, very early on. So ever since then he’s been taken out of class and he’s learning different techniques on how to learn and he actually enjoys the process of learning. Like he comes home and will talk about history or something he learned in science or like there’s a legitimate enthusiasm for learning something new where I never experienced that until college, really. I wish I had some of the opportunities that he had not only them recognizing it but also learning a different way” (P3).

#### **Theme D: Parents Engage in Adaptive Strategies**

When an LD is suspected or confirmed in their child, parents often responded with adaptive strategies to cope. Two text-based categories illuminate the typical kinds of strategies parents may employ: (1) Parents seek evaluation and/ or intervention; and (2) Joining and connecting.

All parents in the sample described seeking school-based or private evaluation and/ or intervention for the child when an LD was suspected. Parents articulated varying degrees of comfort and confidence with this process, and several articulated the stress they experienced in having to wait for services. One mother without LD shared,

“... this happened in the summer. And so we were stuck, because being, you know, type A New Yorkers, we knew we were going to treat this. You know, he was going to get evaluated, blah, blah, blah, blah, blah. But we were stuck

because no one was there to talk to us until September. So those two months were horrific in the sense that we were self-diagnosing” (P10).

Likewise, another mother with LD described the stress of the process of evaluation within the public school system.

“I was like -- I -- I started to feel really, really lost about what to do and started making phone calls and getting estimates of how much it would cost to have her tested and you know, a psych and what was covered by insurance and what wasn't. And then finally I got in touch with the Department of Ed and they, you know, they could do it, but it was like the very end -- last couple of weeks of the summer, and they said, you know it doesn't make sense to do it now, it should be done in the school, you need to submit a letter and we'll have it done in the school” (P6).

A mother without LD described her immediate search for a private school for her son after leaving a difficult meeting within her son's public school. “And literally I left that meeting -- I was like in my gym clothes and I said, ‘I'm going to all the private schools. I'm going to figure out, like, even though they all accepted people, I'm going to figure out a way -- I just want to see if any of the private schools have room’” (P1).

When parents either suspected or confirmed their child's LD through testing, many recounted joining and connecting with friends, family members, other parents of children with LD and adults with LD for advice, emotional support and reassurance, and a sense of solidarity (75% LD; 71% Non-LD). One mother with LD shared about the way in which her family bolsters her confidence in her son's ability and future. She reflected,

“I called my brother...and he was like, don’t let them tell you what your son is capable of – those institutions...and to this day, you know, he sees [my son’s] strength because as a parent you don’t always see their strengths...as a parent you’re so focused and worried on their weaknesses and how they are going to affect their life that you can’t always see their strengths and so I really look to my family, especially my brother and my father about just to point out to me his strengths” (P7).

One mother described contacting every person she could find who had familiarity with the special education setting to which her daughter was admitted. “That’s when I started talking to everyone. I was like ‘who do you know at [the special education school]? Do you know anyone at [the special education school]?’ And I amassed a list of like seven people and I started calling them. And my husband was calling people he was getting names of. And we were talking to everyone” (P4). Another mother shared a similar motivation in reaching out to others, stating, ““There was a point where I was talking about it just to get information from other people, not necessarily because I felt comfortable about it ...” (P9).

Some parents referred to their openness with others about their child’s LD, indicating a desire to normalize LD but also as a way of supporting others who may be in the same situation with their child. A mother without LD stated,

“I’m totally open. Like I share it with everybody. I really do. I mean I just talk about it all the time just because I feel like I don’t want there to be a stigma and I don’t want other people to—I don’t have a problem with it and I guess I’m trying to lessen the stigma. So I talk about it, I just bring it up all the time...so that

somebody else might say, oh, my kid does, too. You know, whatever. Or just to make it like an okay safe thing to talk about... I just try to normalize it.” (P2)

A father with LD revealed his openness while also touching on the sense of shame and a general tendency to hide concerns or a diagnosis from others.

“And so [my son] has his issues and...if it comes up I’m going to talk about it openly. I’m not going to pretend that he doesn’t have an issue. He’s got a problem and maybe someone else is secretly had the same problem with their child and they need someone to talk to” (P3).

One mother with LD talked about the central importance of meeting successful adults with LD, and the way in which these encounters help her to feel renewed hope and decreased anxiety about her son’s future.

“This past couple of weeks meeting [adult with LD] has changed my life drastically. I think I’ve changed, yeah, really just like meeting a grown person who is successful that has an LD. As a parent of a child with an LD it’s like ‘my son will be able to function and be successful as well.’ Like I can’t even describe how monumental the experience of meeting this gentleman...has such an impact on me. Such an impact...like you know what, my son does have talents and...like the talents will become clearer the older he gets. Like these younger years are just so hard for kids like this, you know” (P7).

### **Theme E: Parents Engage in Avoidant Strategies**

Some of the thoughts, actions or behaviors that parents engage when they suspect their child’s LD appear to be avoidant. This theme is demonstrated through the following

text-based categories: (1) Parents get “political” or engage in sociopolitical commentary about LD; and (2) Parents hide, minimize or deny their child’s struggle.

All of the parents with LD and none of the parents without LD employed language about LD that read as “political” or appeared to be commentary of a sociopolitical nature. One mother with LD talked with great passion, referring to the divide between LD and non-LD, the inequality in educating children with LD, and the ways in which those with LD are devalued because of their difference.

“You know, if we could -- if we could just get her over this hump. And I guess, I mean that’s what -- what -- what pulls at me as I say that, is God damn it, it’s not about the hump. The hump is -- the hump needs to be looked at, not just for -- for my daughter, but for all children, because the hump is -- is resonating in families all over the world. The hump is a way of thinking that only includes one perspective. And that is that ‘reading is learned like this. This is how we learn to read.’ And everybody else who doesn’t learn to read that way is put on this side of the divide. And I -- I feel like whatever percentage of children who have this so-called disability, there’s -- there’s a reason they have it. It’s not, I mean I -- I hate the term disabled. They’re not disabled, they’re differently abled. And why aren’t we universally looking at the differently abled persons and teaching reading, understanding it better so that it’s not a disability, it’s a -- it’s another ability. And that -- and that there’s another pathway that maybe even more children would resonate with, and would not lose their spirit in the process of it” (P6).

Similarly, a father with LD blamed “society” for excluding and devaluing those with LD. He stated,

“What society has done is said no, no, no, here is what the norm is and everybody who doesn’t fall within this grid like I said before is not normal. But I don’t think that’s fair. Like who got to make up those rules? Some human being made those rules up. But we’re all following suit” (P3).

All of the parents without LD hid, minimized or denied their child’s disability at some point in their journey. Strikingly, this phenomenon was not present in any of the interviews with parents with LD. Several parents expressly hid their child’s LD or details about their child’s LD from others. One mother recalled keeping her son’s diagnosis and evaluation from her son’s school, noting that she didn’t feel safe to share. “I didn’t like show the evaluation to everyone...I think if the school had been a little more open then I think it would’ve -- I would have done it. But because they weren’t it’s -- that’s -- that’s why. It didn’t feel safe, yeah” (P8).

Parents minimized the extent or severity of their child’s LD. One mother shared, “I find great solace in the fact that...it’s just not full-on learning disability. He has a slight processing issue, but it’s not really -- like who gives a shit really, like whatever” (P1). This same mother talked about intentionally minimizing her son’s struggles with learning. She recalled, “When we were applying to the private schools, I was very clear that it was not a learning disability...I was very intent on emphasizing or minimizing its severity. Because I didn’t want them to think he was going to have so many special needs that he wouldn’t be a viable applicant” (P1).

Other parents engaged in or referred to a tendency toward denial of their child's struggle. One mother shared, "It's very interesting when it's your own children. Because you're, you know, you just, you know, it's almost like you don't want to hear about it so then it's not ---It's like if you don't hear about it, it couldn't be" (P9). Another mother recounted, "I didn't believe it [a doctor's suggestion of a potential problem]...I was angry that they had said that. You know, I didn't feel like it wasn't gonna happen with him...I felt like, I don't know, he was just sort of perfect whatever he was" (P11).

### **Theme F: Schools and Professionals as Holding Environments**

Under certain conditions the schools and various professionals in these families lives become "holding environments" as parents navigate their child's needs. This theme is represented by the following four text-based categories: (1) "He feels seen by these people"; (2) Transparency; (3) Confidence in professional's ability; and (4) Professional as attuned advocate.

Half of the parents with LD and just over half of the parents without LD felt their child was "seen" by the professionals with whom their child interacted, and that this experience was of considerable importance for their child and for them as parents. One father with LD referred to his son's behavioral improvement, linking this directly to the close connection and strong relationship the teachers had with his son. Multiple parents talked about the personal impact of witnessing a teacher's validation of their child. One mother without an LD shared succinctly, "You know, many cases it's the [teachers] that have loved him that have had an impact on me" (P11). A different mother without an LD stated,

“I think that the best of them [teachers] have always seen the best in him. And in reiterating that to a mom who too often sees the deficits and the concerns, they've allowed me to go day-to-day. And the people who have said he will change a million times in front of your eyes, which is true. Because when you're stuck in it or when I was stuck in it, that's the thing that's hardest to appreciate” (P10).

Another mother without an LD reflected,

“I can hear that he's, you know, having struggle or whatever, but it's just -- I guess if someone gets him. You know, that they get him. And they know how great he is. And that it's not about, you know, that he was disorganized or he lost his keys 25 times last year. You know, in the end you can get another set of keys made. You know, but it's like -- that's what I would rather people focus on is they -- they just understand him” (P8).

