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Keith Allred
Boise State University

Christine Hancock
Boise State University

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Keith Allred Boise State University E-mail: keithallred1@boisestate.edu Christine Hancock M.A., Early Childhood Studies, Boise State University

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Abstract

This expository article critically reviews the literature from 1950-2010 regarding educators' perceptions of parental response to disability. Pre-service, practitioner, and professional literature are examined to explore the views presented to teacher candidates during the process of professional induction. As this literature relies upon the stage model of grief associated with Kübler-Ross' (1969) description of the acceptance of death, the effects on parent-professional relations and cultural understandings of disability are critiqued. The paper presents an alternative framing of parental response to disability emerging through positive psychology. Recommendations, based upon a disability studies in education perspective, are made regarding changes in the teacher induction process in the United States and how values-based practices informed by the emancipatory orientation of positive psychology can lead to more effective collaboration between educators and parents.

We assert that the typical U.S. teacher's perceptions of parental response to disability in 2012 are not markedly different than the perceptions of teachers 50 plus years ago. Informed heavily by Kübler-Ross' stage model of grief introduced in *On Death and Dying* (1969), these perceptions link the concepts of disability, death, and mourning, an assumption that negatively impacts cultural understandings of disability as well as ongoing interactions between parents and teachers (Ferguson & Ferguson, 2006). The purposes of this article are to: (1) examine the influence of Kübler-Ross' stage model in shaping the traditional approach regarding parental response to disability; (2) analyze how that approach has impacted educators and schools as they have dealt with parents; (3) discuss an alternate paradigm, positive psychology, for framing parental response to disability; and (4) provide recommendations based upon a disability studies in education (DSE) perspective for those collaborating with parents of students with a disability.

Kübler-Ross in Context

The influence of Kübler-Ross' (1969) model, which suggests that individuals move through denial, anger, bargaining, and depression before reaching acceptance of death, has come from within the field of education and without. Over the past 40 years, the stage model has seeped into western popular culture. *On Death and Dying* (1969) exists in more than 160 editions or formats, and has been translated into more than 10 languages (worldcat.org). While Kübler-Ross' work and the stage model of grief are recognized internationally, this article focuses on educators and parent-professional relations in public schools in the United States,where some have described this work as part of the cultural consciousness (Dogan, 2004; McDonald, 2009; O'Rourke, 2010). With little critique of its applicability, the stage model of grief has been used to describe events from the homesickness of new college students (Bosman, 2007) to the aftermath of a computer crash (Ruzich, 2008). Kübler-Ross' stage model has been labeled a "cultural phenomenon" (Dogan, 2004) and a trope of television (tvtropes.org). Dogan (2004) noted, "When most people use or hear the phrase, 'he is in denial,' it is Kübler-Ross's 'version' of denial that most often frames their perception of its meaning" (p. 25). Popular culture frequently invokes Kübler-Ross when people undergo significant life changes, and this paper explores some effects of the cultural impact of the Kübler-Ross model on education in the United States.

The Traditional Approach to Parental Response to Disability

We will review the professional literature on parental response to disability in roughly 20 year time periods, from (a) 1948-1968, (b) 1969-1989, and (c) 1990-2010, noting seminal articles and overall trends. This organization allows for an examination of texts published prior to *On Death and Dying* (1969), literature contemporary with the book, and more recent work. Ferguson (2002) analyzed professional approaches to parental response in special education literature over the past 100 years, and suggested that an interpretation of this literature must identify hidden assumptions and cultural expectations in every era. Historically, parents were characterized as "Neurotic," "Dysfunctional," "Suffering," or "Powerless." Ferguson asserted that from the 1920s-1980s the medical model was extended to families in explanations of parental response. Krauss (1993) was quoted: "For decades, researchers examining families of children with disabilities explicitly assumed a high degree of pathology in family functioning" (as cited in Ferguson, p. 127). What led researchers and educators to presume that the birth and/or diagnosis of a child with a disability had such adverse effects?

1948-1968

A sociohistorical perspective suggests that parental adaptation to disability during the 1948-1968 period and professional responses thereto were essentially rooted in the psychodynamic tradition. The writings of Freud and other like-minded professionals were the lens through which parental response to disability was generally viewed. Stone's (1948) article in *AJMD* was one of the first in professional literature to address what she referred to as parents' "psychic pain." Boyd (1951) indicated that parents went through three stages in reacting to the diagnosis

of disability in a child: a focus on the self, a focus on the child, and a focus on advocacy. Beddie and Osmond (1955), while arguing that institutionalization of infants with disabilities was unethical, inadvertently helped to legitimize the idea that mothers grieved at the birth of their children with disabilities. Less than a decade later Solnit and Stark (1961) and Olshansky (1962) introduced the notions of "mourning" and "chronic sorrow" as common parental responses to disability. These responses presume that parents experience the "death of a perfect child" when they learn that their child has a disability: the child hoped and planned for no longer exists. Examination of subsequent literature (e.g., Farber, 1959; Grays, 1963; Hay, 1950; Kirk, Karnes, & Kirk, 1968; Koegler, 1963; Rosen, 1954; Ross, 1964) indicates ongoing discourse regarding the dynamics of parental response to disability. In short, during the 1950s and 1960s, the birth of a child with a disability was widely viewed as a tragedy by society, and parents' reactions were typically viewed as pathological by diverse professionals partially as a result of their psychodynamic paradigm.

1969-1989

The period from 1969-1989 was characterized by a "stage theory" of parental reaction to disability. Although previous authors proposed various stages of parental response to disability (e.g., Grays, 1963; Hay, 1950; Kirk, Karnes, & Kirk, 1968; Koegler, 1963; Rosen, 1954), Kübler-Ross' (1969) book *On Death and Dying* crystallized the notion that parental response to disability was best captured by a stage theory of grief. Kübler-Ross' model of accepting death provided an avenue to expand the notions of mourning, sorrow, and the death of a perfect child introduced in 1948-1968, and also supported the medical model of disability prevalent at the time. This interpretation of her stage model presumed that parents would progress or not through denial, anger, bargaining, and depression before reaching acceptance of their child's disability. Understandings of parental response to disability that emphasize grief and the implied loss of the "ideal" child contribute to the marginalization of people with disabilities. A deficit-based conception of disability is implicit in such constructions of parental response (Ferguson & Ferguson, 2006). As McGuire (2010) pointed out, when parents grieve the loss of the "expected" child, they "do not mourn disability, they mourn *because of it*" ("Mourning the Figure of the Stillborn," par. 5).

Though Kübler-Ross did not intend for her model to be extended to parental response to disability, she inadvertently linked the two in an interview with a terminally ill mother whose son was "emotionally disturbed and retarded," when Kübler-Ross observed that the mother "accepted the full facts [of your son's disability] step by step just as you did with the diagnosis of leukemia" (p. 180). This connection was not explicitly addressed in any of the reviewed literature.

Bowlby and Parkes (1970) further reinforced the stage model of parental response. Drotar, Baskiewicz, Irvin, Kennell, and Klaus (1975) examined parental response to disability empirically, and concluded that parents did indeed experience stages of grief. Methodological issues and confirmation bias largely explain their findings, such as interview questions that presume the presence of stages (Blacher, 1984). Regardless, a host of other publications

targeted at various professionals working with parents essentially endorsed the stage model of parental response, while handbooks and manuals developed for educators working with students with disabilities during this period tended to explain parental response in terms of a stage model or in terms of emotions associated with a stage model, such as denial or anger (see Table 1). Many of these sources specifically referenced Kübler-Ross' model as the basis for their work.

