

STRESSES IN THE LIVES OF PARENTS OF CHILDREN WITH DISABILITIES: PROVIDING EFFECTIVE CAREGIVING

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SUMMARY

Families of children with significant developmental delays and disabilities must contend with stressors produced both by the prejudices and fears, the 'countertransference' reactions, of the larger society, and by the conflicts and griefs which arise within the family's own interactions and dynamics. The nature and substance of these stresses are reviewed, both from a societal context and from the context of the nuclear family environment. Themes of social deviance, isolation, and blame attribution are examined, as are problematic parent - professional relationships, and the impact of a disabled child on various family subsystems. Therapeutic responses to chronic family stresses appropriate to a range of health care professionals are explored. The article concludes with a summary of caregiving strategies helpful in developing healing relationships with families of children with disabilities.

KEY WORDS—Disabled children, handicaps, societal reactions, developmental stresses, parental grief, family coping.

Approximately 10-20 per cent of children in the United States have some form of chronic problem affecting their physical health, while 2-3 per cent have an actual limitation on normal activities.¹ Often, at some point in their history, the families of these children will seek counseling or psychotherapy. Almost all will expect and rely on supportive, compassionate relations with their primary physicians and other health care professionals. Yet relatively few psychotherapists are trained to work specifically with this population; and few physicians and health care professionals are trained specifically to deal with the emotional and psychological caregiving aspects presented by these families. In particular, the average health care professional may be illprepared to understand the interaction of societal prejudices and idiosyncratic family reactions which create the unique environment of the family of a child with disabilities. Further, the average health care professional may not be sufficiently aware of how his or her personal attitudes and biases may impact routinely on interactions with the family.

For the past five years, I have been involved in leading support and discussion groups for parents of developmentally delayed children, and have engaged in psychotherapy with several individual families having a developmentally delayed or disabled child. When I initially began this work, I had had little actual exposure to the world of disabled individuals. The subsequent years profoundly influenced my thinking regarding the nature of therapy and the nature of human suffering. They also helped me to realize how the sensitivities and understanding I had developed through exposure to this population had enhanced the caregiving I was able to extend to these families. It is my hope that some of what I learned may be presented systematically to help other health care professionals improve their own caregiving skills with families of handicapped children.

SOURCES OF STRESS

Stresses with which families of handicapped children have to cope come from two primary

sources: the larger society, including extended family and friends, and the internal dynamics of their own nuclear family. There has been an unfortunate, although understandable, tendency to study families of handicapped children in isolation from their social context² (for an opposite example, see Darling, 1979).³ This has resulted in an emphasis on identification of apparently pathological or dysfunctional parental coping patterns, eg 'doctor-shopping' or 'overprotection'. However, these same patterns, when viewed as responses to the biases and misperceptions which society consistently inflicts on disabled individuals and their families, become more understandable and logical. Doctor-shopping, for example, may be motivated not only by parental shock and denial, but also by parental perception of the original physician as insensitive and uninterested in their child.⁴ Similarly, overprotection may be a logical response to a society which frequently behaves in uninformed, punishing, callous, or cruel ways towards their child.⁵ Thus, an important focus for health care professionals must first be in understanding the societal pressures exerted on these families, and then in helping the families to cope with these contextual stressors.

Of course, of equal importance are the psychological and behavioral responses of individual family members and the family unit as a dynamic whole to the presence of a child with disabilities. These responses are partly a product of the society of which these family members are also a part, and in part may be a function of idiosyncratic psychodynamics of the particular individuals in the family. The competent health care professional needs to know both how to identify these stressors and how to help families develop strategies for coping with them.

THE NATURE OF COPING

Coping may be considered as efforts made by family members and the family as a whole to master conditions of harm, threat, or challenge when routine or automatic responses are not readily available or useful.⁶ Coping may be appraisal-focused, problem-focused, or emotion-focused, or all three simultaneously.⁷ It may employ strategies of approach or strategies of avoidance.⁸ Coping is interactive with the way the family evaluates the nature of the stressor.⁹ For example, a family which defines the birth of a child with congenital

anomalies as a challenge will cope very differently from the family which views this event as a threat. Coping may eliminate or modify conditions giving rise to problems; may perceptually control the meaning of experience in a manner that neutralizes its problematic character; or may keep emotional consequences of problems within manageable bounds. Coping is considered a functional, healthy response because it involves purpose, choice, and flexibility, adheres to reality and logic, and allows and enhances affective expression, in contrast to both defense mechanisms and fragmentation.¹⁰ From the family perspective, effective coping:

1. maintain satisfactory internal conditions for communication and family organization;
2. promotes member independence and self-esteem;
3. maintains family bonds of coherence and unity;
4. maintains and develops social supports; and
5. makes some effort to control the impact of the stressor and the amount of change in the family unit.¹¹

Constellations of family coping have been identified as serving the following functions:

- (a) Maintaining family integration, cooperation, and optimistic definition of the situation.
- (b) Maintaining social support, self-esteem, psychological stability.
- (c) Developing an understanding of the medical situation through communication with other parents and medical staff.¹²

SOCIETAL REACTIONS

One of the most startling and unwelcome discoveries parents of a disabled child quickly make is that they must learn to deal not only with their child, but with the omnipresent, ill-informed and judgmental comments and actions of the world around them, including the reactions of total strangers.¹³ There is perhaps no other problem families have to face which is influenced to such a great extent by responses of the larger society. Thus, it is of primary importance to locate the family of the developmentally delayed or disabled child in its social context. To ignore this reality, to attribute dysfunction solely to pathological interactions within the family, is to make a fundamental and tragic mistake.

In large part, social reactions to a disabled child do not differ dramatically from those to a disabled

adult, but they tend to be less direct and more masked, with the consequence that some of the more negative responses devolve onto the family as a whole rather than the affected child. For example, it is not uncommon for the disabled child to be viewed with a combination of awe and pity, while the child's family is simultaneously judged to be denying, difficult, and uncooperative. Further, it is a depressing reality that not only do non-disabled adults make judgments about disabled children and their families but their non-disabled peers do so as well. It has been established that children as well as adults hold negative attitudes towards disability, and that these attitudes tend to increase with the age of the child.¹⁴ Thus, families must contend with prejudicial reactions not only in adults, but in the very youngsters whom they hope will be their own child's friends and companions.

