

PARENTS OF MENTALLY RETARDED PEOPLE

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Mental retardation refers to a complex sociocultural phenomenon characterized by difficulty in complying with cultural values regarding intellectual and social behavior. Retarded persons tend to violate such cherished cultural values of Western society as intelligence, emotional independence, economic self-sufficiency, and physical attractiveness. As a result they have traditionally been rejected, isolated, stigmatized, and deprived of society's resources. Until quite recently, having a retarded child was generally considered to be a source of shame and indicative of serious deficiencies in one or both parents. Lack of understanding of the causes of retardation has further contributed to social ostracism and to a general tendency to deal with mental retardation through denial. The possibility of having a retarded child is so traumatic and the causes are still so poorly understood that most people typically exclude the possibility from awareness. Furthermore, our culture has not established satisfactory rituals or practices for dealing with mental retardation. The prevailing approach has traditionally been to abandon the mentally retarded as "hopeless" and to exclude them from society. This situation has been recognized in the report of the Strasbourg Symposium of the International League of Societies for the Mentally Handicapped (1967):

To comprehend the handicap, to see what needs doing and to do it, when these three components exist, there is a pulse of communication between the handicapped person and the rest of the community, and everyone, not alone the handicapped, benefits....

In relation to mental handicap, these conditions are difficult to achieve.... Because we don't know what to do we feel helpless. In the face of human distress, which we can do nothing to alleviate, we are embarrassed — so we put the problem out of mind and do nothing.

Professional Mishandling of Parents

When parents have turned to professionals for help in the diagnosis or treatment of a child suspected of being mentally retarded, they have all too frequently met with disappointment and frustration. Many professionals have known little about mental retardation, in spite of being trained in one of the biological or behavioral sciences. They have tended, therefore, to react with "embarrassment" and to "do nothing." Furthermore, professionals trained in mental health have, until recently, typically considered parents of retarded children to be "disturbed." They were likely to attribute to these parents such "problems" as: (a) inability to "accept" the fact that their child was retarded, usually attributed to "denial of reality"; (b) pathological depression, usually assumed to be the product of "internalization of unacceptable death wishes" toward the retarded child; (c) overprotectiveness of the child, stemming from repressed latent hostility toward the child; (d) irrational hostility, usually focused on professionals, interpreted as "displacement of hostility" originally directed toward the child; and (e) tenuous marital relationships, resulting from "displacement and projection" of hostility.

As a result of the general lack of understanding of mental retardation by many professionals and the prevalence of destructive stereotypes of parents of the mentally retarded, it is not surprising that professional handling of parents has often been less than helpful. Some of the most frequent types of mishandling are described in what follows.

Ignorance

In spite of great technological advances with respect to mental retardation during recent years, a surprising number of professionals in the medical and behavioral sciences have little knowledge about the condition. Misdiagnosis and dispensation of misinformation are still common. Some parents are still assured that their child will "outgrow" the difficulty, and others are confronted with the "hopelessness" of their child's condition and are urged to proceed with immediate institutionalization.

Hopelessness

Those who apply a medical model to mental retardation tend to view it as an "incurable disease" and hence as "hopeless." This orientation generates self-fulfilling and self-limiting prophecies that impede the development of retarded individuals. Furthermore, parents readily detect such defeatist attitudes and either develop similar expectations or resent those who adopt such a negative approach toward their child.

Referral Ad Infinitum

Parents are often accused of "shopping around" and drifting from one professional to another in the vain hope of receiving a satisfactory answer to their unresolved questions. Although some parents are undoubtedly prone to such behavior, in many cases professionals have initiated the referrals. Such referrals may reflect lack of expertise in mental retardation and/or reluctance to confront parents with the traumatic conclusion that their child is retarded. In some cases professionals seem less able to "accept" retardation in a child than the child's own parents.