Table 1. Contemporary Influence of Kübler-Ross' Stage Model on Parental Response to Disability Literature (1969-1989)		
Professional Literature	**Practitioner Handbooks and Reference Guides**	
Endorse a Stage Model	*Endorse a Stage Model*	*Use Attributes of the Stage Model[a]*
Bowlby & Parkes (1970)	Love (1970)	Attwell & Clabby (1969)
Drotar Baskiewicz, Irvin, Kennell, & Klaus (1975)	Martin & Nivens (1980)	Southwest Ed. Dev. Laboratory (1976)
Sieffert (1978)	Philp & Duckworth (1982)	
Huber (1979)*	Meyerson (1983)*	
Mour (1981)*	Mori (1983)*	
Bassoff (1982)*		
Oriphory & Peters (1982)*		
Moses (1983)		
Honig (1984)*		

Note. *Reference Kübler-Ross

[a]These texts describe parental response to disability using common attributes of the stage model (e.g., anger, denial) but do not explicitly endorse a stage model.

Table 1 illustrates support for the stage model in special education literature during 1969-1989. Authors of both professional literature and practitioner handbooks used the Kübler-Ross as a basis for their work. Of the nine professional pieces that endorse a stage model, five referenced Kübler-Ross. Similarly, 2 of 5 teacher handbooks explicitly addressed the Kübler-Ross model.

Concurrently, Blacher (1984) asserted through a comprehensive review of parental response research that there was very little empirical support for the stage model. Hindsight suggests that relatively little attention was given to Blacher's conclusion, which could be thought of as a "repugnant fact," a finding contrary to the accepted paradigm more easily ignored than addressed (Mead, 1932). Thus, despite an absence of significant empirical support, the stage model became embedded in the culture of schools because it (a) was sustained through a dominant paradigm, professional publications, and practitioner guides, and (b) served as a

powerful metaphor that was easily remembered by educators. However, the last years of the 1969-1989 period can be viewed as a transition away from the psychodynamic tradition.

Other professionals during this period sought to determine whether any positive affects existed in the family associated with a child having a disability (e.g., Affleck, Tennen, & Gershman, 1985; Stoneman, Brody, & Abbott, 1983; Stoneman, Brody, Davis, & Crapps, 1989; Wikler, Wasow, & Hatfield, 1983). While findings were mixed, such work suggests that some professionals were concerned about the limitations of the traditional approach to parental adaptation to disability and its deficit orientation.

1990-2010

The 1990-2010 span can be likened to the quiet preceding a paradigm shift (Kuhn, 1970). By the 1990s more professionals had begun reconceptualizing disability and parental response to disability. The growth of disability studies as a field pushed for examinations of common constructions of disability and the social values that shape these understandings. With regard to parental response to disability, the work of Taylor and colleagues (1983, 1988) introduced the notion of "positive illusions" and suggested that in certain circumstances (e.g., breast cancer) people experiencing crisis had better outcomes when they held to what professionals perceived as unrealistic expectations. Roll-Pettersson's (2001) research suggested that the mourning model was not adequate in capturing parental response, and Ferguson (2002) noted that more sophisticated theories of family functioning and subsequent research posited that families were more accurately viewed as "Adapting," "Evolving," and "Supported." Thus, there was growing dissonance among some researchers with what had become the *institutionalized* stage model of parental response, coupled with other explanations reflective of attitudinal changes in society regarding disability.

Turnbull and Turnbull (1993) and others (Affleck & Tennen, 1993; Turnbull et al., 1993) began examining the notion of cognitive adaptation as a way to frame parental response. Ulrich and Bauer (2003) suggested that parents experienced different levels of awareness regarding their child's disability over time, noting that movement across levels of awareness (e.g., understanding) resulted in significant change that was described as transformative. This notion of "transformation" integrates into a decade of research and writing on parental response by Scorgie and colleagues (Nota, Soresi, Ferrarai, Wilgosh, & Scorgie, 2005; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & McDonald, 1996; Scorgie, Wilgosh, & McDonald, 1999; Scorgie, Wilgosh, & Sobsey, 2004). After conducting qualitative and quantitative studies of parental response to disability across several diverse cultures and numerous types of disability, they developed a theoretical model that identifies several facilitative processes for parental transformation. These researchers describe transformation as various positive, life-long outcomes emerging from family life management (Scorgie et al., 2004).

Several relevant macro-level initiatives were also launched in the last quarter century. First, P.L. 99-457 (1987) ushered in an era of Early Intervention services based upon family-systems theory. Consequently, families for the past 25 years have been able to access a range of family-

centered services largely unheard of in earlier times. Parents now have access to various forms of formal and informal support that may facilitate more positive parental response.

Second, Seligman and Csikszentmihalyi (2000) among others launched the positive psychology movement. Concurrently, the emergence of psychofortology validated the notion that disability can be a source of enhanced growth and development (Naidoo, 2006). Social scientists conducting research based upon this paradigm are presenting evidence that psychological resources such as positive illusions contribute to one's physical and mental health in the midst of very difficult life circumstances (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). Valliant's (2000) research indicates that there are adaptive mental mechanisms that may essentially serve transformational (i.e., life enhancing) purposes for people facing various crises.

Positive psychology attempts to confront the deficit model and move beyond pathologizing individuals, but it remains necessarily linked to those concepts. According to Seligman and Csikszentmihalyi (2000), "The aim of positive psychology is to begin to catalyze a change in the focus of psychology from preoccupation only with repairing the worst things in life to also building positive qualities" (p. 5). Positive psychology presumes that people either possess or can be supported in acquiring knowledge, skills, and attributes that permit them to overcome crisis, significant hardships, and other challenging experiences, and it is in this capacity that it has often been linked to discussions of disability. While positive psychology remains connected to assumptions about the undesirability of disability, it emphasizes the power of personal interpretation on the effects of an event, and in doing so, creates space for a broader range of parent voices.

Also in 2000, Disability Studies in Education (DSE) became a special interest group within the American Educational Research Association (AERA). Recognition of DSE as a field by AERA represents a formal beginning for the field and a certain coalescence of conceptual framework. Connor, Gabel, Gallagher and Morton (2008) detailed the emergence of DSE, and described the field's desire to contextualize disability; promote full inclusion of individuals with disability; reject deficit models of disability; and privilege the "interests, agendas, and voices of people labeled with disability" (p. 448). These commitments share a number of assumptions regarding human growth and development and disability with positive psychology. Thus, DSE may be a means of bridging positive psychology, disability studies, and the more traditional fields of general and special education.

Third, Servaty-Seib (2004) noted that since the work of Kübler-Ross there have been significant advances in grief theory. She indicated that contemporary conceptualizations of grief and mourning emphasize flexibility, balance, and individuality. Bonanno (2009) also questioned the continued relevance of Kübler-Ross, arguing for a more positive view of grief based on his interviews with bereaved individuals.

Thus, the convergence of: (a) widely available Early Intervention services that support families in a social milieu more accepting of disability; (b) an emerging transformational orientation regarding parental response; (c) a movement (e.g., positive psychology, DSE) that reframes how

adults deal with experiences such as presence of disability in their child; and (d) grief theory no longer based primarily on the stage model, are individually and cumulatively serving to help significantly alter our understanding of how parents respond to their child's disability. Furthermore, these factors broaden our understanding of the *range* of possible parental responses to disability from the relatively narrow options circumscribed by the grief model.