Disability and Normalcy

Even in this day and age, where disability is 'out of the closet' so to speak, social responses to disability remain frequently pejorative, negative, judgmental, and provoke what can be an overwhelming sense of deviance and inadequacy in the family of the handicapped child. First and foremost, although disability in fact exists on a continuum with 'normalcy', in most people's minds it is treated as a dichotomous entity; either one is disabled or one is not disabled. This very perception conveniently creates a two-world phenomenon, i.e., the world of the able-bodied and the world of the disabled. These worlds are perceived as distinct and non-overlapping, except under very specific and delimited (and from the point of view of the disabled child and her family, often demeaning) conditions; as, for example, when the able-bodied world mobilizes through a telethon to raise money for the disabled.¹⁵ As one father poignantly expressed this discovery of the existence of two largely separate realities, 'When I learned my son had this chromosomal abnormality, it was like stepping through a door into another world, where I had never been before, and knew no one. I was alone.'

One way the world of the non-disabled has of protecting this reassuring dichotomy between itself and the world of disability is to view the child with a serious impairment as being exclusively defined by that condition. In other words, even in her daily life, the child becomes in effect her disability (this has been labeled 'the spread effect');¹⁴ and by

extension, the family becomes identified closely or exclusively with the disability as well.¹⁶ 'Oh, the Gonzales family. You know, the one with the Down syndrome child.' One mother I interviewed remembered with anguish how her own mother, in informing other relatives of the birth of her daughter with Down syndrome, neglected even to mention the infant's weight, length, sex, or name. The little girl immediately became 'the Down syndrome baby'. The 'spread effect' refuses to acknowledge the affected child as a young individual who happens to have an anomalous condition but who also shares many qualities and characteristics in common with other non-disabled children; rather, it views this child as a wholly distinct and separate entity from those who populate the non-disabled world.

Between the two worlds of disabled and non-disabled there is little easy interchange or camaraderie. Within the American culture, disabled individuals (even disabled children) are often viewed as abnormal, deviant, sometimes threatening. Too often, they may come to comprise a disliked, despised class, not unlike India's historic untouchables. At times, disability may appear almost unAmerican, because of its connotations of dependency, vulnerability, being a loser, all conditions which go against dominant American values.¹⁷ Of course, while India has a long history of clearly demarcated class structure, this country is based on egalitarian principles. Therefore the democratic fiction is culturally maintained that we treat disabled individuals equally with non-disabled individuals. However, such pretenses of equity are often only superficial.¹⁴

Fear and handicap

It is particularly difficult to acknowledge feelings of fear or discomfort when confronted by a handicapped child. Therefore these feelings are often masked by pity, or an equally false admiration, which rather than integrating the disability into the totality of the person focuses exclusively on how that individual has 'conquered' his/her disability. This approach, while congruent with the classic American success story, communicates an exacting message to disabled youngsters and their parents, since triumphing over adversity is only one of many modes of coping necessary for successfully adapting to a chronic disabling condition. Yet parents and children alike are left with the implicit message that they should be superhuman, always brave, long-

suffering, ingenious, and good. When children with disabilities and their families fall short of these exaggerated expectations, it provides the justification for the expression on the part of society of more negative, critical emotions. Thus, individuals with disabilities also learn that it is their own fault when they are treated badly by society, as though it were through their own inadequacies that they have failed to earn the approbation of the larger community.

Most people possess psychological organizing schemata which prevent the uncomplicated assimilation of threatening material.¹⁸ Common assumptions which many of us make to get through the daily business of life without being overwhelmed by anxiety include the following: (1) I am intact and invulnerable; (2) there is a just world; (3) my world has meaning and coherence; and (4) I am in control of my own life. The presence of disability challenges all of these cognitive assumptions. Simply seeing a child or individual with a disability arouses significant personal concerns about vulnerability, threat, unfairness, chaos and arbitrariness in the world, helplessness and lack of control. Most people are not prepared to engage in the arduous and time-consuming psychological work necessary to resolve or reconcile such issues. One of the easiest ways of reducing the cognitive dissonance created by the disparity between these assumptions and often unpleasant reality is to put emotional (and even physical) distant between oneself and the threatening material. It is a common observation of many families with a developmentally delayed or seriously impaired child that people avoid them, acquaintances don't call, friends are reluctant to pick up their infant and no longer make luncheon dates, and neighbors pretend not to see them during chance encounters.

EMOTIONAL DISTANCING RESPONSES

Perhaps even more painful to the parents is facing the adoption of emotionally distancing strategies by friends and acquaintances. One of the most common of these is blame attribution.¹⁹ If we can believe there is a reason why something horrible happened to someone else, then logically we can avoid this reason and therefore avoid the horrible consequence. However, since again it is difficult to directly blame a child, society often resorts to blaming the parents of that child. 'They were too

old to have another child.' 'She should have had an abortion.' 'She didn't take care of herself while she was pregnant.' Many of us, faced with the essential irreversibility of a handicapping condition, feel afraid. Because fear tends to make us feel so out of control, we often overlay our fear with anger. Looking for an outlet for this anger, we can sometimes allow parents of children with disabilities to become a convenient target.

On the opposite end of the continuum from blame is what might be referred to as providing 'quick-fix' meaning. This type of response often occurs when individuals cannot tolerate the anguish and distress of the people they are supposedly consoling. Consequently, they attempt to create an instantaneous sense of universal rightness and orderliness. Their responses assure grieving parents that they were chosen for this task (presumably divinely appointed), that this child is a blessing, and that God is testing them.²⁰ Whatever the intent of such remarks, their function almost invariably is to anger and alienate even the most devout listener. What is particularly irksome about such responses in their trite, clichéd, and knee-jerk quality. They convey that the family members have no right to feel anger, despair, grief—any of the emotions which they are almost inevitably experiencing. Moreover, to label someone as special, or chosen, no matter how flattering the context, also serves to increase emotional distance between speaker and listener. To be special is to be different and separate from all the other 'ordinary' people in the world, and adds to the sensation of deviance which families of children with disabilities are already facing.

