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## CHAPTER 9

# The Loss–Grief Cycle

## *Coming to Terms with the Birth of a Child with a Disability*

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Life and loss are fickle friends. They are at times intimate, at other times aloof and shadowy, and at still other times, smashing, even mangling. Birth itself is the first human encounter with loss as the infant is thrust from its primal uterine home—contained, still, placid, and all-sustaining. With each successive breath, humans lose their life. The loss is so subtle and pervasive that the experience is subliminal, barely piercing the membrane of consciousness. Yet, other losses crash into consciousness, wreaking their own kind of havoc, annihilating one's confidence in even the most fundamental expectancies of everyday life. This chapter is concerned with just such a loss—the birth of child with a developmental disability.

The addition of a new child into the family system can be a marvelous and joyously anticipated event. On almost all counts, it is also a revolutionary event because it sets into motion a cascade of adjustments, accommodations, and adaptations at almost every level of daily, relational, and psychological life. Given a healthy child and adjusted parents, the necessary transformations are made, for the most part, as a matter of course, some more readily and others certainly with the effort of coping. However, the birth of a child with a disability presents a remarkably different scenario and signals a potential threat to the spirit as well as to the daily and future life of the parents. The losses, both tangible and psychological, not infrequently precipitate a reaction of grief.

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This chapter is dedicated to the families, children, and staff who participated in The Family Centered Resource Project (Model/Demonstration 1975–1978; Outreach 1979–1987), funded by the United States Department of Education, then the Office of Special Education, Handicapped Children's Early Education Program (HCEEP), and the Pennsylvania Department of Education.

Enduring appreciation is also extended to Eula and Glen Boelke, founders of the Effective Parent Program in Grand Junction, Colorado, who not only contributed significantly to the development and dissemination of this work but also were courageous pioneers and tireless change agents, forging new channels of communication and collaboration among parents and professionals in the field of infant and early childhood intervention.

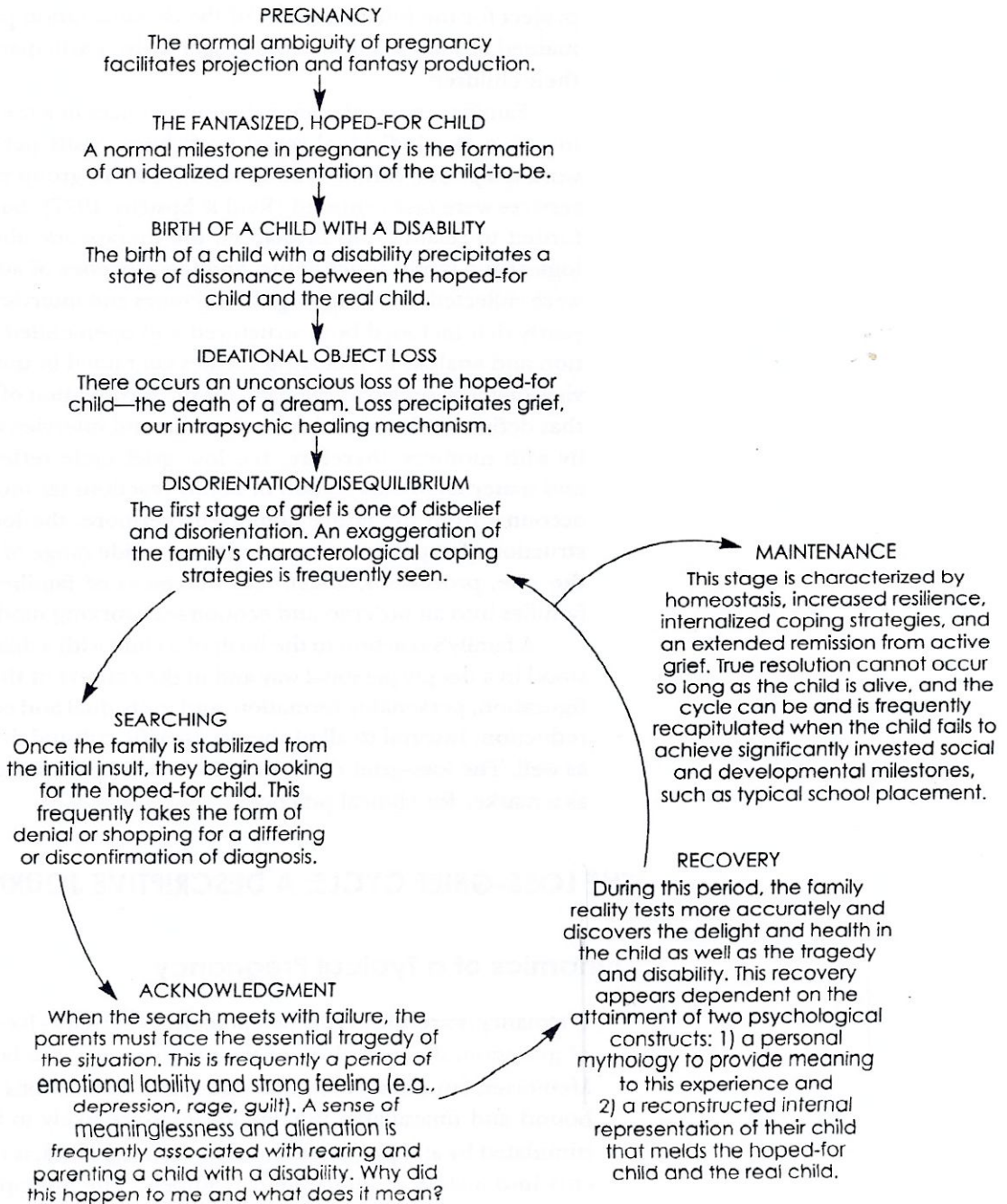
The loss-grief cycle (Foley, 1983, 1986) plots one course of themes and markers experienced by a group of parents in their adaptation to having an infant or toddler with a severe disability (see Figure 9.1). For clinicians, this model may serve as one point of reference to interpret behavior, suggest formulation, and guide a course of support and healing. Conceptually, the loss-grief construct has its roots in the paradigm of mourning associated with the birth of a child with a disability proposed by Solnit and Stark (1961). The formulation presented and elaborated on here is derived both from metapsychological theorizing and from data collected as part of a longitudinal clinical investigation that in the context of contemporary methods would most closely correspond to qualitative research.

