
**Strategies for
Working with Families of
Young Children with Disabilities**

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Chapter 11

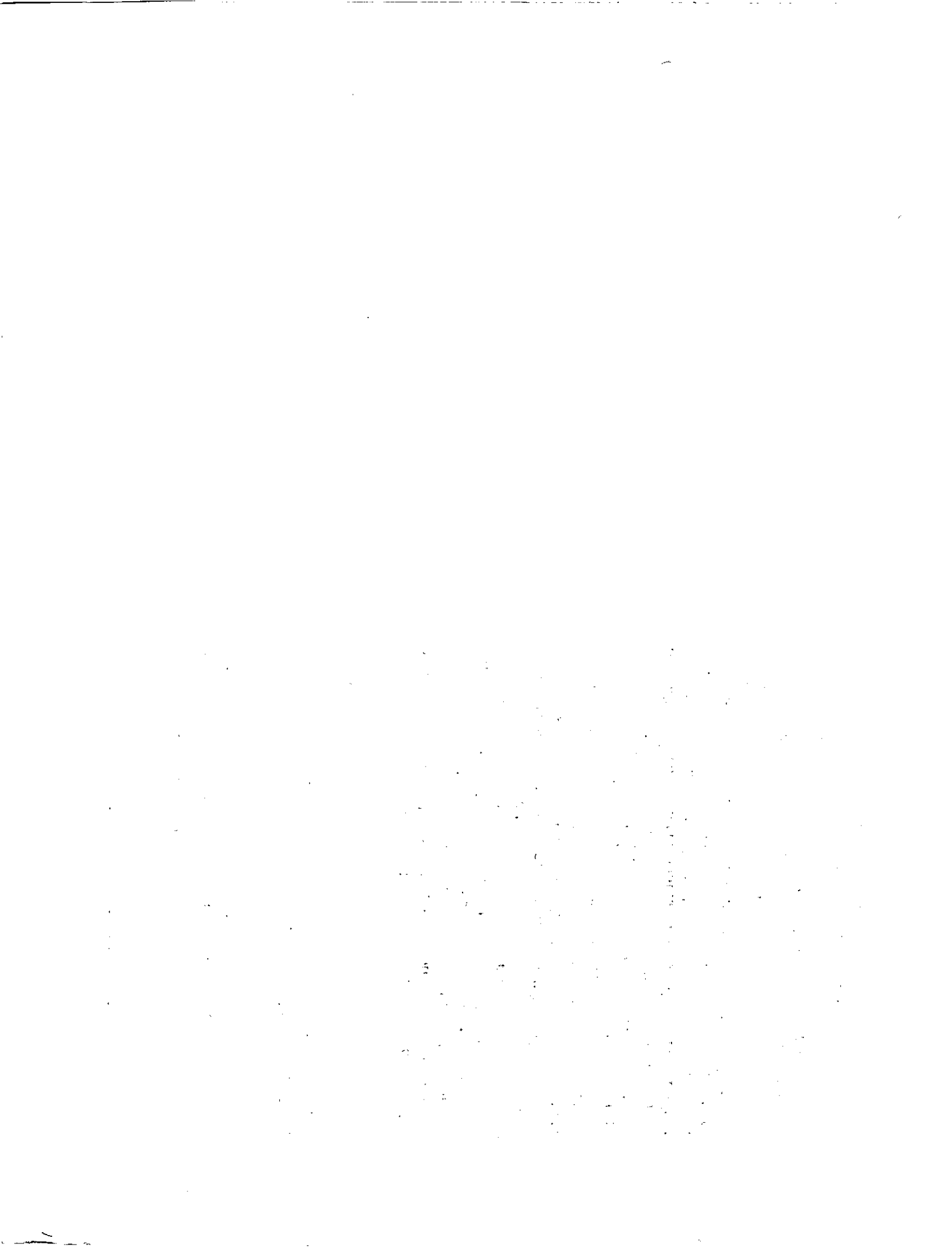
Strategies for Working with Families When a Child Dies

Jennifer Smith Stepanek
and Sandra Newcomb

Remarkable advancements in lifesaving technology since the 1970s have led to increased survival rates for premature infants, survivors of traumatic events, and individuals with disabling or life-threatening conditions. As neonatal and pediatric care continues to improve, more children are living longer and fuller lives. However, this progress has led to a concurrent increase in long-term morbidity, including chronic health conditions and early death (National Commission to Prevent Infant Mortality, 1988; Newacheck, 1993).

Professionals who provide services to young children with disabilities are subsequently encountering a growing number of young children who are technology users or considered medically fragile (McGonigel, Kaufman, & Johnson, 1991; Taylor & Gortler, 1993). When working with children who have life-threatening conditions, the possibility of death becomes a reality, although it is undeniably difficult and challenging to comprehend. The death of a child is an unnatural loss and an experience that can lead survivors—both family members and professionals—to question their roles in the child's life, their choices, their work, their personal lives, and their spirituality.

Because the death of a child can be challenging in so many ways, preparing professionals to be aware of issues related to loss and to be ready for the potential of a child's death is essential. Clinical, social, and emotional issues related to loss are highly relevant to family and professional decision making, attitudes, and abilities (Jellinek, Catlin, Todres, & Cassem, 1992). Furthermore, competent



professional support can facilitate coping as families anticipate and deal with the finality of loss (Harmon, Glicker, & Siegel, 1964).

With the emerging shift toward family-centered services and the broad notion of what constitutes family-centered care and support, many competent professionals often develop close ties with young children and their families (Dunst, Trivette, & Deal, 1994; Shelton & Stepanek, 1994). Caring professionals working with children who have life-threatening conditions and their families must then also work through the pain of loss themselves. Thus, both professional and personal development related to understanding grief, mourning, and bereavement are important for early intervention and special education service providers (Taylor & Gortler, 1993).

This chapter discusses strategies to help professionals 1) understand grief and loss from both professional and personal perspectives, 2) develop policies and practices that promote comprehensive and quality services for families facing loss, 3) work with families after the death of a child, and 4) manage professional and personal loss in ways that foster individual growth.

UNDERSTANDING LOSS:

FAMILY AND PROFESSIONAL PERSPECTIVES

The knowledge and skills of practitioners can be enhanced or diminished by the quality of the relationships they establish with young children and their families (Eggbeer, Fenichel, Pawl, Shanok, & Williamson, 1994; see also Chapter 2 of this book). To be prepared for a relationship that may involve the death of a child, service providers need to understand the basic terminology and processes associated with loss, both for the family and for themselves personally. This can help professionals build a stronger framework for working with families (Gortler, 1992). This section contains information about loss in general, unique features surrounding the loss of a child, gender-related differences in coping styles, and the importance of self-reflection about personal experience related to loss.

Literature concerned with loss has distinguished three major terms: 1) *grief*, 2) *mourning*, and 3) *bereavement* (Access to Respite Care and Help [ARCH], 1993; Taylor & Gortler, 1993). *Grief* refers to an individual's personal experience of loss. It represents the internal feelings associated with loss, which subsequently affect external behaviors. *Mourning* is the outward sharing and expression of pain and grief in a supportive environment. It incorporates the cultural and religious rituals associated with grief. *Bereavement* encompasses the entire process of grief and mourning, as well as the

process of moving on and subsequent personal growth. These distinctions are especially important because many people in society feel permission to grieve, but they cannot mourn. This can interfere with a successful bereavement process (ARCH, 1993).

