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ABSTRACT

The author reviews research pertaining to parent behavior in relation to child development, repercussions of disability on family life, and techniques for helping parents of disabled children. Section 1 considers theoretical bases of parenting and normal development; biological, psychological, and social factors in the genesis of handicaps; parent adaptation of disability; the role of parents toward the disabled child; and children in families with disabled parents. A second section addresses the psychological trauma experienced by parents when informed of their child's disability, repercussions of the disability on the lives of mothers and the couple, the clinical importance of grandparents in family dynamics around the disabled child, siblings of the disabled child, and repercussions to the family in view of the sociocultural context. A final section focuses on parental guidance in outpatient clinics and in the home environment, the relationship between parents and professionals (both in terms of conflict and mutual help), family therapy and parents' groups, the role of parents' organizations, and fields of future research. Noted among findings are that there is a need for a "third person" as mediator in order to fight isolation of families with handicapped children. Other findings are that social class does not influence psychological adaptation to disability but does play a role in social adaptation, and that parents' associations seem to perform a regulatory role in the system of help to disabled persons. Following a bibliography are copies of commentaries with the following titles and authors: "Comment on Childhood Disability and the Family" (E. Zucman); "Between Earth and Sky--Commentary on Childhood Disability and the Family" (W. Roth); "Commentary on Childhood Disability in the Family--The 'Added Handicap'" (G. Blom, et al.); "The Summer Family Conference--An Adventure in Counseling Families with Handicapped Children" (L. Park); and "Disability in the Family--The Relation between Parents and Professionals" (B. Dyssegaard). (SW)

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# CHILDHOOD DISABILITY IN THE FAMILY: RECOGNIZING THE ADDED HANDICAP

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3

2

# CONTENTS

PAGE

ABSTRACT	5
ACKNOWLEDGEMENTS	6
PREFACE	7
INTRODUCTION	8
PARENTAL BEHAVIOR AND CHILD DEVELOPMENT	10
• Regular parenting and normal development: theoretical bases	
• Discussion of biological, psychological and social factors in the genesis of disability	
• Parent adaptation to disability	
• Role of parents towards their disabled child	
• Children in families with disabled parents	
REPERCUSSIONS OF DISABILITY ON FAMILY LIFE	26
• Trauma of parents	
• Repercussions of the disability on the lives of mothers and lives of couples	
• Grandparents and the disabled child	
• Siblings of the disabled child	
• Repercussions on the family in view of the sociocultural context	
HELPING PARENTS	40
• Parental guidance	
• Parents and professionals: relationships in conflict	
• Parents and professionals - mutual help	
• Family therapy and parents' groups	
• Role of parents organizations	
CONCLUSIONS	53
BIBLIOGRAPHY	56
COMMENTARIES: U.S. Perspectives	64
- Kathryn Meadow	
- William Roth	
- Gaston Blom, M.D.	
- Leslie D. Park	
- Birgit Dyssegaard	

# Childhood Disability in the Family: Recognizing the "Added Handicap"

## Abstract

This monograph is divided into three general themes with many sub-themes:

- Parent Behavior in relation to child development
- Repercussions of disability on family life
- Helping Parents

Cutting across these three themes, Dr. Zucman speaks of the *added handicap*, confirmed by many French and foreign works. *This added handicap* is, in part, an outgrowth of what she calls the *violence of disclosure*, the insensitive way the disability of an infant or child is revealed by professionals to the parents—and the subsequent feelings of isolation, guilt and anger which the parents (especially the mother) experience.

It is Dr. Zucman's contention, as well, that the misuse of psychoanalytic theory has contributed to conflictual parent-professional relationships because of the emphasis on guilt.

Parents and professionals are becoming more aware of the repercussions of this added handicap on the overall development of the disabled child. Dr. Zucman traces the development of family therapies and self-help groups and parent organizations. She emphasizes throughout her work the damage that the professional—i.e., physician, educator, social worker, rehabilitation worker, etc., can do if information is presented to parents insensitively or if information is consciously or unconsciously withheld. She tends to emphasize, without glorifying, the importance of parents organizations in helping parents. Although there are many difficulties with parents groups, what is of utmost importance is that these groups have evolved from the *initiative of the parents*, professionals are viewed as desirable "third parties" for helping the child to develop and helping the family to maintain as normal as possible a role in society. The concept of the need for a "third party" to provide support and relief to the family is discussed throughout the monograph.

