FAMILY-LEVEL INTERVENTIONS FOR RETARDED CHILDREN: A MULTIVARIATE APPROACH TO ISSUES AND STRATEGIES.

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ABSTRACT

This paper considers issues and strategies of household-level interventions for families of retarded children. A perspective regarding retardation and a statement of the relevant levels of analysis is set forth in the introduction. Section I considers the specific issues facing families with retarded children. The second section has two parts: 1) a review of the literature concerning interventions aimed at families with retarded children, and 2) suggestions for future research and intervention efforts.

INTRODUCTION

The conceptual framework adopted in this paper views retardation as a set of transactions between the specific developmental disabilities of individuals and the societal definition of retardation as a stigmatizing condition affecting all members of the class or persons labeled as retarded (Dexler, 1964; Edgerton, 1967; Goffman, 1964). The societal definition of retardation affects families with retarded children because it influences the way in which retarded persons are treated by members of various service professions (e.g., physicians, teachers, etc.), by strangers, and by family friends, neighbors, and kin.

In order to study these transactions, we need to focus on many different levels of behavior. Relevant foci would seem to include individual family members, the family as a small group, the social network of the family, the local community, and the culture in which the family lives (Bott, 1957; Farber, 1964; Scott & Howard, 1970; Speigel, 1971).

Several investigators have shown the utility of focusing on these different levels of behavior in order to more adequately describe (and, therefore, intervene more effectively with) individuals or families under stress. Hill's (1958) paradigm of familial response to stress views crisis as the result of an interaction between events, the family's definition of events, and the family's crisis-meeting resources. Parad and Caplan (1960) describe a framework for diagnosing families in crisis that takes into account 1) family life style, i.e., the reasonable stable patterns of family organization, subdivided into three interdependent elements of behavior; 2) intermediate problem-solving mechanisms, representing the family life style in action in a situational context that calls forth the family's efforts for coping with stress; and 3) need-response pattern, i.e., the ways in which the family as a group perceives, respects, and satisfies the basic needs of its individual members. This particular approach is closely related to the work done by Lindemann and his colleagues at the Wellesley Project (Klein & Lindemann, 1961), which, in turn, derives from
Lindemann’s classic study of acute grief (Lindemann, 1944). The Project was designed to develop and implement community preventive services to deal with life-cycle crises. According to Klein and Lindemann, “Preventive intervention shares with such remedial efforts (as brief psychotherapies) the need to make a careful assessment of the individual’s social role and the significant role relationships in which he is involved. Hence the weight of emphasis shifts from the individual alone to the individual enmeshed in a social network. The unit of inquiry, planning, and intervention is, therefore, not the individual patient alone but rather the individual and one or more of the social orbits of which he is a “member” (pp. 286-287). Farber’s (1964) model of the crisis process, which he has applied specifically to families with retarded children, includes the on-going, reasonably stable pattern of family organization, coalition changes and distortions of the ongoing family patterns, the revision of coalitions with extra family individuals and groups, and the rearrangement of age, sex, and generational roles in the family. Finally, Speigel’s (1971) work with families focuses on the family as 1) a collection of individuals; 2) an organized small group; 3) a major unit of the total social system having structural and functional characteristics which extend through the whole social system in a network of articulation with other sub-systems; 4) an agency for the transmission of cultural values; 5) a social unit existing in a particular locale or territory.

Not only must family behavior be examined at these different levels, but the relationship between levels must be respected. Speigel (1971) from his transactional orientation, Piaget (1970) from his structuralist perspective, and various workers influenced by systems theory (Bateson, 1972; Watzlawick, Beavin, & Jackson, 1967) have all argued that there are ordered relationships between these various levels of behavior. Only by understanding such ordered relationships can we hope to achieve perspectives that are not bound to the limitations and distortions inherent in the process of viewing phenomena from only one or a small number of vantage points and which do not isolate behaviors from the contexts in which they occur. With specific reference to family behavior, Speigel (1971) has suggested that focus be placed on the interactions between adjacent level phenomena: that, for example, family investigators focus on the interaction between the individuals in a family and the family as an organized social group; and on the interaction between the family as a group and other societal groups; and on the interactions between the family in its social network (Bott, 1957) and the particular community and culture within which the family group lives. The nature of the questions under scrutiny in this paper seem to lend themselves to such transactional perspectives.

I

The most sophisticated general statement of the issues encountered by families with retarded children is that of Wolfensberger and Menolascino (Wolfensberger, 1967; Wolfensberger & Menolascino, 1970). Three types of crises faced by such families are delineated by these investigators: 1) the novelty shock crisis; 2) value crises; and 3) reality crises.

Characteristically, the novelty shock crisis occurs when the diagnosis of retardation is presented to unsuspecting parents. Even a normal birth is a stressful situation (LeMasters, 1957). Parents are in a high state of expectancy. They
often have preconceived notions with regard to the sex, appearance, future statuses and achievements of their child. The birth of an abnormal child violates these expectancies and places the parents in danger of feeling ignorant and incompetent. For while the abnormality of the child often indicates to parents that their expectancies for the child need to be altered, parents generally are uncertain as to how the expectancies should be altered and what they can realistically expect the capabilities of their child to be.