Grief and mourning are universal yet complex and painful processes (Jackson, 1992). However, the way that individuals experience and deal with issues of loss can be quite personal. One substantial body of literature suggests that individuals progress through a series of stages after the death of a loved one. These stages typically include shock, denial, anger, bargaining, depression, submission, and reinvestment (see, e.g., *Compassionate Friends*, 1990; Jackson, 1992; Kübler-Ross, 1975; Weber & Fournier, 1985). In contrast, other literature indicates that not everyone progresses through these stages in a linear fashion, in the same order, or at the same speed (ARCH, 1993). For instance, Moses (1992) suggested that rather than a linear progression through stages, the movement is cyclical. The stages and associated feelings may come in any order, and individuals may experience some or all of the stages at once.

There are also a number of feelings that are typically identified with the various stages of grief and mourning, including denial, sadness, anger, guilt, anxiety, loneliness, fatigue, helplessness, shock, numbness, and confusion (Kübler-Ross, 1975; Moses, 1992). Behavioral manifestations may include sleeplessness, lack of appetite, social withdrawal, and crying (ARCH, 1993). In some cases, when these typical responses to grief are repressed, adverse effects have been identified such as outbursts of anger, substance abuse, or personal illness (Schiff, 1988).

With all the responses generally associated with loss, it is important not to overlook feelings of hope. Hope can help sustain energy in stressful and difficult times and can help individuals "define positive outcomes toward which they can reach" (Powers, 1993, p. 126). For example, when forced by the loss of a child to examine very basic beliefs related to life and death, some parents and professionals have reached new levels of spirituality (Kelley & Kelley, 1993; Stepanek, 1995a).

The Loss of a Child

For most parents, the worst trial they can face is the death of their child. Fortunately, most parents do not have to face this pain. However, many individuals do experience such a loss or know someone who has. Because such a loss is unique, general conceptualizations about grief are less applicable (Guntzelman, 1992; Rando, 1986; Schiff, 1988).



One potential difference in the bereavement process for parents is the length of the grieving period. Although broadly defined time frames have been identified for typical stages of grief and mourning (Compassionate Friends, 1990; Kibbler-Ross, 1975), the grieving process is often lengthened when a child dies. For example, in one study of 34 adults who had experienced 55 instances of perinatal loss, frequent or intense feelings related to the loss lasted for 44 years (Rosenblatt & Burns, 1986).

Guilt, particularly questions relating to what could have been done differently to prevent the death, is common when a child dies (Guntzelman, 1992; Schiff, 1988). The unique way in which children are dependent on their parents can increase this sense of guilt (Rando, 1986). Other features of the parent-child relationship that make the loss of a child unique and grieving more complicated include the amount of caregiving required, the complete dependence of the child, the unnatural timing of the child's death, and the unexpected sequence of events (child dying before parent).

Certain parental responses are common but may make others uncomfortable. Preoccupation with death, looking for similarities to the deceased child in other children, carrying objects that are reminders of the child, and avoiding places that are reminders of the loss are examples of such responses. Other parents have reported responses such as the following:

- Feeling like one is going "crazy"—crying one minute and laughing the next
- Watching for the child to take a breath during the wake period, days after he or she has died
- Taking pictures of the child at the wake or funeral service
- Missing the child's smell and touch, and missing the professionals and even the equipment that may have supported the child's life
- Feelings of not wanting to live without the child and yet not wanting to die
- Wanting to hold and rock the child after death
- Choosing to have the child's wake service in the home, rather than at a funeral parlor
- Wanting to participate in the child's wake and funeral service, such as by writing or singing passages or songs, by choosing readings, or by being one of the child's pallbearers. (Stepanek & Newcomb, 1994)

Each of these reactions can be healthy to some point, because they help facilitate the bereavement process through expressions of grief and mourning.

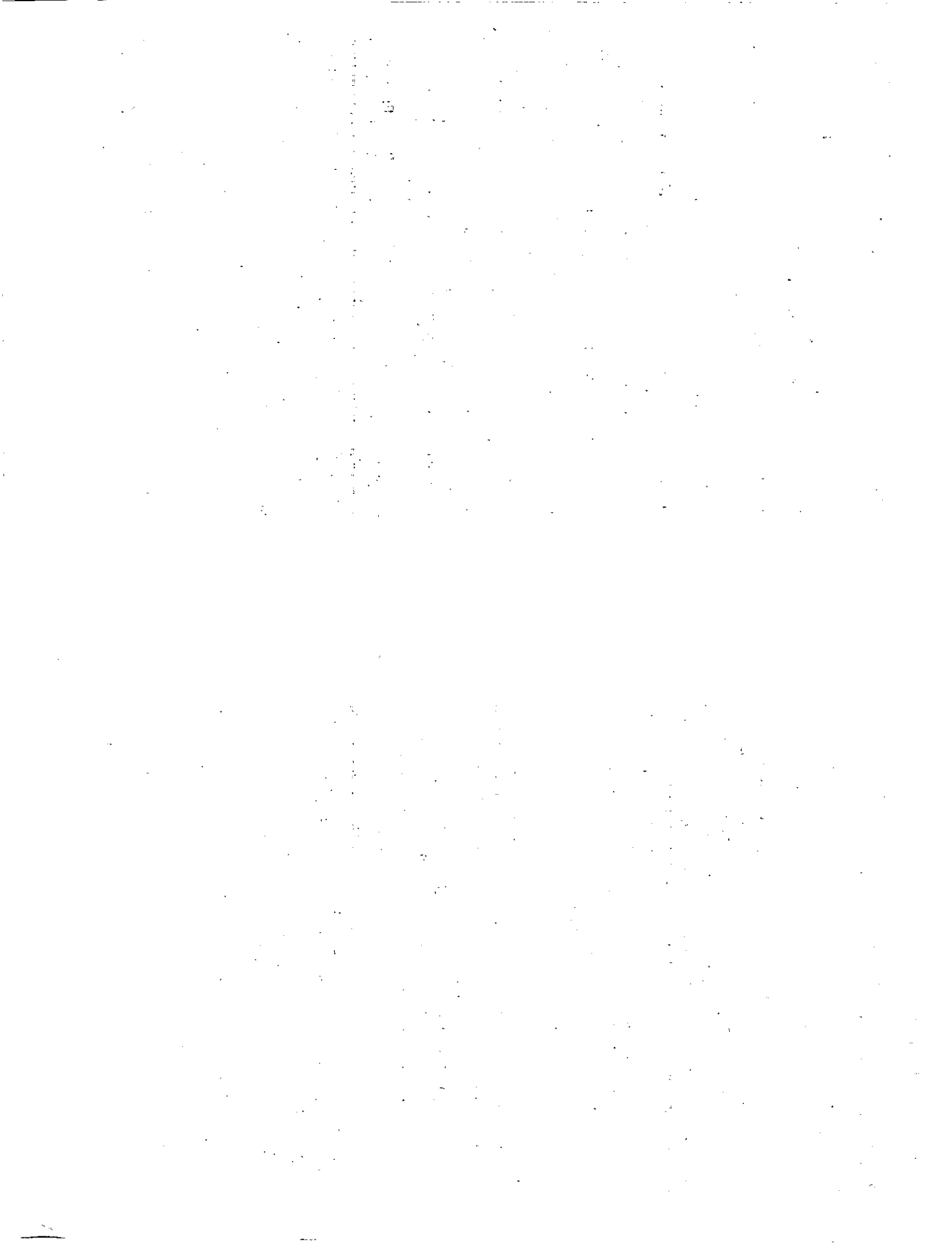
In addition to parents, other family members also are affected by the death of a child, including surviving siblings, grandparents, and other extended family members. Even siblings yet unborn to the bereaved parents can be affected by the loss of a child, because such an intense loss can affect emotions and parenting styles for a prolonged period (Sahler & Friedman, 1981). Furthermore, the younger the deceased child, the younger the parents, or the fewer number of years the family has been together as a unit have all been found to adversely affect adaptation to loss (Powers, 1993; B.D. Schatz, 1986). Family adaptation can also be affected by specific circumstances surrounding the child's death. By recognizing and appropriately responding to such potentially far-reaching effects, professionals can help facilitate a supportive environment for the bereavement process.