Emphasis in the monograph is given also to the need for professionals to recognize the importance of (1) not taking away the parents role and (2) not professionalizing the parents. When parents become overly concerned about technique, they can lose their effectiveness as just plain parents. In addition, professionalization of parents often can lead to neglect of other siblings with resulting resentment and disruption to the family and family life.

Zucman refers to literature that calls the disabled child the *revealer* of existing conflicts within the family. This is used to counter the more negative theories which imply that a disabled child is the *creator of havoc* in family life.

Zucman feels that the "added handicap" caused by insensitive disclosure

and subsequent isolation can be avoided through specialized programs for hospital staffs and other professionals who would then be able to provide an open atmosphere for disclosure and for information-giving and sharing - which would ultimately cut down on what Zucman and others call the "unspoken." It is what is "unspoken" (feelings and information which are not brought out into the open) that creates additional anguish for the parents.

Dr. Zucman elaborates on the various themes and subthemes of this literature review using 133 references.

### ACKNOWLEDGMENTS

The bringing to fruition of this monograph has required the efforts of many individuals to whom we are extremely grateful. *George Engstrom*, the Project Officer for the International Exchange of Experts and Information in Rehabilitation with the funding agency, the National Institute of Handicapped Research, has certainly supported our efforts, *Ms. Anne LaCombe* carried out the initial translation from the French to English; *Ms. Theresa Brown*, Project Secretary, and *Ms. Elizabeth Halsey*, were involved in the typing of the translated manuscript; *Dr. John Mulhard* provided assistance in the editing. Several other individuals offered suggestions.

With the budget crunch upon us, we have been fortunate to have for our monograph series the typesetting services of Dawn Advertising Services provided at a very reasonable cost through Dawn's president *Daniel Halpern*. The printing and distribution of the monograph is being carried out by Altru Health and Rehabilitation Services. *Dr. Gaston Blom* of Michigan State University, *Dr. Naomi Karp* of NIHR, *Mr. Leslie Park* of the United Cerebral Palsy Center of New York and *Professor Ronnie Gordon* of the Institute of Rehabilitation Medicine, organized and facilitated meetings and seminars where Dr. Zucman interacted with over 200 U.S. professionals with a strong interest in disability as it relates to the family.

We are also very appreciative of the interest and involvement of those individuals whose commentaries appear in the back of the book. *Gaston Blom*, *William Roth*, *Leslie Park*, *Birgit Dyssegaard*, and *Kathy Meadow*. We feel the commentaries can be useful in shedding additional light on the topic.

Numerous others, we know, affected and were affected by Dr. Zucman when she visited the U.S. These associations, we assume, will lead to even greater interest and concern regarding the affects of disability on the family.

## ABOUT THE AUTHOR AND PREFACE

Elisabeth Zucman, M.D. is a French physician working in pediatric physical medicine and rehabilitation in Paris, France. She has written several articles on disability and the family which have been published in France. Currently, she is doing research with Centre Technique National D'Etudes et de Recherches sur le Handicaps et les Inadaptations (National Technical Center for Research and Study About Handicaps and Maladjustments) This organization has been responsible, since 1975, for keeping the French government informed about:

- 1) Intervention
- 2) Prevention, education, rehabilitation and social integration
- 3) Institutional needs
- 4) Policies evaluation

Studies conducted at the C.T.N.E.R.H.I. focus on and relate to these priority areas much in the same way that research done through the National Institute for Handicapped Research relate to priority areas in rehabilitation in the U.S.

Dr. Zucman was selected by C.T.N.E.R.H.I. to research the topic area of Childhood Disability and the Family because of her published track record on the topic and because of the deep concern and caring which she brings to her work with children and their families. The World Rehabilitation Fund is pleased that Dr. Zucman agreed to submit a version (in French) of her work for C.T.N.E.R.H.I. for our monograph series.

