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The Impact of Initial Diagnosis: Mobilizing Family Resources

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Introduction

The elements that foster growth in developmentally disabled children are no different from those needed by any other child. Children grow as a result of a complex interaction of physical, social, emotional, and cognitive elements. Most of the professionals involved in the habilitation of impaired children subscribe to the basic tenets of Holism, i.e., to the belief that one must deal with a whole child (Friedlander, Sterritt, & Kirk, 1975). For example, a professional who attends exclusively to a child's learning mechanisms is doomed to failure. A child is not a random collection of separate parts. Children are a unified and complex integration of many facets which each influence the other. For this reason, treatment approaches for developmentally disabled children need to address all parts of the child. Parents are one part of a child's complex makeup. They are an element of the unified whole that comprises "the child." It is as futile to separate parent and child conceptually as it is to separate hydrogen from oxygen in water. Separate them and the original "subject" ceases to exist! The habilitation of impaired children must include the parent as an integral component of the whole child.

This chapter focuses on the relationship between the professional and

parent in the developmentally disabled child's habilitation process. In particular, it will examine those aspects that are often counterproductive to habilitation in the medical, special education, and therapy areas.

For many years parents of impaired children were actually excluded from the treatment process involving their children (Busecaglia, 1975). When they were finally brought into the process, the professionals who dealt with them often had little understanding of family dynamics. The emotional impact on the parent of having an impaired child was neither acknowledged nor addressed clinically. Further, the parents themselves had little understanding of what was happening to them or their family. The unfortunate outcome of this universal social/emotional ignorance was stressful interactions and hurt feelings. The following are examples of such feelings shared with "third parties":

From a parent: "I'll never forget the doctor's incredible insensitivity...."

From a professional: "If it wasn't for this hysterical, overprotective mother...."

From a parent: "You get the feeling that they [the professionals] don't care about you or the kid; all they care about is keeping their job and avoiding hassle."

For over a decade many habilitation and rehabilitation professionals concerned with children suffering from developmental disabilities have become aware that they cannot treat a child's sense, function, or limbs in isolation (Friedlander et al., 1975). Programmatically it is becoming more evident that the Holistic approach has been generally accepted as *the way to approach* child development. Children, not functions, develop and grow. Such thinking has been the impetus behind both research and clinical applications of the early intervention concept with developmentally disabled children. The earlier the intervention, the more contact between parent and professional. Understanding the parent-professional relationship is as important to the habilitation of children as understanding any other function involved in a multidisciplinary approach.

The implementation of a truly Holistic approach to habilitation is extremely difficult. No professional can be trained to perform in all areas. Actual interdisciplinary cooperation requires a level of trust, respect, and confidence that is seldom seen. Habilitation professionals are frustrated by slow progress, hard-to-define successes, criticism from all sides, and stressful work environments that reflect the enormous responsibility of habilitating developmentally delayed children. Within this context, many professionals feel that parental feelings pose a powerful threat to a successful Holistic habilitation program (Brazelton, Koslowski, & Main, 1974). Again and again,

it becomes evident that parents and professionals have a substantive shared challenge to habilitate the developmentally delayed child.

There can be preexisting differences between parents and professionals that make it difficult for them to relate to each other. People come from varied religious, ethnic, racial, social, economic, and educational backgrounds. Sometimes these differences alone preclude comfortable parent-professional relationships. However, problems of so general a nature are seldom at the core of communication breakdowns.

Parents of developmentally disabled children, particularly right after an initial diagnosis, experience powerful feelings that dramatically influence their relationships with professionals who work with their children (Moses, 1977). In addition, most professionals feel intense emotional involvement in their work and have feelings that dramatically affect how they relate to parents. These emotional and interactive dynamics will be addressed in this chapter, along with recommendations aimed at mobilizing family resources after the parents receive the initial diagnosis.

Parents, Impairment, and Grief

When parents await the birth of a child they generate dreams about who that child will be *for them*. Often such dreams are of a very personal nature that is central to the parents' lives. The experience of anticipating the birth of a child is a primitive one that stirs deep feelings. Unfulfilled needs, yearnings for the future, struggles with personal deficiencies, and intense fantasies can all be attached to this yet-to-be-born child. For these reasons the attachment to the expected child and the parental dreams are inseparable (Moses, 1981).

When an initial diagnosis of developmental disabilities is received by a parent, a grief process begins. The parental dreams are almost always shattered by learning of the disability. To be actualized, dreams generally require a wholly intact child. Therefore, the initial diagnosis often marks the destruction of a cherished and significant dream. In order to continue with their lives the parents must grieve the loss of their dreams. Unfortunately, that loss is often so personal and elusive that few people are consciously aware of what is happening. Indeed, the parent frequently does not understand the process and finds that there is much confusion in addition to the feelings of grief.

Grieving is the process through which an individual can separate from a significant lost dream (Moses, 1977). Grieving stimulates a new look at one's social, emotional, and philosophic structures. Grieving facilitates personal growth through a reevaluation of core-level values and attitudes. Unless they

Grieve, parents cannot separate from the dream attached to a lost person or "object" and, in essence, die with whomever or whatever is lost. Such people lose a present and future orientation and focus only on the past — on the "good old days" before they sustained the loss.

Grieving is primarily an emotional process. The feeling states experienced are not epiphanic; that is, they have no specific order, one is not a prerequisite for another, and, indeed, some can be felt simultaneously (Moses, 1981). Grieving starts spontaneously and appears to require no learning period. The feelings that result seem to be intrinsic, cross-cultural, and are even evidenced in some animals (Lewis & Rosenblum, 1974).

The feeling states of grief include denial, anxiety, guilt, anger, and depression. There is no true order to these feelings, although denial and anxiety are often experienced first, with depression, guilt, and anger usually clustering together. Two, three, and even four feelings can be felt simultaneously or alternately. Feeling states can return and be reexperienced in new contexts.