Gender-Related Differences in Coping

A growing body of literature suggests that styles of grieving tend to be gender related (Dannrosch & Perry, 1989; Guntzelman, 1992; Powers, 1993; Rando, 1986). For example, in their study of responses to loss, Dannrosch and Perry (1989) found that fathers exhibited steady, time-bound adjustment, whereas most of the mothers reported more chronic distress interspersed with crises. Both fathers and mothers reported feeling deep sorrow, although mothers were more likely to express negative affect related to the sorrow than fathers. Additionally, fathers reported that they preferred not to dwell on feelings, whereas mothers preferred being allowed to express their sadness.

The grieving process for mothers is often intense and lengthy (ARCH, 1993; Compassionate Friends, 1990; Rando, 1986). Because mothers are often their children's primary caregivers, they face coping with the loss not only of their children's future but of their own role. The result can be sensory deprivation because the mother is no longer able to love, care for, or nurture the child and because there is no feedback (e.g., touch, smile, words, activities) from the child. Although both parents must deal with memories of the child that are triggered by environmental cues directly related to a personal sensory experience with the child, this tends to happen more often with the mother (B.D. Schatz, 1986).

For fathers, the grief process is more often internal and may become apparent in indirect ways (see, e.g., ARCH, 1993; Compassionate Friends, 1990; W.H. Schatz, 1986). W.H. Schatz (1986) noted that traditional social roles and attitudes can impede paternal expressions of grief. These include the following stereotypes: 1) males are strong and always in control of emotions; 2) males should win when competing; 3) males protect their families and possessions;



4) males are the providers, problem solvers, and fixers for their families; 5) males control things, including their environment; and 6) males are self-sufficient.

Although it is important to avoid stereotyping, awareness of the potential for different styles of grieving can keep communication open and foster mutual respect for individual coping styles within families (Guntzelman, 1992; Powers, 1993). Both mothers and fathers move forward in life and recover from the loss, but neither forget their children, and their lives will never be quite the same (B.D. Schatz, 1986).

Sudden and Unexpected Loss

For some families there is time to process and prepare for the death of a child. For others, a child's death may occur suddenly and unexpectedly. Many of the supports for families who have children with life-threatening illnesses, such as information about resources or anticipatory planning, are not in place when a child dies suddenly. A major factor that distinguishes between reactions to death from illness and sudden death is shock (Sanders, 1986). For parents who must deal with sudden death, the shock component may create grief reactions that are more intense and longer lasting (Parks & Weiss, 1983). In such cases, the shock phase can last for months or even years (Sanders, 1986). Although most parents feel a loss of control with the death of a child, this is intensified when their child dies suddenly and unexpectedly. A world that was orderly and predictable becomes chaotic and unpredictable. Parents do not know what to trust. With no time to even imagine a world without the child, new shocks are often forthcoming. A sudden reminder, such as a special toy or song, can recreate the sense of shock (Sanders, 1986). This feeling of helplessness can then lead to feelings of extreme frustration and anger. Service providers need to remember that any parental grief reaction may be intensified if the child's death was unexpected.

Professionals' Reactions to Loss:

The Importance of Self-Reflection

When working with children and families who are facing loss, a professional needs to consider his or her own reactions to loss. Many adults have unresolved issues related to grief they experienced as a child or young adult (ARCH, 1993; Fitzgerald, 1992). To better support families facing loss, it is helpful if service providers are aware of their own personal issues about grief and can work toward resolving these issues. Self-reflection (Beckman et al., 1996; Jellinek et al., 1992; see also Chapter 2 of this book) is a critical part of preparing personnel to address loss.

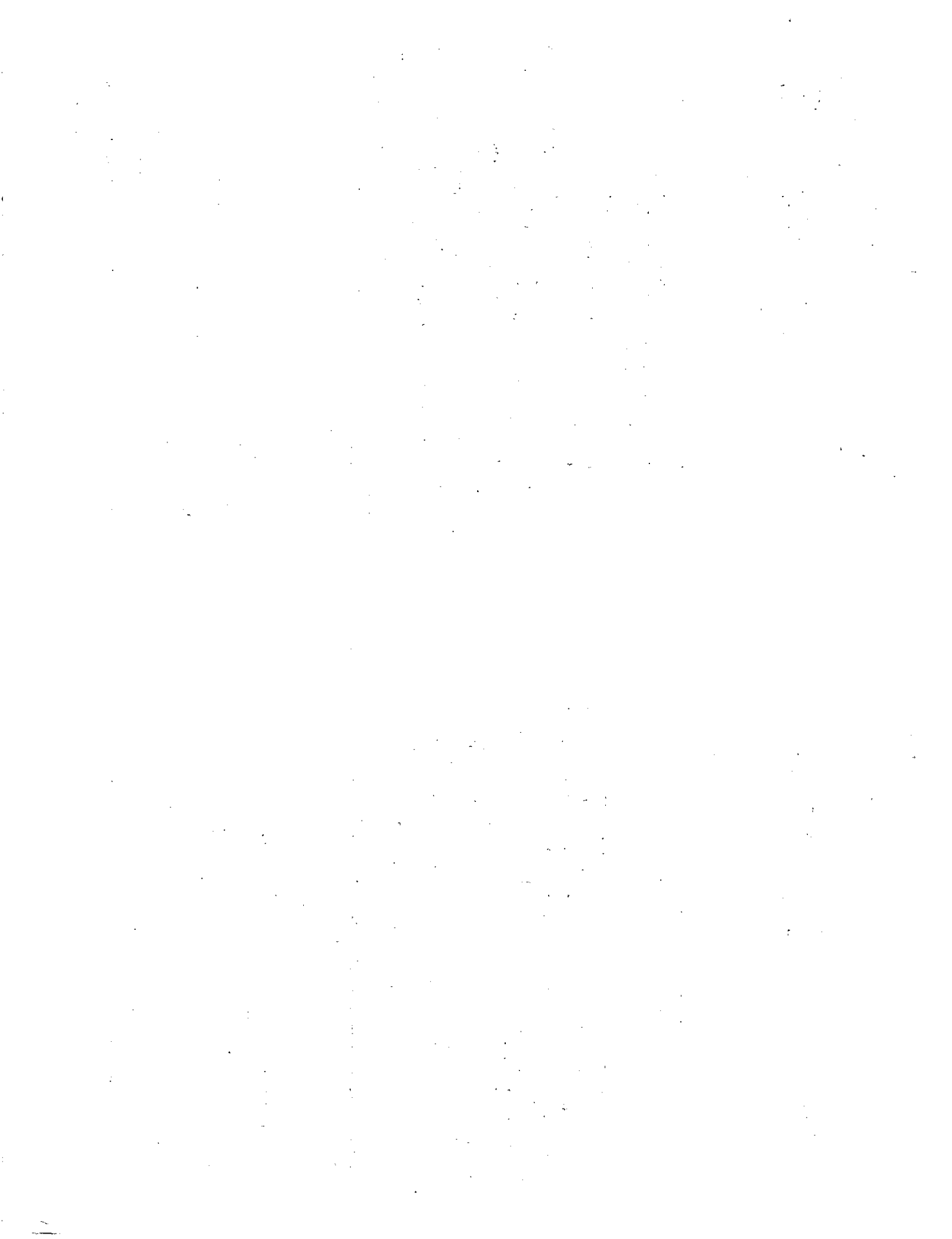
For professionals who react strongly to funerals or to the very concept of death, Fitzgerald (1992) offered some suggestions for dealing with long-standing grief issues. She recommends that service providers seek help through an in-depth examination of reactions to loss guided by a skilled professional. This process can help providers identify and deal with their own grief issues. Understanding personal issues, experiences, attitudes, and feelings related to loss prepares professionals to offer support to families facing loss.