Value crises occur when parents' reactions to their abnormal child are more to a construct in their own minds (their valuation of the child's labeled status) than to objective characteristics of the child. An example of such a crisis is that experienced by some parents as they become aware that their child will be unable to achieve professional status or some other expectation which the parents hold for the child. The shattering of such expectations frequently blinds parents to competencies the child has or can develop.

Reality crisis concern both the short and long term management of the retarded child. Recurring reality crises occur when a child does not learn the basic self-help skills and thus remains dependent upon family members for longer than they may expect, wish, or be able to tolerate (Grossman, 1972; Holt, 1958). Further, reality problems having to do with adjusting to and meeting the needs of the retarded child may alter with every developmental change of the child (Farber, 1964; 1968).

Several points of clarification regarding this typology are warranted. First, the categories are not mutually exclusive. Wolfensberger and Menolascino single out as separate crises issues which may well be experienced by families as different aspects of a single dilemma. Indeed, many clinical observers (Buktenica, 1956; Grossman, 1972) have noted that parents of retarded children are often responding to the demands of more than one type of crisis simultaneously. Secondly, the duration of each type of crisis is unknown. Finally, it is unclear which of the crises, if any, are ultimately resolvable. To put it another way, we do not know which of the crises are likely to remain as recurrent issues of importance for any given family. Nor do we know whether there are relationships between these types of crisis, i.e., whether familial response to one type of crisis influences the likelihood of the family experiencing other types of crisis or whether the way in which a family deals with one type of crisis has any effect on the family's success in mastering the other kinds of crisis if they do occur.

While it is clearly the child's retardation that is the threat or problem to which the family must respond, for American parents, this problem has at least two distinct aspects: 1) issues raised for the family because the child is a person with a stigma (Goffman, 1963); and 2) issues raised for family members because of the child's specific incaptabilities.

The first set of issues arises because of the culture's valuation of the qualities, skills, or performances used as the criteria defining the class of retarded persons (Dexler, 1964). Schwartz (1970) has noted that "Mental retardation is one of the most pervasively negative labels with which a person in this society can be saddled. To be so identified is to be confronted with a devastating social identity, such that 'denial' and 'passing' seem to be the only ways in which the mentally retarded person can avoid the consequences of this definition." (p. 77). This judgment is supported by many studies which have shown that popular stereotypes of
the mentally retarded do exist in this culture, and that the stereotypes are negative (Edgerton, 1967; Haywood, 1971).

Edgerton (1967) has speculated that the effects of being labeled as retarded are so fundamental because the person so labeled is thought to be completely lacking in basic competence. Whereas other stigmatized persons are thought of as retaining some limited competencies despite their defect (even the mentally ill are thought to have areas of competence), the "retardate," by definition, is incompetent to manage his own affairs, and this incompetence is irremediable and long-term (Schwartz, 1970). Finally, when a person is defined as retarded, persons other than the retarded person himself are negatively labeled. Close relatives, particularly parents, are suspect since it is commonly believed that if a child is mentally deficient, his relatives are likely to be genetically or psychologically defective, or both. Schwartz (1970) notes that this "imputation of parental responsibility for the defect has a double meaning. At one and the same time, parents are 'blamed' for causing the disorder and are presumed incapable of handling it" (p. 78). This spread of the stigma from the child to the parents, referred to by Goffman (1963) as stigma contamination, introduces a significant barrier into parents' relationships with others (Farber, 1964, 1968; Schwartz, 1970).

Moreover, the cultural valuation of the retarded status places parents of retarded children in a dilemma which is the result of a conflict between cultural values. On the one hand, parents are expected to love and care for their children. On the other hand, parents are also aware that retarded children are not quite worthy of their love and care because they are not "fully human" (Edgerton, 1967). This dilemma is made even more painful because of the possibility of stigma contamination and because parents of retarded children are likely to share in the negative cultural valuation of the retarded (Schwartz, 1970).

For some parents, the force of this dilemma is mitigated by their religious beliefs which may provide them with a conceptual framework through which they can understand the "meaning" of their child's retardation (Zuk, 1959; Zwerling, 1954). This conceptual framework is likely also to serve as a "plan" (Miller, Galanter and Pribam, 1960) by which parents guide their actions with respect to their retarded child (Farber, 1968). For other parents, this dilemma is likely to result in their denying either that their child is retarded or that they have negative feelings toward the child (Buktenica, 1958; Farber, 1964, 1968; Grossman, 1972; Wolfensberger, 1967). Although within the context of the dilemma posed to parents of retarded children, such denials are not surprising, all too often it is just this context which is ignored when the concept of retardation as a disease entity is presented to parents by medical or other service personnel (Schwartz, 1970). Further, while understandable as a response to a tragic dilemma, parental denial is often coupled with behavior that is not supportive of the optimal growth of the child, such as an unwillingness to work with the child or to assess the child's capabilities in a realistic manner (Farber, 1968; Grossman, 1972; Wolfensberger, 1967).

Another common effect of the child's retarded status is to create for parents the necessity of finding some "meaning" for the child's stigma. This task has several dimensions: 1) constructing an explanation for the retardation; 2) interpreting the stigma to a variety of persons and/or organizations; 3) assessing the
current and likely future impact of the child on the ongoing familial patterns; and
4) deciding whether changes in relatively stable family patterns will be required,
and, if required, whether they will be possible.