Successful grieving appears to be dependent upon significant human interactions; that is, one cannot grieve alone. The support that a parent of an impaired child needs in order to successfully grieve may come from the professional who is working with the child as well as from the spouse, friends, religious groups, the community, and/or parent organizations. Unfortunately, many of the prevalent cultural injunctions in western society inhibit the spontaneous grieving process. The emotions that are displayed as part of the grieving process are often rejected by both the grieving individual and by "supportive" others. Ironically, many of the people trying to help bereaved individuals inadvertently frustrate the process. They easily reject the feeling states of denial, anxiety, guilt, depression, and anger as being pathologic. Most do not recognize such states as being part of a normal and necessary grief experience. Often they respond with diagnostic labels or expressions of disapproval.

Few people wishing to offer support recognize that each feeling serves a specific function which separates the parent from a shattered and cherished dream. When the parents can separate, they are then able to generate few dreams. Hopefully, such new investments can incorporate the developmental disability and stimulate the emergence of a coping process. Understanding the value of the emotional states associated with grieving is central to offering parents what they need in order to grieve successfully.

Since conventional wisdom views the stages of grief as pathologic, and professionals as well as parents are influenced by such "wisdom," the following details of the grief process are offered to encourage new supportive attitudes. Denial, anxiety, guilt, depression, and anger are each presented as

constructive parts of a difficult parental growth struggle that is precipitated by an imposed significant loss.

Denial

Denial is the feeling state that is most often identified as a destructive parental attitude. Its effects can indeed disrupt early intervention or consistent treatment. This can be a problem as denial is a normal, natural, and necessary part of healthy grieving. It can be manifested in a number of different ways, however, its effect and impact are the same. Denial keeps the parent from being overwhelmed with the feelings associated with having a developmentally delayed offspring.

Parents might deny the existence of the handicap, deny the permanence of the handicap, or deny the impact of the handicap. Although each manifestation serves the same purpose, the effect and impact upon the professional can be quite different. The parent who denies the existence of the handicap rejects what the diagnostic professional has to offer. This can create tension. The professional may feel insecure and defensive about the diagnosis, or he may become quite angry at the parent who is rejecting what he believes to be an "invaluable truth." The parent who denies the disability's permanence can create all sorts of confusion in the mind of the professional. Parents may become involved in unusual interventions that traditional professionals may not easily accept. Indeed, this is a time when parents can be quite vulnerable to quackery. When a parent denies the impact of the handicap, a most peculiar alliance between the parent and the professional can occur. Such a parent can present himself and the state of the habitative arts in such a fashion that both parent and professional will collude to deny. An example of such denial follows:

Please understand, doctor, we are not an ordinary couple. Both of us are well educated and committed people. We have good resources at your disposal and are very aware that this is no longer a period like the Dark Ages where they locked up handicapped people and threw the key away. Why, we now have wonderful special education, terrific new specialties, and even new federal, state and local legislation aimed at enhancing the lives of handicapped people and indeed, treating them the same as everyone else. We understand that our child has Down syndrome, but we really don't feel that it's a big deal.

A professional might respond to such parents by congratulating them on their "wonderful resources and attitudes that will obviously be an asset to the child and our relationship," missing the imbedded message being shared by the parent, which is denial of the disability's significance or impact.

Most professionals will unequivocally identify denial as "a serious rehabilitation problem." To do that is to violate the unity between child and parent. The stage of denial is central to a successful grief process.

We all live in a world filled with jeopardy. To live and grow comfortably in the face of jeopardy, healthy people create illusions of safety that allow them to survive what our awful things in this life happen to other people. It is impossible to prepare for terrible occurrences. Therefore, when something awful happens, e.g., when parents are confronted with an impaired offspring, they are wholly unprepared to deal with the event. Denial buys the time that the parents need in order to gain the internal strength and the external supports necessary to cope with having an impaired child. Internal strengths, often called ego mechanisms, lie dormant in a person, untested until circumstances require their presence. External supports can include determining which friends can be relied upon, which professionals should be involved, what information needs to be accumulated (educational, legal, organizational, or conceptual—as in the learning of the new language of disability), etc. It takes an enormous amount of energy to gain ego strength and external support to face so immense a challenge. Characteristically, people who are denying are defensive and agitated, while absorbing an enormous amount of input indirectly. Yet on the surface they deny that such input is even being registered. The implications of this paradox are substantive for the professional.

The following are a series of issues and suggestions aimed at constructively facilitating the function of parental denial while supporting and reinforcing the role of the professional. At the time of the initial diagnosis it is suggested that material be presented in a concise, simple, and brief form. Seldom can parents hear much more than the child's diagnostic category. Two follow-up appointments should then be scheduled. The first should be structured to encourage the parents to call when they feel able to hear more information. The second appointment is based upon crisis intervention research that marks the six-week period of time as a significant point in crisis management (Caplan, 1964). After six weeks the most dramatic manifestations of shock reactions have run their course. At that point, professionals can more clearly see how well the parents are dealing with having a developmentally disabled child. Therefore, it is recommended that a second appointment be made on or after the six-week period. Throughout the continuing diagnostic process and through the early intervention activities, professionals can continue to share verbal and written information with the parent even though the parent might not appear to either want or use the information. It is also of value to link parents to parent organizations and parent groups, especially if such groups use peer self-help persons for support. It is important for the professional to

decide how to deal with denial. The professional who believes that it is his job to convince the parent of the nature of the disability and to persuade the parent to follow through on all recommendations may experience disappointment and frustration if the parent is denying. Rather than trying to fight the denial, it might be helpful for all concerned if the professional continues to share information, suggestions, and recommendations while supporting the legitimacy of the parent's denial around this difficult-to-accept reality.