Each time a service provider works with a child who has a life-threatening illness, reflective examination of related issues can help the provider become more aware of personal and professional abilities or limitations that may affect his or her work. Once these past issues have been addressed, there are a number of ways to prepare for current and future issues (Jellinek et al., 1992). Table 1 identifies questions that can serve as catalysts for ongoing self-reflection and preparation for meeting the needs of the child and family.

In addition to self-reflection on personal and professional loss, practitioners must also establish personal and professional work-related goals (Stepanek & Newcomb, 1994). During such a process, it may be necessary to redefine professional roles and responsibilities. For instance, Stepanek and Newcomb (1994) suggested that objectives include more than typical intervention tasks. First, actions such as taking the time to find creative activities that meet both the educational and emotional needs of the child and not being afraid to touch or hold the dying child communicate that someone cares. Second, professionals can convey the message that the family is not alone by such actions as sitting with a parent at the hospital or visiting the family at home. Finally, providers can communicate that

Table 1. Self-reflection questions for professionals

- How much do I understand about the situation, including the child's diagnosis and prognosis?
- Have I ever been in a situation such as this before?
- What can I contribute to support this family?
- What more can be done, what should change, and what should be avoided to better help this child and family?
- Am I getting enough support from my supervisor?
- How do I feel about my relationship with the child and with the family?
- How do my personal spiritual convictions affect how I deal with this child and family?
- How do I feel about holding, touching, and working with a dying child and his or her family?
- What type of contact with the family will I feel comfortable with and be able to maintain after the death of the child?



the child is important and meaningful by creating memories for the family that will live beyond the child.

To effectively help children and families cope with loss, professionals need to have knowledge of grief and coping processes, to recognize their own grief reactions, and understand the effects of grief on themselves and on children and families (Moses, 1992). When professionals take care of themselves, mentally and physically, and have peer and professional support, it becomes easier for them to see the child as a child first and an individual with a life-threatening disability second. Professionals can then work toward providing as typical an experience as possible for the child while communicating the value of the child to the family.

CREATING A SYSTEM OF SUPPORTS FOR FAMILIES AND PROFESSIONALS

Working with children who have life-threatening conditions can be a challenging yet rewarding experience (Harper, 1993). It is important for providers to establish collaborative relationships with the children, families, and other caregivers (Healy & Lewis-Becket, 1987; Shelton & Stepanek, 1994). It is also important that service agencies establish policies and practices that support professionals in their work. This section examines ways to facilitate quality care and support services at the system level. An organized approach to service delivery at the system level can help both professionals and families cope with the complex issues surrounding the loss of a child. This preparation can lead to a better understanding of the dynamics of grief by administrators, supervisors, and other personnel.

Developing Crisis or Bereavement Plans

A comprehensive crisis plan or bereavement program for professionals and families is helpful because it is not unusual for an entire staff to grieve and mourn for a dying child (Harper, 1993). The usefulness of developing a protocol for handling the death of a child has been described by a number of authors (Hodge & Graham, 1985; Rose & Stewart, 1993; White, Reynolds, & Evans, 1984). Bereavement plans can offer guidelines to help professionals at all levels better understand their roles in supporting families before and after the death of a child (Stepanek & Newcomb, 1994). Such programs can also help professionals respond to the unique and varied needs of bereaved families for anticipatory and follow-up support. Formal bereavement plans provide valuable information and examples to professionals, such as sensitive ways to acknowledge the child's

birthday or 1-year death anniversary, information about additional supports available for family members, and ways to determine when ongoing professional support should be phased out. Specific components that can be included in a support plan are identified in Table 2.