Veil of Secrecy

Some professionals are still reluctant to share information with their clients, allegedly because the information would be too threatening, too uncomfortable, or in some other way would be destructive to the client. This "veil of secrecy" may conceal the more fundamental reason that some professionals minimize their own feelings of insecurity by maintaining a monopoly on information of potential value to their clients.

Deaf Ear Syndrome

Parents occasionally get the feeling that certain professionals are incapable of hearing some of their statements. They may get the impression that they are perceived by the professional as complete ignoramuses, so that any suggestions they might make regarding their own child are categorically ignored. It is not surpris-

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ing that such parents have at times become infuriated when their most earnest requests have been totally unheeded. This not uncommon professional disregard of parental suggestions or information may be the result of destructive stereotypes of parents.

Omniscience

In contrast to the professionals who candidly admit ignorance regarding mental retardation, others exude impressive confidence in their own pronouncements. Although they may convey the impression that they possess the key to all ultimate knowledge, these professionals frequently hoard much of this precious commodity behind the "veil of secrecy" described above, perhaps in the belief that the naive parents would be overwhelmed by exposure to the fountains of knowledge available to the professional.

Omnipotence

Professionals who adopt an omniscient attitude often also adopt the myth of professional omnipotence, that is, they assume that only professionals have the wisdom to make sage decisions about other people's destinies. Parents are still told what to do with their children; and even when "individual program plans" are formulated by sophisticated interdisciplinary teams, the parents (and the retarded client himself) are often still excluded from the deliberations and decision-making process. Instead, parents are informed after the fact that the team has reached certain conclusions.

Parents as Patients

In view of the negative assumptions held by many professionals regarding parents' emotional maladjustment, it is not surprising that they tend to perceive parents as prime candidates for counseling or psychotherapy. Hence parents may be thwarted in obtaining desperately needed information regarding their child's condition and the availability of services to meet his needs. Instead they are likely to find that professionals are eager to unravel their intrapsychic conflicts and to explore their marital problems and other areas of "maladjustment."

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Unfortunately, the objectives of therapeutic approaches to parents of retarded children are often unrealistic and inappropriate. Two of the most popular but unrealistic objectives are getting parents to "accept" mental retardation and "lifting the depression" that seems to be a common parental reaction. Though parents may fully understand that their child is retarded, it is unrealistic to expect them to "accept" this fact with blandness and equanimity, since it affects very fundamental values and existential issues, as described below. "Chronic sorrow" has been described as the "normal" (in contrast to pathological) parental reaction to having a retarded child (Olshansky, 1966).

Parental Reactions

Mental retardation is a formidable handicap in a complex society such as ours, which places great emphasis on intelligence and has little tolerance for deviation from cultural standards. Hence the perception of retarded persons as subhuman organisms is still prevalent (Wolfensberger, 1969). It is not surprising, therefore, that most parents faced with having a retarded child, even if they are well adjusted, are likely to experience major psychological stress. Reactions to this stress vary considerably from person to person, but there are some common patterns (Roos, 1963).

Loss of Self-esteem

A serious defect in one's child may be interpreted as a defect in one's self, particularly when a parent identifies closely with his child. Our society tends to foster the concept that children are extensions of their parents and reflect on their parents. Life goals may be abruptly and radically altered when it becomes obvious that one's child will be perceived as a "loser" rather than a "winner."

Shame

Parents may anticipate social rejection, pity, or ridicule and related loss of prestige. These expectations are all too often

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quite realistic. Social withdrawal is a common consequence, as is the propensity for associating with other parents of handicapped children.

Ambivalence

Since a retarded child's relative lack of achievement and tendency toward irritating behavior are prone to increase parental frustration greatly, the ambivalence normally experienced toward one's children is likely to be greatly intensified toward a retarded child. Frustration is likely to generate anger and resentment, which may lead to death wishes toward the child and feelings of rejection, typically accompanied by guilt. Inconsistent shifts between rejection and overprotection can be expected.

Depression

As already noted, chronic sorrow can be anticipated as a non-pathological reaction to having a retarded child. Typically, parents are disappointed in their child and realistically concerned about his future. To some, mental retardation symbolizes the death of the child and hence precipitates the type of grief reaction associated with the loss of a loved one.