If, on the other hand, the denial process were assaulted, and the parent were somehow forced to experience the impact of the impairment without inner strength and external supports, they would probably undergo an emotional collapse. Parents who are denying are not suffering from a logical deficiency, nor are they incapable of understanding what is being presented to them. A clinician can be sure that there are many people telling the parent that he is stupid, destructive, behaving inappropriately, or shirking responsibility by denying. The parent needs someone who accepts, even embraces, the validity of denial. There are few people who are able to give denying parents what they need most: recognition that they are loving parents who, for good reason, cannot currently engage actively in their child's habilitation.

An illustrative case comes to mind about parents who had just been told that their three-year-old was severely retarded. Neither parent showed much of a reaction. When queried about their lack of response, they answered: "That's okay, ain't none of us too smart in our family." The shocked and somewhat chagrined professional tried to explain that retardation implied much more than their concept of "not too smart." In response, the parents stated that both of them had taken a long time to learn to talk and walk and that it was obvious that this professional was overreacting and that "everything would turn out all right." The unstated goal of the professional was to get the child into a special education program. He believed that acceptance of the diagnosis was a necessary prerequisite. To his surprise, when he finally suggested that the child be enrolled in an early childhood program, the parents readily agreed "as long as they didn't call the kid no bad names." The implication of the child going to a special program was of no concern to them. However, they were not yet ready to face the emotional impact of having a "retarded child." Until the professional could come to recognize the parents' issue, he was courting a power struggle that he would surely lose, thereby depriving the child of services and debilitating his own sense of effectiveness.

Since the mechanism of denial affords the parents the opportunity to gain inner strength and to find external supports as they concern the emotional impact of having a retarded child, the denial ultimately ceases when the parents attain sufficient strength and support. Denial then ceases to exist because it has served its purpose.

Anxiety

Generalized feelings of anxiety are often evidenced by parents of impaired children while they grieve the loss of a significant dream. The anxiety is related to an important balance between the following: responsibility for the welfare of another human being and the right to have an independent life of one's own. Maintaining this balance requires many personal and internal adjustments. The event of having a developmentally disabled child disrupts whatever internal balance existed prior to the diagnosis.

Parents often report shock and dismay at discovering that *they* are their child's own medical, educational, and therapeutic manager. The child seems so vulnerable, the professionals often convey a sense of emergency, and there are conflicting messages from many different sources. There is so much to be learned, and so much seems to hinge on learning it properly. All this new pressure and responsibility is heaped upon the already existing pressures and responsibilities of the lives they lived prior to having an impaired child. Such pressure often provokes anxiety.

A mother in her mid-thirties who had given birth to a severely multihandicapped daughter candidly shared the following story, which illustrates her anxiety:

I used to be the kind of person who would say (and sincerely believe) you do everything and anything that you can for a child, especially a child with problems. Now I'm not sure, I mean, it's much more complicated than that. Lots of times I wonder if we wouldn't all be better off if she died. You know, at times I think that we have all reduced ourselves to her level of living—just barely surviving from moment to moment, constantly struggling, using all of our energy just to get through a meal.

Please don't misunderstand, no one could love a child more than I love her! It's just that my whole life could be devoted to taking care of her and nothing more. The best advice that I got from anybody this year came from a check-out girl. It was really quite simple and self-evident, but I had lost the thread and needed to hear it. She said, "You've got to continue living your own life—giving up on who you are is not helping your daughter, and it's destroying you. You have a right to a full life, too, you know!"

I still haven't been able to do what she said—it's real hard. When I think of myself, I get real worried about my daughter being short-changed; when I ignore my own needs, I worry that my life is just slipping away. Sometimes the pressure gets so bad that I forget my marriage, friends, and everything, and when I see that that's happening, I get even more upset. Somehow all this pressure has got to stop!

The parental feelings of responsibility are overwhelming and the temptation to become a "professional parent" of a developmentally disabled

child is very strong; simultaneously, there are overwhelming temptations to desert. Such conflicting feelings can create circumstances rife with anxiety. The attitudes of professionals and other parents of impaired children can strongly influence the amount of pressure that a given parent feels. In truth, however, definitions of responsibility come through personal struggle. To accomplish a rebalancing of one's external responsibilities versus the maintenance of one's right to have a full life takes an enormous amount of energy and a tremendous amount of skill. Anxiety serves as an important mobilizer of energies while simultaneously focusing those energies upon the important habitative tasks at hand.

Parents who are experiencing anxiety as part of the grieving process are in need of support from others who accept the legitimacy of such feelings. It is counterproductive to give a parent an injunction requiring that he or she "calm down." This period is one when "calming down" is not only impossible, but maladaptive, for the anxiety itself is the facilitator of the restructuring of attitudes concerning responsibility. It is also a time when realistic expectations need to be clearly spelled out, along with an understanding that parents have lives beyond caring for their impaired children.

Further, parental unwillingness to do certain habitative activity is acceptable, and not indicative of a destructive or noncaring parent. An overstressed, overwhelmed parent ends up doing nothing, while appearing intensely involved with doing everything. Parents who can minister to themselves, and give themselves permission to reject certain aspects of the habitative process, will in the long-run be more effective child-growth facilitators. Often a professional's overzealousness in "saving the child" will frustrate the parent's ability to resolve the anxiety phase of grieving.

Guilt, Depression, and Anger

A mystery throughout history has been the way people attain feelings of meaningfulness about their existence. The elements that go into one's personal existential significance are perhaps the most complex of our sociophilosophic and emotional concepts. Complicated and hard-to-define variables—such as capability, ethics, causality, order, fairness, potency, evaluation, morals, rewards—all weave together to create the material substance that defines one's existential purview. Any significant loss that precipitates a crisis affects this complex interweaving. Parents of impaired children find themselves restructuring fundamental issues of the meaning of life as part of their grieving process. Specifically, the feeling states of guilt,

depression, and anger assist in the process of existential restructuring (Moses, 1981).

