

# FOCUS ON EXCEPTIONAL children

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## Dysfunctional Families of the Student with Special Needs

*Debbie Daniels-Mohring and Rosemary Lambie*

This article describes the characteristics of dysfunctional families in which there is a child with special needs. The focus here is on helping the professional understand the structure of these families with the particular challenges posed by four broad groups of disabilities: physical disabilities, including chronic illness; behavior disorders, including social maladjustment; learning disabilities; and mental retardation.

It is helpful for educators to recognize the family patterns that researchers have observed in working with families of a child with recurring behavioral, emotional, or physical symptoms (Berger & Jurkovic, 1984; Minuchin et al., 1978). In recognizing these family patterns, educators can have more realistic expectations of the families with which they come in contact. In addition, this information enables teachers, counselors, and other professionals to relate more authentically to families. The acceptance and understanding that such authenticity provides form the basis of relationship building between school and home that leads to trust and mutuality of problem solving. A parent who hears understanding in the voice of school personnel is far more likely to unite with, as opposed to challenge or undermine, what educators are trying to create with his or her child.

### FAMILY SYSTEMS AND THE CHILD WITH SPECIAL NEEDS

#### Family Changes

When a child is diagnosed with special needs, a series of predictable and important changes occur within the family. First, the parents are required to focus extra energy on the diagnosed child to insure that the child receives help from the available resources. The parents may need to obtain evaluations of the child, medical follow-up, and special tutoring (Buscaglia, 1983).

Second, siblings of the child are made aware of the problem and are asked, either directly or indirectly, to make allowances for the special child (Atkins, 1987). A third change occurs when professionals outside the usual family structure are included in important family decisions and begin to receive information about the workings of the family that previously had been private.

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A fourth development is the feeling, within many families, of being stigmatized as a result of the identified child's problem (Goffman, 1963). Families often begin to form a common identity around the presence of a child with special needs. For example, people may refer to them as "the family with the Down syndrome child" or "the family with the handicapped child" rather than "the Jones family" or "the lawyer's family." The more visible and profound the disability, the greater the potential for stigmatizing the family. In addition, because of the special problems often associated with caring for a child with a disability, parents may feel more tied to their homes and thus more isolated and lonely (Kew, 1975; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981). Finally, parents may feel that they have lost control over their lives and that physicians, diagnosticians, educators, and counselors are in control (Sloman & Konstantareas, 1990).

### Family Reorganization

These four basic changes begin a process of reorganization in the daily family life and structure that is far-reaching in its implications. Just as the falling of the first domino will lead to the eventual collapse of an entire chain of dominoes, the diagnosis of one child within a family system will affect all other members of that system. Adapting to a diagnosed child requires flexibility on the part of all family members. Following diagnosis of a child, boundaries that were clearly defined are renegotiated and functional roles of family members change. For example, parents who both work outside of the home and have established patterns for taking care of housework, meals, and errands may face the struggle of adjusting schedules so that one parent can be free to take a child to doctor's appointments or special treatment facilities.

### Life Cycle Adjustments

Effective reorganization of the family around a child with special needs requires changes at each developmental stage (Buscaglia, 1983; Haley, 1973). A family with a toddler with a disability will face the struggles of toilet training, limit setting, and nurturing. As the special needs child becomes a teenager, the family will have to meet the demands of biological changes, independence issues, and identity formation.

As in all families, these varied life cycle demands will require flexibility and adaptability. In families with a child having special needs, the life cycle of the family is often interrupted, and sometimes arrested, at the point of diagnosis (Kew, 1975; Wilchesky & Reynolds, 1986). For these families, the diagnosis is such a crisis that the family is unable to adapt and maintain flexibility. Thus, the family structure "freezes" at the life cycle stage it was experiencing at the time of the crisis (Hughes, Berger, & Wright, 1978).