## THE FAMILIES AND THE WORK

Twenty-one families, all of whom had an infant or toddler with a diagnosed developmental disorder, were followed longitudinally for 2 years as part of a model/demonstration project funded by the U.S. Department of Education, Handicapped Children's Early Education Program (HCEEP). The aims of the Family-Centered Resource Project (1975-1978 demonstration cycle; 1979-1987 outreach cycle) were to develop, field-test, and validate an innovative model and method of intervention for young children with disabilities and their families that could be disseminated and replicated at other sites regionally and nationally. The project represented an inter-agency collaboration among The Pennsylvania Department of Education, The Berks County Intermediate Unit, The Berks County Easter Seals Society, and Albright College.

The 21 families who participated in the project were self-selected. They were predominantly Caucasian (90%), middle class, employed, and intact (86% married and living together). Forty-eight percent classified themselves as suburban, 19% as rural, and 33% as urban. One African American family and one family from the Philippines were also represented in the sample. One mother was widowed, one parent divorced, and another separated.

The children consisted of 14 boys and 7 girls with a mean age of 21 months at the time of enrollment but with an age range of 3 weeks to 46 months. Fifty-seven percent had a diagnosis of cerebral palsy, 19% had a diagnosis of seizure disorder, and another 19% had a diagnosis of a severe or profound developmental delay. One child had a diagnosis of Down syndrome and another had a diagnosis of autism. All of the children demonstrated significant developmental delays as measured on standardized instruments. Three of the children were the only child in their families, and eight were the first-born children in their families. Seven of the children had only one sibling, and three had eight or more siblings. One child was adopted. Nineteen of the families participated in the



**Figure 9.1.** The loss–grief cycle: A descriptive journey. (From Foley, G.M. [1983]. The grief cycle. In C. Amon & D. Smith [Eds.], *Parents encouraging parents* [p. 21]. Denver: Colorado Department of Education. Adapted by permission.)

project for the full 24 months of the demonstration phase, and two families remained affiliated but were no longer active participants following the death of their children.

Families received comprehensive services in a transdisciplinary format that included two individual social work home visits per month, follow-up social work telephone contacts, and monthly parent group meetings. The social work services were task centered (Reid & Epstein, 1977), but careful attention was afforded to relationship formation, the therapeutic alliance, individual psychological and family functioning, and the processes of adjustment over time. Data were collected from ongoing clinical notes and interviews conducted three times yearly that included both structured and open-ended questions. An identification and analysis of recurring themes contained in the process notes and interview material served as the basis for the formulation of the markers and themes that define the loss-grief cycle. Sessions and interviews were conducted primarily with mothers; therefore, the loss-grief cycle reflects maternal experience and maternal interpretation of family reactions far more than it does firsthand accounts from the entire family. Furthermore, the loss-grief cycle is a reconstruction of experience that condenses a wide range of individual differences in the rate, procession, affect, and outcomes of families and individuals within families into an ordered and economical working model.