Please note that these feeling states are inextricably interwoven; however, for purposes of understanding their individual impact upon the parent, guilt, depression, and anger will be examined as though they were separate elements. Each feeling state corresponds to a major core element that elevates life's meaning in the following areas: commitment, competence, and justice.

Guilt is perhaps the most disconcerting of all the grief states, causing distress to both parents and professionals. Generally, it is expressed in one of three ways. The first is evidenced by parents who believe that they caused their child's handicap. Their stories often involve the taking of drugs during pregnancy, the hiding of known genetic disorders, the contraction of an avoidable disease, or other occurrences that the parents felt were under their control. This manifestation of guilt appears to be the most logical, and yet it is the least common. Because of its plausibility, it seems the least difficult to accept. The second way that parents of developmentally delayed children manifest guilt does not appear to be as logical. It is reflected through the parent's belief that the impaired child is a just or fair punishment for some specific or awful action that the parent committed in the past. There need not be any direct connection between the nature of the past "transgression" and the nature of the impairment. The third manifestation of guilt common in parents of impaired children is that of a *de facto* philosophic nature. This is reflected in the parent who basically states, "Good things happen to good people, and bad things happen to bad people." Such a general belief leaves the parent feeling guilty simply because the impairment exists.

It is hard for many professionals to accept that so painful and debilitating a feeling state can have any positive, growth-facilitating elements. In the context of grief, guilt is the vehicle that allows parents to reevaluate their concepts of causality; that is, their beliefs about how they impact the world, the validity of their morals, and the usefulness of their ethical structures. In summary, guilt helps them reevaluate the function, effectiveness, and value of their central life commitments.

Each person holds within himself a personal belief system that acknowledges control over certain events, while permitting other occurrences to be left to the whims of chance. How and when one defines certain elements as his or her "fault," while attributing their occurrences to fate, is an individual and internal process. The goal is to develop a functional system that allows one to effectively deal with the vicissitudes of life. A healthy stance on commitment avoids the absurdity of assuming full responsibility for all life events, and avoids the equally absurd position of disclaiming responsibility for anything. The guilt which parents of developmentally

disabled children experience precipitates a reevaluation of the limits of their accountability.

A useful exemplary case is that of a young couple who had two developmentally disabled children. The mother felt that the first was due to the fact that they married at a very young age. She felt that her body was ill prepared to properly carry an infant. The youngest child's disability was felt to be somehow related to the amniocentesis that she requested in order to determine if the second child was impaired. Ironically, the amniocentesis did not detect the impairment, but left the mother believing that the insertion of the needle actually caused the impairment. At the same time the father had a very different viewpoint. He had long felt rage toward his parents, rage that severed communication with them well before the birth of their first child. In some fashion that was never clearly explained, the father associated the past stresses with his parents with the disabilities of the children. It was an especially difficult issue for him to share, as he prided himself on being concrete and logical and these feelings were "so obviously illogical."

This young couple, although appearing very different from each other, were together struggling with the same issue: "Why has this happened to me?" The sensitive professional might attempt to explain to these parents the "scientific" basis for each of their children's impairments. Professionals in the early intervention areas need to be aware that guilt does not yield to argument, cajoling, coercing, or even irrefutable scientific evidence. It becomes clear, indeed, that scientific explanations are extremely limited. They do not adequately touch upon "why" questions. Indeed, most scientific explanations will further the belief that such painful life events have more to do with a person's moral, ethical, and responsibility issues than with anything else. For these reasons, the best thing a professional or significant other human being can do for such parents is to sensitively listen and accept the legitimacy of guilt feelings in so painful a circumstance.

In order to work through the guilt feelings involved in having an impaired child, the parent must be able to share feelings with an empathic, significant other. The professional who fills such a role might do so by offering acceptance through an attitudinal framework exemplified by the following response: "If you truly believe that you caused your child's impairment, no wonder you feel so badly. Tell me about it." The temptation on the part of most professionals is to try to take away the guilt. Only the very exceptional person is able to validate the legitimacy of the parent's feeling without seeming to confirm a judgment of fault. To offer such a relationship is to offer a unique opportunity that facilitates growth.

Nothing will accelerate the course of guilt feelings. There are events, however, that can aggravate this difficult phase. If the professional can accept guilt as a normal, necessary, and facilitative element of grief, a more

substantial and ultimately constructive relationship with the professional will likely result. In contrast, the professional who views guilt as psychopathologic, or who has a condescending view toward parents who manifest guilt, will impair the partnership. After guilt successfully serves as the vehicle for the reexamination of attachment and impact, i.e., communal existential values, it will outlive its usefulness.

Incidentally, the manner in which the parent manifests the guilt often reflects the nature of the particular handicap. For example, many parents who have mentally retarded children connect that disability somehow to show they themselves have used their intellect in the past. For instance, a parent might say, "Isn't this an *apropos* punishment for my having wasted the intellectual skills I possess?" or "Isn't this an appropriate punishment for a person who only valued other people in terms of their intellectual prowess, and behaved condescendingly toward people who were not as bright as I." Again, it is the empathic professional who can offer the most to a parent presenting such a feeling. There is nothing to be cured or fixed. There is only a feeling state to be dealt with.

The second facet of grief that deals with one's inner existential core is that of depression. For the purposes of examining depression's impact upon grief, the rather simple definition of depression as "anger turned inward" will be adequate. One might ask, "Why is the parent of a developmentally disabled child feeling self-anger?" The answer to such a question offers some insight into the issues involved in the depression.

It appears that each human being has the need to feel competent. This need is complicated when one examines the various definitions of "competence." What does it take to be a competent father, a competent mother, a competent wife, a competent professional, or a competent anything? What it takes is indeed most personally and individually defined by the person who is struggling with the question. Further, definitions of competence change as one grows older. Therefore, definitions of competence are often different even for the same person.