Self-sacrifice

Some parents dedicate themselves entirely to the retarded child, make great personal sacrifices, and adopt a "martyr" approach to life. Family disruption, including neglect of other children and marital conflicts, may accompany this pattern.

Defensiveness

Parents may become hypersensitive to perceived criticism of their retarded child and respond with resentment and belligerence. In extreme cases they may deny the existence of retardation, rationalize the child's shortcomings, and seek professional opinions to substantiate their own conviction that "there is really nothing wrong" with him.

Although these parental reactions to retardation are recognized by many professionals in the areas of mental retardation and mental health, serious existential conflicts that tend to overwhelm parents are typically completely overlooked by professionals. Many professionals may feel uncomfortable discussing such conflicts, since they are common to most members of our society and usually lie relatively dormant in most people. Usually professionals prefer dealing with the traditional "parental pathology" and effectively avoid recognizing parents' existential conflicts. They may have no easy answers to these conflicts and may feel uncomfortable as their own unresolved conflicts threaten to become reactivated.

The degree to which parents experience existential anxieties as the result of having a retarded child is dependent on many factors, including the importance they accord children and whether or not the retarded offspring is an only child. Some of the critical existential conflicts common to parents of retarded children include the following.

Disillusionment

Our society fosters myths that lead to totally unrealistic expectations. As children we learn to anticipate success, achievement, wealth, love, and status. We expect wise parents, loving and lovable mates, and perfect children. Experience gradually erodes these unrealistic expectations of ourselves and others, leading to a long series of disillusionments in ourselves, in others, and in life in general.

Our yearning for perfection is often channeled into our children, through whom we hope to realize our frustrated aspirations and our thwarted dreams of achievement and happiness. A retarded child is usually an unsuitable vehicle for fulfilling such parental hopes, so he represents a major disillusionment — often the culmination of a long series of disappointments. When the child symbolizes failure as a parent, serious disillusionment in self is likely. If no other children are present, the possibility of eventual fulfillment through one's children is lost forever, and the parent may desperately seek other avenues to self-advancement, or may develop a feeling of pervasive hopelessness.

Aloneness

Man's deep-rooted need for intimacy is never completely fulfilled. There is no way to transcend individual boundaries and to share feelings and perceptions fully with another. Often the last desperate hope of overcoming aloneness is through our children — products of our bodies, shaped into our image, literally extensions of ourselves. A retarded child may thwart this hope, because of his limited capacity to communicate and achieve intimacy. Hence, parental feelings of aloneness are likely to be intensified, and parents may feel that they have lost the final chance to achieve intimacy.

Vulnerability

Early fantasies of omnipotence are soon shattered as the young child is repeatedly confronted with his dependence on others and his helplessness to cope with the world. As he matures, he learns that others, too, are not omnipotent, including his parents, teachers, and heroes. Pain, injury, illness, and failure all attest forcefully to personal vulnerability, the tenuousness of one's control over the world, and, indeed, the fragile nature of life itself.

Having a retarded child reactivates these feelings of vulnerability by painfully reminding the parent that his most precious possessions, his dearest dreams, can be completely annihilated, and that neither he nor anyone else can do anything about it.

Inequity

From earliest childhood we are conditioned to believe that fairness and justice ultimately prevail. Most members of our society have adopted an orientation to life based on the premise that "good" will triumph and that, in the unlikely event that our judicial system falters, some greater force will ensure that heroes are rewarded and villains punished. When faced with retardation in his child, the parent is overwhelmed by the enormity of the apparent inequity; and his natural reaction is to ask, "Why me ?" In his desperate search for an answer to this question, he is likely to entertain two possibilities: either he deserves the "punishment," because of

grievous "sins," or the world is neither fair nor just. The former alternative generates guilt, remorse, and self-recrimination; the latter endangers fundamental ethical, moral, and religious beliefs.