The task of finding meaning for the stigma involves both value and reality
components. In fact, the distinction, made earlier for heuristic purposes,
between issues raised for the retarded child’s family as a function of the child’s
labeled status and issues raised on account of the child’s specific developmental
delays is a false one. The issues are inseparable. Reality issues have value com­
ponents and value issues have reality aspects. The complexity of the rela­
tionships between value and reality aspects is evident if the transitions surrounding
any of the types of crises delineated by Wolfensberger and Menolascino (1970)
are examined in detail.

For example, the novelty shock crisis begins when the diagnosis of the child’s
abnormality upsets parental expectations for the child, i.e., it begins with value
issues. However, feelings engendered in parents by the destruction of their
expectations may lead them to screen out the information that would otherwise
help them in forming realistic expectations for the child and in working with the
child to maximize his development (reality issues). Moreover, the child’s delay
in attaining the developmental milestones used by his parents as an index of their
competence with regard to the child serves as feedback to the parents that they
are not behaving competently with the child (Schild, 1964; Speigel, 1971; White,
1969). This failure to perform competently in a major social role (parenthood),
may well be punishing or disturbing to parents (value issues). Further, feeling
that they are not competently handling the child may cause parents to decrease
the amount of contact they have with the child (reality issues) and may increase
parents’ negative feelings about the child (value issues).

Hopefully, this brief sketch conveys some of the complexity of the inter­
weaving of unsolved value and reality issues that so often confronting families with
retarded children. Such families are not dealing with a single crisis or with a crisis
with a single aspect. For them, as for King Claudius in Shakespeare’s Hamlet,
“When sorrows come, they come not single spies, but in battalions.” Moreover,
thus far we have focused only on transactions within the nuclear family and
have, therefore, understated the complexity of the issues.

One complication arises from the fact that some of the support systems which
would normally facilitate problem mastery may themselves also be problems
for the family. For example, the persons most likely to help the members of the
family of a retarded child in coping with the demands they face (e.g., extended
family members, friends, and neighbors) are also the people whose disapproval,
should they define the family in negative terms because of the child’s stigma, will
be most destructive to the family’s coping efforts (Farber, 1964, 1968; Goffman,
1963). Holt’s (1958) study of the problems encountered by parents who were
engaged in caring for their “severely retarded” child at home indicates that two
thirds of the families involved found their neighbors to be either “objectionable”
or “reserved.” Further, even when families said that their neighbors were helpful,
this often meant that the neighbors would help with other “normal” children but
not with the retarded child. Additionally, in those families where parents were
able to get away for some relaxation by themselves, this was so only because
relatives were available to care for the child.
Farber (1964) has presented some data suggesting that families with retarded children characteristically resolve this dilemma by reducing the amount of interaction they have with their previous extra-familial contacts. Holt (1958) describes about 60 percent of the families in his study as being "socially isolated." Additionally, some of these families increase contact with the groups most likely to "understand" and sympathize with their predicament, i.e., other families with retarded children. Yet, the price for obtaining the solace of these new contacts is that the family, even more than before, must define itself in terms of the child's stigmatized status (Goffman, 1963).

Another complication arises because before parents are able to assess realistically the impact of the retarded child upon their family, they require access to information that will guide them in setting reasonable expectations for their child. However, given the "state of the art" of ameliorative efforts with retarded children, parents' informational needs cannot be met satisfactorily at present because sufficient valid information about the developmental capabilities of retarded children is unavailable. For example, currently available estimates of probable developmental achievement of some classes of retarded children are based upon the performance of institutionalized persons. Furthermore, interventions which might yield information about the effectiveness of educational procedures have generally been begun when the persons involved were at least several years old (Bricker & Bricker, 1971; Dybwab, 1969). Thus, we lack evidence about the capabilities of retarded children who have grown up in more "normal" environments (Nirje, 1969) and who have been exposed to planned learning environments (interventions) from birth onward. Given what we do know concerning the negative effects of institutionalization (Blatt, 1969; Goffman, 1961; Wolfensberger, 1969a) and about the positive effects of some early intervention projects (Bricker & Bricker, 1971, 1972), it should be clear that we have not yet created environments that can be said to maximize the growth and development of retarded persons (Hunt, 1961). Therefore, service personnel cannot tell parents what they may reasonably expect of their retarded children for we just do not know what, under better circumstances, the capabilities of such children might be.

This lack of knowledge can lead to harrowing circumstances for parents who must, for years, live in ambiguity, uncertain as to what they may expect of their child. Unfortunately, this ambiguity is not resolved when the child develops beyond the early expectations of parents and professionals. Rather, such gains may lead parents to again hope that their child might "pass for normal" (Goffman, 1963). If, despite developmental gains, the child still does not pass for "normal," the parent may well experience again the value aspects of the novelty shock crisis because, once again, his hopes for the child are thwarted (L. Vincent, personal communication).

A third complication arises from the fact that, even when necessary information is available, it is either not given to parents or it is given to them in ways that do not perceive as helpful (Blumenthal, 1969; Koch, Graliker, Sands, & Parmalee, 1959; Kramm, 1963; Wolfensberger, 1967). Schwartz (1970) has analyzed the reasons for this in a detailed study of the strategies used by mothers of retarded children in dealing with the medical care system, the first system parents are likely to encounter.
Schwartz reports that first contacts with the medical care system are likely to be with a general practitioner or pediatrician who is not likely to give the parents a clear understanding of their child's problem. Often, this is so because early diagnosis is not possible. However, even when an early diagnosis has been made by the professionals involved, families frequently are not told about the nature of the child's difficulty until considerable time has passed. Kramm (1963) reports that although mongolism (Down’s Syndrome) can be accurately diagnosed at birth in about 85 percent of cases, 46 percent of families in her study were told that the child was normal. Thirty-eight percent did not know the truth until the child was more than one year old, and in more than half the cases, until the child was more than three years of age.