Depression is the grief state that helps the parent rework a definition of competence within the context of having a developmentally disabled child. Issues of competence break down into three facets: potency, capability, and criteria for evaluation. The depressed person usually questions all of his judgments in these three areas. Such questioning is evidenced by the following "depressed" types of statements: "I am a weak (impotent), useless (incapable), and worthless (without value) human being." Parents of impaired children often view themselves as awful people because they seem to have no impact on something very important to them, something they want very much to change but can't.

Depression is generally viewed in Western culture as a pathologic state. This is unfortunate, as depression is a normal, necessary, and healthy part of

grieving. Instead of professionals supporting such feelings they generally treat the depressed person with special deference and a peculiar carelessness that often inhibits the expression of this important grief state. It would be far more helpful if the professional were able to openly accept the fact that having a developmentally disabled child is a very depressing event in the life of the parent. In truth, there is little that the parent can do to "make the child totally normal," which is indeed what most parents want to do more than anything else.

A case that dramatically demonstrates the impact of depression upon the bereaved parent is one of a woman who was an accomplished professional in the field of developmental disabilities. After many years of working in this area, she found herself in the ironic position of being the parent of a severely impaired child. When she spoke of the circumstances she stressed repeatedly that her knowledge, experience, and exposure to the field only served to show her the true limitations that existed. She felt worse off, not better off, than parents who did not have the rich background that she did. Basically she was saying that all of her education and experience were impotent, useless, without value in the face of trying to "cure" her child. And further, she was so sophisticated in the area that she even felt it inappropriate to wish for his cure as opposed to rejoicing around the assets that he still possessed. Many people around her found it difficult to deal with her since they believed that she should be "more optimistic" and "have a more positive attitude" than a less knowledgeable parent. As a result, she was not able to comfortably and openly express her depression. Instead, she adopted a cynical, hard, angry exterior that other people accepted as evidence of a determination to help her child. In truth, her inability to work through her feelings prevented her from arriving at new definitions of competence that would make it acceptable for her to have a child with the types of problems that her son had.

When she finally encountered a professional who related to the feelings of depression with support, acceptance, and encouragement, she was able to feel the anger towards self, the sense of impotence, the sense of valuelessness, and the feelings of "nothing meaning much of anything." After she explored these feelings, shed tears, permitted herself to withdraw for a period of time, and considered the meaning of her experiences, she was then able to let go of her old way of looking at things, and to allow herself to become more of an "ordinary person" than ever before.

It often takes special internal strength for the professional to sit down with a parent who feels immense depression. It takes even more strength to accept what appears to be a pathologic state. A facilitative atmosphere can grow out of statements as simple as "Tell me more about your feelings." Or "It sounds as though you feel hopeless. Do you, and if so, why?" Or "It sounds as though the birth of Johnny has turned your life upside down. Can you tell me what kinds of things have changed since his condition was diagnosed?"

Input from a professional can make a difference. Depressed people do not need cheering up. They do not need someone to deny them the right to feel depressed. Instead, they need someone who will allow them to feel the legitimate depression that they are experiencing, and further, to be available to talk with them about their sense of impotence. Unfortunately, most of us were taught to relate to depressed people in ways which inadvertently leave them feeling misunderstood, stupid, crazy, and/or destructive, in addition to depressed. Depression is part of a normal, necessary, and self-sufficient process of grieving that allows parents to separate from their lost dreams and fantasies. There is, indeed, value in "wallowing in self-pity" and "crying over spilt milk." Since what constitutes reality for each individual is reality as one perceives it, life truly is as bad as one thinks it is.

As parents are permitted to experience depression within an environment of acceptance, they will likely reevaluate their definition of fundamental competence. Such redefinition permits self-acceptance in spite of not being able to "fix their child." Again, it is the significant other who can offer an atmosphere that facilitates this discussion of grief. Quite often a professional in the field is the significant other.

Parents of impaired children feel anger, even rage. This particular feeling state is a most frightening one for all concerned. Most of us were raised to believe that feelings of anger are inappropriate under all circumstances. This particular attitude is most unfortunate in the context of grieving since anger is an integral facet that facilitates the struggle that parents go through to put their lives back in order.

Each person appears to have an internalized sense of justice that permits him to move within society without undue anxiety or fear. An unpredictable event, such as having an impaired child, threatens one's feelings of security about universal justice. Whenever one's sensibilities about worldly order and fairness are disrupted, one feels, at the very least, frustrated. Frustration, agitation, aggravation, irritation, and annoyance are all words that parents of impaired children find on their lips at one time or another, along with the words anger or rage. Long ago, psychologists noted that frustration leads to aggressive feelings (Miller, 1941). Parents who are frustrated by the birth of an impaired child feel anger toward that child who has intruded upon their lives and substantially disrupted them. To have an impaired child is expensive, embarrassing, time-consuming, energy-consuming, and shattering to the entire family constellation. On a more psychologically primitive level, most parents feel that all this disruption and pain has been "caused by" the impaired child.

Since anger toward children is considered heinous by most parents, they often displace these angry feelings onto others. Most commonly, spouses, the impaired child's siblings, and, of course, professionals are targets of this displaced anger. Such displacement is most unfortunate since parents are

often in need of support from the very people whom they may be alienating through their anger. As an alternative, parents may direct their anger and feelings of injustice toward God, science, or "the general order of things." They can also find solace in directing their anger into fertile areas concerned with methodological controversies concerning the treatment of their child. This type of displacement can usually elicit empathic understanding more easily from the people around them, yet it too prevents the parents from confronting the roots of their anger, the feelings of injustice that are attached to the birth of a developmentally disabled child.

A note of caution here. Professionals are ordinary human beings and therefore liable to make errors. Indeed, there are some professionals in habilitation fields whose personal motives prompt them to behave insensitively. Parental anger generated under such circumstances may be appropriate, and seems to have little to do with the anger that is part of the process of grieving. Thus, not all anger represents displacement. It is only the parental anger that seems to have little basis in reality that is likely to be displacement. Under all circumstances, whatever complaints a parent presents to a professional should be carefully listened to and examined.