Approximately one-quarter of the total sample (25% LD; 29% non-LD) referred to the importance of transparent communication with schools and professionals regarding concerns about their child. One mother without an LD recalled her son's teachers noting their concern, stating “They were saying ‘we're not saying anything definitely but we're just saying this is what we're noticing and you should know’” (P2). Another mother without an LD who had repeatedly experienced a lack of transparency in her daughter's school recounted her relief when a school professional did open up about concerns.

“And I felt like she was doing me a service by coming clean and saying that maybe you should look, like she would do better elsewhere. Because no one else was saying anything. ...I think in general if it wasn't for her we might still be at

[the same school] next year. I don't know...I definitely was thankful, very thankful that someone came clean with me" (P4).

One mother with an LD shared her experience of being able to observe her son's testing, noting how reassuring and insightful it was for the process of her son's evaluation to be transparent.

Parents articulated a sense of reassurance when they felt confident about the professional's ability to understand and address their child's struggles. 75% of parents with LD and 43% of parents without LD referred to this phenomenon. About the tester she chose to evaluate her son, one mother with LD stated, "We felt like she was just someone who could capture who our son was...So, you have to almost find the person that you feel comfortable 'cause in essence this is a person who is judging your child, right? They're testing them, they're making judgments about them and so you have to feel comfortable" (P7). A father with an LD recounted his impression of the special education school his son ultimately attended. He shared,

"I think that it was the only school that was willing, that was not only going to teach him how to read first of all, but they weren't going to do it in a mean miserable way. Like you know it wasn't like just sit here and we're going to teach you how to read. But it was like very thoughtful" (P5).

Similarly, after interviewing for a seat for her daughter in a special education school, a mother without LD shared, "They spent like an hour with her and they were like we can help her with this, this. We see that she's got what everybody else has here. You know, it was like she would fit in so well" (P4).

Half of the parents with LD and 43% of the parents without LD spoke of the importance of professionals' capacity to be attuned to the experience of parents of children with LD. Some parents specifically referred to having an "advocate" within the school setting, noting the way in which this person helped them feel more hopeful and understood and less isolated. Other parents spoke of the moments when they felt "held" by professionals who offered them verbal reassurance and comfort. One mother with an LD shared,

"I think the most important pieces that have helped me as a parent individually has been words like patience, it takes time, this is a process, it doesn't happen overnight, don't worry. When I heard the words 'don't worry,' like that just lifted fifty percent of the burden. Because what it said to me was we're going to be o -- she's going to be okay, you know. Just -- just you don't worry. We're going to -- you're going to get through this. Like, I've seen this before, she's not unique. You're not the only one dealing with this issue. And I guess, yeah, I mean just hearing that, whenever anybody is going through anything, those are the kinds of things you need to hear. But especially when it's, you know, it has to do with your child. It's like a joining a kind of joining the parent. A holding, a reassuring, a lifting of some of the burden and responsibility and sharing of that -- a knowing that -- that a parent doesn't intuitively have. Because we're just looking at it, or I'm just looking at it as like this isolated, insulated individual problem and -- and what the professional does is it -- it attaches us to the bigger world of this, you know, area that they have unbelievable amounts of knowledge. And that it's not --

like it demystifies the whole process by just saying, you know, don't worry. We understand this. This is the way it goes. This is the way it works" (P6).

Another mother without an LD talked about feeling reassured in moments when professionals told her that there were "things to do" to help her child. This same mother recalled with gratitude how the evaluator provided accessible explanations for both her and her son about his LD. She shared, "Afterwards she met with all of us and then she met individually with Julio. And she explained to him about his brain and how his brain was special and she gave him a little rubber brain, which we still have" (P2).

### **Theme G: Schools and Professionals as Invalidating Environments**

Many parents spoke at length about difficult encounters and relationships with professionals that led them to feel invalidated. Four text-based categories represent this theme: (1) Parents know something is not right and the school is in denial; (2) Imagined or real rejection; (3) School is resistant to engaging or offers ineffectual interventions; and (4) "They don't understand my child."

Half of the parents with LD and 57% of the parents without LD told about moments when they expressed concerns to educators at their child's school and these educators denied sharing the concern or did not see any cause for concern. One mother without an LD referred to repeated experiences of educators telling her that her son was "fine" during moments when she raised concerns. She shared,

"I didn't think he had a reading issue, but it just wasn't coming together. And so that's when I kept sort of pushing them on. There just doesn't seem like something -- something's not right here, you know? And they kept saying 'no he's

fine, he's fine'....and toward the middle, end of the year, I sort of said, 'you know, I think -- I think that -- that, you know, he needs -- he needs something else.' And then they were like 'no, no it's fine,' you know. And then in first grade the same thing happened" (P8).

Another mother without an LD echoed this same frustrating experience. She shared, "I remember that the teacher throughout the meeting tried assuring us that she was just, you know, is doing fine. She's on grade level. Which there was no way she was...I mean she clearly didn't see it" (P4).

Some parents talked about difficult meetings with school personnel in which they were met with resistance. A father with an LD spoke angrily about his experience of a meeting in which the school—even after having an extensive neuropsychological evaluation done—continued to tell him that his son was "fine." He recalled,

"And then we brought our psychologist. And they had their reading specialist...the reading specialist said look he's reading at first grade... no problem. And like she said to my wife, you know, 'why don't you let us teach him how to read and you stop worrying... You don't worry about it. He's doing fine. There's no issue here. And thank you for your report, Miss Psychologist'" (P5).

Other parents expressed their opinion that teachers are "nervous to bring it up" with parents. A mother with an LD recounted how it wasn't until she mentioned her concern that teachers actually began to suggest any need for evaluation or intervention. She explained that this experience led her to feeling isolated and, in general, sets the stage for adversarial relationships between parents and educators.

Half of parents with LD and 71% of parents without LD recounted moments of imagined or real rejection in their encounters with school professionals. Parents described actual moments when their child was rejected from or counseled out of a school because of their learning disability. One father with LD shared, “I tried to get him into a Montessori school that I thought was really good. And the Montessori school I was honest with them which may have been a good or bad thing. But by being honest with them they couldn’t see their way past that and were like really unsure about having him” (P5). A mother without LD talked of her anger at her son’s rejection from his school stating, “I said like ‘fuck you, I’ll figure out a way to pay for him to go to private school.’ Like you don’t think he’s good enough for your school? This is -- this is rigid” (P1). A mother with LD discussed the way in which rejection from educators “makes you feel, as a parent, that your kid is not worthy” (P7). One mother without an LD talked about keeping her son’s evaluation from school personnel for fear of rejection. When she finally did share the evaluation, she grew concerned that it negatively tinged his teachers’ impressions of him. She shared,

“I’m thinking that like what are they thinking about him, you know what I mean? I mean at this point now that they have this like formal sort of evaluation in hand...And she [teacher] sort of implied that, like she was like, well, you know, do you think it’s the right place for him? It’s almost like she read the evaluation and then changed her, do you know what I mean, changed her thoughts about him” (P8).

Half of parents with LD and 57% of parents without LD referred to schools being resistant to intervention or unable to provide effective intervention for their child. One

mother with LD described the slow process of receiving even meager interventions within her daughter's school setting. She recalled,

“Every time we overcame a hurdle or an opportunity presented itself, I felt like -- I felt like we were a starving family, where we were given a crust of bread here, a bowl of soup there. Like every little blessing that came was enough to get us through to the next meal. But it still to this day has not felt like we've actually sat down and had a banquet.” (P6).

She went on to describe any intervention as feeling like a “Band-Aid” that doesn't actually address “the heart of the problem.” Other parents talked about the way in which they experienced educators' promises of intervention as “empty words” with no follow-through. A mother without an LD recounted conversations with educators at her son's school in which she was expressly told that the accommodations he required were not offered at the school.

“I asked for some of the things [accommodations] that they [tester] had listed that could help him. A lot of it was like oh we don't do that here...I got a similar sort of response even when he was in math in seventh and eighth grade or sixth and seventh grade when his OT was saying that he should really use graph paper for math. And they were like, well we don't do that” (P8).

A mother with an LD shared her impression that administrators are concerned about appearing to “favor” certain families and this concern blinds them to the benefits of certain accommodations for certain children. She stated,

“I know that there are parents who try to get away with a lot of things for their kids but when there are specific reasons sometimes administration just gets so

tangled in their webs. You know, they don't see through the real benefits for the child versus the parents just pushing or wanting it for the child, you know. I think they get kind of like hung up on their administrative duties" (P7).

Just under half of the parents without LD and 25% of the parents with LD felt that educators or other professionals did not understand their child. One mother without LD recounted, "-- it's like they don't understand who he is and so they're not able to -- I don't think they should be giving him a break, but I think -- I think they could be working with him in a little different way. I guess that's part of this" (P8). A father with LD stated, "[The teacher said] I think he's getting himself in trouble in doing stuff because he's bored. And I said, like, you know, you're just absolutely wrong. You know, you do not understand what is going on with this child" (P5).

### **Theme H: Expansion of Compassion and Empathy**

Parents described experiencing a deepening of compassion and empathy as a result of parenting their child with a learning disability. Some parents also described shifts in compassion and empathy in their own parents as a result of being the grandparent of a child with LD. Two text-based categories represent this theme: (1) Expansion of compassion and empathy in parent; and (2) Expansion of compassion and empathy in grandparent.