Insignificance

Young children imagine that they are important figures occupying a central role in the scheme of things, but maturity brings the sobering realization of individual insignificance. Although it is patently clear from history that billions of human beings have lived trivial lives and that all but a miniscule minority are doomed to eternal obscurity, we are raised — some more forcefully than others — to expect to achieve greatness or, at least, "meaning." When greatness escapes us, we compromise with our early aspirations by seeking meaning in fulfilling important and satisfying social roles: husband, wife, father, mother, and so forth. The disappointment in the parental role that having a retarded child often causes may intensify feelings of insignificance by denying such parents one of their few opportunities to achieve "meaning."

Past Orientation

Human beings have a unique capacity to transcend the present; they can recapture the past or project themselves into the future. Avoiding the present and future by retreating to the past is associated with various morbid states, and projecting oneself into the future is usually interpreted as mature planning and optimism. An orientation toward the future tends to be related to anticipation of happy and satisfying events, whereas the expectation of unhappiness and frustration tends to "block" projection into the future and foster orientation toward the past.

Most parents look forward to their children's future with enthusiasm, anticipating such pleasurable events as scholastic achievement, excellence in sports, graduation, marriage, birth of grandchildren, and career achievements. As a result, they tend to have an optimistic future orientation. In contrast, parents of a retarded child typically view their child's future with apprehension and as a source of increasing frustration. They fear their child will suffer from scholastic failure, exclusion from schools, inability to work

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or to work only at a menial job, problems in sexual adjustment, inability to live independently, and a life of loneliness and isolation. Furthermore, services usually become increasingly inadequate as the retarded person ages, increasing the parental frustrations. Hence, the future typically holds little promise for parents of a retarded child, and they tend to shift from an orientation toward the future to one toward the past and from an optimistic to a pessimistic attitude toward what lies ahead.

Loss of Immortality

The anticipation of inescapable death is a major source of human existential anxiety. One common approach to achieving a type of symbolic immortality is through one's children. Grandparents' legendary preoccupation with their grandchildren attests to the cultural emphasis placed on continuation of the "family line." When a child is retarded, this potential avenue to immortality is threatened; when the child is an only child, this chance for immortality is denied the parents, and they are faced with the inescapable prospect of their own finiteness and ultimate loss of identity.

Parent Organizations in the United States

In view of the serious, chronic frustrations experienced by many parents of retarded children, it is not surprising that they have learned to turn to each other for assistance and support. Yet formal parent organizations are of relatively recent origin. In the United States, parents began to form local groups long before the establishment of a national organization. The first of these groups, which eventually became a member unit of the national association, was founded in 1933 as the Council for the Retarded Child, Cuyahoga County, Ohio. It was not until 1950 that what is now the National Association for Retarded Citizens (NARC; formerly the National Association for Retarded Children) was founded by representatives of approximately 20 groups from 13 states.

The major factors responsible for the formation of the NARC have been described as lack of adequate community services for retarded citizens, popular concern regarding questionable condi-

tions in state institutions, potential federal funding for mental retardation services, general neglect by professionals, and burgeoning technological advances promising hope for the mentally retarded (Mead & Brown, 1966; Roos, 1970).

The growth of the NARC has been impressive. In 1951, the association included 125 units with approximately 13,000 active members. By 1955, the membership had grown to 35,000 members in 412 units. A 1961 survey was distributed to 787 local member units with an estimated membership of over 65,000. In 1969 there were 1,370 units and 140,705 members. And by 1975 the association had over 1,800 state and local member units and a membership of approximately 250,000.

Although parents have played a major role in the establishment and growth of the NARC, membership has not been restricted to parents. Indeed, the proportion of nonparents has increased through the years. A survey of 14 member units in 1952 revealed that three-quarters of all members were parents, that 21% of the units had parent members exclusively, and that only one unit had an equal number of parent and nonparent members. By 1969 Segal (1970) found, in an intensive study of four large local units, that in some units the parents had become a minority. The most recent survey of NARC's membership revealed that 51% of the total membership were parents (NARC, 1975).