Like the other feeling states of grieving, anger serves a unique function. One's sense of justice is violated when an unfair event such as parenting an impaired child befalls a person. Anger is the vehicle that permits the parent to restructure their concepts concerning justice. The parent of an impaired child who is able to incorporate the seemingly unfair event of having an impaired child "without just cause" will generate a more reality-based internal sense of justice, allowing that parent a more comfortable system that can better explain or accept life's unpredictable occurrences.

It is crucial for parents to recognize and deal with the anger that they might feel toward their impaired child. Professionals can help by accepting and relating to that anger when it is presented. This is difficult. Parents who are "reacting" to an amorphous injustice are generally easier to accept than parents who express direct feelings of anger toward their children. Professionals have often chosen the habilitation fields because of their sensitivities toward children with special problems. Many professionals become quite attached to the children with whom they work, and further, view parental anger as inappropriate, destructive, and illogical. Thus, a natural block evolves, inhibiting communication between parent and professional.

The professional who wishes to facilitate growth in the parent as well as in himself would do well to examine the role of anger in his own life as well as his feelings about parents who express anger. Parental anger in general, and anger directed toward the child in particular, is usually part of a normal, necessary, and healthy grieving process. It is important at this point to distinguish between the concept of anger expression versus the "acting out" of anger. Parents who can talk about feelings of anger with significant other

people are unlikely to act it out. When parents do act out, there are two basic forms that the anger may take. Anger can be demonstrated either through extrapunitive or overprotectiveness. The extrapunitive parent often couches severity within a socially acceptable context. He becomes a severe disciplinarian, demanding, and critical under the guise of helping the child overcome the emotional effects of disability. The parent behaves angrily without admitting to having such feelings or thoughts. The overprotective parent, on the other hand, disguises the feelings of anger in another manner. He maintains an attitude designed to show how "unangry" he is. "I am so loving and caring and involved in my child that I can't even discipline him, or make a demand upon him; that would look too much like punishment." Either way of manifesting anger through these acting out modes is inappropriate and most assuredly destructive for the child as well as the parent. Therefore, it is incumbent upon professionals to understand the dynamics of anger, to examine their own motives closely, and to accept a parent's expression of anger as a preventive measure against potentially destructive parental acting-out.

The set of parents about to be described serve as a good example for illustrating the anger dynamic. Both parents were in their early thirties and worked at skilled jobs in a factory setting. Their third child turned out to have a complex set of disabilities, the most serious of which was nonspecific, pervasive brain damage. These people valued self-sufficiency and were mistrustful of "college-trained" professionals. Their son's disability forced them to rely upon services offered through a university setting. In short, their child had put them into an uncomfortable circumstance that they had avoided prior to his birth. The mother presented herself in a particularly threatening fashion by constantly taking notes on anything that was said. The father sat in the background shaking his head disapprovingly and offering a passively resistant front to any suggestion or observation that was offered. The parents continually reiterated that some other high-level professional, a friend of theirs, was going to "review and scrutinize" what these "persons in training" were offering to them and their child. The tensions between the parents and clinicians were complex, continuous, and debilitating. In short, this was a disastrous parent-professional partnership.

Finally, after many months of this uncomfortable stalemate, a breakthrough occurred through the honest sharing of a physical therapist. Somehow this young woman was not threatened by these parents, but rather moved by their dilemma. One day the physical therapist talked openly to the mother, saying that she was frightened of her. She stated further that the constant note taking, critical comments, rejecting gestures, and veiled threats were making her uncomfortable. The therapist expressed the fear that it might influence her effectiveness with the little boy. The mother was surprised to

learn that she could have such an impact upon a professional and began to speak of the discomfort she had experienced at being "forced to come to this place," to feel the vulnerability of having a child that she did not understand, and further, at "being made an object under a microscope." (Two-way mirrors were common in this setting.) Gradually, more and more material was shared that essentially spelled out the unfair, stressful, unjust, and generally frustrating circumstances that confronted these parents. Imagine being forced to seek services from people whom you did not respect or trust. Suddenly, you are confronted with a team of professionals who question, evaluate, suggest, and direct you in something as personal as child rearing. The situation may engender an enormous amount of resentment. Only through open sharing, careful listening, and sensitive acceptance were these parents able to begin to struggle with their own internal ideas of what was a just or fair world.

It is the rare professional who will be able to recognize that parental anger is part of grieving and should be accepted and facilitated. Yet, if the professional can tolerate the displacement of anger and/or the parent talking negatively about the child, such interactions are very helpful. Parents who are able to talk with significant others about their anger are less likely to become either extrapunitive or overprotective. If allowed expression, if seen as acceptable, if indeed incorporated as part of the normal process of grieving, the anger of parents of developmentally disabled children may be used to restructure their internal sense of justice and thereby help them to move to higher levels of functioning.

Attitude change in parents is facilitated by the three feeling states of guilt, depression, and anger. These three grief states precipitate a struggle with the existential values that people continually rework in the face of substantive loss, i.e., primary significance and meaning, definitions of human competence, and internal sense of order and justice. Attitude change then serves as the prerequisite for active coping with the impact of the disability.

The Parent-Professional Relationship as Significant Grief Facilitator

The grieving process as described is a feeling process that permits the parent of a developmentally disabled child to separate from dreams and fantasies generated in anticipation of the birth of that child. The inability to successfully separate from such a dream is devastating to both parent and child. If the parent does not generate new dreams that the child can fulfill, then each day the child will be experienced as a disappointment and a failure

in the eyes of the parent. This parental disappointment will ultimately be communicated to the child, leaving the child feeling as though he or she is indeed a source of pain to the parents. If, however, the parent is able to separate from the dream, there is the distinct possibility that the child will be accepted for who he or she actually is. Such acceptance is an important prerequisite of attachment, and full attachment is a prerequisite of overall development and growth (Brazelton et al., 1974). It is within this context of development that the concept of facilitating grief becomes an important tool in the intervention and habilitation of developmentally disabled children.