Half of the parents with LD and 86% of the parents without LD spoke directly or indirectly about experiencing greater levels of compassion and empathy. One mother without LD talked about the transformative power of being her son's mother. She shared,

“I have no words for the gratitude that I feel...[he] asks of me implicitly to be honest and vulnerable with myself in a way that I don't know I was quite capable of in my adult life...a kind of rawness that sometimes hurts. A love that is so fierce and so much depth and breadth to it that it, it asks of you to rise in a different way and you do...my compassion and my empathy has deepened so much” (P11).

Several parents referred to increased patience in the face of their child's LD. One mother without LD stated,

“I don't think I ever thought 13 years ahead, but I think this experience kind of taught me to think a year at a time...I've definitely become more patient...it's not going to come easy and I have to be more sensitive...Sometimes patience is knowing that, like he is exhausted at page five and he's really tired” (P9).

A father with LD reflected, “I've become more patient. I've learned to let a lot go...not every little thing is life changing. You know? It takes a lot of time and energy to steer a ship. And that's what I've learned” (P3). One mother without LD who is also a teacher talked about how her son's struggle and diagnosis directly reduced her tendency to be impatient and judgmental of her students' difficulties with learning.

Both of the fathers with LD (50% LD) talked about how their own parents' compassion and empathy grew as a result of having a grandchild with LD. In contrast, only just over one-quarter of the parents without LD referred to this phenomenon. Both fathers reported some measure of healing from or accounting for the wounds they suffered as child in their relationship with one or both of their parents. One father shared, “My parents have apologized time and time again about it. My mother told me that her

biggest regret in life is how she raised me. You know? Which was really nice to hear”

(P3). A mother without LD shared,

“My mom actually, because now she's sort of very different and having gone now to grandmotherhood has done wonders for her. And she was actually very helpful...I think it was sort of therapeutic for her having had two boys and she was very supportive. I mean I still was conscious that maybe she would still think he was stupid, but she -- all that she wasn't able to do for my brother for -- due to her own immaturity or the time or the lack of knowledge about it -- I think that there was value to her. She was very supportive and, in fact, has given up a little bit of money towards the private school and has been really, really -- they actually, like adore my kids as grandparents” (P1).

### **Theme I: Seeing the Child, Healing the Self**

Parents were able to hold their child’s weakness alongside the strengths and unique gifts of their child. In some cases, parents described ways in which through seeing and experiencing their child, they could begin to heal the wounds from their childhoods. This theme is organized within the following three text-based categories: (1) Balanced representation of the child; (2) The capacity to experience the child as a separate subject; and (3) Parenting the child heals the self.

Throughout the interviews, all of the parents represented the strengths and unique gifts of their children alongside the struggles their child endured. When referring to strengths, some parents noted their child’s special athletic ability; others noted their child’s creative and artistic abilities. Several parents referred to their child’s exquisite

sensitivity and capacity to connect to others on an emotional level. One mother without an LD shared,

“He worked at [a creative arts camp] this summer...And he loved sitting around talking about the kids and thinking about like ‘this child has this issue’ and ‘how can we support that child.’ There’s such a deep caretaking and... I mean, I think he was born with it” (P11).

A father with an LD reflected,

“...he is always very concerned about other people...he is very mindful of how other people are feeling. And if there is some upset in a classroom or if there is some upset at home he is very aware of it and he’ll be the first one to let the teacher know if there’s a problem...” (P5).

A mother without an LD shared about her son,

“He has a -- just a capacity to see beyond -- almost like a searing insight. And a capacity to ask questions, have thoughts that really go to the depths of both people's souls and his own. So he just -- it's almost like a -- a different vision” (P10).

Some parents talked about the process of normalizing and accepting their child’s weaknesses, viewing them as just one part of the totality of their child. A mother with LD shared, “You know, there’s so much more to my child than just his weaknesses” (P7).

One mother without an LD shared,

“I think that what I had to say to myself so many times is like everybody's brain has like strength and areas of less strength and it really is a matter of like in some ways this is just something that identifies us -- like the limitations and areas of

strength. And that some of the time too, which I don't even know if this is true, but I say it a lot, it's like if one area is extremely strong, then there is less strength somewhere else" (P1).

Just over half of the parents without LD (57%) revealed through their interviews a capacity to differentiate and view their child as a separate subject. There was no evidence of this phenomenon in the interviews with parents with LD. One parent shared her admiration for her child's unique thought processes stating, "I'm like, 'honey that's amazing that's what you thought of that!' Because I'm, again, like I'm that literal person, like concrete. Very—I'm very concrete sequential and he is not" (P2). Another parent reflected on how she was able to "clear" her deeply held preconceived notions about the central importance of academic success to allow space for her child's experience of struggle (P4). One mother referred specifically to focusing on what is best for her child rather than easiest for her. "You want to find the best environment for your child and it's not necessarily about finding what's easiest and convenient for you" (P9). Another mother weighed in on how she perceives her son's simultaneous reluctance and need to separate. She offered,

"He cares very much what I think and I would say at this point, too much what I think because if he likes something and he senses or thinks he senses that I don't agree with it, I don't like it, then it will make him feel like either he shouldn't or that I think he shouldn't and that isn't comfortable for him. I mean, being acutely aware of this for some time now, I'm like pretty good at neutrality, not great but like pretty good so I can just, you know, not be reactive or try to put that out

there. But he's sensing what I'm thinking and feeling a lot. And it's definitely stressful for him sometimes and it's stressful for his relationship with me" (P11).

75% of parents with LD and 55% of the parents without LD spoke about their own processes of healing, either from the wounds they experienced in childhood as a result of having an LD or in general. This healing was directly or indirectly linked to the experience of parenting their child. One mother spoke movingly of how becoming the mother of her son with LD allowed her to shed the defenses she developed as a result of her upbringing. She reflected, "I didn't have the need for those defenses anymore. I didn't want them anymore because they weren't going to serve me but they weren't going to serve my child, you know" (P11). One father with LD referred to his increased understanding of the connection between his dyslexia, his creativity and the way in which he processes information.

"I definitely think like in that much more 'out of the box' way and much more creative which I now have learned people with dyslexia tend to do things like that because they- for whatever [reason] either they're compensating or their brain is just wired so therefore I might organize my thoughts in a different way" (P5).

A mother with LD who had described the pain of her childhood experience articulated her belief that her artistic giftedness is a direct result of her LD. She shared, "I'm -- I'm an incredible artist... I don't say that because I'm bragging, I just know that the way I perceive the world and the way I use materials happens because of my reading disorder" (P6).

Several parents also talked about their growing ability to be gentler with themselves in the process of parenting their child. A father with LD shared, "If he fails it

doesn't mean he's failed. And when he fails it doesn't mean that I fail" (P3). A mother without LD reflected, "I think I've, I mean I've learned that it's, you know, this isn't easy. And not to be so hard on myself. Not -- trying not to feel like it's because of me" (P8). A mother without LD recounted her increased ability to trust herself as she parents her child with LD. She shared, "As a parent it teaches you to really trust your gut...they always say that, but it's true. You know your child better than anyone" (P9).

### **Theme J: Moving Toward Acceptance and/or Struggling in Limbo**

Parents appeared to be at various points on a continuum of acceptance of their child's LD. Three text-based categories form this theme: (1) Putting it in perspective; (2) Ongoing effort to feel secure; and (3) Active internal struggle toward acceptance.

75% of parents with LD and 71% of parents without LD were able to put their child's LD and their experience of being a parent of a child with LD in perspective. Some parents compared their child's LD to what they perceived as worse fates as a way of gaining perspective. One mother without LD stated, "There are worse things...like you think it's so major. And it is major. I'm not trying to take anything away from that, but I mean it's just like -- it's -- it's something that you can work with. It's -- it's not terminal" (P8). Similarly, another mother without LD shared,

"I think I just put it in perspective. He doesn't have cancer. His learning disability is not severe. He comprehends. Like my sister has told me over and over like she would so much rather have this problem than the other. So I mean that's what I just think, I just think of that. And just am so, like I just feel so

lucky. And there are so many problems in the world and there are so many kids with problems.” (P2)

Several parents talked about the prevalence of LD as a way of gaining perspective. One mother shared, “You know, it's so prevalent. Learning disabilities are not -- you're not in the minority” (P9). Other parents focused on the fact that every parent has some difficulty with their child. A mother without LD reflected, “You see that’s the thing I figured that’s what I’ve found, too, that every parent has something with their kid” (P2).

Some parents referred to their acceptance of their child’s struggle. One mother without LD shared her perspective that the struggle presents an opportunity for growth.

“We talked a lot about conflict and how conflict is an opportunity for growth...it’s a part of the human experience, conflict. You know, whether it’s externally with loved ones or work people or strangers or whether it’s internally” (P11).

A father with LD shared,

“And it’s kind of like there’s nothing you can do about the fact that your son or daughter has this thing. You can’t change it so just embrace it...Do what you can to help. But trying to fight it or ignore it or pretend it doesn’t exist or mask it or hide it doesn’t do anything because you will never succeed at doing that. So just embrace it and love your kids for who they are” (P3).

All of the parents with LD and none of the parents without LD either directly or indirectly indicated some ongoing effort to feel secure. Feelings of insecurity for these

parents primarily emerged around ensuring that their child was in a suitable academic environment. One father shared,

“There’s always questions...I really thought we had done right by him and we were sending him to this private school and spending the money and I thought we were done, you know? ...it was a big shock for me...it’s that worry and that for me is just like, you know, it’s just constant...” (P5).