The Legacy of the Kübler-Ross Model

For more than 60 years, the professional literature focusing on parental response to disability has been predominantly based on a deficit model. The stage model of grief was widely embraced by special educators and other professionals (e.g., counselors, social workers) to explain parental response. Consequently, notions such as chronic sorrow were woven into the fabric of school cultures. After several generations, ideas associated with the stage model (e.g., denial) became conventional wisdom in most public schools. While there is very limited empirical support for the stage model (Blacher, 1984) and some researchers who examined parental response through different lenses found evidence contrary to the grief model (e.g., Nota et al., 2005; Roll-Pettersson, 2001; Stainton & Besser, 1998; Wikler et al., 1983), many 1990-2010 texts continue to depict a deficit model (e.g., Bowes, Lowes, Warner, & Gregory, 2009; Friehe, Bloedow, & Hesse, 2003; Krehbiel & Kroth, 1991; Penzo & Harvey, 2008).

Helff and Glidden (1998) compared presentations of parental response to disability in research literature from the 1970s, the 1980s, and the early 1990s. They found that while negativity decreased over time, there was no increase in positivity. As such, this deficit approach typically remains the most visible explanation of parental response historically available to educators (see Table 2). Because the deficit model presents a limited and limiting view of individuals with disabilities and their families, continued emphasis on parents' progression through the stages of grief prevents educators from building more complex understandings of disability and its relationship to cultural values. Additionally, educators focused on parents' grief may be unaware that they are contributing to the prevalence of the medical model of disability. On the other hand, family-centered Early Intervention services, a transformational model of parental response to disability, and an emerging paradigm anchoring research examining parental response, as well as a more nuanced understanding of grief, run counter to long-held beliefs in public schools.

Table 2. The Continuing Deficit-Based Perception of Parental Response to Disability			
Perception	**1948-1968**	**1969-1989**	**1990-2010**
Parents must cope with the "symbolic death" of a perfect child.	*In the mother's mourning reaction to the loss of the healthy child, her wishes for and expectations of the desired child are crushed by the birth of the*	*It is important for us as educators to become aware of the grieving process and how it relates to parents of the handicapped in their acceptance of the symbolic*	*Most parents who must cope with a child with serious disabilities face two major crises. The first is the "symbolic death" of the child who was to be.*

	defective child. —Solnit and Stark, 1961	*death of their child.* —Witcher, 1987	—Kirk, Gallagher, Coleman, & Anastasiow, 2009*
Parents experience "chronic sorrow."	*Most parents who have a mentally defective child suffer chronic sorrow throughout their lives.* —Olshansky, 1962	*Our findings suggest, first of all, that chronic sorrow does not seem to be an abnormal response; rather, it is a normal reaction to an abnormal situation.* —Wikler, Wasow, & Hatfield, 1981	*Recurrent sorrow and frequent feelings of inadequacy are persistent emotions that many parents experience as they gradually adjust to having an infant with a disability.*
Parents move through stages as they respond to the diagnosis of their child's disability.	*"Misery loves company"; but I never fully appreciated that until I joined the Parents' Group. That was the first stage of growth of a parent of a mentally retarded child, the stage where one is entirely subjective, concerned almost wholly with himself and the effect that things have upon him.* —Boyd, 1951	*For most parents, initial shock, disbelief, and a period of intense emotional upset (including sadness, anger, and anxiety) were followed by a period of gradual adaptation.* —Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975	*Reactions move from denial of the disability diagnosis to anger at the diagnosis, to bargaining with the experts involved in the diagnosis, depression, and to acceptance of the disability. Acceptance of the diagnosis can take years, as frequent reminders of the disability cause families to reexperience the grief.* —Ray, Prewitt-Kinder, & George, 2009
Parents' experiences can be understood through Kübler-Ross' (1969) stages of grief.		*Although the grieving process these parents experience has been described in a variety of ways by many experts in the field, the five stages of grief as identified by Kübler-Ross (1970) seem to best describe the process.* —Oriphory & Peters, 1982	*Kübler-Ross (1969), in her powerful book On Death and Dying, suggests that families will cope with death (and, by extension, with the disability of a family member) first by denying reality. Any [special educator] who has worked with parents of newly diagnosed children knows that denial is a powerful impulse in*

			these parents. —Bowe, 2007*
Inability to progress through the stages of grief can harm parent and child.		*The grieving process […] permits the parents of a developmentally disabled child to separate from dreams and fantasies generated in anticipation of the birth of that child. The inability to separate from such a dream is devastating to both parent and child.* —Moses, 1983	*The sense of loss related to the diagnosis [of disability] may provoke a grief reaction, which, if not resolved, could lead to depression and other problems for the family and the child.* —Friehe, Bloedow, & Hesse, 2003

Note. * designates introductory special education textbooks.

Table 2 outlines various aspects of a deficit-based perception of parental response to disability present in special education literature throughout the three reviewed time periods. Since the 1948-1968 period, literature has addressed the concept that parents must cope with the symbolic death of their "ideal" child when they learn that their child has a disability. Similarly, the ideas that parents experience "chronic sorrow," and that parents move through stages as they respond to the diagnosis of disability have been in place since the 1948-1968 period. Since 1969, the Kübler-Ross stage model of grief has been applied to parental response to disability, and this interpretation has continued throughout 1990-2010. Finally, the perception that the inability to progress through the stages of grief can harm parents and their child emerged in the 1969-1989 period and continues during the 1990-2010 period.

Implications of the Stage Model for Pre-service and Practice

The second section of this paper addresses implications for educators arising from these changes. To appreciate the impact of this literature on teacher-parent relations it is useful initially to consider professional induction, the process whereby candidates undergo a rigorous, extended period of education and training in order to qualify as a member of a profession. There are two noteworthy components to professional induction. First, a formal program of professional education is generally carried out by an institution of higher education (IHE). Second, extensive professional socialization takes place both within an IHE and in the public schools (Skrtic, 1995). Textbooks play a vital role during professional education induction, as such texts are a primary vehicle for maximizing the authority and credibility of a profession's knowledge tradition (Barnes, 1982; Kuhn, 1977; Skrtic, 1995). Pre-service teachers are especially vulnerable to the "received knowledge" found in textbooks because such knowledge

is accepted on faith in the institution and the professors dispensing it. Thus, textbooks have a significant impact in the paradigm acquisition a pre-service teacher experiences during the induction process (Kuhn, 1970; Skrtic, 1995, 2004).

Examination of special education textbooks typically addressing parental response to disability suggests that the stage model, or artifacts from the 1960s literature, often continues to frame parental response. For example, the 12th edition of *Educating Exceptional Children* by Kirk et al. (2009) references parents experiencing the death of a perfect child, while Hardman, Drew, and Egan (2008), in the 9th edition of *Human Exceptionality: School, Community, and Family* present a detailed description of four stages of parental response to disability. Another text (Bowe, 2007) included Kübler-Ross among the typical philosophies of early childhood special education: "Three approaches are found in ECSE today: developmental, behavioral, and other, including work by Abraham Maslow (1954) and by Elisabeth Kübler-Ross (1969)" (p. 7). Several texts noted some research regarding positive affects in the family because of the child with the disability. However, in many instances the pre-service teacher is not presented with enough information regarding parental response to develop a more sophisticated understanding that transcends the deficit model.