A family's reaction to the birth of a child with a disability can only be understood in a deeply personal way and in the context of the family history and configuration, personality formation, and individual and collective styles of tension reduction. Integral to all of this are specific cultural differences and influences as well. The loss-grief cycle, therefore, is at best a sketch to be used judiciously as a marker for clinical practice.

## **THE LOSS-GRIEF CYCLE: A DESCRIPTIVE JOURNEY**

### **Dynamics of a Typical Pregnancy**

Pregnancy is a fertile period psychologically as well as biologically. Over the course of gestation, the inner lives of the parents are apt to become more permeable. Memories, fantasies, emotional states, and associations that might otherwise be bound and unavailable to consciousness are likely to be freed. This material, stimulated by and projected onto the forming child, is the "grist" that woos parents into a state of attachment readiness. The anticipation, hope, and open-ended possibility that the forming child evokes motivate the family to face the tremendous adjustments ahead—some pleasurable, some a matter of sheer endurance.

Parents project the best that they are and the best they hope to become onto the unborn child. Thus, the unknown child serves as a perfect projective screen and a socially acceptable and adaptive object of healthy parental narcissism. As gestation unfolds, parents create an image of the “idealized child,” which in many cases approximates the personal as well as collective ego ideal of the family. This new ideational love-object serves to mobilize motivation and affection for the real child to come.

Of course, parental projections are always mixed. Anxiety, fear, and negative self-images also form a part of the overall representation. But when the parents’ self-esteem is realistic and positive and their own parental introjects are primarily good, positively colored projections are more than likely to outweigh negative ones. Moreover, the parental portrait of the unknown child may offer important clues to the parents’ own history, wishes, fears, and possible adjustment to the birth and early parenting and attachment styles (see Chapter 8).

## Reality and the Birthing Experience

Realities have a way of falling short of fantasies, even in an event as wondrous and miraculous as birth. The birthing experience and the newborn him- or herself may not quite match parental expectations—one possible psychological contribution to postpartum letdown. Yet, given a healthy child and adjusted parents, the disappointment is apt to be fleeting as accommodations are made and parity is achieved between the fantasy child and the real child.

The dissonance between the hoped for and the real is less readily resolved when the infant is born premature, ill, or with a physical anomaly or disability (Hughes, McCollum, Sheftel, & Sanchez, 1994). In this context, *birth* means both literal birth and figurative birth to include when an older child is identified with what heretofore may have been an invisible or only suspected disability. Although the birth of a child with a disability is a loss less total and less final than loss by death, it is nevertheless the violation of a hope and the death of a dream, no less real and perhaps no less painful (Moses, 1983). Such loss holds the potential to topple an individual’s mental well-being, alter his or her established ways of operating, and challenge his or her worldview—that interrelated web of beliefs, values, ideas, and feelings that stand as a bulwark against the anxiety of the unknown (Gombosi, 1998).

In the hearts and minds of the parents, therefore, a wide gulf of ambiguity and anxiety is likely to form between the healthy, hoped-for child and the real child. The tangible loss of an intact child precipitates yet another invisible but no less real loss—the death of the hoped-for, idealized child. In reality, the loss is not a single incident of loss but over time a cascade of cumulative losses (Naseef, 1997; see also Bruce & Schultz, 2001).

Loss, in turn, precipitates grief. They are related phenomena as grief is the spontaneous and inherently healing response of the psychic system to loss, not unlike the way in which swelling and fever are physiological responses to infection. Although grief is more typically associated with death, and the children in this project were alive, parents were sometimes unclear about and unable to identify the psychic loss as a contributing source of their feelings or even to identify their reaction as grief. Availing themselves of the process of grieving proved healing for most parents, however, but to embrace grief was challenging because the process is painful and the reflexive response is to avoid pain even if it proves beneficial. As a result, helping parents to grieve in order to heal became a therapeutic aim. The progression of that grief broadly assumed the following form.

### Disorientation/Disequilibrium

Only 20% of the participants were enrolled in the project at the period of initial identification; many of the data collected were retrospective. The initial reaction was reported to be one of disorientation and disequilibrium ranging from disbelief to shock and panic. One parent described herself as "shattered, thrown over." Some parents responded to the news with muted registration and numbness, needing to hear the same information over and over to be sure it was not all part of some bad dream. As in most stress reactions, variations on fight, flight, or freeze were manifest.