One mother stated, “I’m not seeking for her to compete in the world with everybody else. I’m seeking for her to be the best she can be within her own situation. And so, it’s really just a matter of having her in the situation where she feels good about herself” (P6).

Another mother talked about the struggle to maintain her focus on building her son’s confidence while simultaneously having to surmount the many hurdles within her son’s school. “It is a constant struggle for the parents who like trying to instill the confidence in their child but...the parents are constantly having to climb these walls and go over these hurdles” (P7).

Half of the parents with LD and just over a quarter of the parents without LD demonstrated some ongoing and active internal struggle toward acceptance. One mother without LD admitted, “...those children [mainstream children] are people I identify with...I understand those children...the bottom line is -- I don't want anybody else's child...But I do wish parenting him were easier for me” (P10). Another mother without LD shared,

“There was definitely part of me that thinks people with learning disabilities oftentimes are more gifted, kind of like people with mental illness oftentimes are better artists I think than -- so I do think that there's definitely part of me that

thinks that and then there is another part of me that still equates it with dumb, as much as I know. Don't ever tell anyone I said that" (P1).

One mother with LD talked about the effort it takes her to resist succumbing to the evaluating the worth of her child on the basis of standards dictated by "bureaucracy of education." She said, "You have to just change your mind and believe it and it's hard when your child has an LD, it's hard" (P7).

## **Chapter 5: Discussion**

### **Introduction**

This study investigated the intrapsychic experience of parents of children with moderate to severe learning disabilities and compared the experiences of parents with and without learning disabilities. The influences of interpersonal, familial and systemic dynamics were also considered as these elements likewise affect the parents' internal experience. The inquiry was guided by the following three overarching research questions:

1. Given the powerful internal processes involved in parenthood, how does a child's moderate to severe learning disability affect a parent's intrapsychic experience?
2. How do external variables influence the intrapsychic experience of parents of children with learning disabilities?
3. In what ways are the intrapsychic experiences of parents with learning disabilities similar and distinct compared to each other, and compared to parents without learning disabilities?

This chapter offers a discussion of the findings from the data organized into four theoretical constructs (see Table 1): (1) Diagnosis as a Threat to Parental Narcissism; (2) Parents Engage Containing and Stabilizing Strategies; (3) The Centrality of Schools and Professionals; (4) Striving Toward Acceptance. Taken together, these four constructs form a theoretical narrative of sorts through which a nuanced understanding of the similar and different experiences of these particular parents of children with learning disabilities might be captured. Clinical implications and recommendations for professionals who

work with parents of children with learning disabilities, limitations of the study and possible directions for future research will be addressed.

### **The Theoretical Narrative**

#### **Diagnosis as a Threat to Parental Narcissism**

The findings in this study confirm existing theoretical and clinical literature that suggests having a child with a disability poses a significant threat to parental narcissism and self-esteem (e.g., Abrams and Kaslow, 1976; Als & Brazelton, 1984; Elson, 1984; Farjardo, 1987; Lax, 1972; Solnit & Stark, 1961). All of the parents in this study described with varying degrees of intensity a cascade of emotional responses to their child's learning disability diagnosis. Parents felt fear, anxiety, guilt, shame, disillusionment and other emotions in the face of their children's diagnoses. They experienced painful isolation, viewing themselves and their children as apart from the "normal" world. These emotional responses signaled the effect of the diagnosis on underlying psychological processes, specifically parental narcissism. While all parents in the study appeared to experience this threat, three important variables emerged in the findings that influenced the severity of the blow, the quality of the parent's response and the capacity to "recover" from this narcissistic trauma: the nature of the parent's identification with the child, the tendency toward psychological merger, and the quality of the parent's relationship with his or her own parents throughout childhood, adolescence and adulthood.

While a parent's identification with his or her child ideally promotes empathy (e.g., Sadow, 1984; Schwartz, 1984; Terman, 1984; Winnicott, 1971) these

identifications also placed parents in this study at risk of narcissistic trauma, both those with LD and those without. Comparatively, the parents with LD experienced more intensified identifications to their children with LD. Because of the degree to which the parents with LD felt linked to the “defect” in their child, they experienced greater levels of psychological vulnerability and thus were at greater risk of narcissistic trauma (Lax, 1972; Rothstein & Glenn, 1999). For example, while the parents without LD experienced guilt over the presence of their child’s LD, the quality of the guilt that parents with LD experienced was strikingly different. Rather than “blaming” the presence of the LD on some external force (“I took the Zoloft while I was pregnant with him” P1) or a failure to properly perform some task of parenting (“I didn't give him enough tummy time when he was a baby” P8), the guilt that parents with LD experienced was derived from believing that a quality internal to them, namely genetics, had caused the LD (“I just thought it was a genetic thing that he was that way because I was that way. That I passed it along it to him and that made me angry, it made me upset” P3). In addition, all parents experienced feelings of fear, anxiety, and uncertainty, but only parents with LD expressed having had trauma-like reactions to their child’s diagnosis (“It’s like, it -- it really is like -- like I’m having flashbacks of that experience” P6). Finally, the desire to protect one’s child was distinct for parents with LD. All parents wanted to protect their children from feeling badly about themselves or from invalidating experiences with others, but parents with LD expressed strong desires to protect their child from the experience they had as children with LD.

Identification with one’s child serves both parent and child. However, for optimal psychological growth and health the parent must also, in the presence of these compelling

identifications, work to view the child as a separate subject, as an individual unto him or herself (e.g., Parker, 1996; Sadow, 1984; Schwartz, 1984; Terman, 1984). For many of the parents with LD in this study, the intensity of the identification with the child made separation a more complex task, and moments of psychological merger were more common and in some ways more confusing than for parents without LD (“You’d think that in that situation I got -- I might actually be -- be more sympathetic and -- and like easier on her. But in fact, I think it’s -- it’s -- it’s made me feel angry at times...And push her beyond what she can do” P6). The two fathers with LD both of whom had sons with LD expressed mild envy of the accommodations and support their sons’ were receiving (“I wish I had some of the opportunities that [my son] had not only them recognizing it but also learning a different way” P3).

Yet, in various ways, both sets of parents “collapsed” the space between themselves and their children. Some parents without LD talked explicitly about a painful loss of connection to their child and the reality that their child’s struggle kept them from maintaining a much-desired fantasy of “likeness” with their child (“... not feeling as close to him when he doesn't reach his potential, because his father and I are ‘reach potential’ kind of people” P10). During these moments of merger, parents within both groups experienced their child’s LD as a kind of psychic threat, exposing to the outside world the parts of themselves about which they felt deep shame (“...we would be exposed...it just brought up so many anxieties about our intelligence” P1).

Parents’ early relational experiences with their own parents, along with their experiences as students, emerged as crucial variables that marked the quality of their internal experience and response in the face of their children’s LD. When parents

described having had a parent who was unable to imagine their internal experience as children and respond in an attuned and validating manner, they were at greater risk for narcissistic trauma in the face of their child's LD, experienced more complex moments or periods of merger with their child, and struggled with acceptance and resolution. This pattern emerged strongly in three of four of the parents with LD and two of the seven parents without LD, all of whom explicitly described invalidating relationships with their parents, some even emotionally abusive, along with repeated negative experiences as students. These findings bring to mind concepts from attachment theory (e.g., Ainsworth, 1978; Main et al., 1985; 1995); theories of mentalization (e.g., Fonagy et al., 1995; 2002), the enduring effects of parental misattunement and intersubjective failures (e.g., Stern 1985) on a child's budding narcissism; and theories regarding the profound power that failures with mutual regulation and interactive repair have on the child's psychological self (Tronick & Weinberg, 1997).

In contrast, and further substantiating research on the enduring effects of early attachment relationships and parental reflective function, those parents who described supportive relationships with their parents, even in the face of negative experiences as students (with or without LD) fared far better than those whose parents were unable to respond in an attuned manner. A striking example of this is participant #7, a mother with LD, who described in detail her experience of having attuned parents. She explicitly detailed the role they played in helping her to feel secure during childhood, adolescence and even now, as a parent of a child with LD. Her narrative was distinct from the other parents with LD, all of whom described suffering from parental rejection, sometimes severe, as a result of their parents' response to their struggles with learning. She was also

the only parent who noted the protective aspect of having had an LD, namely, that her family was “not new to this” and thus was better prepared on all levels to manage in the face of her son’s LD.

### **Parents Engage Containing and Stabilizing Strategies**

In the wake of their child’s diagnosis, many parents begin to find ways to contain their considerable fears and anxiety, stabilize their self-esteem, and ultimately mobilize in order to advocate for their child’s needs. For some parents, this mobilization is immediate, and serves as the primary instrument for containment and stabilization. Most of the parents in this study—both those with and those without LD—engaged in adaptive strategies to cope, demonstrating a capacity to reach out for resources and support from partners, family members, friends, professionals, adults with LD and other families with children with LD. In order to engage in these adaptive, support-seeking behaviors, parents had to tolerate feelings of shame and guilt, risk exposure, and press through to advocate for their children’s needs. This capacity to “join and connect” to others around the experience of having a child with LD appeared to be crucial in the parent’s process of healing.