In a similar review that addressed parental response to perinatal death in midwifery textbooks, Cameron, Taylor, and Greene (2008) concluded that while discussion of parental response changed slightly over time, current textbooks neither critique traditional psychological theories of grief, nor promote alternatives to the Kübler-Ross model. Thus, it is plausible to conclude that many teacher inductees over five decades (1960s-2010) have been provided with information via their texts such that their perceptions of parental response may be negatively skewed or limited by stereotypical thinking.

The second part of the professional induction process, largely taking place in the public schools, is arguably more influential. One outcome of the professional socialization that occurs as new teachers are absorbed into the culture of a school and overall into the profession is that the professional becomes deeply committed to a particular knowledge tradition (Skrtic, 1995). Skrtic (1995, 2004) asserted that the effectiveness of the induction process into special education is such that practicing special educators rarely question the adequacy of their knowledge tradition. The authors assert that the same notion is equally applicable to the general education induction process. Consequently, education inductees over this past half century have largely continued to be socialized into the institutionalized stage model of parental response by mentors whose perceptions were shaped almost exclusively by the stage model. Given that the stage model is alive and well in public schools, new teachers are typically socialized into that paradigm. Thus, in both significant phases of professional induction new educators are receiving outdated information and perspectives.

There is a growing consensus that generally, relationships between parents and schools are significantly less than ideal (e.g., Ferguson & Ferguson, 2006; Scorgie et al. 2004; Ulrich & Bauer, 2003). Some characterize parent-professional relations as dysfunctional and that families of students with disabilities are enmeshed in a school culture most often marked by

stereotypes rather than engagement (Ferguson & Ferguson, 2006; Harry, 2002; Miller-Marsh & Turner-Vorbeck, 2010; Pushor, 2010; Snow 2001).

While numerous factors may impact the effectiveness of parent-professional relations, the attitudes and perceptions of both parties influence the success of the partnership (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Sonnenschein, 1981; Summers, Hoffman, Marquis, Turnbull, Poston, & Nelson, 2005; Ulrich & Bauer, 2003). A fundamental thesis of this paper is that these relationships are undermined to some extent by the negative effects resulting from the stage model. When the stage model has largely shaped an educator's perception of a parent, a number of inaccurate beliefs and assumptions can result. Most significantly, the stage model presumes that the parent is adversely affected by their child, and that most likely those negative effects are life-long. Confirmation bias further suggests that typically one sees what one expects to see. Thus, educators primed to see parents in denial will have no difficulty finding evidence that the parents of their students display denial.

Sonnenschein (1981) identified numerous perceptions of parents held by professionals that may hinder the development of strong, positive relationships. At least three of these negative perceptions are reinforced by (if not actual outgrowths of) ideas associated with the stage model. For example, she noted the potential perception of "parent as vulnerable client," meaning that the parent is in need of help at least partially as a result of their child. A similar perception is that of "parent as patient." Sonnenschein noted Rud Turnbull's (1978) observation regarding his treatment by some professionals: "I had suddenly been demoted from the role of professional to that of 'parent as patient,' the assumption by some professionals that parents of a retarded child are emotionally maladjusted and are prime candidates for counseling, psychotherapy or tranquilizers" (as cited in Sonnenschein, , p. 62). Sonnenschein also pointed out that professionals may hastily label parents when there is a disagreement or difference in opinion, resulting in the perception of the parent as "pushy, angry, denying, resistant, or anxious." The stage model provides a ready supply of counterproductive labels that are easily applied to parents. In the first author's professional experiences in public schools over the past 30 plus years, numerous parents were labeled as in denial by teachers. As a result, when a parent is in "denial," the professional is then in the best position to make the final decision when there is disagreement. Such a rationale illustrates conventional wisdom in many schools arising out of the stage model, where denial is typically identified as the first stage.

The following excerpt illustrates how pre-service literature can reinforce such teacher behaviors: Bowe (2007) explicitly endorsed Kübler-Ross' stage of denial. "[F]amilies will cope with death (and, by extension, with the disability of a family member) first by denying reality. Any [educator] who has worked with parents of newly diagnosed children knows that denial is a powerful impulse in these parents" (p. 11). Ferguson and Ferguson (2006) asserted that "perhaps the single most common 'script' that professionals impose on parents is the Kübler-Ross stage theory" (p. 221).

An Australian study that examined parent-professional relations provides further insight into how perceptual differences can affect relationship dynamics. Kearney and Griffin (2001)

phenomenologically examined the experiences of parents of children with significant developmental disabilities. The authors concluded that such parents were "between joy and sorrow"—with joy coming from their experiences with their child and sorrow largely emanating from their experiences with others. In particular, professional approaches that implied messages of negativity affected parents. Parents considered their continuing hope and optimism as "defiant," as they were aware that such beliefs were (1) in opposition to those of professionals, and (2) left them "open to accusations of 'denial of reality' and 'nonacceptance'" (p. 586). These differences in perception illustrate continued issues associated with educators holding onto a grief-based stage model: it remains relatively easy for professionals to pathologize parents (Roll-Pettersson, 2001; Scorgie & Sobsey, 2000).

An Emerging Paradigm: Positive Psychology and Parental Transformation

Section three of the paper presents a targeted introduction of an alternate approach for understanding parental response to disability, positive psychology, as well as the findings of salient research on parental response to disability that is not based upon the stage (grief) model. Positive psychology and psychofortology presume that parents: (a) have an innate capacity, or intrapersonal resources, to overcome a significant unexpected event (birth or diagnosis of child with disability), and (b) over time typically experience increased understanding regarding their parental role that results in further personal growth and development.

Positive psychology and DSE share several values centered on an emancipatory orientation and an interdisciplinary approach: a desire to address lived experiences of individuals with disabilities, a desire to transcend the medical model, and a desire to reframe research by considering new questions (Connor et al., 2008; Ferguson & Ferguson, 2006; Naidoo, 2006). In education, some of these values are beginning to reshape established practices. For example, Sheridan, Warnes, Cowan, Schemm, and Clarke (2004) described a new model for parent-professional interactions, Family-Centered Positive Psychology (FCPP), and noted how one such application was effectively used in schools. A key principle of FCPP focuses on using family strengths and capacities to access family resources.

Similarly, Dunst and Trivette (2009) recently introduced their revised model of Early Intervention services now known as "capacity-building family-systems" intervention practices. Their model is congruent with the notions of FCPP and the presumption that professionals' perceptions of parents are instrumental in empowering parents. For example, they emphasized that it was more appropriate to address family "concerns and priorities" than family "needs and aspirations." Thus, a positive psychology orientation aligns with an evolving understanding of disability and recommended practices that support family strengths in education.

A number of researchers have identified intrinsic resources that influence how parents may respond to disability, and can contribute to positive, long-term outcomes. Such resources in positive psychology have also been called general resistance resources (Anotovsky, 1993) and adaptive mental mechanisms (Valliant, 2000). Taylor (1983, 1988, Taylor et al., 2000) has

pursued research studying individuals who have developed "positive illusions" to cope more effectively with personal crisis. Positive illusions are personal perceptions of physical and/or psychological status in a crisis experience that are typically considered unrealistic, or even indicative of denial, by the professionals working with the individual. Almost counter intuitively, though, there is consistent evidence that fostering positive illusions is a strong predictor of a positive long-term outcome.