However, because of certain problems encountered in the preparation and translation, considerable editing and revisions have taken place with the difficult goal of maintaining the original flavor and intent while attempting to make it more comprehensible to U.S. audiences. It is our hope that the reader will find the ideas expressed in Dr. Zucman's work, as well as in the commentaries, thought-provoking and useful. *Please let us know your reactions by completing and returning the questionnaire in the back of the book.*

Diane E. Woods  
Project Director  
International Exchange of Experts  
and Information in Rehabilitation

June 1982



## INTRODUCTION

### Motivation and Working Hypothesis

I have been in contact for twenty years as a medical professional with physically and mentally handicapped children, in most cases with the multiply-handicapped. In that capacity I have repeatedly heard parents expressing their pain and anxiety over the condition of their child. They also voiced the added pain and anxiety arising from the difficulties they encountered in their contacts with different professionals, particularly physicians and educators. This additional burden being so frequent and so constant appeared to me to differ from a mere psychological displacement by parents of their trauma. I consider it important to understand the mechanism. Indeed, concerning the treatment of physical, sensory and developmental disabilities, we have no alternative but to accept the fact that our therapeutic resources are limited. But it is time to reject professional behaviors that risk inducing supplementary anguish.

I had this in mind when I started analyzing the French and English literature on disability and the family for the last ten years. To clarify my working hypothesis I raised the following questions:

- Can theoretical bases concerning the mother-child relationship as well as the genesis of disability explain certain attitudes of certain professionals? Have these theoretical bases evolved during the last ten years? Do they comprise new elements that could modify parents' and professionals' interactions?
- Do the cultural patterns (Anglo-Saxon, Latin, Mediterranean . . .) that influence family models also modify:
  - the familial repercussions of the disability?
  - the attitudes of professionals?

The pragmatic interest of finding answers to these questions first motivated this work, with the questions guiding my reading of French and foreign works. There is no question that subjectivity creeps into both my choice of references and the analyses of documents.

### Characteristics of the References Received

I started with 360 references and progressively reduced their number to 133, guided by the content of the document itself and by the necessity to limit the size of this publication. A number of foreign references whose titles and/or authors seemed important could not be located in France, despite my attempts. I am fully aware of the lack of some of the most recent U.S. and U.K. references.

Two thirds of the 133 references cited were published between 1976-1980 and the remainder in the preceding five years. The national origins of the publications were as follows. France, 40 percent, U.S.A., 30 percent, United



Kingdom, 15 percent, and the remaining 15 percent came from Switzerland, Canada, Israel, and Belgium. Medical professionals and staffs accounted for 60 percent of the works, research and academic workers, 30 percent; and parents the remainder. Developmental disorders and emotional disorders were the most frequent focus of the papers reviewed, but there was considerable diversity and a substantial portion dealt with the multiply-handicapped. As one would expect, the dominant themes were parent behavior and child development, the impact of disability on family life, and modes of helping parents with disabled children.

The general outline of my work presents the distribution of themes and sub-themes emerging from the 130 references. (Refer to the Table of Contents for a complete listing of these themes and sub-themes).

# PARENTAL BEHAVIOR AND CHILD DEVELOPMENT

## REGULAR PARENTING AND NORMAL DEVELOPMENT: THEORETICAL BASES

Works published in the 1950's and 1960's having an essentially psychoanalytical approach, had emphasized the very basic importance of the mother-child relationship. In the 1970's, on the contrary, diversified theoretical works based on different methods and approaches, challenged the psychoanalytic concepts and refined them.

For instance, the concept of maternal instinct has been the object of major criticism:

The philosopher BADINTER (1980) describes the evolution of maternal love and expectations from mothers from the 17th century to our days. Her attack on the guilt generator myth of maternal instinct is clearly stated and has been rapidly popularized - thanks to the very title of her work, *Love, Besides*. Her socio historical study demonstrates that "maternity is a gift, not an instinct."

Questioning maternal instinct is but one aspect of the old controversy between innate and acquired that was encouraged by numerous papers in the 70's. Concepts were enriched by new contributions and widely popularized, the increasing importance given to familial and social environment is the theoretical basis for implementing social action programs of prevention (PRINGLE, 1974).

In the perennial controversy over what is innate and what is acquired, new theories about parental contributions to the child's development are as follows:

The combination of both constitutional and environmental factors is now accepted (PRINGLE, 1974, LAUTREY, 1980), although discussions over the functions of either factor are far from being closed.

SUOMI, (1976) took over experiments by HARLOW on rhesus monkeys raised without mothers. Many child development theoreticians, and especially French psychoanalysts (SOULE, 1978) had used, among other theoretical bases, Harlow's experiments to comfort the death-giving mother, guilty of the developmental disturbances of the child.

SUOMI proposes two drastically new interpretations concerning the middle and long-range repercussions of an early lack of mother's care:

The young motherless monkey's behavior disturbances are reversible, even if only relatively. This point emphasizes the impact of the secondary environment on the young motherless monkey's development.