These findings support empirical studies that highlight the role of socio-ecological factors in adaptive coping. These factors include the extent of felt partner support (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989), the quality of family relationships (Dyson, 1993), the presence of extended family support (Sharpley et al., 1997), experiences of peer support (Ditrano & Silverstein, 2006; Stallard and Lenton, 1992), ability to access and utilize community resources (Dyson, 2010) and the existence

of professional support (Resch et al., 2010; White & Hastings, 2004). Underlying this capacity to adapt is a sense of self-efficacy (Bandura, 1986), a belief that adaptation is possible (Johnson et al., 2006) and a capacity to maintain a positive frame of reference even in the face of significant challenges (Harris & McHale, 1989). Essential to these parents' ability to access support and resources is a capacity—even momentary—to view their child as a separate subject (e.g., Abrams and Kaslow, 1976; Lax, 1972; Solnit and Stark, 1961).

While parents engaged in adaptive coping behaviors, they also employed avoidant strategies to contain fear and anxiety and stabilize self-esteem. All parents with LD relied on poignant commentary about societal or political conditions that they believed kept those with LD in subjugated positions. None of the parents with LD hid, minimized or denied the existence of their child's LD. This was in striking opposition to the parents without LD who *all* either hid, minimized or denied their child's LD, but never got “political” about their child's LD. This phenomenon speaks to important differences in the internal experiences of parents of children with LD.

The exclusive use of hiding, minimization and denial by the parents without LD emerged as primary strategies employed to ward off the narcissistic threats to which they were exposed by virtue of their child's LD. For some parents, minimization or denial appeared to be unconscious (“I didn't buy it. I didn't believe it...I was angry that they had said that and I was just sort of like, that's not gonna happen. You know, I didn't feel like it wasn't gonna happen with him” P11). For others, hiding or minimizing their child's LD was intentional, and used expressly as a method of protecting self-esteem (“And then once we got the numbers though, I never told anyone the number, ever...I

didn't want it out there. I wanted my interpretation to be what was publicized... Like, you know, we're not telling anyone. We can give them a general idea. We're not telling numbers. We're not showing it to anyone" P1).

Perhaps because the parents with LD had experienced LD first-hand, the use of denial in any form was made more difficult, while the intensified identifications these parents felt to the child made the urge to fight for recognition all the more compelling. Strikingly present in each of these parents' commentary were strong references to exclusion from the mainstream that signaled the well-documented and painful psychological, social and emotional effects of having lived a life with a disability (Bucholz, 1987; Coen, 1986; Garber, 1991; Herman & Lane, 1995; Kafka, 1984; Migden, 1990; Moore, 1995; Myers, 1989; Shane, 1984; Shessel & Reiff, 1999; Silbar & Palombo, 1991). In their commentaries, these parents were fighting for equity, for recognition, for a definition of "able" that expanded to include them and their children, in spite of their differences ("And I -- I feel like whatever percentage of children who have this so-called disability, there's -- there's a reason they have it. It's not, I mean I -- I hate the term disabled. They're not disabled, they're differently abled. And why aren't we universally looking at the differently abled persons and teaching reading, understanding it better so that it's not a disability, it's a -- it's another ability" P6). These parents were fighting for the sociocultural conditions that would promote not only their children's healthy self-esteem, but their own as well.

### **The Centrality of School Personnel and Other Professionals**

Parental adaptation and coping in the face of a child's learning disability is directly linked to the quality of relationships the parents have with particular social

systems external to the family system (Pentyliuk, 2002; Resch et al., 2010). This study confirms these findings, and locates school personnel and other professionals as central in the lives of parents of children with learning disabilities. The parents in this study spoke at length and with great passion about the positive and negative experiences they had with professionals with whom they consulted to meet their child's needs.

The data suggests that school officials and other professionals perform essential "holding" functions (Winnicott, 1971). Parents felt more secure and hopeful in the context of empathic, attuned, "collaborative and contingent" (Ainsworth, 1978) interactions with professionals, and thus, were more confident that their children's needs would be met. The text-based categories speak to these holding qualities, and underscore the trust and confidence parents felt within the context of relationships characterized by these qualities. Parents felt more trustful when interactions and relationships with professionals were characterized by transparency ("[His teachers] were saying 'we're not saying anything definitely but we're just saying this is what we're noticing and you should know'" P2). They were reassured when they and their children "felt seen" by professionals ("She saw his strengths and the weaknesses...she was actually able to work with him on... I felt fantastic, because I know he felt fantastic" P8). Their confidence was buoyed when they believed that the professional with whom they were working was capable of helping their child. Indeed, the extent to which appropriate resources and interventions were delivered from professionals within and outside of the school setting corresponded to these parents' sense of security. Given the narcissistic vulnerabilities these parents experience, establishing safe and secure connections between professionals and parents is elemental to the success of the relationship.

Over the course of repeated negative encounters, school personnel and other professionals may also come to represent invalidating forces in parents' lives. Findings from this study substantiate existing literature that speaks to the profound impact of professionals' failure to engage in collaborative, transparent and sensitive processes with parents (e.g., Crown, 2009; Kroth, 1987; Turnbull, 1983; Waggoner & Wilgosh, 1990). Parents in this study spoke of needing professionals to demonstrate an ongoing awareness of the daily demands and strains they face as parents of children with LD. They expressed anger, frustration and insecurity when they felt their child was not "understood" by his teachers, seen only for his difficulties, and not for his unique gifts as well ("It's like they don't understand who he is" P8). Further, they expressed great frustration about the extent to which their children's needs were minimized, ignored or went unmet, confirming findings from previous studies (e.g., Dyson, 2010; Resch et al., 2010; Waggoner & Wilgosh, 1990). For example, a mother without an LD shared, "...the reading specialist at the school said, 'We don't think it's that bad.' I was like 'are you kidding me? Like the report is in front of you.' The psychologist is right here and they're still questioning it" (P9). In the presence of invalidating experiences, parents felt greater isolation, increased fear and uncertainty, and a deep sense of insecurity about their child's fate. These feelings and qualities cluttered the relationship with additional conflict further complicating parents' process of advocating for their child's needs.

Just as children develop secure attachments to parents who are reflective, attuned, and appropriately responsive during moments of rupture, so do parents experience much needed security with professionals who offer something similar. Conceptualizing the relationship between parents and professionals in such a way could illuminate not only

the reasons underneath the frequent roadblocks in these relationships, but also the ingredients that lead to successful collaborations.

### **Striving Toward Acceptance**

It has been theorized that becoming a parent provides a person with important opportunities to rework and resolve past conflicts across developmental phases, leading to structural change (Benedek, 1959) further self-consolidation (Farjardo, 1987; Sadow, 1984) and more mature forms of empathy (Elson, 1984). Confirming these theoretical formulations, many of the parents in this study spoke of poignant personal transformation and increased empathy for themselves and others as a result of parenting their child with LD. Almost all of the parents with LD and half of the parents without LD spoke explicitly about the way in which parenting their child with LD supported their own healing from the wounds of their childhood. Coupled with the influence of parenting, some parents also described their experience of healing through their own parents' expanding empathy and compassion in the face of their grandchildren's LD. These grandparental transformations appeared instrumental in helping some parents work through unresolved wounds from childhood.

While many parents explicitly referred to their own growth and demonstrated acceptance of their children, others—especially those with LD—remained in a kind of limbo state, struggling to feel secure or to more completely come to terms with the reality of their children's LD. This journey toward acceptance was complex and non-linear with unstable resolutions for some of the parents in the study. Though the reasons for this are

difficult to expressly apprehend from the data, perhaps parents' successful journey toward acceptance was contingent upon their engagement in a process of mourning.

As has been theorized, mourning the loss of the fantasied child enables parents to see the unique gifts of the real child in front of them (Solnit & Stark, 1961) and is essential to the parents' capacity for acceptance and ultimate healing (e.g., Abrams & Kaslow, 1976; Farjardo, 1987). Yet mourning is dependent upon the parent's ability to come to view the child as a separate entity, rather than merely a damaged part of the self of the parent (Als & Brazelton, 1984; Shabad, 2001). Thus, perhaps the most crucial determinant of transformation and acceptance emerging from the data was the parents' capacity to achieve psychological separation from their child in the wake of sufficient mourning, a far more complex process for most of the parents with LD (e.g., Archowitz, 2000; Herman & Lane, 1995).

Unresolved loss or incomplete mourning, paired with a tendency to merge with one's child may explain in part some parents' difficulties with acceptance and healing. Yet, the stressful realities of navigating the needs of a child with an LD should not be minimized. Uncertainty about one's child's future is an inherently insecure position from which to achieve resolution. Moreover, with each passing developmental phase or milestone, crushing fear, anxiety, shame and guilt may be reawakened yet again as one observes one's child passing through—or struggling to overcome—new hurdles. Thus, access to and availability of adequate and appropriate information, resources and support from professionals emerge as critical variables, mitigating the effects of the child's LD and creating a more stable context within which parents may move toward acceptance.

### **Implications and Recommendations for Professionals**

The overarching aim of this study was to positively influence the manner in which all parents of children with LD are understood, represented and treated by the professionals with whom they must interact to secure necessary services for their child. The findings from this study echo findings from previous studies that suggest that when parents feel well-supported by professionals during times of considerable stress, they are better able to respond effectively to the needs of their child (e.g., Ditrano & Silverstein, 2006; Keller and Honig, 2004; Resch et al., 2010). Further, the findings suggest that adversarial relationships and interactions with professionals become yet another source of stress for parents, diminishing the reserve of emotional energy necessary to adequately mobilize in the face of their child's LD. Given the high numbers of children and adolescents diagnosed with learning disabilities (Cortiella, 2011) many psychologists, school personnel and other service providers currently do or inevitably will treat and/or evaluate such children and their parents. It is hoped that the following recommendations will prove useful to the many professionals who serve this population.