Affleck and colleagues (1982, 1985) noted that mothers of high-risk infants who used "cognitive adaptations" were more likely to cope effectively. Cognitive adaptations can be likened to positive illusions. Turnbull (1985; Turnbull et al., 1993) and associates (Summers, Behr, & Turnbull, 1989) have examined the link between positive adaptation (several different types of cognitive adaptations) and coping in families, and concluded that use of such strategies should be viewed as a family strength.

Research in the United States, England, and Australia over the past decade has examined the role of parental resiliency factors such as optimism, self-efficacy, benefit finding, mindfulness, and hope in responding to a child with disability (e.g., Bayat, 2007; Blacher & Baker, 2007; Hastings, Beck, & Hill, 2005; Hastings & Taunt, 2002; Kearney & Griffin, 2001; Kuhn & Carter, 2006; Lloyd & Hastings, 2008, 2009). There is increasing evidence that the presence and use of such internal resources are predictive of how well the family manages with the child. Stainton and Besser (1998) noted that ironically, under the deficit or psychoanalytic model, coping and adaptation were primarily viewed as the avoidance of negative outcomes. Thus positive outcomes were not anticipated, and in earlier research were likely overlooked.

As early as the mid-1980s, several researchers, including Abbott and Meredith (1986), followed by Behr, Murphy, and Summers (1992), Erwin and Soodak (1995), Meyer (1995), and Stainton and Besser (1998) began reporting that parents revealed various positive outcomes (e.g., path to learning through experience and challenge) associated with their child with a disability. More recently, other theorists and researchers (Schaef, 1992; Scorgie & Sobsey, 2000; Ulrich & Bauer, 2003) have further refined the notion that parents are likely to have experiences over time directly related to their child with a disability that contribute to their personal growth.

Together, the work of Scorgie and Sobsey (2000), Scorgie et al. (2004), and Ulrich and Bauer (2003) illustrate a process of positive change that positive psychology would term stress-induced growth (Pearsall, 2003). Scorgie and Sobsey described "transformational outcomes," significant, positive changes parents experience and attribute to life with their child. These changes include transformations such as personal growth, improved relations with others, and changes in philosophical or spiritual values. Ulrich and Bauer (2003) described parents as developing progressively deeper levels of understanding regarding disability and their child as a result of transformational experiences, which could be likened to epiphanies. Parents of a child with a disability undergo processes of image-making, meaning-making and choice-making as they answer questions about their family such as, "Who am I as a parent?" "Why did this happen?" and "What will I do?" (Scorgie et al., 2004). While these questions are unsettling, they need not be linked only to concepts such as "psychic pain" or Kübler-Ross' (1969) anger stage.

As Scorgie et al. (2004) conclude, "positive transformations seem to occur in the midst of stress, pain, and difficulty" (p. 105).

It is further noted that parents of students with disabilities would almost universally agree that the birth and/or diagnosis of their child entailed far more stress, pain, and difficulty than they ever imagined (e.g., Klein, 1984; Searl, 1978). The birth and/or diagnosis of a child with a disability is typically a profound, life-altering experience that is not totally comprehensible to those who have not gone through it personally (e.g., Boyd, 1951; Snow, 2001). Parents have often used terms such as grief and mourning to describe some of what they initially experienced (e.g., Green, 20002; Klein, 1984). Part of the durability of the grief model is that it resonates with certain parents. Some parents have undoubtedly moved through stages illustrated by the grief model. However, from a life-span perspective it is generally accepted that few if any parents want to be defined based on a single experience, traumatic or otherwise.

Scorgie and Sobsey (2000) noted that past emphasis on the negative aspects of parenting a child with disability often blinded professionals to the potential of transformational experiences. Kingsley's (1987) classic parable of parental response to disability, "Welcome to Holland," is an example of the insight that parents can acquire over time. By likening the experience of parenting a child with a disability to planning and leaving for a vacation in Italy but somehow arriving instead in Holland, Kingsley acknowledged the heartache a parent endures, but her focus is overwhelmingly on the positive aspects of the experience. Scorgie and Sobsey assert that "catastrophizing professional myths" (e.g., chronic sorrow) can be conveyed to parents explicitly or implicitly and that such communication may lead to a form of self-fulfilling prophecy. Further, Scorgie et al. (2004) concluded that the "denial of choice and control" hampers transformational processes. They linked this limitation to school systems as well as common struggles in parent-professional relationships.

Other internal resources include ethnicity and religiosity. In Hispanic (Heller, Markwardt, Rowitz, & Farber, 1994; Hershenson, 1992; Rehm, 1999; Skinner & Bailey, 1997; Zea, Quezada, & Belgrave, 1994) and African American (Ellison, 1995; Rogers-Dulan & Blacher, 1995) families having a child with a disability, there is evidence that when parents have strong religious beliefs, they are more likely to attribute value and benefit regarding their child's disability. Harry (1997, 2002) noted that the ethnocentrism of most special educators interferes with their ability to understand that the cultural and religious beliefs of various minority groups regarding disability are not denial. There is also evidence that religiosity, regardless of ethnicity, has significant positive influences on parents' perceptions of their ability to adapt to their child with disability (Marshall et al., 2003; Tarakeshwar & Pargament, 2001).

Critical examination of empirical literature regarding parental response to disability reveals surprisingly little support of the stage model (Blacher, 1984; Ferguson, 2002; Roll-Pettersson, 2001). Rather, over the past 25 years a growing body of literature supports the notion that parents often experience significant personal growth in adapting to their child (e.g., Nota et al., 2005; Scorgie & Sobsey, 2000; Scorgie et al., 1996; Scorgie et al., 1999; Scorgie et al., 2004). We

would go so far as to suggest that the psychodynamic or pathological paradigm of parental response to disability widely embraced by educators has had an iatrogenic effect upon parent-professional relations. That is, while the stage model of parental response to disability is no doubt well intentioned, it inadvertently contributes to an inaccurate and disempowering view of parents by educators that inhibits the parent-teacher collaborative relationship.

Implications for Educators

The grief (stage) model is an artifact of the psychodynamic tradition. This model coincidentally aligns with the medical model of disability and was quickly embraced by its adherents. Notions (e.g., denial) associated with this approach were institutionalized several generations ago. However, continued reliance on this approach by educators undermines the development of fully inclusive schools both philosophically and pragmatically. Disability studies, and more recently DSE, have shed some light on how social institutions such as schools employ a deficit model to shape interactions with families of students with disabilities (Ferguson & Ferguson, 2006; Rice, 2006). Our examination and analysis of the education literature and the teacher induction process provides further understanding regarding some of the consequences associated with special educators' over-reliance on the Kübler-Ross model to explain parental response to disability.

There is now sufficient empirical evidence and theoretical support to warrant changes in how educators perceive parental response to disability. What is required is widespread recognition in professional literature and throughout the induction process of a more sophisticated orientation that acknowledges the transformative nature of parental experiences. It is critical that teacher educators provide a nuanced and expanded explanation of parental response to disability. Multiple representations of parental response are a better reflection of reality than a single, dated representation. Similarly, those charged with professional development responsibilities in public schools should be proactive and see that materials and training reflect the most current understanding of parents' transformative experiences.