Supervision for Professionals

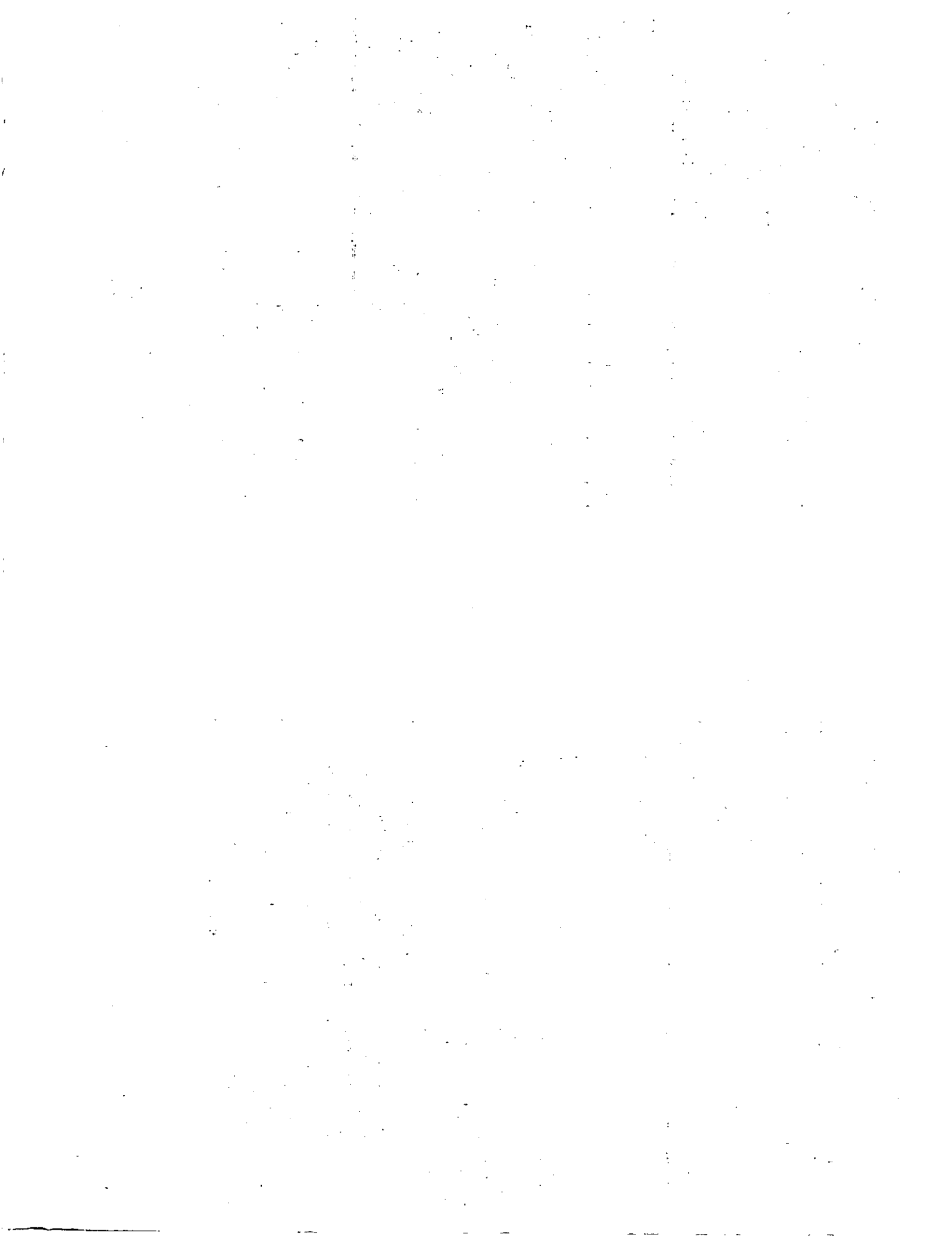
For service providers, another useful source of support can come from a well-established supervision process (Beckman et al., 1996; Eggbeer et al., 1994; Stepanek, 1995b; see also Chapter 2 of this book). Particularly before and after the death of a child, supervisors must be able to support the professionals with whom they work so that they are best able to support the children and families they serve (Harper, 1993). In addition to providing support, understanding, and acceptance, supervisors can also help service providers balance their need to "fix" things for children and families.

Peer Support and Collaboration

Establishing a network of peer support and collaboration is another important way to ensure quality services (Johnson, Jeppson, & Redburn, 1992; McGonigal et al., 1991; Shelton & Stepanek, 1994). According to Harper (1993), caring for a dying child needs to be a shared experience, because the burden can be too great for any one person. Furthermore, Healy and Lewis-Becket (1987) reported that collaborative peer partnerships can create an atmosphere of respect for the dignity of a dying child and preserve the family's right to take part in decisions about appropriate treatment.

Table 2. Components of a support plan

- Information sheets that describe the program, the roles of different service providers, and potential resources
- Checklists that can be used to record information about the child and about family preferences and priorities
- Guidelines for normalizing a child's and family's routine and environment
- Guidelines for capturing mementos and creating memories that will exist beyond the child
- Information about emotional, spiritual, financial, and other supports available throughout the experience
- Guidelines for professionals who are establishing follow-up programs, including routine support letters, newsletters, and dissemination of educational materials for families after the death of a child
- Information about memorial services and anniversary events for families and professionals



SUPPORT FOR FAMILIES BEFORE A CHILD DIES

Professionals can show respect for a family and for their child by providing support in various ways. This section identifies some of the ways professionals can help families prepare for the death of their child.

Maintain a Family-Centered Approach

To be consistent with a family-centered philosophy, professionals need to respect family-identified priorities for their child, including preferences for medical goals, developmental activities, educational intervention, and daily routines (Stepanek, 1995b). It is also helpful to offer family members opportunities for privacy and special time with their child as they prepare for death and separation (Healy & Lewis-Becket, 1987; Stepanek & Newcomb, 1994, 1995). This is especially important when circumstances (e.g., hospitalization, ongoing presence of home health care providers) require the frequent presence of service providers in the family's daily life.

Encourage Family Involvement

Families can be encouraged to remain involved in their child's development, care, and services. Professionals can help family members identify specific ways to comfort, entertain, and support their child. It is also important to support regular living patterns and to help families maintain ongoing routines and activities (Healy & Lewis-Becket, 1987; Powers, 1993), thus helping the child's life remain as typical as possible. Moreover, family members can build on the memories they will have after the death of their child.

Encouraging families to be involved in their children's care and decision-making processes can also foster a needed sense of control. This is especially important because most family members feel helpless in caring for their children. The amount of control and involvement varies, however, depending on a child's needs and on the abilities and desires of each family member. Some family members may want only to choose their child's clothes each day. Other family members want to be involved in all aspects of medical and developmental care and intervention, from bathing to administering medications and monitoring life-support equipment. Professionals can provide opportunities for family involvement at different levels of care. However, the amount and type of involvement must be the choice of each family member, thus ensuring that services remain individualized.

Support Family Preparations

Professionals can support the family's preparations for the loss of their child, such as decisions regarding personal involvement in in-

tervention plans or decisions about the child's place of death and burial.

In a study of maternal bereavement, LaRoche (1984) found that mothers who experienced physical contact with their baby just before or after death and mothers who were involved in making burial arrangements for their infants were less likely to experience prolonged depression. Families can hold, rock, wash, dress, and carry their child's body to the car that will take the child home or to a mortuary for wake or burial services (Kübler-Ross, 1985). According to New England SERVE (1989), families should always have the opportunity to practice cultural or religious ceremonies or rituals around the death of their child.

Often, however, families do not know what is right or helpful related to their child's care before and after death. Professionals can provide information about what other families have found helpful and can be available to participate in discussions about family wishes and options for the child's death and funeral (Healy & Lewis-Becket, 1987; Stepanek & Newcomb, 1994). Professionals can wait for family cues that they wish to discuss arrangements and can respond in a way that does not cut off or make the topic taboo. Asking directly, "Would it be helpful to talk about the arrangements?" or "Would it be helpful to know what other families have done?" may open the door for such a conversation. Healy and Lewis-Becket (1987) suggested that service providers listen carefully as children and families express their concerns and that they consider emotional as well as educational needs. Providing opportunities to discuss concerns and fears about the care of a dying child and the death process are essential to comprehensive support.

Address Feelings

Although it is important to guard against stereotyping, service providers can also help families prepare for loss by addressing unspoken but typical feelings. Families can be allowed to display anticipatory grief and to express a range of emotions without being judged. Wild (1986) shared portions of a letter from a bereaved parent, who asked that professionals not judge family members by their response to anticipatory or actual grief. It takes time to come to a place where a child's death can be accepted and dealt with appropriately. It is important neither to demean parents' concerns nor to dash their hopes.

Provide Information

Empowering families involves providing them with information about the child's disability, available resources, and how to actively participate in their child's care (Sciarillo, Wachtel, & Gilbert, 1993).



Service providers can help families understand their child's condition. Providing information about the typical stages of grief and coping, or about changes in family and child functioning that may create particular stress (Healy & Lewis-Becket, 1987; New England SERVE, 1989; Powers, 1993), also will help family members better understand their reactions to the loss of their child.