The specific process of how life cycle adjustments are made will depend somewhat upon the family constellation and sibling position of the disabled child. A family with four children ranging in age from infancy to 15 years old, the youngest of which is diagnosed with spina bifida, will automatically have more potential caretakers to share the load than one in which the diagnosed child is an only child. However, in order to insure normal development for the older children in the family, the parents must juggle car-pooling for various functions, entertaining peers, and so forth with taking care of the disabled infant. The parent with an only child will have none of these demands.

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In addition, the extent of adjustment will depend upon whether or not there is a parent available in the home on a full-time basis and whether or not the family has adequate social network supports (Gallagher, Beckman, & Cross, 1983). Thus, in looking at family adjustments, it is important for the professional to know something of the make-up of the family of the identified student. Specifically, important information would include numbers and ages of siblings, sibling position of the student, parents' work status, and involvement with extended family. In knowing these types of family information, the educator can build the relationships that are essential in collaboration between parent and school.

None of the family adjustments previously described is a problem in and of itself. In fact, the adaptations of parents, siblings, and professionals are necessary when a child presents physical, emotional, or intellectual symptoms. However, problems arise in families when these changes become frozen in time. For example, when parents continue to focus the same amount of energy on the special child as they did at the initial diagnostic stage, the child's independence may be compromised. When parents continue to expect nondisabled siblings to treat the diagnosed child as different, the siblings will eventually begin to resent the expectations, and the child with special needs will end up feeling isolated and incompetent. When professionals continue to delve into the daily life of the family, all family members may begin to feel compromised and intruded upon.

### Family Characteristics

Teachers, counselors, and other professionals working with a student with a disability who continues to have difficulties adjusting to classroom demands should look for these predictable family characteristics:

- dysfunctional family boundaries
- overprotection
- lack of conflict resolution
- parental asymmetry
- marital relationship subordinate to parental roles

These structural characteristics are symptomatic of chronic family dysfunction that will impact the child's school adjustment.

Not all families experience such problems, but when they do these diagnostic signs are indicators that the family either has not faced and resolved the implications of the child's dis-

ability or has not been able to move past the initial adjustments required when the child was first diagnosed. The specifics of how these characteristics manifest themselves differ from family to family. However, within areas of disability we can find some predictable indicators of family distress that fall into the categories listed above. The following subsections are designed to give the school professional a window into observing these families with a different eye; an understanding of the common struggles faced by families with a child having special needs. Such an understanding provides the basis of relationship building that allows for mutual problem solving between parents and schools.

### PHYSICAL DISABILITIES—CHRONIC ILLNESS

For purposes of our discussion, this category of symptoms will include illnesses such as diabetes, asthma, chronic allergies, chronic pain, attention deficit hyperactivity disorder, and mild cases of spina bifida, cerebral palsy, or multiple sclerosis. We have not included in our evaluation the impact of more serious illnesses such as cancer, leukemia, or AIDS. In this section we describe patterns that have been observed in dysfunctional families having a child with chronic illness or physical disability. The mere presence of a chronic illness in a child does not predict whether the family will be dysfunctional (Ferrari, Matthews, & Barabas, 1983).

### Dysfunctional Family Boundaries

In dysfunctional families having a child with a physical disability or chronic illness, individual differences of any family member such as likes and dislikes, opinions, and needs related to age are not well-tolerated or are ignored. In addition, personal privacy is at a minimum (Liebman, Minuchin, & Baker, 1974). A good example of this type of family is one in which all children have the same allowance, bedtime, and household rules regardless of age. Typically, there is very little accommodation for developmental differences between the needs of a first grader and a middle-school child in these families. As one 10-year-old child with seizures expressed:

I went to my girlfriend's house and she got dressed in the bathroom with the door shut. I couldn't believe it. At my house, you're not allowed to close doors. My parents think if you close a door you're trying to hide something, or maybe I'll have a seizure. What if I just want to get dressed without being seen?

Dysfunctional families of children with physical disabilities tend to exhibit clear indicators of enmeshed family boundaries. The child with the physical problem is particularly vulnerable to the intrusiveness of other family members. In many ways, this pattern is a predictable outcome of having a medical problem. How many of us have commented on the lack of privacy in hospitals and other medical settings? When a child is required to undergo physically intrusive procedures on a regular basis, and his or her physical health and well-being depend on these procedures (for example, catheterization), the entire family tends to be aware of the child's physical condition. In addition, older siblings, grandparents, and even close friends may be given permission to intervene in the child's physical routine or management.