The central task of this initial period was regulation and reestablishment of homeostasis. It followed highly individualized patterns but appeared to be determined by the established coping styles of individuals within a family and the family system collectively. In other words, people rely on the methods of tension reduction and regulation that have worked for them in the past. These reactions tend to be intense and in proportion to the magnitude of the stressor (Moses, 1983).

Unless the patterns were psychotic or significantly destructive to self or others, no attempt was made to alter the parents' style during the course of providing service. The assumption in working with families during this period was that if the manifest patterns of self-regulation and coping had been successful in the past, they would be effective now. For the most part, this proved to be the case.

However, the intensity of feeling and reactivity were sometimes frightening and threatening to the integrity of both self and family, and feelings of "falling apart" or "spinning out of control" were reported. Psychological holding, containing, slowing down, thought stopping, delimiting projective "catastrophizing," and providing a safe and supportive ambiance in which to express the unthinkable all proved to be helpful strategies when employed judiciously and sensitively.

## Searching

Once a relative emotional equilibrium had been reestablished, the searching phase commenced. Searching, described as the normal hallucinatory stage of grief by Bowlby (1980), has been graphically documented in cases of the death of a spouse. Surviving spouses reported both sightings of individuals with an uncanny resemblance to the deceased and hearing the footsteps of the deceased walking toward a place where pleasant moments had been shared. Such experiences were interpreted as unconsciously determined responses to searching for the lost persons and the feelings associated with the deceased. Searching of similar function, if not kind, was noted in the participant parents who sought after the spirit of the hoped-for, typical child never born—an often disappointing search but nonetheless a normal and necessary one in the healing process.

Searching took two broad but related forms with variations on theme. The first was strategic denial—not a denial of the existence of a problem but **denial of the magnitude and intractability of the problem**. If one could only see through the disability or its full spectrum, then the real child became the hoped-for child or at least a closer approximation and the loss was resolved or minimized. This coping mechanism short circuits or limits the intensity of the grief response at its inception.

The second related response was a searching for alternative opinions, sometimes literally taking the child from expert to expert with a latent wish that the diagnosis, its severity, or its natural history would be refuted. Searching tended to be buoyed by optimism, sometimes even colored with the urgency and zeal of a mission. **It is an important interlude during which passive is turned to active and feelings of purpose and determination elevate the mood and restore hope, making searching absolutely essential for some parents to sustain the emotional endurance needed to persevere** (Affleck & Tennen, 1991).

Not infrequently, practitioners are made anxious by this reaction (a counter-transference response that may have more to do with the practitioner than the parent) and may abruptly and prematurely attempt to “awaken” parents to the seeming reality of their circumstance. Such interpretive efforts can weaken the parents’ coping stamina over the long run. The need for parents to feel empowered and hopeful promotes normal and necessary relief and emotional refueling at this stage, which may enable them to face the challenges that are likely *to lie ahead*. *It is important to note that such strategic denial is different from a pervasive and unyielding distortion of reality. If a coping strategy crystallizes into a fixed defensive position, then an adaptive adjustment is likely to be imperiled. But to shatter a beneficial, situation-specific coping effort abruptly or with undue harshness is apt to prove more harmful than helpful.*

It is critical for practitioners to remain available to parents through this searching interlude to help them navigate what may be a precarious passage between searching and blind finding, between coping and defense, between hope and self-delusion. Parents may be supported to seek a second opinion, explore complementary interventions, or take a measured interval to “wait and see.” The primary provider indeed plays an important role as ballast and leveler, serving as a reliable and trusted base of support, reflection, and guidance to parents as they gather new information in their search. **As is generally true throughout the course of development, exploration and searching are best executed from a secure base. The risk of becoming tied to endless searching is amplified when parents have no trusted professional resource with whom to process and resolve conflicting opinions or think through difficult decisions and are forced to consult with yet another new professional** (Turnbull, Turbiville, & Turnbull, 2000).

Often, transition to acknowledgement cannot begin with a sense of peace or confidence until the parents feel convinced they have exhausted their search. It is not unlike a person receiving a diagnosis of terminal illness needing to “leave no stone unturned” in the hope of revealing a diagnostic error or discovering an unorthodox cure.