Create Memories

Another way that professionals can support the family is to do activities with the child that create memories for those who will eventually grieve the loss of the child. Some activities that can generate treasured keepsakes include playing with stickers and painting. These are often enjoyable activities for young children, and the resulting projects can be given to family members to remember the child or collected and given as mementos at a later date. Examples of such projects include making place mats, bookmarks, wall hangings, and pencil holders.

Depending on the child's age and developmental skills, professionals may need to be more involved in a young child's creative activities. Hand-, finger-, and footprints of a young child are an infinite source of keepsake projects such as tee-shirts, neckties, wall hangings, and holiday ornaments.

Taking pictures of a child with a life-threatening condition is a sensitive and important way to create memories for the family. Pictures can be taken of both typical and therapeutic activities, creating a lasting impression of all the things that were done for the child. Additionally, a videotape capturing the events of a typical day can be a compassionate gift to a family facing the loss of a child.

SUPPORT FOR FAMILIES AFTER A CHILD DIES

Parents may need unique and specific support after the death of their child, because they experience the emotions that occur during the grieving, mourning, and bereavement processes (Guntzelman, 1992). It is not uncommon for family members to seek the support and company of the service providers who helped care for their children (Stepanek & Newcomb, 1994). When parents lose a child who had been ill or who had a disability, they may also feel the loss of many individuals who supported them during their child's life. Parents may seek information about the child's life and death from the practitioners who knew their child, and they may need to have this information repeated often (Stepanek & Newcomb, 1994). In a study of 165 families experiencing stillbirth, Kellner, Donnelly, and Gould (1984) found that parents desired contact with their baby,

attention to their feelings, counseling, and information about the cause of their baby's death. Such support, along with assistance in gaining access to peer and professional support, is an important follow-up service (Healy & Lewis-Becket, 1987; New England SERVE, 1989). This section examines strategies for providing support to family members after the child's death through professional presence, support, and respect. It also briefly examines the support needs of siblings and barriers to the bereavement process.

Be Present

Professionals can remain sensitive to the magnitude and permanence of a family's loss while offering strategies that can relieve the emptiness of grief constructively (Sahler & Friedman, 1981). Understanding and respecting that family members must travel through all of their grief-related emotions, rather than go around them, can help facilitate the bereavement process (Stepanek, 1995a). It is important to be open to various emotional responses and to reassure the family that these feelings, activities, preferences, or preoccupations are typical responses to an unnatural event.

Two of the greatest gifts a professional can give a parent are time and presence. When parents lose a child who has an illness or disabling condition,

... they need the support of people who actually knew the child... since people who only knew of the child are more likely to treat the death as the death of a "handicapped child," rather than focusing on the fact that a parent has lost a child. (Harry, 1992, p. 15)

Being available to listen and to share stories and information about the deceased child is perhaps one of the best ways to help a grieving family (Compassionate Friends, 1990; Gortler, 1992). Professionals can be present at many different points. If imminent death is possible or anticipated (e.g., the child may not survive a necessary surgical procedure, the child's condition becomes critical), it may help for a familiar service provider to offer to be with the family. This may be especially important if the family does not have a natural support network. Even if the family declines, letting them know that they are not alone and that their child truly matters can be a source of support. In making such an offer, however, it is important not to interfere in any way with the family's existing support network.

It can also help to listen as the family tells stories about the child. These memories are part of the healing process for families (Stepanek & Newcomb, 1994). Professionals can also share their own stories and memories about the child with the family. This



helps build the family's memories of the child and reaffirms the child's importance to others.

It is important that service providers attend any religious rituals around the child's death and maintain some type of contact with the family just after the death (ARCH, 1993; Compassionate Friends, 1990; Stepanek & Newcomb, 1994). Although it may be a difficult and emotional experience, such participation demonstrates that the child was important to the professional and provides a powerful message of caring and support.

The first few days after a child's death are typically busy, and then life returns to the usual routine for those supporting the family. However, life may not proceed so easily for the family. In the weeks and months following the child's death, parents can feel isolated and very much alone. Professionals who made regular home visits on a certain day of the week may want to avoid putting another child into the now-unavailable time slot during the first 2 or 3 weeks after the child's death. Although caseloads and system demands may make it difficult, it can sometimes help both the family and the professional to visit the family on the usual day and time during the week after the funeral. This conveys a message that the child is not so easily replaceable. It can also help the family become accustomed to the loss of what had become a way of life for them. A service provider can offer such support by saying something like, "I know this Tuesday I'll be thinking of Marcela. Would it be okay if I came by to visit you at that time?" Direct questions that make offers and leave room for the family to decline are a sensitive and acceptable way to offer such support.

If an autopsy has been completed, professionals who have worked with the child may find that the family wants to discuss the results with them. Even though the medical information contained in such reports is not within the expertise of many service providers, parents may appreciate the perspective that trusted professionals can offer. This may be particularly true when service providers have been working with a child for a long time or when they have developed a strong collaborative bond with the family. If a family member brings up the topic, the provider can ask a direct question such as, "Would you like to talk about that?" or "What was that (getting the report) like for you?" Direct, open-ended questions communicate a willingness to listen but also that the family is in control of the discussion.

For many organizations that regularly deal with the death of a child, follow-up for families extends at least 1 full year (Rose & Stewart, 1993). A formal bereavement plan, as discussed previously

in this chapter, may be useful. In the absence of a formal plan, service providers can support families by remembering birthdays and anniversaries. A call, a card, or a visit at this time can be extremely meaningful (Compassionate Friends, 1990; Gortler, 1992).

Finally, another way to be present for the family is with remembrances. This not only helps families but also can simultaneously provide an outlet for professionals who grieve the loss of the child (Guntzelman, 1992; Rose & Stewart, 1993; Stepanek & Newcomb, 1994). Examples of such remembrances include the following:

- Helping the family create a memory book
- Framing and presenting craft or art projects done by the child or pictures of the child
- Creating a needlepoint or quilting project that incorporates the child's birth and death anniversaries, or some of the child's and family's clothing
- Planting a tree or establishing a memorial to the child
- Writing an original poem about the child who died or framing a poem written by a parent
- Making a donation to a memorial fund

Be Supportive

In addition to being present, there are other ways to support families who have lost a child (Compassionate Friends, 1990). Although there are no real right or wrong ways to share sympathy, family members have reported that some ways are more helpful than others. Professionals can point out that intense feelings of grief are typical and that different people have different responses to grief and coping. It is also helpful to emphasize that the form of such feelings is highly individual and that feelings are likely to vary from moment-to-moment and day-to-day. This support can "both validate the presence of feelings as normal grief reactions and facilitate an important step in breaking a chain of responses that may not be useful or constructive" (Powers, 1993, p. 126).

It is important for providers to be aware that some families find certain well-intended statements unsupportive and even hurtful. Examples of such statements include "You can have more children"; "He or she is in a better place"; "Your child is happy now"; "You must be so relieved that it is over"; "You need to go on with your life"; "Don't let your other children see you cry"; "I know how you feel"; or "It was God's will." Expressions of sympathy that imply a child is replaceable or somehow "better off" can disallow the grieving person's feelings. Furthermore, these statements can indirectly encourage denial of the person's pain by minimizing the loss



(Guntzelman, 1992; Stepanek & Newcomb, 1994). Professionals need to acknowledge and accept the family's grief and pain without diminishing the importance of the child or the parent.