There are other common, unhelpful reactions encountered by families of handicapped children which serve primarily to create emotional distance between the family and the speaker. Entrenched denial of the child's medical condition is not widespread in society as a whole, but is frequently found among extended family members and close friends. Entrenched denial may include denial of fact ('She can't have Down syndrome'), denial of implication ('She will be the first girl with Down syndrome to attend Harvard'), and denial of feeling ('My granddaughter does have Down syndrome, but it has never bothered me'). Numerous reports have highlighted the therapeutic potential of transitory, limited, situational denial,^{21,22} in contrast to denial which remains constant and pervasive despite new information or developments and has a dysfunc-

tional impact for the family and/or the child.²³ It is important for the prospective caregiver to distinguish between these modalities.

Another common, distancing strategy which parents of children with disabilities frequently encounter might be called 'tough-it-out realism'. This mode of interaction takes a variety of forms: 'Face reality', 'Calm down', 'It doesn't do any good to worry', 'It's not your fault', 'Things aren't as bad as you think'. Again, the function of such remarks is to attempt to exert an arbitrary and premature control over the situation, usually for the peace of mind of the speaker rather than the listener. The main emphasis of such an approach combines minimization²⁴ of the distress with evocation of the putative hardiness of the family members.²⁵

While each of these strategies has its place in the parental coping armamentarium, behavioral instruction and commands to alter feeling states are extremely ineffective in producing real change in an individual. Family members are usually helped not at all by such statements, although the speaker may congratulate himself or herself on being rational and down-to-earth.

Victimization and/or glorification of the handicapped child and his or her family are really two manifestations of the same problematic, distancing response which most families of disabled children have to contend with at some point in their lives. In the first form, the child (and, by extension, the family) becomes an object of pity and of frequent rescue attempts. The disabled child and his or her family are viewed as somewhat less than human, certainly incompetent, dependent, and floundering, clearly in need of someone to set things right again in their lives. Conversely, others may adopt the opposite approach of attributing all good things to the disabled child and family: 'These children are always happy', 'That family is really remarkable the way they always handle their problems', 'Tim's mom never lets anything get her down'. In each case, such responses, whether categorizing the family as victims or superheroes, tend to dehumanize the family, and separate them from ordinary people who are not burdened with handicapped children.

Pathologizing of parental grief

As a society, we are geared towards dealing with situations which are acute, dramatic, and technologically oriented. It is no coincidence that the

automobile accident has become such a forte of modern American medicine. But we are less well prepared to deal with losses which are incurable, and unfixable.^{26,27} Concomitantly, we are also quick to pathologize the grief which often accompanies such losses. Once, showing a videotape of a family with a five-year-old son with cerebral palsy to a medical resident, I asked her to characterize some of the emotions she was seeing on the screen before her. 'That is a pathological grief reaction,' she answered decisively. 'How did you make that diagnosis so quickly?' I asked in some surprise. 'It was easy,' the resident replied. 'The books say normal grief only lasts one year, and this kid is five.' Workers in the field of grief and loss take exception to the rather arbitrary guidelines for grieving laid out in some standardized texts.²⁸ But the fact remains that, as a culture, while we are willing to extend sympathy and compassion to our fellows, we expect them to snap back to normal in a brief period of time. Anything else would be far too anxiety-arousing for us to tolerate. When confronted with a situation which is chronic, long term, in which very likely the family will never duplicate their 'normalcy' prediagnosis, society tends to be rejecting and impatient.

THE SOCIAL ROLE OF THE DISABLED

There are many theories in existence to explain the discomfort of non-disabled persons in the presence of those with disabilities. Briefly, these theories include the following: (1) in the presence of disabled persons, non-disabled persons are reminded of their own vulnerabilities;²⁹ (2) most individuals experience a fear of 'strangeness' and differentness, a kind of physical xenophobia, when confronted by disability; (3) an underlying belief persists that handicaps represent punishment from God for evil behavior;³⁰ (4) the core of people's rejection of the disabled lies in their basic fear of death;³¹ and (5) non-disabled individuals fear persons with disabilities because they fear a loss of mastery and control.

All of these are plausible explanations. Certainly, some of these themes are reflected in research findings which show that the disabled person 'most liked' by non-disabled individuals is one who is least responsible for the disability (high victimization) and most successful at coping (high mastery).³² Thus, the depressed, desperate AIDS patient, held personally accountable for his

situation, frequently meets with rejection and hostility rather than compassion and support. On the other hand, most people respond with enthusiasm to stories like that of a young man, paralyzed from the neck down in a drunk-driver accident, who has gone on to become a renowned artist, holding a paintbrush between his teeth. This profile conforms to strongly held cultural values about the proper 'patient role', a role which should never be self-inflicted but if acquired should consistently be met with courage and fortitude.

In fact, society allots only a few roles to disabled people themselves, none of them especially healthy from a psychological standpoint.³³ Generally, the disabled individual is allowed a certain helplessness and dependence not permitted non-disabled individuals. This permission is extended to disabled children, who are often treated as helpless infants despite their chronological years and level of emotional needs. There is also a certain social acceptance for the individual to be martyred to their condition or disease. Thus we allow the disabled individual to become a spokesperson for his or her particular medical condition, in effect to assume the public persona of being that condition.³⁴ Finally, society tends to expect disabled individuals to be either extraordinarily bad (where outer deformity is a sign of inner evil) or extraordinarily good (where a saintly personality has risen above the burden bestowed on it).³⁵ Thus we allow the disabled to be victims and martyrs, heroes and leaders, saints and sinners. What society finds more difficult is simply allowing disabled individuals to exist as people.

The above provides a thumbnail sketch of the social context in which most families of disabled children attempt to function. It is not meant to discount individual acts of sensitivity, support, caring, or involvement by specific members of society. It is also not meant to diminish the impact of legal developments such as Public Law 94-192, which mandates accommodation of disabled children in the public school system. Despite such developments, however, the environment in which the families of disabled children find themselves continues to emphasize overall the deviance, the strangeness, the non-belonging of their child and the family as a whole.

STRATEGIES OF CAREGIVING

First, of course, parents of handicapped children need understanding and support when they share

anecdotes about their experiences in the non-disabled world. Out of ignorance, fear, or a sense of inadequacy and lack of control, the caregiver can often minimize parental perception of society's punishing and rejecting responses. It is important for caregivers to listen attentively and respectfully to the parents' shock, anger, and pain at encountering this brave new world.

Normalization of their experience is also helpful to parents. Sometimes families are embarrassed or self-conscious to mention the negative, painful reactions they experience from society. Then, the caregiver can mention that other families have had experiences similar to these, and that they are quite difficult for most people to deal with.