Even when an early diagnosis is made, parents are frequently informed of it in a way which they considered “hard-hearted” and are given little concrete help about what to do next or how to handle the problem of their own feelings. “What seems to occur is that in the face of difficulties of diagnosis, uncertainty of prognosis, or the limited medical treatment that can be given in a number of instances, physicians tend to fall back on ‘medical’ techniques for handling lack of knowledge, medical uncertainty, or highly emotionally charged situations; namely, they cut short the contact, make abrupt and brief pronouncements, and refer the parents to someone else. Even though the social and psychological considerations often are the paramount considerations, the physician continues to function as if he were dealing with purely medical questions” (Schwartz, 1970, p. 81).

Ample documentation (Wolfensberger & Kurtz, 1969) is available which indicates that parents of retarded children often experience the same sorts of difficulties with nonmedical service personnel. Moreover, unless parents are skilled at dealing with the service agency network of the area in which they live, they are unlikely to gain easy access to alternative competent sources of information and, as indicated earlier, they may find it difficult to turn to kin or friends for help when their needs are ignored or badly handled by service personnel.

Finally, even when parents do receive information and sensitive treatment from service personnel, in many communities the kinds of services needed to maximize the growth and development of retarded children are not available until the child is of school age. Thus, even though both professionals and parents may be alert to the need for early intervention, service programs may be unavailable. The fact is that the major sources of redress for reality crises lie outside the family, lie in social institutions and political processes (Dybwaab, 1969; Wolfensberger, 1969b). Thus, in order to obtain the services their child needs, parents may have to engage in long and difficult political battles. However, many lack the skills, the energy, or the allies for this. Nonetheless, changing the allocation of community resources, or changing the pattern of access to already existing resources, is a political process requiring group action.

One cautionary note seems needed at this point: generally, in this section the reality faced by parents of retarded children has been described as grim and almost unbearably complex. This is true. However, it is also true that many families find their experiences with their retarded child not at all grim, but rather enriching and challenging, indeed. Grossman (1972) in her study of college-aged siblings of retarded children, notes that 45 percent of the siblings were judged to
have benefited from the experience of growing up with a retarded sibling. “In our clinical judgments, those who had benefited had a greater understanding of people, more tolerance of people in general and handicap in particular, more compassion, more sensitivity to prejudice and its consequences, more appreciation of their own good health and intelligence than many of their peers who have not had this experience, as well as a sense that the experience had drawn the family closer together” (pp. 93-94).

II

The literature on intervention with parents of retarded children is a disappointing one (Wolfensberger, 1967). Problems are rarely translated into well-defined hypothesis; sampling is not adequate to the problem; adequate controls are totally lacking; descriptions of procedures used are too vague to permit replication; reliable and valid measurement instruments are not used; and there is too much speculation. There is no need for a detailed review of this literature since Wolfensberger (1967) has recently provided an excellent one. What is needed is a discussion of the representative approaches included in this literature. For, as Campbell and Stanley (1966) have noted, when expert practitioners in an applied field tend to persist in asserting the utility of certain notions, although these notions have never been tested adequately, it is likely that the persistent formulations do capture some true aspect of the situation. Thus, we shall begin this section with a description of representative intervention strategies and the assumptions underlying them.

In general, these strategies fall into three categories: 1) the psychiatric approach; 2) behavior modification; and 3) didactic approaches. The psychiatric approach is based upon the assumptions that intrapsychic data are of paramount importance and that the birth of an abnormal child is an event of catastrophic proportions for parents. Psychiatric practitioners see parents as needing therapy. Their goal is to have parents “work through” their (presumably negative) feelings toward their retarded child. In theory, when this is done, the parents will be able to “accept” the child. Examples of this approach are Beddie and Osmond (1955); Cummings and Stock (1962); Goodman (1964); Mandelbaum (1967); Schild (1964); and Solnit and Stark (1961).

The psychiatric approach is by far the most prevalent one. The classic psychiatric source for the understanding and management of catastrophes such as the birth of an abnormal child is Lindemann’s (1944) paper on the symptomatology and management of acute grief. Studying psychoneurotic patients who had lost a relative during treatment, relatives of patients who had died in the hospital and bereaved disaster victims, Lindemann concluded that:

1. Acute grief is a definite syndrome with psychological and somatic symptomatology. These include: somatic distress, preoccupation with the image of the deceased, guilt, hostility, and a loss of one’s usual patterns of conduct.

2. This syndrome may appear immediately after a crisis; it may be delayed; it may be exaggerated or apparently absent.

3. In place of the typical syndrome there may appear distorted pictures, each of which represents one special aspect of the grief syndrome (Lindemann, 1944, p. 141).
The task of the therapist is to help the patient free himself from his bondage to the deceased, readjust to the environment in which the deceased is missing, and to form new relationships. A major barrier to the successful completion of the grief work is that patients “try to avoid the intense distress connected with the grief experience and to avoid the experience of emotion necessary for it” (Lindemann, 1944, p. 143). Descriptions of such resistances — and of strategies designed to overcome them — comprise the major portion of the psychiatric literature on counseling parents of the retarded.