SUOMI's experiments show the function of social stimuli provided by young monkeys to motherless ones, in the reversibility of disturbances due to deprivation. These primary results need experimental confirmation, but so far they suggest more attention be paid to the role of siblings and age peers as far

as the affective and social stimulation of motherless children is concerned.

The concept of "attachment" which issued from such experimental research, expanded considerably in the 70's. RUTTER's (1980) important synthesis of works of the last thirty years, examined the successive reevaluation of the concept of deprivation of mother's care. He highlights the successive reevaluations of the concept of attachment, showing its complexity. He also analyzed the specificity of the primary or principal attachment, based on the notion of monotropy and the evolution of (the concept of bonding, implying reciprocity between mother and child, each stimulating the other to build the attachment which is the basis of future social and personal behavior.

The theoretical bases of the concept of "attachment" are now so solid that French (SATGE, 1976) and British (KLAUS, 1972) physicians view it as the cornerstone of the psychoclinical study of the repercussions of premature birth (as it drastically separates mother and newborn child) on the child's biological and emotional development.

More recently, RUTTER (1981) and especially by ANTHONY (1980) describes the concept of "vulnerability" of the child. The authors note that the impact of the deprivation of maternal care were not identical quantitatively and qualitatively for all children. Then they describe differential vulnerability and isolate factors that could explain different outcomes.

They concentrate on factors capable of protecting the predisposed child, such as, being the first born, benefiting from a stable relationship with one parent or a familial or extra familial substitute (provided it is a permanent substitute), being a male, and living in the country or in a small town. All these factors appear in their preliminary research on vulnerability as ones that are protective and even capable of leading to a new "syndrome of the psychologically invulnerable child." According to ANTHONY, this syndrome is mainly the result of the ability to conceptualize the stress experienced.

French epidemiologists (DAVIDSON and CHOQUET, 1980) rely less on the concept of vulnerability, instead they question the concept of deprivation, stressing the provision of early medical and social prevention.

From observations of 115 infants over a period of three years, DAVIDSON established an impact hierarchy of different social and psychological factors on the child's health behavior. Of the group, 11 percent proved "vulnerable" (had more than three somatic or behavior disturbances). In groups of children with a stable type of custody, mother or substitute, the frequency is eight percent. But vulnerability affected almost half of the children (47 percent) whose custody was unstable, and it affected two-thirds of the children when unstable custody was associated with factors related to the mother: lack of education, pregnancy experienced as a hardship, lack of preparation for the child's birth, or anxiety and persistent depression.

To conclude this brief summary of the recent evolution of theoretical concepts on regular parenting, we can ascertain that:

- The scientific disciplines used as the basis for these theoretical con

cepts have become widely diversified; and Progress was made in the '70's towards clarifying the factors which constitute the psychological and social environment of the young child. From this theoretical evolution, one can expect a double contribution. On the one hand, programs of medical and social prevention that will be better adjusted to a diversity of needs; on the other, a change in the attitudes of professionals when they become better informed of the diversity and intricacy of the factors at play in the physical and mental health of the child.

## DISCUSSION OF BIOLOGICAL, PSYCHOLOGICAL AND SOCIAL FACTORS IN THE GENESIS OF HANDICAPS

CHOMBART de LAUWE's (1973) extended research on a national level examines the various social and familial factors that can lead to disturbances in the physical and mental health of the child. Studying large populations that she carefully sampled in several regions of France, she described a number of factors: dwelling place, work of the mother, family composition, position of the disabled child among siblings, physical condition and family behavior. She measured and redistributed these factors to arrive at an actual *ecology of development* (or "mesology") from which emerge the following new notions.

- For each factor, there is a threshold beyond which it becomes pathogenic.

She highlights and this is even more significant the summation and interaction of different pathogenic factors. For instance, she describes the circular reactions (pathogenic for the child) that sometimes develop with a) disturbances of the parents', b) poverty of their social environment, and c) resulting aggravation to the precariousness of the couple. She also emphasizes the determining role of sub factors such as frequent moving and uprooting which is now known to sometimes trigger child abuse.

CHOMBART de LAUWE concluded that what she called "psycho-social heredity" weighed more heavily on the child than his biological heredity. The connection between biological and relational factors in the genesis of disability, as observed in certain clinical syndromes and as perceived and experienced by parents and physicians, should be emphasized here.