As a result, the child may have difficulty developing normal personal boundaries around hygiene and health. Teachers may recognize the manifestations of enmeshment in these children who describe, in detail, the specifics of their physical routine, bowel habits, or eating habits in inappropriate ways that identify them as peculiar within their peer network. In these situations, teachers should make sure that the child's right to privacy is respected and guarded in all possible ways. Any talking about physical symptoms should be done alone with a teacher or counselor, not in the classroom.

### Overprotection

Parents in dysfunctional families of a child with physical illness tend to be overprotective and have difficulty with the disabled child's natural attempts to become independent. The fine line between adequate protection and overprotection is a difficult one in families with a chronically ill child. However, results of a study of sixty children and adolescents with diabetes indicated that in families where independence and participation in age-appropriate social/recreational activities was promoted, children perceived themselves as more competent and had better diabetes adjustment than in overprotective families (Hauser, Jacobson, Wertlieb, Brink & Wentworth, 1985).

The parents of a chronically ill child have usually been trained to look for physical signs of distress in their son or daughter and to respond to these signs in particular ways (e.g., monitoring blood sugar, providing medication). When the child is initially diagnosed, the parents and family are required to focus almost exclusively on that child's physical needs to the exclusion of themselves and other children (Beckman-Bell, 1981; Shapiro, 1983). Often when the boy or girl matures and begins to want to take over personal physical

management, the parent who has been in charge feels rejected or displaced. What is this parent to do with extra time now that he or she is no longer needed in this way? Parents may need help at this point to develop a more normal, meaningful relationship with their child (Hall & Taylor, 1971).

Parents of a child with a chronic illness or physical disability often call teachers to make special requests on their child's behalf. It is very common for overinvolved parents to ask that their child be excused from physical education classes or certain classroom activities. Frequently, this is their response to their child's normal complaint about gym suits, heat, dirt, or any of the uncomfortable aspects of the classroom. Of course, any physical disability should be integrated into the physical education and classroom plan for an individual child through adapted exercises. The important role for educators in these situations is to recognize overprotection, withhold judgment of parents, empathetically help parents see what is happening by normalizing their child's complaints, and remain firm on using only medical opinions to excuse students from any classroom activities.

### Lack of Conflict Resolution

Another common reaction of families having a child with a chronic illness is the avoidance of conflict and prohibition toward displaying anger (Koch, 1985). Family members typically have difficulty expressing wants, needs, or feelings other than physical discomfort. Again, because individual differences are ignored, how can an individual have a want or need that is different from that of the whole? Quite often, family members other than the disabled child will have numerous physical complaints, such as headaches, stomachaches, or backaches. It seems that the physical dimension is the only one in which family members can express differences. School personnel should simply observe such occurrences and see if they eventually become part of a pattern that might suggest the need for counseling or outside referral for a student and his or her family.

Anger is an emotion that tends to be avoided in families with a child who has chronic illness or physical disability. Typically, an expression of anger is reinterpreted by the family as an expression of physical discomfort.

A child with diabetes explains:

Whenever I get upset, everyone starts to check my blood sugar. I must be low or high, I can't just be mad.

When conflicts do surface, they are typically ignored, with little opportunity for resolution. As a result, it is common to

find long-held resentments in these families that have never been adequately discussed or understood. The problem of dealing with anger often leaves family members feeling isolated from one another and from members of their social network. Children from these types of families will not typically pose a behavior problem in the classroom. Rather, they will frequently complain of physical symptoms that may be traced to a difficult interaction with a peer or teacher that was not settled. It would be useful for educators to attempt to help the child to see those connections in the classroom setting.