A significant role for the caregiver is to help families improve the way they interface with the outside world. It is not uncommon to hear parents say, 'We're fine when we're at home, with each other. It's when we go out into the world that we have problems.' Similarly, most families refer with a mixture of humor, anger, and tears to the omnipresent 'supermarket phenomenon', in which strangers approach them in public places and ask embarrassing questions about their child. For the mother of a developmentally delayed child, even the simple question 'How old is she?' can produce a torment of anxiety as to whether to reveal the true age (and contend with the ensuing curiosity and pity) or to shave off several months (and then have to struggle internally with her doubts about her own acceptance of her child). Other common and hurtful situations include friends and relatives who are afraid to touch or ask about the child; and overhearing innocent but pejorative remarks about disabled individuals from people who have no idea that the listener has a child with such a problem at home.

In helping parents to deal with the outside world, it is important to help them enlarge their options. Parents tend to respond to these external pressures through avoidance (withdrawal), repression (it's not important enough to talk about; they probably didn't mean any harm), and outbursts of anger. Usually, adopting any of these strategies leaves the parents bitter and guilty.

The social change agent

Other behavioral options, however, are available to them. One is that of educator or social change agent. Many parents discover this role for themselves and derive considerable satisfaction

from it. Often, voluntary adoption of this role signals that the parent is willing to look beyond her own immediate grief to consider some of the larger implications of her child's condition. In this role, parents proactively acknowledge that, because of their child's particular medical condition, they have the obligation and responsibility to help educate the rest of society about this condition. This role emphasizes ignorance rather than malice on the part of the public, and requires rehearsal and preparation for behavior by the parents in commonly encountered situations.

The role of social change is a positive one, and most people who adopt it see themselves as giving back something worthwhile to society. However, it is not a panacea for how to define oneself in relation to society, primarily because it is a public role and leaves little or no room for the individual's personal feelings or responses. In most cases, fearful of a confrontation with the other individual, parents will simply avoid any substantive interaction. In these situations, it is helpful to have parents rehearse stating their personal feelings (in contrast to rehearsing presentation of material of a didactic or educational nature) to an imaginary listener, and then encourage them to actually do so in a real situation. Giving society controlled but honest feedback about the impact of widely held attitudes and behavior towards disabled individuals and their families will certainly increase parents' sense of efficacy and control, and may also have a positive effect on changing misconceptions held by the public at large. When parents' emotions are aroused in an extremely heightened manner, it is often a clue that the other person may have unwittingly touched on an unresolved issue for that parent. In this case, handling the response of the outside world is less important than handling the internal conflicts and ambivalences of the parent. From resolution at that level, a more balanced approach to the public sphere often emerges spontaneously.

Support systems

Other useful strategies for counteracting stigmatized social interactions include encouraging participation in a support group, or even in a group of families with similar problems which has more of a social than a psychotherapeutic emphasis. Such involvement decidedly reduces feelings of isolation and deviance. However, the suggestion of a support group should never be made with the connotation

of 'getting rid of' or dumping a family. Parents are extremely sensitive to the possibility that their problems and suffering are receiving a bureaucratic runaround, a phenomenon which many of them have experienced more than once. Further, many families, especially fathers, need to learn how to actively develop or modify existing social support structures.³⁶ Research indicates that the support networks of families of disabled children have different characteristics than those of families without such children, notably that they are smaller and denser.³⁷ Thus parents may need to learn skills of identifying and communicating with individuals who are able, in part, to meet the family's wide-ranging needs, from help with practical problems of daily living to support for emotional concerns.

CODING RESPONSES OF FAMILIES

Research suggests that families of children with handicaps as a group have greater stress, lower marital satisfaction, reduced psychological well-being, and poorer social support systems than families of non-disabled children.³⁸ Yet reports such as these do not do justice to the richness and complexity of the individual family's experience. The level of parental stress is always mediated by their appraisal of the precipitating stress or event.^{39,40} In fact, it has been shown that the family's perception of implications of their child's condition has the most influence on the family's ability to cope.⁴¹ Thus, it is of critical importance to elicit the unique meaning the family has attached to the event of their child's condition.

PARENTAL GRIEF

Much has been written about initial reactions of parents to the birth of a handicapped infant,⁴² and it is not within the scope of this article to focus directly on this topic. However, any understanding of parental responses to a handicapped child requires acknowledgment that much of this response is not so much psychopathological as part of the grieving process.^{43,44} Parents who appear depressed, paranoid, withdrawn, angry may be mourning broken dreams, the loss of the (anticipated) perfect child.⁴⁵ Initial reactions to the diagnosis of disability include shock and denial. However, long after the initial shock has faded, chronic sorrow,⁴⁶ a much maligned and

misunderstood concept, continues in cyclical fashion, and includes subsequent emotions of anger, despair, self-blame, denial, bargaining, anxiety, fear, and depression.⁴⁷ As part of this process, parents of children with disabilities have to confront awareness of their own and their child's mortality and the essential fragility of life. They also have to face their own fears of differentness, their own negative biases towards disabled persons. While parents attempt to employ the same psychological mechanisms of avoidance and denial that other people use to suppress these feelings, they are generally less successful because the threat is more immediate and omnipresent.

Emotional components

The emotions that accompany the grieving process are often viewed as pathological or socially undesirable. Yet each of them plays an important functional role in generating a sense of healing and resolution.^{4,48} For example, denial can protect the ego from immediate overwhelming assault. Anxiety often helps mobilize the energy necessary to take action towards change. Fear may facilitate the recommitment to attachment, to taking the risk of loving in spite of vulnerability and the possibility of loss. And at times, anger is a reasonable and self-esteeming response to the violation of one's sense of universal fairness and justice.

However, most parents are quick to pathologize their own (and their spouse's) grief. Without waiting for therapists, doctors, and society at large to condemn them, they condemn themselves. The emotions which are a necessary part of coming to terms with their child's disability are seen as somehow wrong, bad, and weak. Thus, it can be extremely difficult for parents to acknowledge the presence of such emotions, or if they do, to experience such emotions without strong negative self-judgment. Normalization of parental feelings and modeling the expression of one's own feelings are both important in promoting a sharing of these emotions.