In recent works, two clinical syndromes exemplify the connection between biological and environmental factors:

- *Psychosocial "nanism" (smallness)* (CHICAUD, 1979) is a syndrome recently described in France and about which little is known. "Frustration nanism" emphasizes the nutritional and social deprivation observed in small sized children from underprivileged milieus and their fast size weight growth when placed in favorable conditions. CHICAUD objectified with standard projective tests the parents' images of 24 small sized children from diverse milieus. The parents' images of their small sized children, compared with that of a control group, suggests that the father's image is commonplace, but the mother's supports

suggestions of her power and, indeed, the parents are *felt* by the child as being overpowering.

- *Epilepsy* is another example of a syndrome long considered purely organic but for which the relational components have recently been studied. GUEY (1970) analyzed with great precision what appears to him, in what is experienced by the child and by his family, as a gap between the anxiety associated with the seizure and the scientific image of epilepsy reconstructed from medical and social information.

Also concerning epilepsy, LONG and MOORE (1979) showed how parental behavior influences the frequency of seizures: 60% of children with authoritative, forbidding parents have clinical seizures versus only 40% of those raised in a less threatening environment.

### Psychological factors in the genesis of handicaps

There is abundant literature on the psychogenesis of mental disturbances in France following the vogue of the old works of well known psychoanalysts, e.g., J. LACAN and M. MANNONI in France, and B. BETTELHEIM in the U.S. (whose translations and commentaries are numerous in France). DURNING (1980), a social science professor, discovered innumerable traces of these early sources in works written by special educators still in training. He considers misuse of psychoanalytical knowledge as the main cause of conflicts between parents and professionals.

From this vast French literature, only three references are used to serve as examples of such harmful misunderstandings.

- BRISQJ (1974) studied mentally retarded children, most of them bedridden, he interprets the death-wish that he sees in mothers as the cause - not the consequence - of the child's handicap.

- DAVID (1976), in a book popularizing psychoanalysis for students of social sciences and for the general public, is a mere echo, among so many others, of the Lacanian concept of psychosis; he sees the young autistic child "in a society devoid of father as a child lost in the unconscious desire of the mother."

- Like GEISSMANN and colleagues (1980), DAVID (1976) conceives the elaboration of a psychosis over three or four generations: "The heavy anal fixation of grandparents prevents parents from being aware of their own anal fixations and makes them so fragile that they are unable in turn to have any life projection for one of their children."

These few examples help to explain the extent of the gap between parents and some professionals. But there is another approach to relational factors in the genesis of mental handicaps utilizing a different language:

- BERGLER (1973), in a popular book translated into French, puts himself in the position of the "professional" advocate of parents. He shows clearly that children are not as upset by the behavior or subconscious of their

mothers as by their own internal fantastical elaborations of their mothers' behavior and subconscious, often masochistically.

-- LEMAY (1979), a French Canadian, studies and presents the repercussions of the deprivation of mother's care on the child's development in a way that does not avoid the issue of the suffering of the child, but does not heap the mother with guilt either. In order to say "I hurt in my mother" -- which is the very beautiful title of Lemay's book -- the child can use three languages: affective, somatic, and cognitive. The author explains therapeutically that all mothers and children are given a sense of mutual responsibility.

### **Social factors in the genesis of handicaps**

One of the first studies that compares with some exactness the respective weight of social and relational factors on the mental health of the child was conducted by CASADEBAIG (1976). He conducted a survey during the academic year (1972-73) of 2,270 children in primary and elementary schools, and 1,663 others in the district Mental Health Center. He compared these two populations and did *not* find significant differences between them in terms of two characteristics, i.e., social and professional category of the father, whether or not the mother worked. The same was true for some family criteria, i.e., position among siblings and size of the family. The only factor that discriminated between the two populations of children was in the rate of separated parents. 22% in the population of children at the Mental Health Center, only 14% in the school population used as the control group.

Other recent works, listed below, deal not with mental health but with intellectual efficiency and instrumental capacities of children. The striking fact observed in French and other foreign works of the '70's concerning social determinants of developmental disorders, is the criticism and sometimes the rejection of the concept of mental efficiency and its measuring tool, the I.Q.

GUAY (1975) demonstrates "the myth of the intellectual incompetence of the child coming from an underprivileged milieu" by insisting that when one uses an optimal evaluation procedure (whether by providing encouragement or by placing the child in a stimulating and relaxed situation), one does not find differences in I.Q. between children from different social, and cultural categories.