In the spirit of values-based practice embraced by disability studies, there is much teacher educators and individual classroom teachers can do. First, introspection can lead one to examine critically personal beliefs and potential biases regarding parental response to disability. While the stage model of response has provided a powerful means of interpreting a range of parent behaviors, it likely has also blinded professionals to other, more viable, interpretations of parental response. After thoughtful deliberation, teachers can reframe how they view parents. The concept of positive illusions provides a tool that may help educators reflect on the deficit model and its impact on professional perceptions. The term positive illusions, emerging out of the medical model, originally captured the notion that some patients' views of their condition were considered unrealistically optimistic in the eyes of the professional. Taylor (2000) found that some patients experienced benefits from their "unrealistic" expectations. Thus, educators may empower parents at times by not automatically dismissing their perceptions as unrealistic. A parental expression of hope is not incontrovertible evidence of denial. In perceiving parents through a new lens, what was once considered a

liability can now is recognized as an asset. Such reframing of parental response is a 21st century application of the strength-based approach to parent-professional collaboration.

Second, educators might seek out more information regarding parents' transformative experiences, and the ways in which parents have utilized or rejected the grief model. The information is available in professional and parent literature (e.g., Badry, McDonald, & LeBlond, 1993; Meyer, 1995; O'Halloran, 1993; Schultz, 1993; Snow, 2001). The richest source of information, however, is students' parents. Teachers might provide parents with opportunities to share their experiences. An immediate benefit will be increased insight into each parent's level of understanding regarding disability. Then teachers may be able to deal more effectively with any misunderstanding resulting from differences in levels of awareness (Ulrich & Bauer, 2003) and tailor their messages at the level each parent will best understand.

Additionally, our historical analysis of literature on parental response to disability may have implications for other professionals working with children with disabilities and their families (e.g., school psychologists). As the process of professional induction in these fields is likely similar to that experienced by educators, more research on the historical and present depictions of parental response to disability in these fields is appropriate.

In conclusion, when all educators recognize parents' transformative experiences as potential family strengths, empower parents by accepting their current level of understanding regarding disability, and honor each family's unique experiences, they will help create an atmosphere of trust and respect not possible through the lens of the stage model. In the spirit of DSE, an emancipatory paradigm regarding parental response to disability should contribute to more genuine parent engagement with schools as well as more inclusive schools. Continued reliance upon the stage model promotes quick, incomplete, and outdated interpretations of the meaning of disability and its impact on families—1960s Polaroid snapshots that could be transformed into rich digital video footage via DSE.

References

- Abbott, D., & Meredith, W. (1986). Strengths of parents with retarded children. *Family Relations, 35*, 371-375.
- Affleck, G., Allen, D., McGrade, B. J., & McQueeney, M. (1982). Home environments of developmentally disturbed infants as a function of parent and child characteristics. *American Journal of Mental Deficiency, 86,* 445-452.
- Affleck, G., & Tennen, H. (1993). Cognitive adaptation to adversity: Insights from parents of medically fragile infants. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 135-150). Baltimore, MD: Paul H. Brookes.
- Affleck, G., Tennen, H., & Gershman, K. (1985). Cognitive adaptations to high risk infants: The search for mastery, meaning, and protection from future harm. *American Journal of Mental Deficiency*, *89*(6), 653-656.

- Anotovsky, A. (1993). The implications of salutogenesis: An outsider's view. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 111-122). Baltimore: Paul H. Brookes.
- Attwell, A. A. & Clabby, D. A. (1969). *The retarded child: Answers to questions parents ask.* Burbank, CA: Eire Press.
- Badry, D. E., McDonald, J. R., & LeBlond, J. (1993). *Letters to our children*. Calgary, Canada: Faculty of Social Work, University of Calgary & Social Work Research Unit, Alberta Children's Hospital.
- Barnes, B. (1982). *T. S. Kuhn and social science*. New York, NY: Columbia University Press.
- Bassoff, E. S. (1982). Identifying, preventing, and treating disturbances between parents and their infants. *Personnel and Guidance Journal*, *61*(4), 228-232.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*, 702-714.
- Beddie, A., & Osmond, H. (1955). Mothers, Mongols, and mores. *The Canadian Medical Association Journal*, *73*(3), 167-170.
- Behr, S., Murphy, D., & Summers, J. (1992). *Users manual: Kansas inventory of parental perceptions (KIPP).* Lawrence, KS: Beach Center on Families and Disability.
- Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? *Mental retardation, 22*(2), 55-68.
- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal of Mental Retardation*, *112*, 330-348.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, *70*(2), 167-184.
- Bonanno, G. A. (2009). *The other side of sadness: What the new science of bereavement tells us about life after loss*. New York, NY: Basic Books.
- Bosman, J. (2007, July 29). When there's no place like home. *The New York Times*. Retrieved from http://www.nytimes.com
- Bowe, F. G. (2007). *Early childhood special education: Birth to eight* (4th ed.). Clifton Park, NY: Thomson.
- Bowes, S., Lowes, L., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with type 1 diabetes. *Journal of Advanced Nursing, 65*(5)*,* 992-1000. doi:10.1111/j.1365-2648.2009.04963.x
- Bowlby, J., & Parkes, C. M. (1970). Separation and loss within the family. *The Child in His Family, 1*, 197-216.
- Boyd, D. (1951). The three stages of growth in the parent of a mentally retarded child. *American Journal of Mental Deficiency, 55*(4), 608-611.
- Cameron, J., Taylor, J., & Greene, A. (2008). Representations of rituals and care in perinatal death in British midwifery textbooks 1937-2004. *Midwifery*, *24*, 335-343. doi:10.1016/j.midw.2006.03.010

- Connor, D. J., Gabel, S. L., Gallagher, D. J., & Morton, M. (2008). Disability studies and inclusive education–implications for theory, research, and practice. *International Journal of Inclusive Education*, *12*(5/6), 441-457. [doi:10.1080/13603110802377482](doi:10.1080/13603110802377482)
- Dogan, D. O. (2004). Appreciating the legacy of Kübler-Ross: One clinical ethicist's perspective. *The American Journal of Bioethics*, *4*(4), 24-28.
- Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., & Klaus, M. (1975). The adaptation of parents to the birth of an infant with a congenital malformation: A hypothetical model. *Pediatrics*, *55*(5), 710-717.
- Dunst, C. J., Trivette, C. M. (2009). Capacity-building family-systems intervention practices. *Journal of Family Social Work, 12*(2), 119-143.
- Ellison, C. G. (1995). Race, religious involvement, and depressive symptomatology in a southeastern US community. *Social Science and Medicine, 40*, 1561-1572.
- Erwin, E., & Soodak, L. (1995). I never knew I could stand up to the system: Families' perceptions of pursuing inclusive education. *Journal of the Association of Persons with Severe Handicaps*, *20*, 136-146.
- Farber, B. (1959). Effects of a severely mentally retarded child on family integration [Monograph]. *Society for Research in Child Development 24*(2, Serial No. 71).
- Ferguson, P. M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education, 36*(3), 124-130, 147.
- Ferguson, P. M., & Ferguson, D. L. (2006). Finding the "proper attitude": The potential of disability studies to reframe family/school linkages. In S. Danforth & S. L. Gabel (Eds.), *Disability studies in education: Vol. 2 Vital questions facing disability studies in education* (pp. 217-235). New York, NY: Peter Lang.
- Friehe, M. J. Bloedow, A., & Hesse, S. (2003). Counseling families of children with communication disorders. *Communication Disorders Quarterly*, *24*(4), 211-220.
- Grays, C. (1963). At the bedside: The pattern of acceptance in parents of the retarded child. *Tomorrow's Nurse*, *4*, 30-34.
- Hardman, M. L., Drew, C. J., & Egan, M. W. (2008). *Human exceptionality: School, community, and family* (9th ed.). Boston, MA: Houghton Mifflin.
- Harry, B. (1997). Leaning forward or bending over backwards: Cultural reciprocity in working with families. *Journal of Early Intervention. 21*(1), 62-72.
- Harry, B. (2002). Trends and issues in serving culturally diverse families of children with disabilities. *The Journal of Special Education, 36*(3), 131-138.
- Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disability*, *9*, 155-165.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation*, *107*, 116-127.
- Hay, W. (1950). Mental retardation problems in different age groups. *American Journal of Mental Deficiency, 55*(2)*,* 191-197.
- Helff, C. M., & Glidden, L. M. (1998). More positive or less negative?: Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation*, *36*(6), 457-464.