The NARC (and similar organizations devoted to the welfare of retarded persons in other nations) differs in several major respects from most national voluntary health agencies. Unlike most of them, it did not originate from the initiative of a professional group interested in a specific disease entity. Rather than beginning as a centralized national organization, local units have tended to precede state and national components of the movement, leading to a strong "grass roots" orientation, which has characterized the NARC throughout its history. Furthermore, NARC members have been extremely active in the governing of the association, resulting in a highly democratic, decentralized structure. Another difference from national voluntary health organizations is that health per se has not been the primary focus of the parent associations. They have not defined mental retardation as primarily a medical disease, but rather as a condition resulting from any number of possible causes and manifesting itself primarily in problems of

learning and adaptation. Historically, deficiencies in educational and residential services have been of greater concern to parents than lack of medical or paramedical services.

The nature and functions of parent groups have typically changed rather predictably as they have matured. The stages identified by Katz (1961) in his study of "self-organized" parents' groups is applicable to most NARC units. These organizations usually originate as a small group of parents joining together and seeking out others with similar problems. As the size of the group increases, meetings are held at which members share information and obtain support and catharsis through intimate, face-to-face contacts. This phase of "informal organization" typically leads to the emergence of dynamic leadership, which shapes the organization through personal influence. Gradually, formal structure emerges as a constitution and bylaws are adopted and leadership roles are formalized and differentiated. Finally, as the organization becomes increasingly complex, paid staff is hired. As late as 1976, however, only a third of the NARCs more than 1,800 state and local units had full-time staff.

The functions of the ARCs have gradually shifted over the years. The earliest functions of meeting the members' needs for emotional support, catharsis, and information typically remain important throughout the life of the organization. Although parents' needs for these services may decline as they learn to cope with their own feelings and gain understanding of the services and possible courses of action open to them, new parents with similar needs continue to turn to the organization. Local parent organizations have remained one of the best sources of information regarding local resources for mentally retarded people.

Early in their development, parent groups usually arranged for services to meet the most urgent needs of their members' children. Inadequacy or inaccessibility of appropriate services in many areas served as a strong incentive for these groups to establish their own direct services. Yet periodic surveys of NARC units has revealed a trend toward gradual relinquishing of direct services as public agencies have increasingly assumed these responsibilities (Roos, 1970).

Although the NARC enunciated a policy that the role of its units was that of obtaining rather than providing services needed by re-

tarded people, this philosophy has not been universally accepted, and many of the association's local units continue to operate major direct service programs. Arguments have been advanced in favor of both operating services and relinquishing them (Roos, 1975).

In spite of continuing conflict regarding the appropriateness of operating direct services, the roles of most ARCs are changing in that they are increasingly concerned with catalyzing social change (Roos, 1970, 1975). For example, one of their most impressive achievements has been their highly sophisticated and effective legislative activities at the state and national levels (Feli-cetti, 1975; Roos, 1972). They have buttressed their legislative activities by establishing productive contacts with state and federal operating agencies. Often they have been involved in drafting and modifying regulations promulgated by agencies to implement legislation.

ARCs have increased their effectiveness by joining forces with other organizations to form coalitions dealing with common interests. These coalitions typically include professional as well as voluntary organizations. ARCs have also fostered social change by placing key members on state and national boards, task forces, and advisory committees. For example, the Developmental Disabilities Services and Facilities Construction Act has furnished a particularly fertile arena for ARCs' direct involvement in planning and evaluating services at the state and national levels.

The NARC has taken a leadership role in establishing major national advocacy and monitoring bodies, such as the National Center for Law and the Handicapped and the Accreditation Council of Facilities for the Mentally Retarded (changed in 1976 to the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons). ARC representatives serve on these organizations' boards of directors, along with administrators and professionals. As a result of these activities, parents have played an increasingly meaningful role in shaping services for the retarded.