### **Parental Asymmetry and Marital Subsystem**

Finally, there is often an imbalance of parental roles vis-a-vis the child with a disability. One parent, typically the mother, has taken over primary management of the child and the other parent is underinvolved. The parent who is in charge of "nurse duty" usually feels overwhelmed and misunderstood, while the other parent feels excluded. These dynamics understandably make for poor communication between the parents and emotional distance in the couple. Often this asymmetry is unknowingly reinforced by school personnel who contact the mother to discuss issues regarding the child rather than including both parents. When dealing with these families, educators need to include both parents in meetings and phone contacts.

The marital subsystem in a family with a child having a chronic illness is usually subordinate to all other subsystems. As a result, studies such as one by Tew, Lawrence, Payne, and Rawnsley (1977) report a divorce rate in families with a child having a physical disability that is twice that of matched control families. Parents in these families often feel compelled to put the disabled child's needs first, any other sibling's needs second, and their own needs last on the list of priorities. As discussed, this dynamic may be adaptive in the initial stages of the child's diagnosis and adjustment but becomes dysfunctional when it continues even after the child has become more capable and mature. The teacher may find these parents willing to offer any amount of time to attend special activities with their child or provide homework supervision. However, they may not have had time alone with their spouse for a vacation or even an evening for years. In these instances, teachers may make suggestions such as parents going out to dinner or lunch together before or after a school conference. Simple, probing questions and reinforcement of time together for parents may help these families become aware of a new possibility in their relationship.

Not all families having a child with chronic illness will demonstrate all of these structural characteristics. In many situations the family dysfunction will be seen in only one area or will be more obvious in one area than another, such as overprotection. The discussion of these characteristics is intended to give the educator a framework from which to observe and understand the family of a child with chronic illness or physical disability.

### **BEHAVIOR DISORDERS AND SOCIAL MALADJUSTMENT**

The wide variety of symptoms that fall within this category precludes identifying many specific family characteristics. However, there are some broad areas of concern that tend to identify dysfunctional families with a child presenting behavior problems.

#### **Dysfunctional Family Boundaries**

Boundaries in these families tend to be either enmeshed or disengaged. Typically within the enmeshed category are families in which a child is chronically depressed, in a repetitive conflict with a parent, or involved in the marital conflict of the parents (Safir, 1966). Enmeshed boundaries are indicated when, metaphorically, the child gets cut and the mother bleeds. When children are asked how they feel about something, a parent may answer for them. Language contains frequent references to "we" instead of "I." Parents in these families tend to be overprotective in the same way as parents of the chronically ill, involving themselves in the child's homework, style of dress, and choice of friends. Indicators of normal differentiation or independence in children are viewed as rebellious behaviors by the parents.

As an example, in one family seen for family therapy, the 8-year-old girl had crying spells. She would frequently cry at night, complaining about how difficult school was for her and how alone she felt. Her mother's response was to sit up talking with her daughter until the child finally fell asleep. Then the mother, who was also depressed, would stay awake all night worrying about her daughter's unhappiness. The next day, when the child was too tired to go to school, the mother would become angry at her.

Another presentation of enmeshed boundaries may be seen in single-parent families where the identified child has taken over the role as emotional supporter and confidant for the custodial parent. Due to the responsible nature of the

*parentified* child, school personnel may not actually view him or her as needing intervention. In reality, the child needs as much assistance as the acting-out or aggressive student. Family counseling may be necessary in order to restore the appropriate parental hierarchy.

Families with disengaged boundaries are at the opposite extreme. Parents provide few limits and are underreactive to their children's behavior (Fox & Savelle, 1987). An example of this type of family is one in which a child who steals is described as "having this little problem with borrowing things." Teachers may feel that parents in this type of family are distant and uninvolved with their child. With children who externalize anxiety by acting out, parents tend to ignore signs of difficulty until a crisis occurs or the problem is pointed out to them by someone outside the family. School personnel generally recognize the possibility that there is a problem in these situations. The challenge is to help the families of these students see, with new eyes, the reality of the situation before it requires referral for special education.