Other authors, BENJAMIN (1978) and DIATKINE (1979) studied large groups of economically deprived French populations. They shed a new light on the mechanisms of serious school failure of "children of outcast parents," which so far had led to treating them as mildly or moderately mentally deficient (E.M.R.). Also emphasized are the repercussions of precarious life conditions on the ability of cognitive learning. For instance, poor housing and the absence of furniture and other objects, hinders the development of body image and language in very deprived families. Very little stimulation is given toward the development of language. The child learns to "do" rather than to "say."

Furthermore, LAUTREY showed that rigid educational systems and values attached to obedience rather than initiative, were typical of underprivileged families. However, these circumstances do not diminish the intellectual capabilities of the child, but they inhibit his ability to use them in a school-learning situation. Later on, shyness and low expectations on the part of underprivileged parents towards future school achievements by their child tend to reinforce failure.

Research conducted by SCHIFF and his colleagues (1978) demonstrated the reversibility of intellectual deficiency under the influence of a change in social milieu. The authors studied school achievements, as well as I.Q.'s of 32 children adopted at an early age by families of a high social level after they had been abandoned at birth by their biological parents of a less privileged social class. The school and intellectual achievements of the adopted children were compared with those of their brothers and sisters in their biological families and with those of a control group from the same social class as the adoptive families. The achievements of adopted children were far superior to their natural siblings' and very close to their adopted milieu's.

*To conclude.* This discussion of biological, psychological and social factors of mental and intellectual deficiency shows that research conducted in the 70's confirms the complexity of multiple factors involved in the genesis of handicaps. It also leads to identifying more specific sub-factors whose impact is often circular and it highlights two new notions still being explored for prevention programs:

- The notion of differential vulnerability
- the notion of reversibility of disturbances

## **PARENT ADAPTATION TO DISABILITY**

### **Interactions are often painful and difficult to objectify**

All parents voice their pain and the intensity of the interaction between them and their handicapped children (FREDET, 1979; GIRON, 1978, HAN-NAM, 1980; HERBAUDIERE, 1972).

More than studies or research documents with a sophisticated methodology, these personal accounts succeed in impressing one with the violence of the emotional affects at play, and present the familial scene where interactions take place, often with the mother as the starting point, often also with children who express themselves through critical episodes affecting their bodies (diseases, accidents) more than through verbal language. The first thing that is striking about these documents is their personal tone, specific to each parent, which convinces the reader that he is in on the intimate scene of individual interactions, where each person speaks for what he is, in his own language. Then, upon reflecting, one retains one image common to all these accounts. that of a constant readjusting of the parents/children interactions,

that of an anxious and painful equilibrium, always threatened and always sought after, in an intense emotional climate.

However, often, professionals, psychologists or physicians view and confirm the intensity of the parent/handicapped child interaction, but not its individuality.

This is how COVELLO and LAIRY (1980) describe the negative but real interaction between the child born blind and his mother as the "untouchable - untouched."

PRINGLE (1974) describes the modeling of interactions from insecure parents - when they do not know what to do in front of the unexpected child - interactions which provoke insecurity for the child who tends to adopt the same attitude towards the handicap as his parents. The interaction is, indeed, recognized by medical and research professionals, however, its mechanisms seem to escape observation.

DARDENNE and his collaborators (1980) studied 30 families in Brittany with children with motor dysfunctions. They observed that the mother/child relationship becomes closer after the child ceases to walk, thereby suggesting that mothers would have a specific psychological profile, as if concentrating on a gestational desire that would lead them to reject contraception and "carry" their child a second time. Why is a psychoanalytical hypothesis chosen instead of a recognition of the concrete reality that forces the mother into more intimate physical contacts with the child from the time he ceases to walk?

MORVAN (1977) conducted research on *Overproduction and "Retardization"* of the mongoloid child. From attitude scales used with a series of mothers and children, he found that, the more overprotective the mother's behavior, the less she was aware of it and the more "retardized" the child.

Here again, one can wonder whether, in the indisputable connection between the I.Q. of the child and the overprotective attitude of the mother, one should not reverse the interaction mechanisms. Could it be, instead, that the more retarded the child and therefore the less autonomous, the more he will appeal to maternal protectiveness.