The successful completion of the grief work involves the patient’s coming to terms with his feelings toward the deceased, expressing these feelings, and finding groups that will support him in returning to the environment and developing new patterns of conduct. Lindemann’s concern is that the patient not be immobilized by his feelings concerning the catastrophe. Yet, it has not been demonstrated that the successful articulation and exposure of a person’s grief feelings alone will necessarily lead to more adaptive patterns of behavior. 10

Gallagher’s (1969) distinction between “primary” and “secondary” rejection seems useful here.

Primary rejection means that the cause of the parental negative attitudes resides in the basic unchangeable nature of the child himself. For instance, we are all familiar with children who are rejected at birth because they do not turn out to be the sex desired by the parent.

Whereas:

Secondary rejection ... represents the expression of negative attitudes based upon unfortunate behavior manifestations of the child himself. ... Not only are these likely to evoke negative reactions from the parents because of their basically unfavorable or unsocial nature, but also because of the parents’ reaction to the frustration they feel at being unable to deal successfully with the child’s problems. (Gallagher, 1969, pp. 124-125.)

If, out of grief, parents manifest “primary rejection” toward their child, the probability of an adaptive, positive parent-child relationship developing is small. (This seems to be the kind of grief Lindemann discusses.) In such a case, the professional’s task is to focus the parents on their attitudes and feelings toward the child. Hopefully, before this is done, the professionals will have established that the parents’ rejection is indeed primary, i.e., that modifying the child’s behavior will not modify the behavior of the parents.

In any case, the grief work as delineated by Lindemann is a more complicated and multifaceted process than that customarily followed by psychiatric counselors working with parents of the retarded. Lindemann focuses both on the working through of the patient’s feelings and on his returning to the environment and having to find persons or groups who will support him in new patterns of conduct. This last element has been neglected by the psychiatric parent counselors. Their aim seems to be the parents’ working through their feelings toward their child. They seem to view the parents’ grief as a monolithic substance that can — and in this view, must — be worked through, once and for all. As if the birth of an abnormal child were the only significant event ever to occur in the family.

These writers ignore the fact that parents and children influence each other’s behavior, that socialization is not an undirectional process, (Bell, 1971; Harper,
that the behavior, temperament, and status of the child profoundly affects family relations. Further, they wholly ignore the situational aspects of living with a retarded child. There is a whole spectrum of management problems that cannot be resolved, once and for all, for as the child grows, each change in his life cycle is a potential source of new management issues. Indeed, nonintrapsychic changes in the lives of other family members — moving to a new neighborhood, illness, the loss of a caretaker sibling through marriage — may cause management problems with the retarded child. Furthermore, it is possible, as Farber (1959, 1960, 1968) has hypothesized, that the presence of a retarded child represents a crisis in the family life cycle, arresting it at the stage where the major family fact is the existence of a small child who must be cared for. Operationally, the retarded person may remain a small child even as his parents grow older and less willing and able to care for him.

Lastly, it is striking, and upsetting, to note that the psychiatric practitioners are often ignoring the wishes of the parents involved. Wolfensberger (1967) comments that “Parents, as is apparent over and over . . . want counseling on child management and facts about retardation. The professionals often prefer to give them therapy” (p. 365). Wolfensberger’s statement receives rather strong support from Holt’s (1958) survey of the needs of parents who were caring for their severely retarded children at home. Overwhelmingly, the needs reported by parents were reality needs: physical exhaustion on the part of the parents (especially mothers) as a function of the extra effort needed to care for the child; mother’s inability to find time to maintain the kind of contact they desired with “normal” siblings and with their spouses; parents never taking a vacation and/or never going out together, etc. Wolfensberger’s argument is further supported by Skelton’s (1972) Toronto study in which groups of parents who had just institutionalized their retarded child and parents who were caring for their child at home were asked to indicate the three areas of greatest concern for them. Both groups indicated that reality issues — obtaining training and education for the retarded child, obtaining companionship for the retarded child, exhaustion on the part of the parents and siblings, etc. — were of paramount importance to them, although the group of parents who had institutionalized their child also expressed significantly greater concern for the effect of the child on the welfare of the family than did the community sample.

It is the strength of the behavior modification approach that it is addressed to the reality needs of parents. The focus of this intervention strategy is on training parents to manage the behavior of their child more successfully. Such management has two major aspects: 1) learning to use methods of “shaping” adaptive child behaviors; and 2) learning to use methods which will result in the elimination or decrease in the frequency of maladaptive child behaviors.