How do parents survive the loss of a profound and central dream shattered by an impairment? How do parents grow from such a trauma and become enhancers of their child's life as well as of their own lives? The answer appears to lie in working through grief in the context of meaningful human relationships. A meaningful relationship is defined as one that gives a bereaved person the human environment in which to feel and share the potent emotions of grief. Grieving is a constellation of feeling states (denial, anxiety, depression, anger, and guilt) that facilitates a personal reorganization, thereby fostering dramatic changes that permit serious loss to become a life-enriching occurrence. To truly help in the growth process of a child, the professional must attend to the grief struggle experienced by the parents. The professional who understands how children develop will accept the legitimacy of Holistic conceptualization, including the parent as part of the monolithic unit called "child." The ideal circumstances for habilitating the developmentally disabled child, therefore, are those where the parent can rely upon the professional to offer a meaningful and significant relationship necessary for successful grieving.

There are a few basic concepts and guidelines that can aid in the sharing process between a professional and a parent, while still maintaining the professional integrity demanded of specialists in the fields. The following suggestions are not offered as "psychotherapy" components, but rather as fundamental elements that can help both professional and parent to positively affect the feelings indigenous to grieving:

1. Maintain a vigilant awareness of the dynamics of grieving; it is easy to forget the process of grief when faced with intense emotion.
2. Review your own personal strengths and weaknesses around grieving past significant losses of your own.
3. Clarity, maintain, and practice focusing on the differences between a feeling and an action. Many actions can be immoral, illegal, unethical, insensitive, and inhumane; feelings are synonymous with being alive, central to dealing with loss, and, therefore, exempt from judgment or criticism.

4. Try to avoid answering direct questions that are of a general or predictive nature, because parents are usually not interested in the answer half as much as in having their concern heard.
5. Try to remember you are not universally responsible for correcting the child's disability, nor the disruption that the disability brings to the family. Limit your concerns to the areas that are consistent with your professional role and expertise.
6. Try to separate the content statements from the feeling statements that are both received and sent by you. It helps to maintain consistency in the modes of communication between parent and professional.
7. Throughout your interactions do not ignore or abandon your professional convictions, recommendations, or programmatic structures; the direct habilitative services offered the developmentally disabled child are always the first priority.

A Personal Note to Parents Only

There is no debating that the parent is unquestionably the most vulnerable person in the parent-professional relationship. That fact, however, does not free the parent of all responsibility for this important partnership. There are some basic prerequisites that parents need to accept if they are going to influence this working relationship in a positive fashion.

While it is clear that successful grieving requires open sharing, there is a decided difference between an emotional presentation of self versus acting out feelings. This distinction is readily seen when children are told, "It's okay to say that you're angry about something, but it's not okay to hit." With adults who are grieving while simultaneously trying to "work with" the source of their grief, the acting out does not usually take the form of hitting. It is far more subtle than that. Making appointments and not showing up, playing professionals against each other, presenting oneself as less capable than one really is, playing "yes, but..." as a way to close down communication, holding grudges while never confronting the "accused professional offender," etc., are some examples of parental behavior that are devastating to parent-professional relationships. Generally, most professionals are hard-working, underpaid, sensitive people who are genuinely struggling with the same child who is offering you so much difficulty. They truly need your advice, suggestions, and help, but will have the same negative reactions to rejection, criticism, and emotional assault as you would, were they to behave that way toward you. All of this describes basic "Golden Rule" human relations that all readers probably know, but that under the circumstances of grievous pain can easily be forgotten.

If the relationship between parent and professional is truly to be a partnership, then the parent also needs to understand some of the dynamics that influence professionals involved with developmental disabilities. Persons attracted to work in the habilitation fields are not usually influenced by the same factors that attract other people to other areas of work. Most certainly, they do not pursue careers in these areas for money, prestige, or power—three of the primary motivators in many other types of work. What does attract people to this work? There is scant research documenting the motives that bring people to the habilitative fields. However, an informal survey of a number of professionals seems to indicate that a larger-than-ordinary proportion of professionals in the habilitative fields are themselves directly involved with a family member who suffers from a developmental disability. That is, they are the sibling, child, or parent of a developmentally disabled person. Further, many of these individuals show a high degree of sensitivity toward the plight of "underdogs."

Diagnosticians, teachers, therapists, aides, etc., have a "burn-out" rate that is substantially higher than attrition rates in nonhabilitation fields (Presley, 1982). Caught between the pressures presented by the child's needs, administrative accounting, parental demands, peer pressure, and their own professional ideals, many professionals have become discouraged and disillusioned with their work. Indeed, the collision between their dreams and fantasies about work, and the severity of a reality filled with pressures and disappointing limits often precipitates a grief response in professionals. If both parent and professional are, at times, suffering with similar issues, then a "rotating magnets" phenomenon can take hold; intense attraction or repulsion can happen from moment to moment. Parental sensitivity to professional stresses can enhance this important partnership. Professionals need the same acceptance of their feelings that parents do!

It is pointless for either parent or professional to try to become "grief diagnosticians," since the feeling states previously described are not experienced in any particular order, nor are they mutually exclusive. That is to say, people feel what they are going to feel when they are going to feel it, and often have two or more feelings simultaneously. Moreover, an attitude of acceptance aimed at facilitating grief would be damaged by an attempt to diagnose a person's grief state, since diagnosing is, by definition, a process of labeling.