The findings from this study support existing suggestions that parents of children with learning disabilities must trust and feel confidence in the professionals with whom they work to support their child (e.g., Solnit & Stark, 1961), arguably even more crucial for parents of children who struggle. These essential feelings emerge only within an empathic and validating relationship with a professional who is mindful of these particular parents' vulnerability (e.g., Amerongen & Mishna, 2004), and the even more acute narcissistic vulnerability faced by parents with LD (e.g., Arkowitz, 2000; Garber, 1991; Linington, 2002; Moore, 1995; Shane, 1984). Professionals ideally actively listen,

validate parents' subjective realities, represent the child's strengths and vulnerabilities in an authentic and sensitive manner, and titrate the delivery of difficult information to match the parents' particular state (e.g., Amerongen & Mishna, 2004). Professionals are careful not to undermine the strategies that parents may employ to cope, and as trust develops over time introduce new skills and strategies and reinforce adaptive approaches already employed by parents. During trying interactions with parents, professionals ideally engage their reflective capacities, imagining the parents' underlying feelings of fear, anxiety, shame and guilt that often produce unpleasant encounters, and responding in measured, non-reactive and reassuring ways. Importantly, professionals tailor their responses to and interventions with parents to account for the culturally influenced meanings that these parents give to their child's LD, (e.g., Neely-Barnes & Dia, 2008).

Echoing prior findings (e.g., Als and Brazelton, 1984; Keller & Honig, 2004; Pentyluk, 2002; Turnbull, 1983; Wilchesky & Reynolds, 1986) the parents in this study valued transparency, collaboration and accessibility in their interactions with professionals. These qualities were a part of relationships that were characterized by trust and confidence and were less likely to become adversarial. To that end, professionals should make efforts to be open and direct with parents about their concerns while simultaneously sensitive and individualized in their delivery. Professionals should use specific and carefully selected examples to illustrate a child's strengths and weaknesses in order to make these difficult conversations less abstract. To the extent possible, professionals should involve parents in evaluation processes, and engage parents in straightforward conversations about the results and implications of these evaluations. This kind of collaborative approach empowers parents, helping them to feel more capable

of responding to and advocating for their child's needs (e.g., Ditrano & Silverstein, 2006).

Parents need professionals to serve as competent resources, providing clear answers to questions, demonstrating specific and accessible interventions that are uniquely tailored to parents' and children's needs (e.g., Keller & Honig, 2004; Resch et al., 2010) and offering useful referrals to additional sources of support (e.g., Dyson, 2010; Kenny & McGilloway, 2007; Pain, 1999; Stoll Switzer, 1985, 1990). Ideally, these relationships are continuous and evolve over time as parents witness their children's unique gifts and accomplishments and repeatedly face the difficult realities of their child's LD.

School communities play tremendous roles in the lives of these parents. Along with the recommendations detailed above, schools can provide a much-needed sense of connection and community for parents of children with LD. Nearly all parents in this study wanted to join and connect to others who faced similar challenges in parenting a child with LD. As a mother without LD described, "I'm kind of excited to start [son's] new school and meet other parents. I think we'll have a lot in common and like a certain respect that you'll completely have for, you know, these other, you know, parents...I mean the equivalent would be a support group. I mean in the end it's trying to find the people -- have the people around you that are most supportive" (P9). School personnel can and should arrange such points of contact, creating small support groups, offering individual support meetings or holding informative talks with professionals who work with children and adolescents with LD and their families. All parents need to feel included in their children's school communities; this may be even more essential for

parents of children with LD who daily face the painful realities of exclusion on the basis of exceptionality (e.g. Ditrano & Silverstein, 2006).

School leaders should make efforts to thoughtfully increase community awareness of and sensitivity toward the diverse range and manifestations of LDs, and the influences of LDs on family systems. In these efforts, they should work to highlight the normality of difference and the appropriateness of differentiation, thus reducing the potential shame that children with LD and their parents often feel. Professional development opportunities for educators should be individualized to match the school setting (i.e., special education setting vs. mainstream setting) and the specific needs of the teachers and specialists within the school setting.

School leaders, along with school psychologists and learning specialists, should formulate comprehensive and appropriately flexible plans for detection of and intervention for LDs. These plans should include careful recommendations for when and how to begin conversations with the parents of children of concern and what actions precede these conversations. When parents are first to initiate a conversation about their concerns, school personnel should take these concerns seriously, following up informal assessment to gather additional information, offer feedback to parents, and if warranted, implement appropriate interventions. Schools should thoughtfully consider how to partner with parents in gathering and making sense of assessment data, and how teachers and specialists will differentiate curriculum and instruction to meet the identified needs of the child. Ongoing informal assessment is essential to ensure that the child's learning needs are being addressed, and when the child is not progressing, goals and plans for intervention should be reviewed and revised accordingly. Parents should be included in

these processes to the extent possible, kept informed of the efforts that educators are making, and the ways in which the child is responding over time. Only after serious attempts at intervention have occurred, if educators find that the child's needs exceed the offerings of a particular school setting, parents should be sensitively informed and guided in finding additional sources of support. Throughout this process, educators should commit to actively recognizing and developing the child's competencies and interests, reinforcing with the child and his or her parents the notion that one's struggles are but a single facet of an intricate, multifaceted mosaic of being.

### **Limitations of the Study**

This study provided a rich and in-depth view of the experience of a small sample of parents of children with LD, some of whom had LD themselves and some of whom did not. The findings that emerged from the analysis of the data echoed existing theoretical, clinical and empirical research on parents of children with LD, a largely understudied group especially within the psychoanalytic literature. However, like all studies, there were a number of critical limitations.

Qualitative research involves the careful analysis and interpretation of text and interviews to uncover important patterns that illuminate a particular phenomenon (Auerbach & Silverstein, 2003). This process is carried out using small samples in order to capture the nuances of individual stories, seen as vital to developing hypotheses and theories about phenomenological experience. While critical to this kind of research, the small sample size is also an inherent limitation, making it difficult to generalize the findings to the larger population of parents of children with LD. Thus, while the

theoretical narrative developed from this sample of parents of children with LD is meaningful, it is also limited in terms of generalizability. Moreover, while the inclusion criteria limited the number of variables in this qualitative study, many potentially important variables were not controlled for and further reduced the possibility of producing generalizable results.

One such variable that was not controlled for or adequately explored was the presence and impact of comorbid behavioral problems in the children of these parents. Behavioral problems in children with disabilities have widely been found to substantially increase parental distress and stress levels (e.g. Baker, Blacher, Crnic, & Edelbrock, 2002; Dunst, Trivette, Hamby, & Pollock, 1990; Johnson, O'Reilly, & Vostanis, 2006; Johnston et al., 2003; Keller & Honig, 2004; Margalit, Shulman & Stuchiner, 1989; Ong, Chandran, & Boo, 2001; Raina et al., 2005; Smith, Oliver, & Innocenti, 2001; Spratt, Saylor, & Macias, 2007). Given this, the intrapsychic experience of parents of children with LD and behavioral problems are likely distinct from those parents of children with LD who do not struggle behaviorally.

Participants in this study were recruited using convenience and snowball sampling, and the researcher drew from existing contacts in settings largely populated by White, upper-middle class families. As a result, the sample of parents in this study, with little exception, was racially and socioeconomically homogenous, a significant limitation in this study. In addition, most of the participants were mothers (82%) and only two of the eleven were fathers. Most parents were married and in heterosexual unions (82%) and all of these parents were earning above \$150,000 annually. There were two single, divorced mothers, one of whom reported earnings of between \$50,000 and \$74,000

annually, and the other less than \$20,000 annually. Because of the homogeneity of the sample, it was difficult to ascertain the influence of these essential identity variables on the experiences of parents of children with LD. Thus, the findings speak more specifically to the experiences of straight, married mothers whose social location afforded them greater access to services and a range of options to support their child. Given this homogenous sample, the study failed to adequately represent the role of financial strain on parents' internal experience, and was severely limited in its exploration of the impact of reduced access to intervention and remediation because of limited financial resources. Indeed, financial strain and its role in the acquisition of resources has been identified as a central concern for parents of children with disabilities in other studies (e.g., Dunst, Trivette, & Cross, 1986; Keller & Honig, 2004; Resch et al., 2010) and thus could be further explored within a psychoanalytically oriented study.

Parents in this study were asked to report whether or not they themselves had an LD, but were not asked to provide supporting documentation to confirm or deny the existence of an LD. Given the ages of the parents in this study, and the emergent state of the LD field during the time they were school-age, this identification was made complicated. For example, it was unclear whether those parents whose self-reports indicated no LD may actually have had an undiagnosed LD. This limitation calls into question the validity of the distinctions made across the two groups of parents within the sample.

The children of the participants in this study mostly attended general education settings, primarily private. Given this, it was impossible to ascertain important differences between the parents' experiences according to the type of school setting.

Future studies could examine the way in which having a child in either an exclusively special education setting or a mainstream setting with or without support services on site might impact parents' internal experience.