Individual differences are wide ranging in the duration, breadth, and depth of searching that families feel compelled to do. Personality style, economic resources, social reference group, and educational status are all contributing factors. Nevertheless, staying with the family in a supportive, clarifying, and gently reality-testing role promotes a reasoned resolution of the searching phase.

## Acknowledgment

Acknowledging their child’s disability transitions families into the third period of the loss–grief cycle, which is often tinged with the coloring of a crisis in meaning (Park & Folkman, 1997). Now resigned to having a child with a disability, parents may see only his or her impairments, and feelings for the loss of the typical child are thrown into high relief. Suddenly, the social institution of parenthood with its methods, support network, prescriptions, and promised joy no longer seems to apply, threatening self-identity and traditional family roles. Attainment of even the most basic developmental milestones may no longer be reasonable expectations for their child but loom as accomplishments to be acquired only with great effort and requiring the expertise of professionals. Good-enough parenting alone is not likely to suffice. No longer “typical parents,” personal aspirations and career goals may be jeopardized as well. One parent spoke of the “death of dreams.”

The result may be feelings of helplessness and isolation. Many of the learned child-rearing prescriptions do not seem to apply to the child with a disability, so



there are few or no role models. Life may seem both tragic and absurd, and what once seemed predictable and assured dissolves into uncertainty and anxiety.

This was an arduous and often abject period in the loss–grief cycle. Parental feelings varied but were apt to be intense and traversed the range of anger, guilt, hopelessness, and/or fantasies of flight. Negative affects might be attributed to the child, spouse, institutions, or helpers. Anger might also be directed inward, contributing to dysphoria and depression. Obsessive thoughts intruded into conscious behavior, sometimes with the complexion of reaction formation. It was difficult for parents to derive a feeling of pleasure from their child who was perceived as “irreparably damaged” and reflective of their own hidden defects (Brazelton & Cramer, 1990). Therefore, apprehensions about institutionalization, wishing the child dead, and abandoning or even killing the child were among a range of reported feelings and fantasies (Gordon, Daniele, & Diller, 1992; Veisson, 2001).

One mother at this stage characterized herself thusly: “I feel like my child is a doll and I’m playing house.” Despite enormous effort, the child did not measurably develop, change, or respond. The parenting experience therefore felt mechanical and make-believe in motion but as if in a dream, leading nowhere.

Therapeutic support, networking, guidance from other parents, and occasional respite care proved effective interventions at this time (Ireys, Chernoff, Stein, DeVet, & Silver, 2001). Expectations about parental involvement in the child’s program were moderated to the parents’ capacities and needs. An emphasis was placed on teaching to the child’s strengths and helping parents to discover aspects of their child that were typical, functional, and related to their images of the hoped-for child. Assisting parents to sustain hope without illusion was a challenging task for all members of the team.

Although this period had a decidedly dark cast, for the most part, families did recover, facilitated by the accomplishment of two psychological tasks: 1) the development of a personal mythology and 2) a reconstruction of the inner representation of the child.

### ***Development of a Personal Mythology***

The development of a personal mythology implies the construction of a belief system and coherent narrative that makes personal sense out of the seemingly tragic senselessness of having a child with a disability. This invention takes many forms; however, the more the mythology was rooted in insight and reality, the greater its healing power. Conversely, those mythologies rooted in magical thinking quickly eroded into chaos and formlessness.

Rollo May (1959) suggested, “Symbols are specific acts or figures . . . while myths develop and elaborate these symbols into a story. They are man’s way of scoring his life, his self-image, and his relations to the world of his fellow men

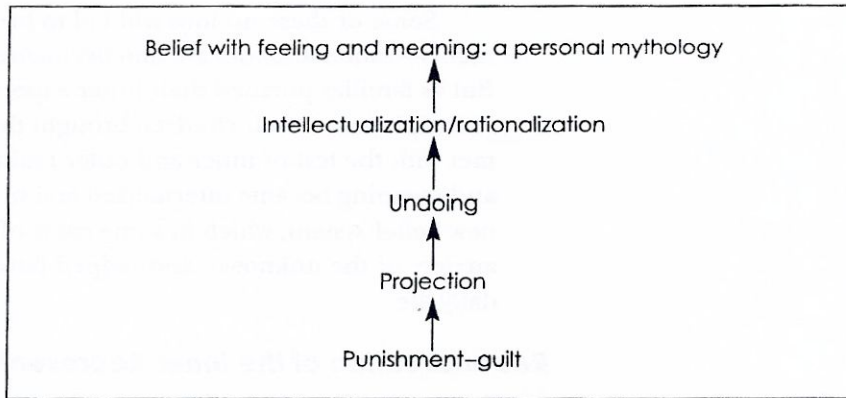
and of nature" (p. 34). In other words, myths convey intensified personal truths and contain a synthesized inner and outer reality wrapped in a fiction. Symbols and myths together "enable the person to experience greater reality in the outside world" (May, 1959, p. 45).