There are many ways to acknowledge the parents' loss. When talking to parents, talk about the child. Use the child's name. Share that you, too, are sorry for the loss. Share your memories or comment on the child's special, positive qualities.

Professionals often want to be supportive but do not know how. One useful strategy is to suggest specific times and places to stay in touch. Instead of saying, "Call me if you want to talk," say, "Can I come over to visit during the child's home visit slot?" Instead of saying, "Call me if I can do anything," offer specific concrete support such as, "I'd like to bring a meal next week" or "Can I make any calls for you?" Being specific offers the family a chance to say "yes" or "no" without putting the burden on them to organize tasks or making them ask for help. In times of extreme stress, it can be difficult for families to know or to express what would be supportive to them (Guntzelman, 1992; Stepanek & Newcomb, 1994).

In addition to listening and providing emotional support, it is often appropriate to touch or to hug the grieving person and to share tears. The tears of a professional may even give the family permission to cry (Fitzgerald, 1992; Guntzelman, 1992; Kübler-Ross, 1985) and can communicate deep caring and commitment. Tears send a powerful message about the importance of the child and the family to the provider.

Service providers can help prevent isolation for the family by identifying supports available locally and nationally. Such professional and peer supports can range from informal gatherings within a community to federally funded organizations providing information to families and professionals. Professionals can encourage family participation in local and national self-help groups (ARCH, 1993). Such supports may exist through extended family, community, churches, schools, or national organizations. It is important that professionals not pressure families to participate in a group or convey personal values, needs, or concerns. Peer support groups can help families realize that their grief is normal and that they are not alone.

Be Respectful and Nonjudgmental

In conversations with other professionals about the child, the family, the death, and so forth, it is important for providers to maintain a tone of respect and empathy. For example, when one professional asks another professional how a parent is coping with the loss of a

child and indicates that a parent is "not doing well," because he or she is crying a lot or is angry about the child's death, it often implies that the parent "should" be coping differently. Instead, concrete answers such as "She is very sad" or "He is spending a lot of time alone" describe the actual coping process without being judgmental and convey that the parent is doing what is needed to cope with the loss (Stepanek & Newcomb, 1994). If a professional is concerned that additional counseling or support may be necessary for a family member, such information can be discussed with respect for the parent and with an understanding of the myriad normal and typical responses to the death of a child.

Be Supportive to Siblings and Other Children

Children, too, grieve the loss of siblings, friends, classmates, and hospital roommates. It is important for professionals to find creative ways to help children understand and mourn the death of another child (ARCH, 1993; Fitzgerald, 1992; Kübler-Ross, 1985; Stepanek & Newcomb, 1995). According to Sahler and Friedman (1981), bereaved children need consistency, involvement, information, and support, just as parents do. Because of their own bereavement, parents may be less available for emotional support and less tolerant of their children's responses to grief. Brothers and sisters particularly may need outside support, such as some continued contact with professionals who cared for their dying sibling.

Siblings often struggle with the cause of the child's death, with guilt related to the death, or with fears that their parents—or even they themselves—will die (Guntzelman, 1992). Professionals and family members should be honest about their own feelings of loss. Modeling appropriate grief responses can give children permission to have a range of feelings as well and can help them work through their own grief.

BARRIERS TO RECOVERY

Often parents' greatest fear is that their child will be forgotten (Stepanek & Newcomb, 1994). For some parents, moving beyond the grief related to the death of the child may seem like a betrayal. Other potential barriers to recovery and bereavement include 1) social isolation, 2) lack of opportunities to talk about the child, 3) avoiding issues and places that are reminders of the child, 4) living completely in the past or memorializing a child or his or her bedroom too long, 5) idolizing the child beyond human capacity, and 6) having to deal with previous unresolved issues related to loss or separation (Schiff, 1988). Parents may resist comfort because a sense of



sadness somehow links them to the child or because they feel guilty if they are not sad. Other times parents may even resent others who have not lost a child and who have a complete family.

Although it is important to respect various responses to grief, styles of coping, and time frames for moving through the bereavement process, some responses should signal concern to professionals. The following are some signs that the grief experience may be overwhelming and the family member may need additional counseling and support: 1) a lack of basic self-care or self-respect, 2) unusual and alarming behavior patterns, 3) suicidal threats or attempts, 4) multiple losses that are overwhelming, 5) severe withdrawal and/or depression, 6) substance abuse, and 7) radical lifestyle changes (ARCH, 1993). In such instances, professionals may want to encourage the family member to seek counseling. However, it is crucial not to judge individuals for their responses to grief or for their personal coping styles.

According to Gortler (1992), when a family loses a child with a disability, they may be dealing simultaneously with different grieving processes. Often they have not fully processed their feelings about the child's disability. Although this aspect of parental grieving is not well researched, multiple losses can complicate the grieving process (Rando, 1986). Thus, parents who are grieving the disability and subsequently grieving death may be at additional risk of a more complicated bereavement. Society does not easily acknowledge the grief of a parent whose child is born with a disability or who is diagnosed with a life-threatening illness (ARCH, 1993). Professionals and caregivers can help such families by labeling their experiences as part of a typical grief process and by being present, supportive, and respectful of their needs and responses to the death of their child.

MANAGING PROFESSIONAL LOSS AND PERSONAL REACTIONS

Recognizing and understanding personal grief after the death of a child with whom there was professional involvement is important, both professionally and personally. The death of a child marks the break of a special connection and a loss of the professional role as it relates to the family (Guntzelman, 1992). Feelings related to grief and loss are real, and death, particularly that of a child, often leads to an intense focus on professional and personal values and beliefs. This section explores strategies for service providers who are coping with the loss of a child.

In accepting personal grief, professionals can achieve personal and professional growth. Loss exposes vulnerability. Loss can be viewed as an opportunity for positive change (Jackson, 1992; Moses, 1992). Coping with the loss can lead to more constructive strategies for working with dying children and their families. Professionals can gain understanding, knowledge, and strength as they work through internal and external conflicts related to a child's death. In so doing, they can add a new human, caring dimension to an already existing capacity to be helpful (Harper, 1993).

Service providers need to allow themselves time, space, and opportunities for grief. This can be facilitated by sharing grief with others who understand the loss, including other professionals who remember the child, other individuals who have been through a similar loss, or even the child's family. However, it is important to use caution when sharing with the family. Although sharing feelings and memories with the family may be beneficial for both parties, it is important that the family not feel they have to take care of or support the professional. It is also helpful to allow oneself to cry, to laugh, and to experience a range of grief-related emotions.

There are a number of supports that can help professionals avoid burnout: 1) a stable and caring work environment, 2) an established bereavement or crisis program, and 3) empathic support from supervisors and other staff members (Harper, 1993). Additionally, the use of creative outlets (e.g., keeping a journal, writing poetry, drawing) can facilitate expressions of grief (Fitzgerald, 1992; Stepanek, 1995a). Taking time to relax can also help establish a sense of renewal and coping.

It can also help to engage in a process of self-reflection, as described earlier in this chapter. Self-reflection can include an assessment of the desire and ability to continue working with children who have life-threatening conditions. It is important for professionals to get both the job satisfaction and the personal rewards they seek while working with children who are seriously ill or dying. Asking oneself *how* to cope and to continue such work, rather than asking *why* to continue or even *why* such work exists, can also help professionals as they struggle to renew their professional and personal goals (Stepanek, 1995a).