The study set out to examine the intrapsychic or internal experience of parents with children with LD, and the effects of external variables on parents' internal experience. Apprehending internal or intrapsychic process is inherently difficult given the nature of unconscious process, the ubiquitous engagement of various defenses, variability in the representation and interpretation of internal life across subjects and experiences, and the complex effects of characterological qualities, often undetectable or at best unsubstantiated within the context of a relatively brief interview encounter. While clear patterns emerged across the interviews, and themes were identifiable that enlivened a particular phenomenology, it remains questionable how adequately this researcher was able to capture and adequately examine intrapsychic experience.

### **Future Research**

This study contributed to a limited body of psychoanalytically oriented qualitative research focused on parents of children with learning disabilities, especially parents who themselves have LD. Given the paucity of such research coupled with the limitations of this study, future research is necessary to round out a more comprehensive understanding of the particular experiences of this population. With further study, professional support can be more adequately tailored to meet needs of parents of children with learning disabilities.

Given the homogeneity of the sample in the current study, future research should focus on the experiences of parents of children with LD from across a variety of racial, ethnic, socioeconomic backgrounds. For many of the parents in the current study, economic stress was not a barrier in their efforts to respond to their child's needs. Arguably, however, for many parents economic stress presents significant obstacles, and parents are thus limited in the kinds of services they might otherwise be able to provide for their child (e.g., Dunst, Trivette, & Cross, 1986; Keller & Honig, 2006; Resch et al., 2010). This was a clear consideration for participant #6, the only participant in the study to earn less than \$20,000 annually. She shared,

“You know, single motherhood has me ---- you know, stretched pretty thin...I mean I've talked to parents who simply do like, they go -- they go from point A to point B. You call this intervention person, you hire this lawyer, you have the test done, you get this tutor, you spend X amount of dollars doing it, and by eighth grade your kid is reading...Like, I've heard it -- I mean, I'm like wow, really? Yeah, but it cost us, you know, forty thousand dollars to do it...Okay. You know, that's one way to do it. But, you know, and they are a two family, you know, two-parent family.”

Comparative research using a racially and ethnically diverse sample of parents may uncover deeper understandings about the ways in which the meanings and responses to LD are linked to culturally bound phenomena. Indeed, social constructionist perspectives of disability suggest that definitions of disability arise within particular cultural contexts, and thus meanings and responses to disability are inevitably diverse (e.g., Ferguson, 2001; Olkin, 1999). While such studies exist within the disability and

psychology literature (e.g. Blacher & McIntyre, 2005; Gardner et al., 2004; Ow, Tan & Goh, 2004) there is a need for psychoanalytically oriented studies which examine these influences on the internal experience of parents of children with LD.

The experiences of the two fathers in this study prompt considerations for future research. Both were LD, had sons with LD, and suffered mightily during childhood and adolescence as a result of their parents' misattunement, and at times, emotional abuse on the basis of their struggles with learning. Gender, specifically masculinity, emerged in the data as a potentially deep concern for the fathers in this study. As memories of childhood reawakened in the face of their sons' LD, they seemed to experience their masculinity as threatened or in need of strident defense, at times becoming "macho" or employing a kind of bravado during the interviews, strikingly uncharacteristic of the mothers in the study ("You know, I have guys that went to Harvard Law that work for me and they couldn't make a dollar if I didn't teach them how to do it" P3). Future research focused on fathers and sons with LD could illuminate the possible effects of LD on their experiences of masculinity.

Migden (2002) has written about clinical work with adolescent boys with LD and their fathers with LD, suggesting that fathers' narcissistic wounds are reignited by their sons' struggles thus prompting anger and criticism directed toward their sons. While the fathers in this study suffered narcissistic trauma, rather than overt anger and criticism directed toward their sons, the data was characterized more frequently by tenderness and a desire to protect their sons from suffering. Thus, this study indicates the need for a more nuanced picture of the experiences of and responses from fathers with LD, especially those fathers who have sons with LD. Likewise, a companion study of

mothers and daughters with LD could illuminate the potential similarities and differences across these groups.

This study did not consider the effects of the passing of time and the shifts in parent and child development on the parents' internal experience. Longitudinal studies may provide important insights into the ways in which parents' internal experiences may shift over time. In addition, a study focused on the parents of adult children with LD may not only illuminate changes over time, but also be helpful in tailoring recommendations for professionals who work with children and adolescents with LD and their families. Further, this focus may prove useful to parents of children and adolescents with LD, offering a glimpse of the possible range of experiences that may be on the horizon and thereby containing the anxiety that comes with the sense of uncertainty about one's child's future.

A companion study focused on the experiences of teachers of children with LD could prove highly useful. Teachers play central roles in the lives of these children and are often subject to a similar but different narcissistic threat in the face of a student's LD. Over and over, teachers are looked to for answers by parents, children and administrators alike and often view themselves as responsible for (or capable of) "fixing the problem." This implicit and at times explicit expectation leads teachers to experience considerable anxiety and fears of failure. Simultaneously, parents are enduring considerable anxiety and fear and trying to protect themselves from overwhelming shame and guilt. Given this highly charged emotional context, the dynamic between teachers and parents can easily take an adversarial or contemptuous tone as both parties work hard to ward off risks of exposure or feelings of shame. Thus, a study focused on teachers of children and

adolescents with LD could round out an understanding of the often stressful dynamics that are created between families and schools.

### **Concluding Statement**

This qualitative study examined the intrapsychic experience of parents of children with LD and compared the experiences of parents with and without LD. External elements were considered, as they likewise influenced the internal experience of these parents. The hope was that the findings from this study would contribute to a limited body of psychoanalytically influenced research on these parents. A further hope was that the findings would improve the quality of support these parents receive from the many professionals with whom they interact to advocate for their children's needs.

Through the use of grounded theory, four theoretical constructs were identified from the data: (1) Diagnosis as a Threat to Parental Narcissism; (2) Parents Engage Containing and Stabilizing Strategies; (3) The Centrality of Schools and Professionals; (4) Striving Toward Acceptance. Taken together, these constructs form a theoretical narrative that details these parents' similar and different experiences. The findings demonstrate the significant threat to parental narcissism, particularly for parents with LD who were acutely identified with their child with LD but also for any of the parents whose relationships with their own parents were marked by misattunement, sometimes severe. Indeed, early relational experiences with one's parents emerged as a protective factor, guiding these parents more smoothly toward adaptation, acceptance and healing. The findings revealed similarities and interesting differences in the ways parents with and without LD contained their fears and anxieties and stabilized self-esteem. All parents

engaged in some sort of adaptive “action” by seeking resources and making connections to others who had some knowledge of LD. Yet all parents with LD utilized a kind of political commentary for containment and stabilization, while all parents without LD engaged in hiding, minimizing or denying their child’s LD. School personnel and other professionals came to represent “holding” or invalidating entities and were central influences in these parents’ experiences. Finally, parents’ journeys toward acceptance were complex, characterized by moments of personal transformation and healing along with lack of resolution and ongoing periods of insecurity. Mourning processes and a capacity to achieve psychological separation from one’s child appeared crucial to healing, feats that were more complex for parents with LD. External sources of support, including access to appropriate services were likewise influential in the parents’ process of adaptation and healing.

Being a parent is arguably one of the most simultaneously rewarding and trying identities a person can inhabit. Given the massive psychological vulnerability inherent in this identity, the urgency a parent can feel to produce a thriving, successful child can be immense. For parents who have children who struggle, the “failure” to produce such a child leads to terrifying moments of helplessness and exposure, but also opens a space for profound experiences of transformation. The professionals who work with these parents and their children serve crucial roles, creating secure spaces in which parents safely experience their vulnerability and refuel to engage necessary resources for themselves and their children. In the context of these attuned relationships, parents find paths toward acceptance, healing, and ultimate transformation.

## Appendix A

### Interview Questions

1. How would you describe your child? Can you think of a character in books, movies or television that best represents your child? Why or how?
2. How would you describe yourself?
3. What words come to mind that characterize who you were as a student? Do you have specific memories that represent the words you've chosen?
4. Before you became a parent what did you picture in your mind when you imagined the child you would have?
5. Did this change at all after your child arrived or at any point in your child's life? How? In what ways?
6. When was the first time you remember giving any thought at all to your child's learning?
7. If so, what did you notice? What did you think and feel then?
8. Who, if anyone, influenced your thoughts, feelings and actions?
9. What was your perception of a "person with a learning disability" or a "child with special needs" at that time?
10. What led you to seek an evaluation for your child?
11. Describe the evaluation process.
12. Think back to the moments during and just after you received feedback from the evaluator. What do you recall of those moments?
13. What was it like to meet with person who did the evaluation? What do you think this person thought of you? Of your child?
14. Can you recount specific instances of sharing information about your child's learning disability with others in your life? Instances of withholding information? Why do you think you shared or withheld?
15. Can you give me an example of how your child's learning disability shows itself? (around the house; within the family; at school; on play dates; on the playground, etc).

16. Can you recount a moment when you observed your child demonstrating competency and experiencing success?
17. Why do you think your child has a learning disability?
18. How, if at all, does your child's learning disability influence how you see yourself? Your child? Your partner? Your other children? Your parents?
19. How, if at all, does your child's learning disability influence your relationship with your parenting partner? (if applicable)
20. Is there a day that comes to mind when you felt particularly worried about or for your child? Do you recall a moment when you just melted down?
21. What about a moment when you felt pride in or hope for your child?
22. What do you imagine for your child's future?
23. What do you do when you feel upset about your child's learning disability?
24. Can you describe your child's teacher? What do you think s/he thinks of your child? Of you?
25. Does your child work with any specialists? (psychologist, tutor, etc.) What do you think s/he thinks of your child? Of you?
26. Describe an interaction with any of these professionals that sticks in your memory.
27. Have you changed through this experience? If so, how?
28. What advice might you give to a parent who is just discovering that his/her child has a learning disability? What do you imagine another parent might feel?
29. Is there anything that you might not have thought about before that occurred to you during this interview?
30. Is there anything else you think I should know in order to understand you better?
31. Is there anything you would like to ask me?