Although major progress has been evident in services for retarded persons, programs are still of ten fragmented and of questionable quality. For example, a recent national survey by the NARC (1974b) revealed that only 40% of the retarded children of school age had access to appropriate public education. Criticism of in-

stitutional services for the retarded is frequent (e.g., Blatt, 1970; Blatt & Kaplan, 1966; Kugel & Wolfensberger, 1969; Roos. In press). As a result of continuing neglect and substandard services for retarded persons, parent organizations have grown increasingly militant. Parents have gradually abandoned their traditional stance of begging and pleading for desperately needed services in favor of demanding services predicated on constitutional rights.

ARCs have become increasingly involved in litigation, focused principally on issues related to right to education and right to treatment (Friedman & Beck, 1975). In general, the courts have supported the concept that institutionalized retarded people are entitled to treatment meeting minimally acceptable standards (e.g., New York State Association for Retarded Children v. Carey, 1975; Welsh v. Likins, 1974; Wyatt v. Stickney, 1972) and that all school-age children — regardless of handicap — are entitled to a public education (e.g., Mills v. Board of Education of District of Columbia, 1972; Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania, 1972).

Professionals and administrators have usually joined parents and other advocates in these suits, sometimes opposing a state government or state-operated facilities. In general, when confrontations with state agencies leading to legal action have occurred, they have typically resulted from problems of timing rather than from conflicts in basic goals or philosophy. Administrators usually concede that services are in need of improvement, but they justify delays in implementing changes on the basis of budget limitations, inadequacy of physical plants, lack of staff, bureaucratic obstacles, and other "unavoidable" impediments to progress. Parents are usually presented plans that incorporate comprehensive services based on progressive philosophy. However, parents are no longer satisfied with plans and rhetoric as substitutes for action. They have grown impatient waiting for an idyllic future that never comes.

A new approach being embraced by parent organizations is the establishment of citizen advocacy programs (NARC, 1974a; Wolfensberger & Zauha, 1973). These professionally directed programs pair selected, interested persons of "normal" intelligence (the "advocates") with mentally retarded persons (the "protege's"). The resulting one-to-one relationships can focus primarily on

meeting the retarded individual's emotional needs, his needs for coping with practical problems, or a combination of both. Advocates are systematically screened, oriented, and professionally supervised. An advisory committee, usually including people with expertise in legal and program areas, is available as a resource to the advocate. Many ARCs are adopting this model as one effective approach to their broad advocacy role.

Another aspect of the changing role of parent organizations is the trend toward formal training programs designed to develop parents' expertise in monitoring and evaluating services. For example, the NARC recently developed a curriculum and set of manuals (NARC, 1972) to train its units in the evaluation of residential services for the retarded. Objective rating scales and concrete strategies for working with administrators and other professionals are included in the manuals. Training programs have also been developed by the NARC to increase its units' effectiveness as change agents. Modular training materials and related workshops have been designed to increase state units' success in relating to federal programs and in ensuring maximum effectiveness in using federal funds to benefit retarded persons. A similar approach has been used to equip the association's local units to foster the development of community-based residential services (NARC, 1973).

These recent developments indicate that parent organizations in the United States, primarily under the aegis of the NARC, have matured into potent, sophisticated advocates for the retarded and their families.

International Developments

The founding and development of the NARC have been roughly paralleled in many other countries. The first national association, the National Society for Mentally Handicapped Children, was established in 1947 in England and Wales. It was followed by the NARC, in 1950. By 1955, the NARC had contact with mental retardation programs in 22 countries, 11 of which had national or federated associations.* By 1963, Boggs reported the existence

*R. Dybwad (1963) The widening role of parent organizations around the world. Paper presented at 41st Annual Convention, Council for Exceptional Children, National Education Association, Philadelphia, Pa.

of national organizations or federations in 26 other countries on 6 continents. In 1975, the International League of Societies for the Mentally Handicapped accepted 82 national organizations as member societies.