In part, the formation of a personal myth was motivated by a need to answer (at least indirectly) the question, "Why?" The will to construct a personal mythology may be a function of the mutative forces of grief itself, which tested the limits of many of the families' existing belief systems to the point of fracture, demanding a deconstruction and reformulation of their story and beliefs along personal lines. The formation of this mythology tended broadly to follow a developmental progression as outlined in Figure 9.2.

It was not unusual for feelings of punishment and guilt to emerge early and to recur often in the reflection and myth-forging journey of families. To feel that having a child with a disability was retribution for some misdeed is not inconsistent with a Western Judeo-Christian ethic that is strongly tinged with the notion that "the wages of sin are death." Therefore, it was not unusual for parents to report searching for their "sins" and, in a sense, **making a case for the punishment-guilt explanation**. Ironically, to subscribe to that view is to validate the experience in their own minds and make it somehow logical, orderly, and, in an obtuse way, within human control by ascribing a self-inflicting cause. Mothers in particular tended to examine their own pregnancies in excruciating detail, trying to pinpoint events or behaviors that might answer the "why" question. Punishment-guilt is a natural and common starting point, but if families remain there, it is ultimately self-defeating.

A second position in the development of a personal mythology was **projective assignment of blame**. Families may attribute the cause to an obstetrical error, environmental pollutants, an undisclosed genetic defect in a mate's family, and so forth. In some rare cases, a single identifiable external event may be contributory, even causal. Regardless, this transition to seeking an external cause represents a step away from self-punishment toward what is more consistent with mental health. However, agencies and practitioners may be among the objects of a family's projections and so reliability, continuity, and a capacity to contain the projections of the family are important aspects of the work during this period. Conversely, termination, ambivalence, or defensive reactions on the part of practitioners may communicate to parents that they are damaging and may serve to affirm deeply held dread that they may have in some way actually damaged their own child and that they themselves also are defective in some hidden way (Brazelton & Cramer, 1990).

Projection was apt to give way to **"undoing."** Not unlike the Kübler-Ross (1969) concept of bargaining, undoing suggests some hope that the problem can and will be reversed or undone by acts of reparation. Family members may throw



**Figure 9.2.** The developmental progression toward the formation of a personal mythology.

themselves into working with the child, volunteering time to the infant program, or raising funds. These may be good causes, indeed, but may be less than altruistic and harbor a covert wish that good work would be rewarded with a spontaneous remission of the disorder. Families are often vulnerable at this time to causes and treatments that may hold out promises that range from merely unrealistic to quite preposterous depending on their degree of pain and desperation.

The emergence of intellectualization and rationalization may suggest that the family is searching for and trying on ideas and beliefs that may impart explanation and meaning and bind anxiety. Potential beliefs are tested and examined against reality. In some families, this took the form of a renewed and vigorous search—not to refute the diagnosis but to find the cause. Pinpointing a specific virus or a genetic defect or simply having a plausible causal hypothesis gave some families a realistic object to blame, a feeling of control through understanding, and was consistent with their style of intellectual problem solving. It also may provide some families with a sense of closure and add another piece to the nagging puzzle of why the event happened at all. However, even with a causal hypothesis, families were still plagued with the question, “What does this child mean for my life and my family?” The will to question is useful because it urges families to press toward personal meaning and experiment with forging a coherent narrative.

As families reflect and self-observe how this event has had an impact on them, they are likely to explore, examine, and experiment with ideas in search of a personally meaningful organizing theme. Some families may turn to traditional religious belief systems or ancient or contemporary forms of spirituality. Others examine how the event has transformed, empowered, or motivated them.

Some of these notions will fail to bring relief and prove to be only experiments—rationalizations and intellectualizations that are fragile and easily shaken. But as families pursued their inner experience and simultaneously stayed open to the pleasures their children brought them, some began to extract a truth that met with the test of inner and outer reality. As these ideas charged with feeling and meaning became internalized and organized, they formed the nucleus of a new belief system, which in some cases offered renewed purpose to life, bound anxiety of the unknown, and helped families cope with the added demands of daily life.