**Appendix B**Demographic Survey

Please fill out the following questions to the best of your ability. If you do not understand or cannot read a question, or need any other help with any part of the survey, don't hesitate to ask the researcher who is happy to help you.

1. What is your age? \_\_\_\_\_
2. Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_
3. What is your sex? \_\_\_\_\_

**4. Race/ Ethnicity:**

How do you describe yourself? (*Check one option that best describes you*).

- American Indian/ Native American or White Alaskan
- Hawaiian or Other Pacific Islander
- Asian or Asian American
- Black or African American (non-Hispanic)
- Hispanic or Latino/a (specify origin) \_\_\_\_\_
- Middle Eastern/ Arab
- Multiracial
- White (non-Hispanic)
- Other \_\_\_\_\_

**5. Place of birth:** \_\_\_\_\_**6. Primary Language(s) Spoken:**

- English
- Spanish
- Both English and Spanish
- Other (specify) \_\_\_\_\_

**7. Religious Affiliation/ Identification:**

- Buddhist
- Catholic
- Islamic
- Jewish
- Protestant
- Other (specify) \_\_\_\_\_
- None

**8. Education:**

What is the highest grade, year or level of school you have completed?

- Never attended school or only attended kindergarten  
 Grades 1-8 (Elementary)  
 Grades 9-11 (Some high school)  
 Grade 12 (High school graduate)  
 GED  
 College 1 year to 3 years (Some College)  
 College 4 years+ (College Graduate)  
 Graduate School (Advanced Degree) Please specify degree: \_\_\_\_\_

**9. Marital status:**

Are you:

- Married (indicate heterosexual or same-sex marriage) \_\_\_\_\_  
 Single  
 Domestic Partnership (indicate heterosexual or same-sex DP) \_\_\_\_\_  
 Civil Union  
 Remarried (indicate heterosexual or same-sex marriage) \_\_\_\_\_  
 Divorced  
 Widowed  
 Separated  
 Never married  
 A member of an unmarried couple (indicate living with/ not living with)

**10. Employment Status:**

Are you:

- Employed for wages (indicate full or part time) \_\_\_\_\_  
 Self-employed (indicate full or part time) \_\_\_\_\_  
 Student (indicate full or part time) \_\_\_\_\_  
 Stay-at-home parent/ homemaker  
 Military  
 Unemployed for more than 1 year  
 Unemployed for less than 1 year  
 Retired  
 Disabled/ Unable to work

What is your occupation (if applicable): \_\_\_\_\_

**11. Family Size:** (include biological, non-biological and adopted children)

How many children do you have?

\_\_\_\_\_

What is/are the age(s) of your child(ren)?

\_\_\_\_\_

How many of your children are biological?

\_\_\_\_\_

How many of your children are adopted?

---

How many of your children are non-biological and not adopted?

---

How many of your children currently live in the home with you?

---

**12. Household Income:**

What is your total household income?

- Less than \$10,000  
 \$10,000 to \$19,999  
 \$20,000 to \$29,999  
 \$30,000 to \$39,999  
 \$40,000 to \$49,999  
 \$50,000 to \$74,999  
 \$75,000 to \$99,999  
 Over \$150,000

**13. Medical:**

Do you or your partner (if applicable) have any chronic medical problems and/or life-threatening medical conditions?

---

*(Serious medical or physical condition that requires regular care)*

If yes, specify:

---

Does your child have a chronic medical problem and/or a life-threatening medical condition?

---

*(Serious medical or physical condition that requires regular care)*

If yes, specify:

---

**14. Your child's learning disability:** *(if you have more than one child with an LD, please include information about both/all children with LD)*

How old is your child who has an LD?

---

At what age was your child diagnosed with a learning disability?

---

What is your child's diagnosis?

---

Who performed the testing?

---

Where does this child fall in birth order? (only child; youngest, oldest, middle child, etc.)

---

**15. Pregnancy:**

Was the pregnancy and birth of this child uncomplicated (full term and normal)?

\_\_\_\_\_

If no, please describe the complications.

\_\_\_\_\_

\_\_\_\_\_

**16. Child's Development:**

Did your child exhibit any noticeable developmental delays or difficulties early in life? (language delay, motor delay, etc.) \_\_\_\_\_ If yes, please describe. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**17. Presence of Learning Disability in family:**

Do you, your partner, or anyone in your or your partner's family have a learning disability? \_\_\_\_\_ If yes, who? \_\_\_\_\_

\_\_\_\_\_

What is the nature of the learning disability?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**18. Your child's schooling:**

Where does your child attend school?

\_\_\_\_\_

What grade is your child in?

\_\_\_\_\_

Did your child attend a different school before his/her current school placement?

\_\_\_\_\_

If yes, what school(s)?

\_\_\_\_\_

Why did your child change schools?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Does your child qualify for services to meet his/her learning and or social/behavioral needs? \_\_\_\_\_ If yes, which services and what is the frequency of these recommended services?

\_\_\_\_\_

\_\_\_\_\_

Does your child actually receive the recommended services to meet his/ her learning and/or social/ behavioral needs? \_\_\_\_\_ If yes, which services and what is the frequency of these services?

---

If no, why not?

---

Are these services rendered in school?

---

If yes, by whom?

---

Are these services rendered outside of school?

---

If yes, by whom?

---

**Table 1: Theoretical Constructs, Themes and Text-Based Categories**

	Total %	LD %	Non-LD %
<b>Diagnosis as a Threat to Parental Narcissism</b>			
Emotional responses to diagnosis			
Fear and anxiety	100%	100%	100%
Traumatic re-experiencing through child's diagnosis	18%	50%	0%
Guilt	91%	100%	86%
Disconnect between fantasy and reality	73%	50%	86%
Desire to protect child	91%	100%	86%
Enduring influence of the relational past			
Negative experiences as a student	73%	100%	57%
Supportive responses from one's parents	27%	25%	29%
Negative responses from one's parents	45%	75%	29%
"We're not new to this"	1%	25%	0%
The space between parent and child collapses			
Child's vulnerability exposes parent to threat and shame	63%	75%	57%
Moments of merger with child	36%	75%	14%
Envy of what child gets/ what they didn't get	18%	50%	0%
<b>Parents Engage Containing and Stabilizing Strategies</b>			
Parents engage in adaptive strategies			
Parents seek evaluation and/or intervention	100%	100%	100%
Joining and connecting	73%	75%	71%
Parents engage in avoidant strategies			
Parents get "political" or engage sociopolitical commentary	36%	100%	0%
Parents hide, minimize or deny child's struggle	64%	0%	100%
<b>The Centrality of School Personnel and Other Professionals</b>			
Schools and professionals as holding environments			
"He feels seen by these people"	55%	50%	57%
Transparency	27%	25%	29%
Confidence in professional's ability	55%	75%	43%
Professional as attuned advocate	45%	50%	43%
Schools and professionals as invalidating environments			
Parents know something is not right; school in denial	55%	50%	57%
Imagined or real rejection	64%	50%	71%
School resistant to interventions	55%	50%	57%
"They don't understand my child"	36%	25%	43%
<b>Striving toward acceptance</b>			
Expansion of compassion and empathy			
In parent	73%	50%	86%
In grandparent	36%	25%	43%
Seeing the child, healing the self			
Balanced representation of the child	100%	100%	100%
Capacity to experience child as a separate subject	36%	0%	57%

Parenting the child heals the self	55%	75%	43%
Moving toward acceptance, struggling in limbo			
Putting things in perspective	73%	75%	71%
Ongoing effort to feel secure	36%	100%	0%
Active internal struggle toward acceptance	36%	50%	29%

*Note: N=11. The percentages refer to the percentage of parents who used the text-based category.*

**Table 2: Demographics**

ID	Age	Sex	Marital Status	Education Level	Income	Race	# of kids	Parent LD	Family LD	Child's School	School Change
1	45	F	M	Graduate Degree	\$150,000 or greater	W	2	N	Y	Private General	Y
2	46	F	D	Graduate Degree	\$50,000-\$75,000	W	1	N	Y	Private General	N
3	49	M	M	College Degree	\$150,000 or greater	W	2	Y	N	Public General	N
4	43	F	M	Graduate Degree	\$150,000 or greater	W	3	N	N	Private Special	Y
5	44	M	M	Graduate Degree	\$150,000 or greater	L	2	Y	Y	Private Special	Y
6	52	F	D	College Degree	Less than \$20,000	W	1	Y	Y	Public General	N
7	39	F	M	College Degree	\$150,000 or greater	W	3	Y	Y	Private General	N
8	45	F	M	Graduate Degree	\$150,000 or greater	W	2	N	N	Private General	N
9	44	F	M	Graduate Degree	\$150,000 or greater	W	2	N	Y	Private Special	Y
10	51	F	M	Graduate Degree	\$150,000 or greater	W	2	N	N	Private General	N
11	49	F	M	Graduate Degree	\$150,000 or greater	W	2	N	Y	Private Special	Y

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