Two major assumptions seem to underlie this approach. One is that parents, because they are the child’s primary caretaker and socialization agent, are the best persons to undertake intervention with the child. Therefore, parental patterns of interaction with the child must be considered if the child’s behavior is to be modified successfully. The second assumption is that training parents to manage their child’s behavior more successfully will also improve the quality of parent-child interactions and increase the likelihood of the occurrence and maintenance of more adaptive behaviors by both the parent and the child.
Research on the effectiveness of this strategy is recent and small in volume (Becker, 1971; Bricker & Bricker, 1971, 1972; Galloway & Galloway, 1971; Guerney, 1969; Roos, 1972). The evidence suggests that parents can learn behavior modification procedures and that, when utilized, such procedures do result in increased competence on the part of the child (Bricker & Bricker, 1971, 1972; Galloway & Galloway, 1971; Roos, 1972). However, it should be noted that in most cases behavior modification techniques have been used only to decrease the frequency of “negative” behaviors rather than as a means of developing new and more adaptive behaviors. The evidence is less clear with regard to the assumption that teaching parents behavior modification skills alters the quality of subsequent parent-child interactions. Galloway and Galloway (1971) present some anecdotal evidence in support of this assumption. However, other anecdotal but relevant clinical data suggest that, for a sizable group of parents, learning behavior modification techniques does not necessarily alter the contingencies controlling their behavior with retarded children. Although these parents may demonstrate in a laboratory situation that they can use operant techniques, they do not in fact, use them in the child’s natural environment (Buktenica, Berger, Fitzgerald, & Rosenberg, 1973; Guerney, 1969).

Clearly, additional research is needed to clarify the conditions under which parents will actually use, in natural environments, the behavior modification techniques they have learned in more controlled settings. In addition, research is needed about the relative efficacy of different methods of teaching behavior modification procedures to parents and about the effects of such procedures on parents’ attitudes and expectations toward their retarded child. Finally, studies investigating the long-term effects of behavior modification strategies on parent and child behaviors are needed.

The didactic approach to working with parents of retarded children involves providing a setting in which factual information about retardation is presented to parents. Topics covered usually include the causes of retardation, the diagnostic process, treatments, the effects of the child on the family, home management, normal child development and its relevance to retardation, the retarded child’s feelings and needs, the interpretation of retardation to relatives and friends, a review of available community services, and a review of national and state laws (Wolfensberger, 1967). Frequently, such groups are sponsored by local associations for the retarded. These associations have several functions: they let parents of retarded children know they are not alone in the problems which they face; they permit a sharing of experiences and ideas between parents of retarded children; and they provide a basis for forming parental pressure groups to lobby for legislation or for the allocation of community resources to services for the retarded (Dybwab, 1969; Farber, 1968; Weingold, 1960; Wolfensberger, 1967).

The list of additional functions performed by associations for the retarded suggests that didactic groups may also have latent functions in addition to their manifest aim of information sharing. Weingold and Hormuth (1953) have argued that since value conflicts are mediated by a process of socialization involving various groupings of society, a very promising intervention effort for persons suffering value crises would be group-derived resocialization. This view is in accord with the findings of researchers in the area of reference group theory (Hyman & Singer, 1968). These investigators have found that a person is more
likely to persist in a given set of behaviors or attitudes if these are supported by
groups that have significance for the person. Further, individuals are more likely
to alter behaviors or attitudes if they also change the groups whose standards
they use, i.e., one's behavior will tend to change in directions supported by new
reference groups.

It is a major function of associations for the retarded to provide just this kind
of support for parents of retarded children. Didactic groups not conducted by
associations for the retarded may also provide this support. While sharing informa-
tion, parents also come to share a view of retardation in general, and of their
own experience with retardation in particular (Goffman, 1963).

We need now to put the merits and limitations of these approaches into some
sort of perspective. Unfortunately, the research designs which have been used to
demonstrate the effectiveness of these approaches are not adequate to permit
testing the comparative effectiveness of the different methods (Wolfensberger,
1967). Research evaluating relative effectiveness is clearly warranted. Design
suggestions for such comparative research may be found in Campbell and
and Frank (1972).

However, even the results presently available suggest that all of the treat-
ment approaches currently utilized fail to help some of the parents to whom they
are offered (Buktenica, Berger, Fitzgerald, & Rosenberg, 1973; Wolfensberger,
1967). This is not surprising since an assumption underlying the way in which
these treatments have been offered is that parents of retarded children constitute
a homogeneous group. Recent findings in the psychotherapy literature (Bergin,
1971; Frank, 1972; Garfield, 1971; Kiesler, 1971) indicate that the above assump-
tion is quite likely to be false. Further, the complexity and diversity of, and inter-
relationships among the issues faced by parents with retarded children would
seem to suggest the need for intervention efforts to be differentiated according to
the specific needs of the family at the time of intervention. However, if we look at
the way in which services are actually offered to parents, we find that parents,
in fact, are not offered differentiated treatments. Rather, service personnel offer
the kind of treatment which they know how to give and which they value because
it is what they know (Wolfensberger, 1969b; Wolfensberger & Kurtz, 1969). That
is, psychiatric practitioners tend to insist that all parents “work through” their
feelings with regard to their child while behavior modifiers insist on training all
parents in behavior shaping and management skills, etc. This unfortunate
practice occurs, most probably, for several reasons. One is that service pro-
essionals are generally trained in only one type of intervention orientation.
Before a professional can offer differentiated interventions to parents, he must
feel competent in the use of different kinds of procedures (Sarason, 1969;
Schwartz, 1970; Lazarus, 1971). Secondly, we lack a base of research knowledge
which will provide decision rules by which professionals could decide which sort
of treatment to offer any given family.