One final word is necessary regarding the timing of grief. Grieving is a process by which parents separate from their now-shattered expectations of a perfect child. As such, it is cyclical although not continuous, because at different developmental stages of life different dreams are being grieved.⁴⁹ Thus, it is inaccurate to think of grief as having a clearly definable endpoint, although throughout the life cycle grief will undergo different manifestations. By the same token, however, chronic sorrow does not imply that the individual is mired in grief

without respite; it is rather that grieving the experience of loss has become a part of the totality of that parent, as much as their name or age.⁵⁰

The grieving process may contain true healing elements, as well as real suffering. These have been conceptualized as follows:⁴⁵ (1) completions, where healing, acceptance of loss, and resolution have occurred; (2) resolution and reformulations, accompanied by an enhanced sense of personal power and a change from prior feelings of helplessness and loss of control to feelings of mastery and competency; (3) transcending loss, in which the individual is no longer bound or determined by loss, but is able to change and grow, having achieved serenity without passivity. Just as the experience of true grief is difficult to recognize, the experience of real resolution and transcendence is often difficult to understand. In the case of the family with a disabled child, rarely does either reaction receive the support and validation it deserves.

DEVELOPMENTAL ISSUES

Issues of child development become vehicles for the cyclic expression of parental grief and are critical in understanding a family's coping responses to a disabled child.⁵¹ One of the most difficult aspects of child development is the inevitable comparisons of one's own child to other children, both disabled and non-disabled. Comparison appears to be a universal parental attribute. Kept in bounds, it is a natural way of learning about child development. However, in our achievement-oriented culture, it often degenerates into a useless, self-defeating competition. Parents begin to see every normally developing child as a sign of their own failure and inadequacy. Even among children with delays, parents use each other's children as yardsticks. The developmental achievements of the superstar in an early intervention class may make that child's parent proud and satisfied. However, this one child's performance may become the measure by which all other parents judge their own children and themselves, and persistently find both coming up short.

Realization of milestones

The classic developmental milestones access parents' grief and fear as well when they are not achieved 'on schedule'. Most parents have rather clear ideas about when sitting, crawling, walking,

and talking should occur. Even if parents are intellectually prepared for the reality that their children will not accomplish these milestones 'on time', if ever, nevertheless when that child reaches the appropriate chronological age it often becomes a period of reliving initial shocks and hurts. For a similar reason, the first birthday (transition from infancy) and the sixth birthday (entering public school) are often particularly stressful for parents. What they face at moments such as these are inevitable reminders of their child's difference from other children, and of the chronicity of his or her situation.

One developmental transition which can prove especially psychologically stressful for parents is that from infant to toddler. Many parents cope in part with their child's small size and developmental delays by treating the child like an infant, even when it may no longer be emotionally appropriate to do so. Many people, including some fathers, have rather low-performance expectations for infants. Such parents appear unusually accepting of a handicapped infant, but these babies are sometimes treated more like playthings than human beings. When these parents realize that their child cannot stay a baby forever, there is a renewed and shocked recognition of some of the more painful implications of their child's condition.

Further, developmental issues can play into parents' drives towards mastery and competence. Developmental tasks are the measures used to assess a child's progress. Thus, especially in this age of the superbaby, it is tempting for parents to fall into a kind of magical thinking: 'If only we do enough, buy enough services, we can "cure" our child.' Delays in accomplishing developmental tasks can fuel parental guilt, and parents' constant query, 'Should I be doing more for my child?' must be considered with caution when what is perhaps really being asked is, 'Can you guarantee me a normal child if I put forth enough effort?' In fact, in terms of child development, it is important to incorporate failure as well as success into both the child's experience and that of the parents. The child's view of self is formed to a large extent by parental attitudes. If the message the child receives is always conditional ('We love you for what you might become rather than what you are') the child's self-esteem may be threatened.

Rules of behavior

As the disabled child moves into the toddler stage, a word about behavioral intervention and

control is necessary. Recently, there have appeared articles in the professional literature questioning the importance of counseling and support groups for parents of handicapped children, and emphasizing the value of training programs which facilitate the development of compliance and socially appropriate behaviors in these children.⁵² Parents themselves have reported that they prefer information on behavioral management to traditional counseling.¹³ Naturally, parents of developmentally disabled toddlers, just like parents of non-disabled toddlers, have an understandable need to exert a degree of behavioral control over their children. At times, parents of children with disabilities will be reluctant to develop this control. Sometimes, discipline and limit-setting are a tacit acknowledgment that their child is no longer an infant and, as discussed above, this admission can be a reluctant one for some parents. Further, any sort of behavioral control may play into parents' ongoing feelings of guilt. Their child has been limited and 'punished' enough, these parents may argue.⁵³ Parents must be helped to realize that unrestricted behavioral freedom in reality does a long-term disservice to their child.

It is possible, however, for parents to make the opposite error. Occasionally I have observed a family where the rules of behavior seem stricter, less flexible for the handicapped child than for non-handicapped siblings. At times, the tacit rule of perfect behavior appears to have enveloped the entire family. Such families may be likely to fall into the trap of seeing themselves as standard-bearers for the entire disabled community. They appear determined to demonstrate that, despite the child's disability, the child (and by extension their family) is 'perfectly behaved'. The result is that the disabled child is often prohibited a normal range of behavior which would easily be permitted a similarly aged non-disabled child. Behavioral control is an extremely important process but it should never become a parent's exclusive focus. Skill building will be successful only when parents have resolved their own feelings about disability to some extent; otherwise, it is not a magic cure-all. Sometimes, unfortunately, it is easier for parents to focus on what they should be doing to improve their child rather than on how they might be simply 'being' with that child.

PARENT-PROFESSIONAL STRESSORS

This latter thought raises an important related issue: the conflict for the parent of a child with

disabilities of being simultaneously parent, teacher, and therapist. In no other situation is a parent forced so completely to share her child with the 'experts'. It is not unusual for parents and professionals to enter into a largely unconscious, but nevertheless intense, competition as to who is the more 'successful' in interactions with the affected child, who is more sensitive and effective in meeting the child's needs.⁵⁴ In no other non-professional contexts is a parent required to master such highly technical and confusing information, and to acquire unfamiliar and sophisticated skills in such areas as motor and language development. Parents may feel enormous pressures from the professional community to parent their disabled child in a certain way, and feel guilty if they do not conform to prescribed standards.⁵⁵ While much of the input from experts is essential, parents may need to remind themselves of their original parenting goals, and not be reluctant to be the kind of parents they had envisioned themselves being before this child was born. Most people with a degree of patience, concern, and training can help a child develop better fine motor coordination. Only parents can give the child the unique and special love which is a result of her belonging to them.