When working with children and families who are in physical or emotional pain, it is essential that professionals take good care of themselves, physically and emotionally. Nurturing oneself by being available to children and families, yet setting limits; by occasionally treating oneself in special ways; and by taking moments each day to renew, relax, and appreciate life are all important in



coping with loss and avoiding professional burnout (Stepanek & Newcomb, 1994). Although the death of a child can challenge feelings related to competency and justness, it need not be an end to career, family, relationships, or hope for family members or for professionals (Stepanek, 1995a). Facing the death of a child can also bring into focus personal values (Stepanek & Newcomb, 1994). Examining beliefs about life, death, spirituality, relationships, and work process can ultimately lead to both professional and personal growth.

CONCLUSIONS

The comprehensive educational needs of infants, toddlers, and young children with life-threatening conditions cannot be adequately addressed without recognizing their medical, health, and family support needs (Sciarillo et al., 1993). However, Gortler (1992) stated:

No one likes to think about death. In fact, ours has been a death-denying culture. . . . And the death of a child? The very thought runs counter to one of humanity's core principles: children are our future, they're not supposed to die. However, as professionals who work with special populations of children, it is our responsibility to prepare for the possibility—and for some, the eventuality—that a child in our care might die. We owe it to these children, their families, and ourselves to be prepared. (p. 11)

Knowledge of the grief process, of available resources, and of one's personal experiences and reactions to loss can enhance the effectiveness of support for children with life-threatening illnesses and their families. The death of a child is an unnatural yet real event. Professionals can help make the grief, mourning, and bereavement processes easier for families by supporting them in ways that convey respect and compassion for each child and family.

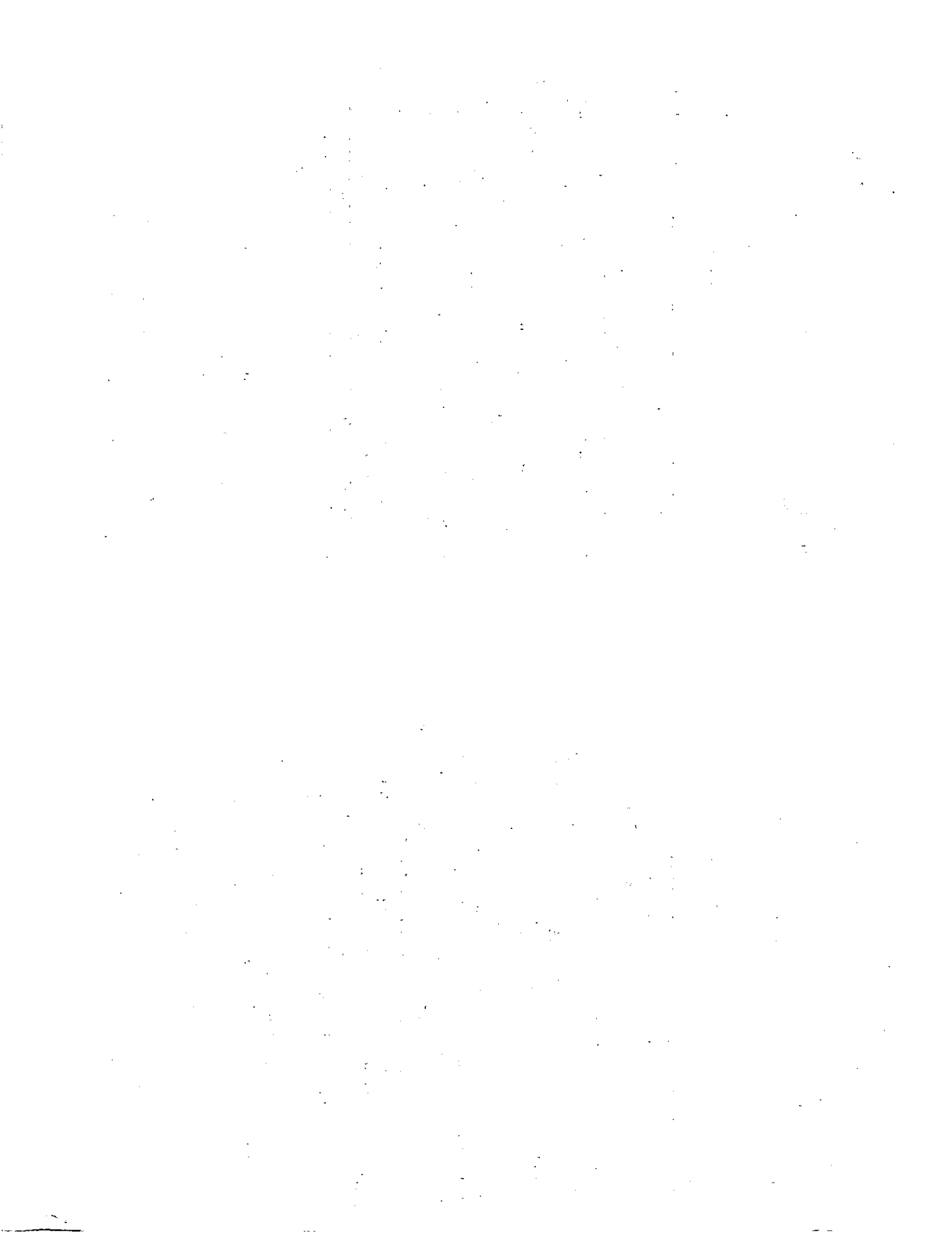
ACTIVITIES AND DISCUSSION

1. Read Case Study IV, the Miller family. Discuss the following questions:
 - a. What is your reaction to this story? How might this reaction affect your decisions about what you would do to support this family?
 - b. During P.J.'s life, what things did the staff do to support his family? Are there other things they could have done?
 - c. Sheila and Linda stayed involved with P.J. and his family even after he made the transition to home-based interven-

- tion with a new teacher and therapist. Why do you think they did this? What would you do in a situation such as this?
- d. In what ways would you suggest the professionals support P.J.'s family during the services?
- e. Imagine that Jackie comes to Sheila and asks, "You knew P.J. so well. Could you or someone from the school say something at the service?" What do you think Sheila would say? If you were in this situation, what would you say?
- f. How might professionals support P.J.'s family after his death?
- g. What are some of the ways that Sheila and the school staff might deal with their own feelings of loss?
2. Describe any experiences you have had working with a child who has died or who was medically fragile or terminally ill. How did that experience affect you and your work?
3. Think back on your earliest memory of loss. (This may or may not involve a death.) What was the loss (e.g., death, move, divorce)? How did you understand the loss at the time? What impact do you think that experience has on your present reactions to loss? Write about that experience. Share your writing with a friend or discuss in a small group setting with peers.
4. In writing or in a discussion with a friend, describe your most significant loss to date. What makes the loss so significant? How did this loss affect you? How did you understand the loss at the time? What significance do you think that experience has on present losses?
5. Read a book about the death of a child. Describe the experience of the child's family. How is this reaction similar to and different from any reactions you have had to a loss? Based on the suggestions in this chapter, what might you have done for the family if you had known them?

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