In a recent (1970) paper, Wolfensberger and Menolascino have put forth a
model for the management of parents of the retarded which proposes “a frame-
work that may be adequate to handle a wide variety of problems and situations,
and that may provide a means for a more judicious selection of management
options” (p. 478). Their model is based upon the typology of crises encountered
by families with retarded children discussed in section I.
With regard to the novelty-shock crisis, Wolfensberger and Menolascino recommend that what parents need foremost is "gentle, andramatic interpretation of the facts, provided in an atmosphere of maximal emotional support... Interpretation should stress those elements which are realistically positive, such as the positive aspects of likely child development and the availability or expected availability of services and resources. To cope with their grief, parents should be helped to get to know parents who have experienced similar traumas and who have made model adjustments. Where a newborn baby is involved, management should not terminate when the mother leaves the hospital but should continue as needed" (p. 480).

In addition, Wolfensberger and Menolascino caution that management for novelty shock must often undo the damage caused by persons who had earlier contact with the parents. In order to provide facts and information to the parents, it is necessary to assess the child. Such assessment should not attempt to attain a certainty that is not possible at the time; instead, assessment should be interpreted as a time-bound process. This emphasis on the need for future reassessment is based, in part, upon the suggestion in the literature that parents in novelty shock tend to become very inward-directed. Successful adaptation requires that the parent broaden his concerns to include the spouse and the child. Thus, management that emphasizes future assessment of the child's progress can help the parent move from a "helpless, disordered dependency to a more adaptive concern about maximizing the child's development. One might say that it is better for the parent to move toward a reality stress situation than to remain in novelty shock" (p. 481).

Wolfensberger and Menolascino indicate that the novelty shock reaction is likely to be well circumscribed and definable. In strong contrast are reality stresses, the crises which most disturb parents. Although professionals can offer useful direct service by training parents in management techniques, in general, Wolfensberger and Menolascino contend that the professional's role regarding reality stresses should be to act as effective advocates or aggressive referral and follow-up agents in seeing to it that someone will provide the management that is appropriate and needed in the specific situation.

Much of the first section of this paper has been devoted to the value conflicts which parents of retarded children are likely to experience. As management measures for such crises, Wolfensberger and Menolascino suggest forms of counseling (such as logotherapy) that are oriented toward the meaning of life and its ultimate values, religious counseling, or resocialization experiences (Weingold & Hormuth, 1953). The aim of all these measures is to help parents arrive at a generally positive view of the meaning of the experiences they have had with their "retarded" child.

Wolfensberger and Menolascino persuasively single out congregational support as one of the most powerful management options here. Congregational support is powerful because it can combine group mediated resocialization with adaptive religious interpretation since most religions permit multiple positive interpretations of a retarded child. "Congregational support implies that a parish, church, or church group shows its acceptance — or continued acceptance — of a family with a retarded child in a number of ways. This would include friendly and frequent socialization with the family, offers of baby-sitting and
other expressions of assistance, active expression of interest by the pastor, and so on” (pp. 485-486).

One treatment procedure that Wolfensberger and Menolascino do not mention which may offer great promise in helping parents of retarded children cope with the variety of crises they encounter is the “network therapy” approach of Speck and his colleagues (Speck & Attneave, 1973; Speck & Rueveni, 1969). Developed as an outgrowth of family therapy, Speck’s approach is to gather the family network — all members of the kinship system, friends of the family, friends of kin of the family, neighbors — and to insist that the family issues be worked on by the network. Speck defines his goal as making “the entire group as intimately involved as possible in each other’s lives, and to (have them) provide a strong sense of tribal support reassurance, and solidarity” (Speck & Rueveni, 1969, p. 183).

Given the fact that many persons live their lives within rather circumscribed limits, within the family network, in fact, then if the network can be mobilized to support a given set of behaviors, the probability of maintaining those behaviors is increased.

One set of major functions for the network would be to help find solutions for various aspects of the reality crises — helping the nuclear family manage the child, helping to locate and obtain needed community resources (working as a political pressure group if necessary), providing socialization experiences for the child.

Further, the network, composed as it is of persons already close to the family, is likely to be the most powerful group available for a resocialization experience. Moreover, there is evidence suggesting that the willingness of non-nuclear family members to support the nuclear family’s decision to maintain a retarded child within the family, even when unaccompanied by tangible help, will increase the family’s willingness to maintain the child at home (Farber, 1959). Lastly, there is a strong pressure to make a deviant status (such as being retarded) the central fact about any holder of that status. A family network could offer counter-pressure, could support the retarded child in defining himself primarily as an individual and not as a “retardate.” Knowing what the adverse and self-depreciating effects of the stigmatized status are for the stigmatized persons (Goffman, 1963; Haywood, 1971), would it not be helpful for the retarded child to spend much of his time in contact with persons who did not socialize him into the stigmatized status? In these ways, then, the family network can also be seen as a useful response to a value crisis.

CONCLUSIONS

Two sets of summary statements seem warranted. The first involves specifying needed research efforts, while the second proposes the necessity for a change in the societal conception of the “nature” of retardation.

At present, the most urgent task for researchers in this area is the development and utilization of research designs capable of assessing the comparative effectiveness of different intervention strategies. The question here should be what treatment, by whom, is most effective for this individual or group under
which circumstances (Paul, 1969)? Even the Wolfensberger and Menolascino model of family management is based on the all too common assumption that all families of retarded children facing a particular type of crisis are essentially alike, and that, therefore, variables differentiating among families may be disregarded. Yet, studies from areas as relevant to this subject as psychotherapy and medicine have shown that client variables such as expectations regarding treatment, socio-economic status, amount of life change experienced during a specific time period, and internal-external locus of control, are important determiners of how long clients will remain in treatment and/or how they will fare in treatment (Frank, 1972; Garfield, 1971; Goldstein, 1962; Holmes & Rahe, 1967; Mason, Clark, Reeves, & Wagner, 1969). Moreover, such family variables as the family’s pattern task organization and the ability of family members to negotiate with one another (Aldous, 1971; Handel, 1972) need also be taken into account.