- Heller, T., Markwardt, R., Rowitz, L., & Farber, B. (1994). Adaptation of Hispanic families to a member with mental retardation. *American Journal of Mental Retardation,* 99(3), 289-300.
- Hershenson, D. B. (1992). Conceptions of disability: Implications for rehabilitation. *Rehabilitation Counseling Bulletin.* 35(3), 154-60.
- Honig, A. S. (1984). Working in partnership with parents of handicapped infants. In M. L. Henniger & E. M. Nesselroad (Eds.), *Working with parents of handicapped children: A book of readings for school personnel* (pp. 109-128). Lanham, MD: University Press of America.
- Huber, C. H. (1979). Parents of the handicapped child: Facilitating acceptance through group counseling. *Personnel and Guidance Journal, 57*(5), 267-269.
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with a developmental disability. *Issues and Innovations in Nursing Practice*, *34*(5), 582-592.
- Kingsley, E. P. (1987/2001). Welcome to Holland. In S. D. Klein and K. Schive (Eds.) *You will dream new dreams: Inspiring personal stories by parents of children with disabilities* (2001, pp. 216-217). New York, NY: Kensington Books.
- Kirk, S. A., Gallagher, J. J., Coleman, M. R., & Anastasiow, N. (2009). *Educating exceptional children* (12th ed.). Boston, MA: Houghton Mifflin.
- Kirk, S., Karnes, M., & Kirk, W. (1968). *You and your retarded child: A manual for parents of retarded children.* Palo Alto, CA: Pacific Books.
- Klein, B. L. (1984). Families of handicapped children: A personal account. In M. L. Henniger & E. M. Nesselroad (Eds.), *Working with parents of handicapped children: A book of readings for school personnel* (pp. 73-81). Lanham, MD: University Press of America.
- Koegler, S. J. (1963). The management of the retarded child in practice. *Canadian Medical Association Journal, 89*(20), 1009-1014.
- Krehbiel, R., & Kroth, R. L. (1991). Communicating with families of children with disabilities of chronic illness. In M. J. Fine (Ed.) *Collaboration with parents of exceptional children* (pp. 103-127). Brandon, VT: Clinical Psychology.
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal of Mental Retardation, 97,* 393-404.
- Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families.* New York, NY: Routledge.
- Kuhn, T. S. (1970). *The structure of scientific revolutions* (2nd ed.). Chicago, IL: University of Chicago Press.
- Kuhn, T. S. (1977). *The essential tension: Selected studies in scientific tradition and change*. Chicago, IL: University of Chicago Press.
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, *76*, 564-575.

- Lloyd , T. J., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: Cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research*, *52*, 37-48.
- Lloyd, T. J., & Hastings, R. P. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 957-968.
- Love, H. D. (1970). *Parental attitudes toward exceptional children*. Springfield, IL: Charles C. Thomas.
- Marshall, E. S., Olsen, S. F., Mandleco, B. L., Dyches, T. T., Allred, K. W., & Sansom, N. (2003). "This is a spiritual experience": Perspectives of Latter-Day Saint families living with a child with disabilities. *Qualitative Health Research*, *13*(1), 57-76. doi:10.1177/1049732302239411
- Martin, L. L., & Nivens, M. K. (1980). The acceptance of exceptionality: A three dimensional model. Retrieved from ERIC database. (ED196195)
- McDonald, W. (2009, December 30). In remembrance: Vivid personalities of a decade. *The New York Times*. Retrieved from http://www.nytimes.com
- McGuire, A. (2010). Disability, non-disability and the politics of mourning: Re-conceiving the 'we.' *Disability Studies Quarterly*, *30*(3/4). Retrieved from http://www.dsq-sds.org
- Mead, G. H. (1932). *The philosophy of the present.* Chicago: Open Court.
- Meyer, D. (1995). *Uncommon fathers: Reflections on raising a child with a disability.* Bethesda, MD: Woodbine House.
- Meyerson, R. C. (1983). Family and parent group therapy. In M. Seligman (Ed.) *The family with a handicapped child: Understanding and treatment* (pp. 285-308)*.* New York, NY: Grune & Stratton.
- Miller-Marsh, M., & Turner-Vorbeck, T. (2010. Introduction. In M. Miller-Marsh & T. Turner-Vorbek (Eds.), *(Mis)Understanding families: Learning from real families in our school* (pp. 1-3). New York, NY: Teachers College Press.
- Mori, A. A. (1983). *Families of children with special needs: Early intervention techniques for the practitioner.* Rockville, MD: Aspen.
- Moses, K. I. (1983). The impact of initial diagnosis: Mobilizing family resources. In J. A. Mulick & S. M. Pueschel (Eds.), *Parent-professional partnerships in developmental disability services* (pp. 11-34). Cambridge, MA: Ware.
- Mour, S. I. (1981). If I need someone to hold my hand, will you be there? *School Counselor*, *28*(5), 356-362.
- Naidoo, P. (2006). Potential contributions to disability theorizing and research from positive psychology. *Disability and Rehabilitation*, *28*(9), 595-602.
- Nota, L., Soresi, S., Ferrarai, L., Wilgosh, L., & Scorgie, K. (2005). Life management and quality of life in parents of children with diverse disabilities. *Developmental Disabilities Bulletin, 31*(2), 155-181.
- O'Halloran, J. (1993). Welcome to our family, Casey Patrick. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 19-29). Baltimore, MD: Paul H. Brookes.
- O'Rourke, M. (2010, February 1). Good grief: Is there a better way to be bereaved? *The New Yorker*, *85*(47), 66.

- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 190-193.
- Oriphory, G., & Peters, G. A. (1982). Counseling intervention strategies for families with the less than perfect newborn. *The Personnel and Guidance Journal*, *60*(8), 451-455.
- Pearsall, P. (2003). *The Beethoven factor: The new positive psychology of hardiness, happiness, healing, and hope*. Charlottesville, VA: Hampton Roads.
- Penzo, J. A., & Harvey, P. (2008). Understanding parental grief as a response to mental illness: Implications for practice. *Journal of Family Social Work*, *11*(3), 323-338.
- Philp, M., & Duckworth, D. (1982). *Children with disabilities and their families: A review of research*. Windsor, Berks: NFER-Nelson.
- Pushor, D. (2010). Are schools doing enough to learn about families? In M. Miller-Marsh & T. Turner-Vorbek (Eds.), *(Mis)Understanding families: Learning from real families in our school* (pp. 4-16). New York, NY: Teachers College Press.
- Ray, J., A., Pewitt-Kinder, J., & George, S. (2009). Partnering with families of children with special needs. *Young Children*, *64*(5), 16-22.
- Rehm, R. S. (1999). Religious faith in Mexican-American families dealing with chronic childhood illness. *Image: Journal of Nursing Scholarship*, *31*, 33-38
- Rice, N. (2006). Promoting 'epistemic fissures': Disability studies in teacher education. *Teaching Education*, *17*(3), 251-264.
- Rogers-Dulan, J., & Blacher, J. (1995). African-American families, religion, and disability: A conceptual framework. *Mental Retardation, 33*(4), 226-238.
- Roll-Pettersson, L. (2001). Parents talk about how it feels to have a child with a cognitive disability. *European Journal of Special Needs Education, 16*, 1-14.
- Rosen, L. (1954). Selected aspects in the development of the mother's understanding of her mentally retarded child. *American Journal of Mental Deficiency*, *59*(3), 522-528.
- Ross, A. O. (1964). *The exceptional child in the family: Helping parents of exceptional children.* New York, NY: Grune & Stratton.
- Ruzich, C. M. (2008). Our deepest sympathy: An essay on computer crashes, grief, and loss. *Interaction Studies.* 9(3), 504-517.
- Schaef, A. W. (1992). *Beyond therapy, beyond science: A new model for healing the whole person*. San Francisco, CA: Harper San Francisco.
- Schultz, J. (1993). Heroes in disguise. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 31-41). Baltimore, MD: Paul H. Brookes.
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, *38*(3), 195-206. doi:10.1352/0047-6765(2000)038<0195:TOAWPC>2.0.CO;2.
- Scorgie, K., Wilgosh, L., & McDonald, L. (1996). A qualitative study of managing life when a child has a disability. *Developmental Disabilities Bulletin, 24*, 68-89.
- Scorgie, K., Wilgosh, L., & McDonald, L. (1999). Transforming partnerships: Parent life management issues when a child has mental retardation. *Education and Training in Mental Retardation & Developmental Disabilities, 34*, 396-405.

- Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin, 32*(1), 84-110.
- Searl, S. J., Jr. (1978). Stages of parent reaction. *The Exceptional Parent*, *8*(2), F27-F29.
- Seligman, M. E. P. & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, *55*(1), 5-14. doi: 10.1037/0003-066X.55.1.5
- Servaty-Seib, H. L. (2004). Connections between counseling theories and current theories of grief and mourning. *Journal of Mental Health Counseling, 26*(2), 125-145.
- Sheridan, S. M., Warnes, E. D., Cowan, R. J., Schemm, A. V., & Clarke, B. L. (2004). Family-centered positive psychology: Focusing on strengths to build student success. *Psychology in the Schools*, *41*(1), 7-17.
- Sieffert, A. (1978). Parents' initial reactions to having a mentally retarded child: A concept and model for social workers. *Clinical Social Work*, *6*(1), 33-43.
- Skinner, D., & Bailey, D. (1997). Constructing a model for understanding how Latino families understand and respond to a young child with disabilities. Paper presented at the meeting of the Gatlinburg Conference on Research and Theory in Mental Retardation and Developmental Disabilities, Riverside, CA.
- Skrtic, T. M. (1995). The special education knowledge tradition: Crisis and opportunity. In E. L. Meyen & T. M. Skrtic (Eds.), *Special education and student disability: Traditional, emerging, and alternative perspectives* (pp. 609-674). Denver, CO: Love.
- Skrtic, T. M. (2004). The crisis in special education knowledge: A perspective on perspective. In S. Danforth & S. Taft (Eds.), *Crucial Readings in Special Education* (pp. 80-95). Englewood Cliffs, NJ: Prentice-Hall.
- Snow, K. (2001). *Disability is natural: Revolutionary common sense for raising successful children with disabilities.* Woodland Park, CO: Braveheart Press.
- Solnit, A. J., & Stark, M. H. (1961). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child, 16*, 523-537.
- Sonnenschein, P. (1981). Parents and professionals: An uneasy relationship. *Teaching Exceptional Children, 14*(2), 62-65.
- Southwest Educational Development Laboratory. (1976). *Working with parents of handicapped children*. Reston, VA: The Council for Exceptional Children.
- Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual & Developmental Disability*, *23*(1), 57-70.
- Stone, M. M. (1948). Parental attitudes to retardation. *American Journal of Mental Deficiency*, *53*(2), 363-372.
- Stoneman, Z., Brody, G. H., & Abbott, D. (1983). In-home observations of young Down syndrome children with their mothers and fathers. *American Journal of Mental Deficiency, 87*(6), 591-600.
- Stoneman, Z., Brody, G. H., Davis, C. H., & Crapps, J.M. (1989). Role relations between children who are mentally retarded and their older siblings: Observations in three in-home contexts. *Research in Developmental Disabilities, 10*(1), 61-76.
- Summers, J. A., Behr, S. K., & Turnbull, A. P. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. S. Singer & L. K. Irvin

(Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27-40). Baltimore, MD: Paul H. Brookes.

- Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the quality of family-professional partnerships in special education services. *Exceptional Children, 72*(1), 65-81.
- Tarakeshwar, N., & Pargament, K. I. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disorders, 16*, 247-261.
- Taylor, S. E. (1983). Adjustment to threatening life events: A theory of cognitive adaptation. *American Psychologist*, *38*, 1161-1173.
- Taylor, S. E., & Brown, J. D. (1988). Illusion and well-being: A social psychological perspective on mental health. *Psychological Bulletin*, *110*, 193-210.
- Taylor, S. E., Kemeny, M. E., Reed, G. M., Bower, J. E., & Gruenewald, T. L. (2000). Psychological resources, positive illusions, and health. *American Psychologist, 55*(1), 99-109.
- Turnbull, A. (1985). *Positive contributions that members with disabilities make to their families.* Paper presented to the AAMD 109th Annual Meeting, Philadelphia.
- Turnbull, A., Patterson, J. M., Behr, S., Murphy, D., Marquis, J., & Blue-Banning, M. (1993). *Cognitive coping, families, and disability*. Baltimore, MD: Paul H. Brookes.
- Turnbull, A. P., & Turnbull, H. R. (1993). Participatory research on cognitive coping: From concepts to research planning. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 1-14). Baltimore, MD: Paul H. Brookes.
- Ulrich, M. E., & Bauer, A. M. (2003). Levels of awareness: A closer look at communication between parents and professionals. *Teaching Exceptional Children, 35*(6), 20-24.
- Valliant, G. E. (2000). Adaptive mental mechanisms: Their role in a positive psychology. *American Psychologist*, *55*(1), 89-98. doi: 10.1037/0003-066X.55.1.89
- Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry, 51*(1), 63-70.
- Wikler, L., Wasow, M., & Hatfield, E. (1983). Seeking strengths in families of developmentally disabled children. *Social Work, 28*(4), 313-315.
- Witcher, A. E. (1987). The process of grief as experienced by parents of children with handicaps. Retrieved from ERIC database. (ED320369)
- Zea, M. C., Quezada, T., & Belgrave, F. Z. (1994). Latino cultural values: Their role in adjustment to disability. *Journal of Social Behavior and Personality, 9*(5), 185-200.