THE EXTENDED FAMILY

Dealing with extended family can also be a source of prolonged stress for parents. Communication between the generations may be difficult because both parents and grandparents tend to focus on mutual protection. Grandparents will make statements which seem unfeeling to their own children ('Have another baby right away', 'The sooner you put this child in an institution, the better') which are frequently motivated by a desire to spare their adult children pain. Similarly, the adult children, not wishing to inflict pain on their own parents, may tend to shut them out from important information or family decision-making processes. On the other hand, grandparents, also out of a misguided attempt not to wound their children, may persist in extremely intransigent denial of the grandchild's condition. In my own experience, it is more often the grandparental generation which advocates excessive doctor-shopping, or which continues to query whether Susie is really retarded despite convincing confirmatory tests and observational data. Grandparents may also cope with feelings of fear and helplessness by becoming remote from the

affected child, or from the entire family. Parents struggling with their own shock and denial interpret such actions as a rejection of their child and, by extension, of themselves. In each suggestion, denial or withdrawal, they hear a criticism of their own ability as parents. Such interactions can create almost irreparable damage between parents and grandparents.

The presence of a handicapping condition in a child usually requires extensive restructuring of both nuclear and extended family.⁵⁶ Thus, the role of grandparents is crucial in influencing the psychological and functional adjustment of the family. The birth of a child is an opportunity for parents to say, 'I am an adult. I am successfully creating my own family.' In this act there is both a declaration of independence and a request for validation. When a child is born with a disability, there may be a sense in the parents of how their act of successful creation has been impaired. The grandparental generation may be extremely helpful in encouraging parents to see that this is not the case. When grandparents are supportive, interested, and involved (as guided by the wishes of their adult children), there is a sense of the generations working together. There is also a subtle shift of roles for both grandparents and parents. The grandparents are there to be helpful, to draw on their own life experience, but also to allow their children to be the primary parents to this new child. Further, it is most often grandparents who act as an informal system of respite care for the mother. Thus, when they are geographically and/or emotionally available, involvement of the grandparental generation is essential to the effective adjustment of the family.

THE MARITAL RELATIONSHIP

Issues between husband and wife are obviously of critical importance in understanding the sources of stress in a family with a handicapped child. It is not unusual for parents to react to their child's disability in different ways.⁵⁷ One parent may be stoic, the other extremely emotional. One parent may collapse, the other may be competent and instrumental. One may be angry, the other depressed. For the preservation of functioning of the family unit, such differences may even be desirable in that they usually leave one adult capable of the tasks essential to maintaining basic family survival. However, they also create gaps of

understanding and empathy between parents. Often, one parent's emotion is a defense against another, more feared emotion which they unfortunately see all too clearly reflected in their partner. Helping parents understand the value of different emotional states, giving permission to allow grief to wear many faces and assume many forms, and exploring each parent's feelings more deeply are important in enabling parents to grieve differently yet together.

Effects on marital roles

One issue which commonly surfaces between husband and wife is related to the traditional family structure which families of handicapped children frequently assume.⁵⁸ Although over 50 per cent of mothers of preschoolers now work outside the home, mothers of children with serious disabilities tend to be full-time homemakers, while the breadwinning functions are performed more exclusively by the father. This traditional structure, which often results because of the complex physical needs of the disabled child and/or the mother's guilt at 'abandoning' a helpless, handicapped child, has several possible consequences. Mothers who had planned to return to a career after the birth of their child may feel trapped and resentful. Further, many mothers complain of being insufficiently supported by their husbands. Because the husbands are at work, the day-to-day care of the child with disabilities (which may be quite extensive) falls directly on the mother.⁵⁹ Sometimes mothers accuse their husbands of a kind of emotional abandonment. In subtle ways, the child with disabilities may become viewed as mother's responsibility, even as mother's child. By default, mother develops a considerable body of both medical and practical expertise regarding the child's condition. This makes father feel even more remote and unnecessary. Often, mother forms a coalition with the handicapped child.⁶⁰ Thus, a vicious cycle of maternal enmeshment and paternal disengagement develops.⁶¹ Paradoxically, while it is usually the mother that protests this situation most vigorously, it may be the father who suffers the most from this estrangement from his family. Research suggests that while mothers' positive coping is primarily related to their relation with supportive friends, fathers' positive coping is related to a supportive relationship with their wife.⁶² Thus, integration of the family unit and appropriate structuring of subsystems are par-

ticularly crucial in families with a handicapped child.

Paternal Stresses

Fathers often express unique concerns regarding their handicapped child. In general, fathers seem to have less support, less networking, and less contact with professionals.⁶³ Fathers may feel the need to be the strong financial and emotional support of the family.⁶⁴ This fulfills the dual function of winning societal approval by keeping the family economically viable and at the same time providing them with a convenient excuse to hide from their own feelings about their child. Families frequently report that while mother grieved during the first six months after the child's birth, it can be two or three years later, when the family is apparently stable and reintegrated, that father will inexplicably collapse. It is also possible that this discrepancy in mourning is due to men's lesser familiarity with infant development, a tendency to see 'babies' as a unitary entity. It may be that fathers are most affected by their child's handicap when the child reaches an age of greater potential interaction with the father.

Some men may be prone to viewing a child as an achievement, an accomplishment, proof of their own competency. A handicapped child, particularly a handicapped son, appears to challenge this interpretation. In the world of work, failure is often dealt with by being left behind. No one lingers too long over their mistakes. When this mentality enters the parenting sphere, the consequences are potentially devastating for both child and parents. Often the handicapped child unwittingly accesses long-buried feelings of inadequacy and insecurity in the father. However, rather than examining these feelings for what they are, there may simply be withdrawal from and avoidance of the child.

As mentioned earlier, fathers have an ideal opportunity to escape from their child and their feelings about their child through work. At work, many men derive a feeling of competence and success. These emotions can be in stark contrast to the feelings of helplessness and confusion which assault them at home. This situation can lead to difficulties in bonding initially with their child, and long term to a sense of non-belonging in the center of family activity. Precisely because it is not required by the circumstances, fathers need to pay special attention to developing a significant role for themselves in the home. Concomitantly, mothers need to be encouraged to make room for father in

the home environment, not require that his interactions with the child simply be an extension of their own, and allow his own personality and values to inform his role in the family. While it is frightening for some fathers to venture into this unfamiliar territory, these excursions can also appear threatening to mother. Both parents need some guidance in creating mutually supportive and involving roles as parents of a disabled child.