### **Overprotection**

Paradoxically, there is often a quality of overprotection in these families. When the child has acted out and is identified by the school or court authorities, the parents often feel compelled to protect their child from these outside influences (Johnston & Zemitzsch, 1988). In this way, the child has the parents' covert endorsement and avoids facing the consequences for the behavior. This type of overprotection operates externally to the family, with outside agencies or the school, but does not operate internally or around personal boundaries as in the families of the child with a chronic illness. This process involves triangulation between the student, the parents, and an outside authority. These triangles limit the emotional functioning of the student with a behavior disorder.

An example of how this type of overprotection might play out would be a student stealing another student's watch. The parents might actually know the truth but staunchly protect their child by suggesting that the other student forgot to retrieve the watch he had asked their child to hold. Some variation of excuse would be provided. Generally, the parents are angry with school personnel in these instances.

In families with enmeshed boundaries, the overprotection tends to work in a different way. Instead of the angry lying, parents would react as if they themselves had been accused of stealing. They would deny the possibility of their child stealing and the thought of investigating that possibility would not likely cross their minds. These parents would tend

to react defensively to contact by withdrawing and becoming unavailable for discussion or mutual problem solving. Prior awareness of dysfunctional family boundaries may help the professional plan contacts that take into account the family climate of overprotection or disengagement.

### **Lack of Conflict Resolution**

In dysfunctional families in which there is a child or adolescent with emotional or behavioral symptoms, the expression of anger and conflict tends to take one of two inappropriate forms. One of these tendencies is exhibited in families where there is a high level of internal chaos and parents tend to feel overwhelmed with the tasks of providing for and structuring family life. In these families, parents are highly reactive to any expression of anger or potential conflict in their children. Discipline may be punitive or abusive in nature, and parents may be physically or verbally abusive of one another as well (Minuchin et al., 1967). Professionals may notice that these parents call their children names when trying to set limits on their behavior or when confronted with the slightest difficulty on the child's part. This type of family dynamic is usually multigenerational in nature and may benefit from referral for outside counseling (Anderson & Goolishian, 1986).

A second type of difficulty with conflict resolution is seen in families where anger is an emotion to be avoided at all costs. In these families, children are taught, either covertly or overtly, that to be angry is to be bad. In contrast, feelings such as sadness, depression, or hurt are seen as acceptable and deserving of parental attention and intervention. In this manner, any conflict or anger between family members is denied and not directly expressed. However, unresolved long-term resentments may result in acting-out or chronic depressive symptoms.

### **Parental Asymmetry and Marital Subsystem**

In many families where a child has an emotional/behavioral problem, there is considerable discord between the parents about the definition and handling of the problem. For example, the mother may identify her son as "depressed" while the father may view the son as "lazy." This type of long-term disagreement and emotional distance between the couple may be a symptom of more extensive marital difficulties. The school personnel dealing with differing parental views must avoid taking sides in this dispute. Eliciting input from both parents is important in families with

this dynamic. The parents may be willing to learn to work together for the benefit of their child while they would not be motivated to settle their differences solely for their own happiness. Again, the marital subsystem takes a back seat to the functions of the parental subsystem.

In this section dealing with behavior disorders, we have referred to a wide variety of problems and symptoms in children and adolescents that may be observed in the school. Given the range of possible behavioral/emotional problems, the structural characteristics that we described should make you familiar with some examples of how these problems manifest themselves in dysfunctional families. However, these descriptions are not intended as exhaustive examples of all the possible ways family dysfunction may be exhibited.

## LEARNING DISABILITIES

The specifics of the structural dynamics in these families depend upon when and how the diagnosis of learning disability was made and how extensive the disability was. Unique to this category of special needs is the elusive quality of the disability. In contrast to, for example, diabetes or mental retardation, children with learning disabilities may have experienced difficulties that have gone undiagnosed for years (Abrams & Kaslow, 1977). Often these children have undergone a series of failures that have led them to feel insecure, poorly motivated, and ignorant. Parents and teachers may have been involved in various attempts to correct the child's school failures through interventions, including homework monitoring, behavioral checklists, punishment, or coaxing (Sloman & Konstantareas, 1990). The longer the child has had school problems with an undiagnosed learning disability, the more likely that the child, parents, and school professionals are frustrated and angry with one another about the struggles around the child's problems.