Most of these associations were founded by parents; but relatively early in their development, professionals and others who were not parents also became involved. Exceptions to this pattern have occurred, however, as noted by Dybwad:

Two examples of national associations which from the beginning were formed as a combined parent-professional-citizen movement are those in Germany (1958) and Eire (1961). In southern Europe, on the other hand, the parents feel it important to keep their identity separate, while in Yugoslavia the organizations are made up of educators, physicians, and parents. Quite a few examples could be given of associations where the initial impetus has come from an individual physician (Turkey), an educator (Uruguay), the speech therapist and the social worker of a Mental Health Clinic (Greece). In Manila, a psychologist went from house to house to find the hidden children so that a school class could be started. (Pp. 3-4)

The International League of Societies for the Mentally Handicapped (International League) was established in 1960, and in 1962 the decision was made to open membership to national organizations dedicated to helping the mentally handicapped in any part of the world. It has become the major international body composed of national voluntary organizations dealing primarily with mental retardation. The International League has been a useful forum for interchange of information, formulation of position statements, and support of legislative and related efforts. The League's purpose was described as follows at the time of its founding:

Through the creation of a common bond of understanding between parents and others interested in the problems of the mentally handicapped, the League hopes to secure on their behalf from all possible sources, the provision of efficient remedial, residential, educational, training, employment and welfare services. The League seeks to realize its objectives by: (a) the interchange of experts and information on the developing services for the mentally handicapped; (b) the exchange of workers in the field of mental handicap between one country and another; (c) the comparative study of legislation in member countries and beyond, concerning the mentally handicapped and the promotion and implementation of some in their favor.

The International League (1967) lists four basic functions of na-

tional parent organizations: (1) creation of public awareness and improved understanding of mental handicap; (2) experimentation and demonstration of novel approaches to dealing with mental retardation problems; (3) influencing government units on behalf of the retarded; and (4) establishment of specialized services for the retarded not provided by other agencies. The League stresses the importance of local associations as a source of support, advice, and information for parents, as monitors of local services, and as developers of needed services not provided by other agencies.

New Parental Roles

As noted above, parents have played a key role in the establishment and growth of the NARC and similar organizations. As members of such groups they have become increasingly skillful and effective as social change agents. As individuals, parents have also adopted new roles reflecting a gradual shift from being passive recipients of services to becoming active participants in the design and delivery of services.

Parents as Members of Interdisciplinary Teams

Parents are increasingly participating actively in the evaluation and programming of their own retarded children. The adoption of this role is a function of the general progress made by parent organizations and of relatively recent scientific developments, including the following:

- Studies have demonstrated the relevance of mothers' teaching approaches to their children's performance (Brophy, 1970; Hess & Shipman, 1965; Wiegerink, 1969).

- The importance of early intervention to subsequent intellectual and emotional development has been experimentally validated (Gray, 1971; Gray & Klaus, 1970; Haywood, 1967; Heber, Garber, Harrington, Hoffman, & Falender, 1972; Hunt, 1961). Environmental deprivation during the first five years of life seems particularly harmful and may lower a child's intelligence quotient (Bloom, 1964).

- Curricula, training materials, and audiovisual aids designed

to assist parents in training their handicapped children are now readily available (e.g., Bijou, 1968; Ferritor, 1970; Gray & Klaus, 1965; Whaler, 1969; Wildman, 1965).

Demonstration programs have already substantiated the effectiveness of parents' systematically training their own handicapped children. As extensions of professional teams, some parents typically have become sophisticated trainers. Preschool programs (Bijou, 1968; Luterman, 1971), programs for severely and profoundly retarded young children (Smith & Murphy, 1969), and programs for brain-injured children (Salzinger, Feldman, & Portnoy, 1970) have been successfully implemented.

The NARC is currently (1976) developing materials, workshops, and audiovisual presentations designed to equip parents of severely and profoundly retarded children to orchestrate training efforts with educators. This national program, funded by the Bureau of Education for the Handicapped, is being disseminated to individual parents through the association's more than 1,800 state and local units.