### **Reconstruction of the Inner Representation of the Child**

Parents hold emotionally saturated representations of their children that embody who these offspring are, who the parents wish they were, and who they might become. When a relative congruence prevails between representations and realities, a greater experience of harmony and authenticity of feeling and relating are likely. With great disparity, feelings may be tinged with dissonance, disappointment, and loss. The second trend to emerge from the data, therefore, suggested that families recovered more robustly as they found some of the hoped-for child in the real child, effecting greater parity between the inner representation of their child and the real child. This congruence helped family members sustain an attachment, find greater pleasure in their child, and “separate from a significant lost dream” (Moses, 1983, p. 13).

The early-formed representation of the hoped-for child, however, is apt to persist, certainly through the early life of the real child. In fact, the disparity between representation and reality may be of great magnitude, exacerbated by interaction with the real child, an ever-present and evocative reminder of what has been lost. One parent said, “Every time I look at my child, I see in my mind’s eye the child I was supposed to have, and the pain is stabbing.” This does not necessarily place parents in a state of chronic sorrow (Olshansky, 1962) but in a position of persistent loss.

Even in reasonably adjusted families, the disparity had some tendency to take on the quality of splitting: the hoped-for child being invested with the good, the whole, and the healthy—the real child invested with the bad, the deficient, and the sick. Such splitting only intensifies the pain families experience when interacting with their real child, a vicious cycle that prolongs the acute grief of the acknowledgment phase.

Practitioners can facilitate the family’s psychological task of reconstructing the inner representation of their child, still strongly tinged with the fantasies of the idealized child, by aiding them in discerning and integrating aspects of the real with the wished-for child, effecting a compromise position that narrows and eventually ameliorates the split. This process of reframing and reshaping the inner landscape appeared in part, of course, to be a function of time but also of

attachment to the real child and a function as well of the grief work itself by which the fantasies and hopes associated with the idealized child are divested and re-invested with associations and positive emotions allied to the real child (Freud, 1957). Acknowledgment becomes acceptance.

Like an artist who physically moves toward and away from his or her work-information as a means of gaining perspective, judging, discerning, and reforming, parents also redefine, reshape, and reconstruct the representation of their own child by psychologically moving toward and away from the real and representational child to gain perspective and integrate objectivity and reflective subjectivity. This dance seems to be an expected and necessary part of the reconstructive process, although the seeming ambivalence it engenders may be disquieting both to parents and their helpers alike. Practitioners, regardless of discipline, need not only tolerate this equivocation but actually use it to help parents in their reformulation, rediscovery, and reinvention of the representation of their child as they move toward recovery.

## Recovery

The mastery of these two preceding psychological tasks tended to usher families into a period of recovery hallmarked by the following:

- A diminution of intrusive thoughts and projective “catastrophizing”
- A lifting of affective numbing and leveling of mood
- A more balanced and realistic appraisal of the child as an individual who possesses both strengths and impairments
- A greater inclusion of the child into the family as a participating member
- A greater comfort in being seen with the child in public
- An increased taking of pleasure in the child
- A more discerning ability to read the child’s cues combined with a greater confidence in the family’s ability to sustain the life and promote the development of the child
- A greater involvement in the child’s intervention with a more realistic appraisal of its aims and outcomes
- An increased capacity to participate in and cope with the demands of daily life
- A greater subjective experience of acceptance and general feeling of well-being

Not every family responded similarly or with like robustness, but a weight in the direction of these markers represented a general trend toward recovery.

## Maintenance

As recovery extended over a period of at least 6 months, families were considered to have sustained an extended remission from grief and entered into what is called *maintenance*, suggesting that chronic sorrow need not be an ongoing reality. The maintenance period was marked by the child's movement from the center of the family system to a more appropriate place in the family dynamics. Families were then able to encourage greater independence for the child and to assume greater independence for themselves, returning to activities outside of the home, returning to work, pursuing an ambition put on "hold," reestablishing friendships, or adding another child to the family. Much credit goes to the families and the practitioners in the project because the families that entered intact sustained no separations or divorces.

The term *maintenance* was chosen because as long as the child is alive and has a disability, his or her presence precludes the kind of closure or resolution that might be experienced in the case of death. Periods of active grieving are likely to recur, especially at times of institutional transition for the child as from early intervention to preschool and then to school. Such transitions tend to reemphasize the discrepancy between where the child is developmentally and where the child might have been. Reexperiencing the loss reignites the grief.