The grieving process is far from a one-time occurrence. Parents of developmentally disabled children repeat and rework the feeling states as the child matures. All parents seem to grieve at the point of initial diagnosis. In addition, each time the child comes to a major milestone that impacts the parent in a new way, grief will once again be experienced. Common developmental points that reactivate grieving are:

1. When the child reaches "regular" school age (for that is a time when comparison between children occurs).
2. When the child reaches puberty (and offers all the dilemmas of adolescence, plus the complexities of the handicapping condition).
3. When the child reaches high school graduation age and the disability negatively affects the child's ability to move on to a more independent manner of functioning.
4. When the child reaches an age where the expectation is that he or she will indeed live totally independently (working, getting married, etc.)
5. When the parents reach retirement age and the nature of the disability is such that the child might interfere with their retirement and require that arrangements be made for the time after their death.

Coping

Since grieving is almost entirely an emotional process, it is clear that there are other processes that occur simultaneously, or in tandem with grieving. The general term of "coping" covers most of the remaining activities that require interaction among the parent, the child, and the professional. Although much has been written since 1960 about the coping process, the most succinct and clear descriptions and definitions of the process were offered by a rehabilitation psychologist named Beatrice A. Wright (1960). In her book, *Physical Disability: A Psychological Approach*, Wright highlighted four major coping processes. Each of these impact the parent in such a manner as to precipitate a change in the value system. The four coping mechanisms are: containing the disability effects, devaluing physique, enlarging one's scope of values, and converting from comparative values to asset values.

When parents first begin to deal with the impact of having a developmentally disabled child, their tendency is to generalize the effects of the disability. They are prone to see the entire life of the child (and often of themselves) as ruined. It is not uncommon for parents to say things like, "My child will never marry; my child will never work; my child will be dependent upon me for the rest of my life." They conceptualize the worst, and then deal with reality. Confrontation with reality is aided by accepting the limits of the effects of the disability. Containment is an attitudinal process. That is, the parent does not permit the concept of disability to contaminate those aspects that need not be affected by the disability. The professional can be extremely helpful during this facet of coping by offering as clear or concise an assessment or diagnosis as possible, particularly an assessment that emphasizes the competencies and assets that are *not* affected by the disability.

If parents can be exposed to functioning impaired adults, it will help with this coping process.

The devaluing of physique, as a coping mechanism, attacks one of the more painful blocks to successfully dealing with handicapping conditions. Western culture seems to place high value on physical attributes, oftentimes judging people according to appearance. Unfortunately, most handicapping conditions are seen as ugly. Specifically, "different" behavior, mannerisms, and peculiarities of gait, speech, or language unique to developmental disabilities are often viewed negatively. The coping mechanism of devaluing physique deals with this issue. Physique is broadly defined here as any detectable manifestation of the disability which might be judged negatively. One has successfully coped with the issue of physique when one has adopted a value system that focuses on those qualities and competencies associated with being human and that ignores or devalues surface qualities.

Enlarging the scope of values works on the premise that most people narrow their value system, experiences, interests, and associations as they grow older. This appears to be true for a great many people. Such narrowing poses a special problem when one has an impaired child whose disability precludes participation in the particular confined lifestyle that the parents have chosen. In order to facilitate the child's growth, the parents must be able to enlarge their scope of values in order to genuinely accept whatever lifestyle the child might pursue. Such an exploration requires parents to examine their own values about what constitutes "the good life." If this process does not occur, then both the parent and the child will feel as though the child's lifestyle is, at best, second-rate and unacceptable.

The last method of coping involves the issues of comparison and competition. Western culture emphasizes winning, doing better than the next person, and comparing one person's performance to another. Such a comparative atmosphere can be uncomfortable for many nonimpaired people. A comparative atmosphere is particularly devastating to impaired individuals and their families. The parent must understand that how one compares with others is far less relevant than the mastery of a skill or the demonstration of a competency. Ultimately, to cope with the child's disability, the parent comes to value the child as he or she is, respecting each new achievement as an asset, without making a comparison with other children. It is through this process that the parent learns to first appreciate the child, and then to focus on the handicap.

Clinical Implications for Initial Diagnostic Period

1. Initial diagnostic feedback sessions need to be concise and simple. Efforts must be made to determine what the parents actually heard and understood. This helps to deal with the response of denial.

2. The second feedback session (scheduled as soon after the first as possible) focuses upon medical, educational, and therapeutic treatment methods. Ideally, details are presented in response to parental questioning.
3. Avoid directly confronting overt resistance or indirect denial; it's useless to do so and compounds the denial process. Instead, use humor, paradoxes, gentle coaxing, pleas, or "soft" persistence to serve the child without disenfranchising the parent.
4. Resist the impulse to calm, uplift, soothe, or disarm the emotionally stimulated parents; permit them to express their grief!
5. Consider the three-part parent program outlined below:
 - *Parent education*, consisting of imparting the necessary medical, educational, therapeutic, legal, and psychological information concerning the child.
 - *Parent support groups*, consisting of meetings focusing on the sharing of emotions affecting the parents.
 - *Parent training*, consisting of sessions where the parents gain skills needed to directly enhance their child's growth.
6. Maintain support groups for diagnostic professionals. Working with families at the early stages of disability is stressful work; don't do it alone!

Summary

The growth and development of impaired children requires attachment, nurturance, and stimulating interaction from care givers. Parents are, most commonly, the primary care givers for their children. They hold the keys to their child's successful development. Professionals in child habilitation must conceptualize the parents and their child as one unit.

The diagnosis of a developmental disability for a child precipitates grieving in the parents. The process of grieving can allow the parents to constructively incorporate the emotional impact of the disability, thereby facilitating the coping behavior desired by professionals. Successful grieving depends upon significant human relationships that support the process. Parent-professional partnerships benefit the child when the partnership attends to the significant human elements of grief.

It is the unconditional acceptance of denial, anxiety, guilt, depression, and anger that constitutes the most positive relationships between parents and professionals. Good working relationships foster attitude changes that prompt coping behavior and, therefore, meaningful strides toward the child's habilitation. The parents who are actively gaining from the process of