PARENT-CHILD FEELINGS

Another source of great stress in families of children with handicaps is dealing with the negative emotions which surface in relation to that child. There are strong societal prohibitions against the direct expression of hostility towards a handicapped child. Nevertheless, children with disabilities are at greater risk for child abuse than are non-disabled children.⁶⁵ Attachment towards infants with handicaps is often delayed, dulled, or apparently absent.⁶¹ As the child grows, maternal withdrawal may occur.⁶⁶ And while overprotection is the more common response, anger at the disabled child also occurs.⁶⁷

Parents may hold unrealistic expectations about their feelings towards their handicapped child, in particular that they should only have and express positive feelings towards this child. It is helpful to encourage parents to distinguish between their anger at their child's condition or disability and the child him or herself. Thus, a parent can feel angry that their child has Down syndrome and still love that child. However, frustration, irritation, and even anger towards the person of the child are also not outside the bounds of normal parental reactions. Once these feelings are placed in the context of parenting interactions with non-disabled children, it becomes more acceptable for parents to see that they may play a role in their relations with their disabled children as well. At this point, the goal becomes not pretending that such feelings do not exist, but rather learning how to modulate them in appropriate and constructive ways *vis-à-vis* their children.

SIBLING ISSUES

Problematic sibling responses to a child with handicaps are also a source of stress for parents. Some siblings do exhibit behavioral problems, school difficulties, or psychosomatic symptoms. A

larger number inevitably engage in competition with the handicapped child for limited parental resources of time and energy. The handicapped child easily can become the center of family concerns. Often siblings feel neglected, or overly burdened by responsibility. The oldest available female sibling may become a substitute caretaker. Siblings also may feel guilt that they are somehow responsible for their brother's or sister's condition; they may fear that they too will be affected.⁶⁸ Nevertheless, the theory of widespread sibling maladjustment seems more fallacy than fact.³⁹ Research thus far has focused less extensively on the more positive aspects of having a handicapped child in the family for siblings which are frequently mentioned by parents, including the development of greater compassion and maturity than other children their age.

CAREGIVING RELATED TO FAMILY ISSUES

It is often easier for parents to focus initially on developing an understanding of themselves in relation to the larger society. Such a starting point allows for the expression of repressed anger, and lessens the feelings of deviance and craziness which afflict many families. Nevertheless, the responses of the family itself must not be shied away from. Using the models of mourning and/or grief work may be useful because they lack the pathological connotations of other forms of psychotherapy. However, some parents may resist accepting this interpretation, because they do not wish to see themselves in a situation of loss. After all, their child has not died. In these circumstances, modeling and normalization are both helpful approaches. Parents are naturally suspicious of 'experts' telling them what they should and should not be feeling. It is helpful simultaneously to encourage contact with other parents who are more open about their own emotional reactions as a way of helping parents accept and admit their feelings.⁶⁹

Facilitating the normalization of the family structure is perhaps one of the most critical tasks which confronts the caregiver. Removing the child with the disability from the center of family attention can be a difficult, but not unattainable, goal. Steps in this direction include strengthening the child's bonds with the sibling subsystem (incidentally, this can have a therapeutic effect in and of itself, as often siblings tend to treat their handicapped brother or sister 'more normally', and

make fewer allowances, than do the parents); strengthening the marital subsystem; involving father in more hands-on interactions with the disabled child; and ensuring that mother has a little space in which to define herself as a person, as opposed to exclusively the mother of a handicapped child.

While a systems approach clearly makes the most theoretical sense in working with a family, often there are practical and pragmatic obstacles.⁷⁰ The availability of the father, who often is working two jobs to provide for the additional financial needs of the family, is very limited. Additionally, mothers may feel more comfortable defining the problem as restricted to the affected child, or that child and his or her siblings. Getting permission from the parents to examine the marital subsystem in relation to the child's disability can be difficult. However, this is the level at which the most effective intervention occurs. Even very basic approaches, such as encouraging husband and wife to spend more time together, or develop more mutual approaches to child-rearing, can have an extremely positive impact on the family.

STRATEGIES FOR CAREGIVING: A SUMMARY

Throughout this article, I have consistently used the word 'caregiving' in contrast to 'psychotherapy' or 'counseling' because of my conviction that, in the helper role, we are often all too ready to assume a family needs help because they are suffering from a clinical psychopathological disturbance. Dr Ken Moses, a clinical psychologist and himself the parent of a disabled child, tells the story of coming to facilitate a support group for parents of disabled children and feeling as though he had entered a laboratory for the study of all major psychopathologies. Only after some time did he realize that what he had been so quick to label pathology were really different manifestations of grief.⁷¹ I believe this is an all too common response among health care professionals. One way we have of distancing from the pain of families in this situation is to diagnose them as crazy. Certainly, formal psychotherapy is indicated in some situations. However, more commonly, functioning in a manner which extends accurate listening, empathy, and respect can go a long way towards helping a family heal its wounds.

The goals of caregiving interventions with families of children with handicaps might include the following: (1) to achieve an understanding of the realities of the child's condition; (2) the management of emotional distress; (3) the appropriate utilization of available resources; (4) ensuring that families attend to other responsibilities; and (5) the facilitation of support and communication.⁷² These goals, in and of themselves, are quite modest. Still, inability to achieve them can lead to chronic stress, disorganization, and dysfunction in the family system.