Although the families were not followed in a formal way beyond the demonstration phase of the project, informal anecdotal data suggested that by walking families through the early cycle of grief in a supportive and therapeutic way, they were likely to internalize coping strategies and adaptive mechanisms that served them well when they reencountered loss and grief.

## CONSIDERATIONS

Although the methodology of this study lacked the control and rigor to presume a certitude or generalizability that might be inferred from more traditional research methodology, the clinical and qualitative information learned from following families over time was deeply personal. The following conclusions may be useful to other practitioners, program developers, and policy makers.

1. Having a child with a disability is stressful, and to react to that stress emotionally is neither unusual nor abnormal. Therefore, grieving and the mechanisms of coping and adjustment, although related to mental health, do not in and of themselves constitute a mental disorder.
2. The adjustment needs of the family cannot be separated from the developmental needs of the child with a disability. Mental health cannot be split off from early intervention, which suggests the need for greater integration in service delivery and professional preparation.

3. Although this chapter has emphasized the intrapsychic dimensions of adjustment, the demands of daily life for families are enormous and constant. Having practitioners in and out of the home in some cases almost continuously is exceedingly disruptive to family life. Simply navigating the system and scheduling appointments can be a full-time job for the parents. Families, therefore, need concrete services and physical help in many areas, which should not be underestimated or discounted.
4. Providing families with a reliably consistent practitioner to guide them through the agency maze, to respond to their questions, to help with paperwork, and to advocate for them is a critically valuable service.
5. Periods of transition are vulnerable times for families. Agencies and schools would do well to anticipate this by providing added support to families at these crossroads. Not only is this a matter of best practice and in the best interest of families but also it may reduce the adversarial tensions that are not unusual during these interludes, decreasing the risk of possibly rupturing a working alliance.
6. In years past, medical and mental health practitioners typically advised parents not to even take the infant with a disability home from the hospital. This effort to spare families the pain of grief was misguided. They grieved nonetheless. Today, the pendulum has swung so far that parents who conclude that rearing a child with a disability is not a possibility have fewer options and are apt to be stigmatized by the parent and professional communities alike. There is no one right way for parents to respond, and therefore they must be afforded a wider range of resources with regard to alternative but equally sensitive and high-quality care of their child with a disability.
7. A significant loss precipitates two major reactions: emotional pain and cognitive bewilderment. Grieving facilitates healing by pushing families to the limit of their feelings and beliefs and presses them to engage in a process of emotional and cognitive reflection and deconstruction. Thus, families reconstruct their beliefs and formulate a personal mythology to make sense out of a seemingly senseless loss. Although this process does not eradicate the pain, it may help families to cope more efficiently by more effectively binding anxiety. It is worth reiterating that the process of grieving is inherently healing; yet, it can challenge and test families to their limits. Grieving forces them to open up to new possibilities in a way that is both frightening and painful: frightening because new possibilities imply uncharted territory and painful because families often relive old pain to create new beliefs.
8. Grieving occurs individually and collectively within families. Individual family members and families as a whole exhibit a wide range of styles, means of

expression, and timetables, some congruent and some conflicting, which make it a very complex process. Working with the whole family system is critical (Brookes-Gunn, Berlin, & Filigni, 2000)—an aim recognized and attempted but not well realized in the Family Centered Resource Project. Considerable research points to the importance of attending to gender differences in patterns of reacting and coping with a child with a disability (Bailey, Blasco, & Simeonsson, 1992; Beckman, 1991; Crowley & Taylor, 1994; Kaplan, Crawford, Fisher, & Dewey, 1998).

9. The grief cycle presented here is essentially task centered as opposed to affect centered. Although the data suggested that a wide range of affects could be expected at varying times, there did not appear to be affect-specific stages. As a task-centered model, therefore, mastery of stage-specific psychological tasks appeared to be catalytic in recovery, including binding anxiety, activating movement through the cycle, and regulating disturbing affects. Specifically, the task of the disorientation/disequilibrium phase is regulation-homeostasis, that of searching, refueling, and acknowledgment—forming a personal mythology and reconstructing the inner representation of the child; recovery—acceptance; and maintenance—coping.
10. Grief takes many forms; with no single path, sequence, or set of “normal” feelings. Bonanno’s findings (2004) suggested that many people are remarkably resilient and display only minor and transient disruptions in response to trauma. Empirical findings reviewed in the same article challenge the validity of the grief construct and grief work as an effective model of intervention for trauma. Ideally, this chapter will stimulate further research into loss and grief as a function of humanity and the validity of the loss-grief model as a construct and method to help families adjust to the birth of a child with a disability.

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