### Dysfunctional Family Boundaries

More than with any other disability area, the possibility for poor communication between families and the school system is inherent in the subtlety of this diagnosis ("Our Son Has Had Trouble..." 1986). Frequently, parents have seen more than one outside professional about their child's problems and may have requested various evaluations of the child that resulted in little or no progress. Without an understanding of the child's disability, parents may blame teachers for poor instruction and classroom management, and

teachers may blame parents for inconsistency or lack of support in an effort to explain a child's school failure.

A letter from a mother of a child with a learning disability illustrates this cycle of blame:

His nursery school teacher said I babied him because he couldn't button or zip.... His kindergarten teacher said I should discipline him more because he was too lazy to learn his letters and numbers. His first-grade teacher called one parent conference after another. I tried to help Henry sit still and learn his letters.... [My husband] says I spoil him.... His folks say, "A few good spankings will set him straight." Mother says I just need patience. Dad says, "...He's all boy." ...The pediatrician says...he's a late bloomer.... I'm trying everything I know how to do. I'm exhausted from trying. (Smith, 1981, p. 150)

In these families, boundary problems may arise not so much within the family as between the family and external resources. From their history of involvement with the school system and other professionals, parents and the child with special needs may have developed a "we/them" mentality. The family's external boundaries may be rigid and inflexible, which may lead to a sense of isolation for all family members. Observing this situation should provide incentive for school professionals to remain patient and continue to strive for an alliance with the family.

### Overprotection

Some parents with a child with a learning disability are overprotective and show enmeshed boundaries (Amerikaner & Omizo, 1984). These family dynamics frequently appear in situations where the diagnosis of the child was delayed and there has been confusion or conflict between the parents and the school system. Many times, but not always, these students have overall levels of intelligence in the average or low-average range and may have been identified as "slow learners" or "mentally retarded." The parent, who feels that his or her child is not retarded and may have seen evidence of the child's intellectual abilities in the home, may feel compelled to protect the child from teasing, labeling, and incorrect school placement.

Another example of overprotection can be seen with the most serious, severe, and all-encompassing disabilities such as dyslexia (Perosa & Perosa, 1981). A child who has a high score on an intelligence test but who cannot read will usually be diagnosed early in the schools. Due to the student's high intelligence, it may be difficult for parents to reconcile

themselves to the fact that their child cannot read normally. They may overprotect their child by lashing out at the schools for poor instruction or programming (Silver, 1984). It is important for teachers to remain patient with these parents until they learn enough about their child's disabilities to understand the symptoms.

As discussed previously, parental protection and advocacy may be important and adaptive in these situations. However, when the parent continues to be overprotective long after diagnosis and placement issues have been resolved, dysfunctional family dynamics will result.

### Parental Asymmetry and Marital Relationship

In these families, as in all systems, the added stress of identifying and dealing with a child having learning disabilities tends to intensify any parental disagreements or lack of cohesion. Frequently, one parent is well-versed in the nuances of the child's diagnosis while the other parent has only a vague idea of how the child's learning disability affects educational performance. Because of this difference, the parent with the most knowledge tends to be the primary person who intervenes by helping the child with remediation or organization. With this potential dysfunctional system in mind, school professionals should work to insure that both parents receive copies of diagnostic reports, attend planning meetings, and have an opportunity to ask questions about their child's disability.

Because of the link between learning disabilities and motivational problems, many parents will have had problems with discipline issues. One parent may feel that the child is trying his or her hardest and should be reinforced for trying, while the other parent may focus on grades and assume a lack of motivation. Behavioral systems may have been tried and failed so that both parents are left feeling as if they, themselves, are failures. This type of conflict may lead to increased distance between the couple and less and less focus on the positive aspects of the marital subsystem ("He Pits Jane and Me....," 1988).