It would seem useful, therefore, for researchers to investigate client and family variables which would help professionals quickly distinguish between parents who need only to be given training and access to resources from parents who will not use techniques in which they have been trained and who will not seek access to resources they have been told about. If this can be accomplished, further research can focus on delineating the conditions which will maximize our chances of tailoring our treatment options to the particular needs and styles of the family with which we are working. Here, questions of the match between “therapist” variables (Truax & Mitchell, 1971), client variables, family variables, and intervention techniques (Bergin & Strupp, 1972) will need to be considered.

A major thrust of this paper has been that the reality encountered by families with retarded children is, in large part, socially constructed (Berger & Luckmann, 1966) rather than being in the inherent nature of things. Since human beings have constructed much of this reality, they can also change it. Given the damaging consequences which have resulted from the labeling of retarded persons, it seems imperative to treat retarded citizens as individuals rather than as members of a presumably monolithic class. Such is also the thrust of the movement in support of the principles of “normalization” in the human services (Dybwab, 1969; Nirje, 1969; Wolfensberger, 1972), a movement which has argued that, to the maximum extent possible, all individuals be helped to function in the ways expected of “normal” persons in the given society. A related and useful proposal here is that of Dokecki and Strain (1973) who have suggested that our society agree to provide as a matter of course services that will help all families manage the tasks of child development in such a way as to maximize the growth of all children. What will most benefit families with retarded children, we believe, is a change in the cultural construction of the “nature” of retardation coupled with a societal agreement to provide those resources necessary to help all families support the growth of their children. Though not easy, the responsibility for such change is ours. For by our decisions, we create the social construction of “retardation” which confronts families with retarded children as implacably as if it were Fate itself.
NOTES

1. Characteristics of such ordered relationships are discussed in Spiegel (1971, pp. 37-84), and Watzlawick, Beavin, and Jackson (1967, pp. 118-148).

2. Spiegel further notes that no transaction is ever observed except through the medium of sets of interactions.

3. The last two of Wolfensberger and Menolascino's categories are very similar to the two types of parental reaction to the retarded child described by Farber (1964). Farber distinguishes between the "tragic crisis" which, he asserts, is typical of families having relatively high socio-economic status, and the "role organization crisis" which, he suggests, is likely to occur among working class families. In the tragic crisis, the "aims, aspirations, and anticipated 'happy' family life is frustrated . . . the child's handicap is regarded by the parents as an uncontrollable event preventing fulfillment of their hopes and aspirations" (Farber, 1964, p. 215). By contrast, in the role organization crisis, the predicament facing parents is one of coping with a seemingly interminable care problem.

4. This position differs in several respects from that of Wolfensberger and Menolascino (1970). They assert that the novelty shock crisis is generally of short duration, that, once resolved, value crises do not reoccur, and that it is only the course of reality crises that are unknown.

5. Ironically, given the amount of information available on the effects of deprived learning environments (Hunt, 1961; Wolfensberger, 1969a), professionals are better qualified to predict the lower limits of development and achievement. This is hardly reassuring to parents. It is also a sorry comment regarding what have been the research interests of professionals in the area of mental retardation.

6. This sentence is overly optimistic since services offered retarded children in school systems are generally not of the kind or calibre that would maximize the growth of these children. For a review of the literature concerning such programs, see Heber and Dever (1970).

7. Even when excellent early intervention programs are available, they, too, can create other dilemmas for parents. Often, in order to implement such programs in what staff consider an optimal fashion, parents may have to alter family rules regarding such issues as which parent works with the child, how much time is spent working with the child, which parent will manage other household tasks, etc. Such changes may cause difficulties for parents who either lack the skills to negotiate changes in such family rules or who place a high value on the rules which predate the intervention effort. At times, staff are insensitive to these difficulties or they attempt to evade recognizing them by dealing only with one member of the family system. For some reason, that one member is always the child's mother. (We are indebted to Steven Rosenberg and Lisbeth Vincent for calling our attention to this issue.)

8. The extremely important work which has been undertaken by various associations for the retarded is a model for the sort of effort described here.

9. Goffman (1963), however, argues that the sort of attitudes expressed by the students in Grossman's study are rationalizations which serve to legitimate the societal definition of the stigmatizing condition.

10. Wolfensberger (1967, pp. 331-334, 348-349) has an especially good discussion of this and related issues.
11. A major difficulty here is the lack of comparable data concerning the effects of such changes on the lives of families with "normal" children. A study currently being conducted by one of the writers will provide some information as to the levels of stress — as measured by the Holmes and Rahe (1967) Schedule of Recent Experiences — experienced by matched groups of families with retarded and families with normal children.

12. Richardson (1968) points out that parents very often focus on the stigmatizing aspect of the child to the exclusion of other aspects, particularly socialization.

13. An obvious extension of this approach would be to include the community people or groups — e.g., classroom teachers, classmates of the child, etc. — who have contact with the family in the network. This approach has much in common with ideas discussed in the literature on "normalization" (Nirje, 1969; Wolfensberger, 1972).

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