Effective caregiving⁷³ has been identified as consisting of several elements:

1. *Clarification and control.* Caregivers must be able to aid parents to examine problems forthrightly, helping them to express the inexpressible and to make explicit the implicit or unstated. Providing accurate information is an essential part of this process. For the caregiver, maintaining a sense of control in the interaction can make the difference between this being an effective or an ineffective strategy. When parents are taking the risk of exploring repressed or avoided psychological material, they need to feel that they are operating in a safe environment where, even if they lose control, the situation itself will not go out of control.
2. *Collaboration.* One of the most common pitfalls of the caregiver role is to put unnecessary distance between self and the object of caregiving. We are often so afraid of our own emotions that we do not allow them a natural place in the helping process, with the result that our efforts convey a cold and mechanical quality. Collaboration implies sharing some measure of the parents' suffering and pain.⁷⁴ It does not mean sharing their distress to the extent that the roles of helper and helpee become blurred.
3. *Directed relief.* This aspect refers to encouraging the expression of pent-up or tacit feelings, which may be shading the entire emotional overlay of an interaction but which the parents cannot directly state. Effective caregiving means not only being able to respond to emotional material offered by parents, but initiating exploration of these areas when parents seems unable to do so independently.
4. *Cooling off.* This is an equally important concept. Emotional expression is vital to the process of recovery in the parents. However,

repeated and lengthy parental excursions into hysterical outbursts do little to further the family's adaptation. Thus, the effective caregiver must also know how to modify the family's tendencies towards emotional extremism.

5. *Encouraging self-esteem and self-confidence.* It is easy for parents dealing with the challenges of a handicapped child, and the challenges of the system meant to serve this child, to feel helpless and incompetent. Esteem-building and validation are critical parts of the recovery process.
6. *Knowing how to share silence and adopt constructive resignation.* A basic skill of the caregiver is knowing how to accept the silence of the family, to know when words and actions, however comforting, are superfluous. It is also important for the caregiver to be able to take the risk of modeling acceptance and letting go, as well as acting and problem-solving. The former skills, though essential to surviving many experiences in life, are much less familiar to and valued by individuals in this society. It is an important function of the caregiver to confirm their legitimacy and importance.

Coping strategies

Caregivers may also focus on recognizing, stimulating and reinforcing coping strategies which have been shown to have a positive impact on parents. A word of caution is appropriate here. I have some reservations about using the phrase 'coping strategies', because of the risk of sounding too mechanistic and technologic. As a caregiver, one must avoid prescriptions for attitude change which only serve to make parents feel coerced, inadequate, and misunderstood. Instead, the emphasis should be on the normalization, recognition, reinforcement, and modeling of such coping approaches. Giving parents an opportunity to talk about why they believe their child is suffering is very different from the caregiver assigning a specific meaning to that suffering. Truly attentive listening to the family will determine whether they are ready to treat their situation humorously or focus on the benefits of their situation. One of the most common mistakes a caregiver can make is to inflict his or her own progression of emotional coping onto the family.

This being said, it is of importance to be able to recognize positive coping strategies in families. These include positive thinking; hope and humour; focusing on others' problems (it could have been

worse); the belief that suffering is inherent in life, and perhaps part of a larger meaning or purpose;⁷⁵ moving the problem to the periphery of meaning, so that its implications are no longer central to the individual's core meaning in life; emphasis on living each day; emphasis on the child's good qualities, rather than on the child's limitations; emphasis on the benefits, rather than the drawbacks, of the child's condition to the family; sharing the burden with others—the effective use of social and systemic supports.^{76,77} Other useful strategies include regular relaxation and time-outs, developing the ability to effectively problem-solve, liberal self-praise, and effective self-instruction.²⁴ Normalization of the child's social interactions as much as is realistic has also been shown to have a positive effect on both parents and children.⁷⁸ However, it is also true that for normalcy to occur, abnormality must first be acknowledged;⁷⁹ and that the possible cost of normalization strategies has not been sufficiently explored.⁸⁰ It may also be helpful to have parents rehearse how to deal with predictable future stressful situations involving their child.⁸¹ Of all these coping strategies, the most important for successful coping seem to be endowing the child's condition with meaning, and being able to share the burden with significant others.

While there is some research evidence supporting the assertion that these attitudes and behaviors have a positive association with individual psychological health and healthy family adjustment, it must also be recognized that the study of coping is still in its infancy, and thus much is left to the clinical judgment of the caregiver. For example, simply considering the above list, we do not yet know how many of such skills, or in what sequence or combination, are considered optimal, although arguments have been put forward that *flexibility* in coping responses is an essential element.⁸³ We also know very little about how different cycles of coping among individual family members affect the health of the family as a whole. These and many other limitations make it especially important that the caregiver be guided not only by the appearance in the family of such coping mechanisms, but by reliable indices of individual and family functioning.

Problems of caregivers

Finally, it must be acknowledged that the caregiver-parent relationship is often complicated by the caregiver's own issues surrounding disability.

Caregivers may experience failure with a chronic, incurable patient as a narcissistic wound, a disappointment of their expectations of being successful healers.¹⁷ Since the child is usually considered immune from attack, less skilful caregivers may defend against their own helplessness and perceived inadequacy by labeling the parents as deniers, complainers, and holding unrealistic expectations. Thus, the caregiver must also know how to care for himself or herself in the caregiving setting. This process involves a willingness to examine one's own fears and frustrations associated with handicapping conditions, and acknowledges that such emotions can affect one's ability to adequately care for another. It is sometimes helpful to develop a mentor relationship with another respected professional in the field who can help the caregiver explore these issues.

It is often difficult for a 'helper', whether doctor, teacher, or therapist, to be truly open to a family's psychological pain. Quite often, their pain triggers remnants of our own pains. In wishing to escape from these feelings, it is easy to communicate impatience, or make a judgment of weakness and self-indulgence against the family. It is time to move on, we say. One has to pick up one's life. However, our ability as caregivers to allow parents to grieve is essential to the healing process.

CONCLUSIONS

In summary, the caregiver must be able to do the following to have a helpful impact on the family of a handicapped child: (1) locate the family in their social and environmental context, and fully understand the pressures, prejudices, and insensitivities with which families must deal on a daily basis; (2) conceptualize the range of parental reactions as part of a grieving process in which parents are mourning both for their child and for themselves; (3) be sensitive to specific developmental, inter-generational, and intrafamilial issues which tend to be catalysts for additional stress in the family; (4) carefully examine their own biases and stereotypes, to ensure that these do not exert a counter-therapeutic influence on caregiving; (5) adopt certain models of being with the family which emphasize respect, empathy, and careful listening, as well as qualities of honesty and authenticity, which will promote processes of resolution and healing within the family. When the caregiver holds these objectives paramount in interactions with the

family, and pays careful consideration to how they might be accomplished, there is every likelihood that a truly therapeutic alliance can be forged between parents of children with disabilities and the professionals whose job it is to help them.

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