School professionals working with families of students with learning disabilities need to observe, probe, and use their experience with each family to get a clear picture of the underlying dynamics of acceptance and integration of the student. Educators should not assume that what families present on the surface is the complete picture of their struggle or dynamics in relation to the student.

### MENTAL RETARDATION

Within this population there are at least two broad subgroups to consider when discussing family dynamics and dysfunction. These groups are Educable Mental Retardation, (EMR) or milder retardation and Trainable Mental Retardation (TMR) or more serious retardation. Since Dunn's (1968) "Swan Song" was published, there has been a gradually increasing momentum for mainstreaming children and youth with mild retardation. General educators in the 1990s will be more accustomed to contact with and exposure to these students and their families. With the Regular Education Initiative (Skrtec, 1991), general educators can anticipate more interaction with families who have children with trainable mental retardation. Therefore, with an eye to this change, we are providing information concerning family dynamics of both groups.

### Dysfunctional Family Boundaries

All parents with a child who has been labeled "retarded" must go through a process of dealing with the realities of their child's limitations and altering their hopes, dreams, and expectations for a "normal" child (Kew, 1975; Strom, Rees, Slaughter, & Wurster, 1981). With EMR children, parents may notice some differences in their child or some delay in developmental milestones, but they may continue to deny the reality of their perceptions until the child reaches school age and is identified by an outside professional. With TMR children, it is more likely that the diagnosis was made early after the child's birth and that intervention was begun in infancy. The family situation with a child diagnosed with retardation is ripe for enmeshment and identification of the child with a disability as the central important characteristic of the family, which leads to the loss of personal identity.

Within families where boundaries are extensively enmeshed, there is often an understanding that the child with retardation will never leave home and be on his or her own. Family members may be apprised of their future responsibility for the child, and family plans are made with the retarded person as a permanent member of the nuclear family. Older siblings may be told early on that it is their responsibility to support this child and take him or her into their households when the parents can no longer provide the necessary support ("I'm Not Going to Be....," 1987).

The dynamics of enmeshment are particularly evident when working with teenagers with retardation whose parents deny the implications of peer relationships, sexual de-



velopment, and vocational issues for their child. For example, many parents do not assume the responsibility for providing guidance regarding interest in members of the opposite sex, sexual protection, or basic family life education that they would normally provide to their nondisabled children (Beavers, Hampson, Hulgus, & Beavers, 1986).

### Overprotection

Family members are reminded daily that the child with retardation is not "normal" and that adjustments must be made to accommodate his or her disabilities. However, the extent to which the retardation will interfere with the child's life depends, in large part, on how far the family will be able to go in helping the child be treated as normally as possible (Mink, Meyers & Nihira, 1984). Parents often believe it is cruel to push a child with retardation to reach for achievements that may be outside of his or her capabilities. So the parents set in their own minds the limits of the child's functioning, which may underestimate the child's potential and work to keep the child within those limits. Parents may believe that their child will be made fun of or used by society if they are not there to protect him or her. If the overprotective parent communicates fear of the world to the child, then he or she is disabled not only intellectually but also socially.

Dudley (1983) conducted an interesting sociological study of twenty-seven adults labeled *retarded*. He lived with his subjects for a period of time so that he could experience their lifestyle firsthand. Dudley found that those of his subjects who had been allowed to openly discuss the realities of their retardation, the realities of societal fear and stigma about retardation, and the demands of adulthood were more likely to be able to adjust than those who had been overprotected.

Again, in the case of overprotective parents, school personnel should observe without judgment and help the parents to free their child gradually from their own fears. Providing an arena for open discussion of questions such as "What does retarded mean? Will I always be retarded? How can people tell that I'm retarded?" may improve communication between students and their parents.

### Lack of Conflict Resolution

In an extensive longitudinal study of 104 TMR children and their families, Nihira, Mink, and Meyers (1981) found that the single most important factor in the school adjustment of these children was the harmony and quality of parenting. With this information in mind, it is clear that con-

flict resolution is an important skill for parents of a student with retardation.