Obviously, not all parents of retarded children will wish to engage in formal training activities with their children. Parents of nonhandicapped children vary greatly in their participation in the education of their children, and there is no basis for assuming that parents of retarded children differ from them in this regard. However, many parents of retarded children will welcome the opportunity to join forces with professionals in working with their children. This new role may help to lessen their feelings of frustration and helplessness and to enhance their self-esteem.

Parents as Decision-makers

Historically, professionals have either tended to assume total responsibility for programming for retarded children or have avoided any meaningful involvement. Parents have typically adopted reciprocal roles, either totally relinquishing responsibility for the child to the professional or assuming complete responsibility for his care. This situation has been changing dramatically in recent years. Public services for the retarded have greatly expanded, and professionals have become increasingly committed to programs for them. Although parents have generally welcomed these

changes, they have also become more insistent about playing a key role in decisions affecting their children.

Parents have been concerned with two types of decision-making: they want to be part of decisions involving their own child, and they want to participate in broader decisions regarding the delivery of services to the retarded in general. With regard to decisions affecting their own child, parents are increasingly being involved in development of individual program plans, particularly in selecting objectives and goals. Many are also developing enough sophistication to query professionals regarding alternative potential courses of action so that they can knowledgeably select among them.

The importance of involving parents in decisions regarding their own children is becoming recognized as an essential ingredient of programming for the handicapped. Provisions ensuring such direct participation by clients themselves and/or their parents are already embodied in national accreditation standards (e.g., Joint Commission on Accreditation of Hospitals, 1973), federal court mandates (e.g., Wyatt v. Stickney, 1972), and federal guidelines (e.g., Intermediate Care Facilities for the Mentally Retarded [ICF/MR] regulations). Policy statements adopted by major national organizations, such as the NARC and the American Association on Mental Deficiency (AAMD), likewise emphasize the critical importance of parent involvement in decisions regarding their child. For example, with regard to individualized program plans, the AAMD states: "Recipients of services and their personal or legal representatives should be given a full opportunity to participate in all phases of the development and review of their individual program plan. Where appropriate, parents should be asked to participate in carrying out the plan, as well" (American Association on Mental Deficiency, 1975. P. 30).

With regard to parents' decision-making involvement with the planning and implementation of delivery of services, recent years have witnessed a major acceleration of direct parental participation. Federal regulations and court decisions have established advisory and monitoring bodies designed to review plans, monitor practices, evaluate programs, and/or approve services. Typically, participation of clients and/or parents is mandated in the composition of these bodies. Through this avenue par-

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ents are exerting increasing influence on services for the retarded.

Looking Ahead

Gains on behalf of retarded people and their families during the past two decades have been considerable. Conditions in the mid-1970s are immensely better than they were 20 years earlier; and it appears that, at long last, centuries of rejection and segregation of mentally retarded citizens and violation of their human rights are coming to an end.

Parents, professionals, attorneys, and handicapped people themselves have successfully capitalized on recent sociocultural changes. In the United States, for example, the civil rights movement, the advent of consumerism, the growing dissatisfaction with proliferation of bureaucracies, the increasing demand for program accountability, and society's growing tolerance for deviation from cultural norms have all contributed to bringing the retarded out of the shadows and to the attention of legislatures, courts, public media, and other change agents and decision-makers.

These recent developments suggest that the future for mentally retarded people and their families will be vastly different from the past. Of course, frustrations will continue during the next few years as the struggle for equal rights and quality services continues. Parents will continue to seek legislation to assure their children lifelong, comprehensive services, and they will probably continue to turn to the courts in occasional angry confrontations when they grow impatient with bureaucracies, traditions, or fiscal deficiencies. But unless the current momentum in the care of our mentally retarded citizens is somehow dissipated, unless the parent associations lose their effectiveness through apathy or internal fragmentation, and unless major sociocultural upheavals reverse current trends, the frustrations will gradually fade, and today's hopes will — at long last — be translated into reality.

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