School professionals may find two types of family dysfunction in conflict resolution in families of students with retardation. One type of dysfunction involves parents who have few or no skills in advocating for their children with retardation. Some of these families have multiple problems, including cultural deprivation, poverty, and intellectual slowness on the part of the parents. Professionals may find that these parents act very compliant and agreeable about their children but then fail to follow through with school requests or training programs.

These parents tend to have few assertiveness skills and may feel that attempts to disagree with school personnel or even to ask questions are of no use in changing their situation. Often these parents are used to heavy questioning and complying with agency rules in order to obtain food for their children, shelter, and medical help. They may have developed a style of nonassertiveness in response to these other experiences. In these situations, school professionals should help the parents formulate and express questions and disagreements, communicate their unique perceptions of the child, and develop a mutual working relationship with the school system over time. School personnel may provide much of the help needed to network these parents.

The other dysfunctional pattern that is common in these families is a heightened level of conflict with agencies, schools, and any professionals who are involved with the student with retardation. Typically, the conflict with schools centers around placement issues and labeling during the student's school career. Within these families, there is often a high level of general anger that may be directed at people outside or within the home. As a result, the families tend to be isolated and have little social network involvement in order to help with the retarded child. It is our experience that, quite often, the intense anger is a mask for overwhelming sadness and guilt that the parents feel toward their child. As emotional expressiveness in families with a retarded child is often limited (Margalit & Raviv, 1983), the parents may have no one with whom they can express these feelings and may have, over many years, projected blame onto outside sources in an effort to avoid looking at their own feelings of blame and doubt.

### Parental Asymmetry and Marital Subsystem

Families in which there is a child with retardation tend to develop the classic situation where the mother accepts pri-

mary responsibility for the child's management. As Berger (1984b) stated:

Because the task of arranging for the youngster's treatment falls mostly on mothers, a predictable structure for families...is one in which there is a very close mother/child dyad. The closeness of this dyad is reinforced by the fact that when agencies that serve handicapped children seek "parent involvement," they tend to mean mother involvement. (p. 144)

This intense closeness is particularly evident in families with a child with retardation because many of the functional living skills and personal hygiene skills that are a long-term part of the training for retarded people, classically fall into the mother's domain. Thus, the close-mother/distant-father dynamic that we have discussed as troublesome in all families of students with special needs easily evolves in families having a child with retardation.

Corrales, Kostoryz, Ro-Trock, and Smith (1983) interviewed and observed 24 families with children having intellectual and developmental delays. They reported significant marital distress in 16 of the 24 couples. In addition, almost all of the families with high marital distress were rated by the observers as families in which one parent had formed a coalition with the disabled child. Professionals can be most useful by helping parents become aware of this dynamic over time and developing strategies to intervene on their own behalf.

A second process that often occurs between couples with a child having retardation is mutual blaming, guilt, and grieving (Turner, 1980). The question "Why do we have a retarded child?" is often answered by one or both parents by looking to genetic history or prenatal care and focusing blame on the other parent. Of course, some of this questioning and wrestling with themselves and with God is a natural part of the process of accepting a child with disabilities. It is when this dynamic continues over a prolonged period that marital distance and dysfunction are inevitable.

Couples need to be helped to understand that the process of grieving for the lost "normal" child and feeling angry about the reality of having a child with retardation are predictable stages for parents of children with disabilities. Rather than turning on each other, the couple needs to be helped to turn to each other for support and resolution of the grieving process. Support groups are invaluable in helping parents with acceptance and grieving. Schools should provide parents with information about the availability of these

groups in their community.

It might be beneficial for general educators to network with special education professionals who are more familiar with these family dynamics to develop a better understanding of families having children with retardation. Mainstreaming of these students provides an opportunity for consultation and cohesion between various educational disciplines that may result in learning on all fronts.

We believe educators can take the information in this publication and relate it to their own students with special needs. When you understand family structure you make wiser choices for interventions. Just as the docent in the museum helps clarify the relationships displayed in a tapestry, understanding family functioning clarifies relationships and allows us to relate to others more effectively. We have found that improved relationships with families benefit the student as well as the professional.

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