### Importance and difficulty of communication

Among many parents' testimonies, that of BUREAU (1979), mother of a child with leukemia, forces one to become aware of the extent of the "unspoken" - of its mechanisms and its interactional repercussions. The physician hardly talks to the parents about the unutterable diagnosis, and not at all to the child. This silence serves as a model in the family unit, between parents and child, and between the parents, allowing for anguish, depression, even rebellion to develop in silence.

The research of ANTHONY (1974a) on family repercussions of terminal child diseases, and that of LONG and MOORE (1979) on the epileptic child's family, confirms the importance of the "unspoken."



The study of ZUCMAN (1978), deals with one of the mechanisms at play in the difficulty of communication within the family which increases the anxiety of interactions. She focusses on the multiplyhandicapped child, in most cases deprived of language and autonomy because of a cerebral motor handicap accompanied by severe mental deficiency. She suggests that the restricted field of experience and communication generates an exclusive relationship with the mother or a mother substitute, that the relationship will be all the more silent, as the child cannot use the medium of verbal language and as the mother, attached to her child but cut off from other social contacts (with the father, the other children, friends), does not have enough resources left to talk. Such relationships sometimes turn into total symbiosis, unless a social "third person" intervenes in time to prevent it. The risk of mother/child symbiosis comes from the mother's isolation within the family itself, it is not a metaphor but an almost biological reality. In some exceptional cases, the mother's death was soon followed by that of her multiplyhandicapped child, no matter what might have been the quality of the care available after the mother's death.

### **Objectifying the modalities of communication**

The importance and difficulties of communication within the family justified many studies and research in the 70's which focused on the verbal interactions between mother and handicapped child.

We chose three examples of studies on communication:

- KOGAN and TYLER (1977) studied verbal and non-verbal interactions between mother and child in three groups they compared (normal children, motor handicapped children, mentally deficient children).

They concluded that mothers of motor handicapped children have a pattern of interaction which is more directive but also warmer than the other two, mothers of mentally deficient children have the lowest rate of both verbal and non-verbal interactions, but also they are the least punitive of the three groups.

CONNOR and STACHOWIAK (1971) compared modes of family oral communication in three groups of socially matched families where a child aged 10 to 12 had been singled out at school for being either "high adjusted," "low adjusted," or mentally retarded and placed in a special class. Verbal exchanges were analyzed according to 9 criteria qualifying communication in terms of interaction. Their results show that:

- The group with a "low-adjusted" child is characterized by its lack of cohesiveness and a communication style which is confused, avoids conflicts, but does not function on the basis of consensus.
- The group with a "high-adjusted" child is characterized by a high level of cohesiveness, frequent open verbal conflicts, with an articulate, clear style of communication.
- The group with a mentally deficient child is characterized by a style of

communication with strong, very defensive cohesiveness. Verbal interactions within the family group show that younger, normal children yield the right to speak to the older handicapped child who expresses himself in the same manner as his younger siblings.

These various modifications in communication between siblings seems to offer a kind of cohesiveness which is more comfortable and reassuring for each member of the group.

-MARSHALL and his collaborators (1978) conducted a semantic study on verbal operants used between mother and child (age 3 to 5). The research encompassed a group of 20 mentally deficient children (I.Q. below 67) and a paired control group. The semantic analysis of every verbal exchange over 15 minutes long showed significant differences between the two groups. A much higher rate of echolalic repetitions was found in mentally deficient children. A comparison between the mothers of the two groups showed a higher frequency of questions asked by the mother of her retarded child. Several hypotheses are proposed by the author to try and explain this observation: Could it be a way of controlling the child? Could it be a sign of the asymmetry in the verbal interaction?

This study of communication seems to open a new field of research from which a more objective knowledge of interactions between mother and handicapped child can be expected.

### **Towards a reciprocal adaptation**

A number of works of the 70's emphasize familial equilibrium, as it is sought after and recreated by a reciprocal adaptation.

RIESZ (1977) describes, as a mother and an educator, the interaction between herself and her mongoloid daughter in their everyday life, and she concludes her description of their life of 5 years together by saying: "The handicapped child makes his parents grow."

The study by TOMKIEWICZ (1973) goes beyond the classic terms of "rejection" and "overprotection" because these words serve to stereotype parents' behavior in as much as their explicit demands need decoding if one really wants to understand their meaning. An application for institutionalization, for instance, does not necessarily mean rejection of the child but can be instead an appeal for help. He proposed that familial equilibrium and toleration for the child do not necessarily go together and are liable to evolve with time. Taking into consideration, the different forms of familial equilibrium established around a handicapped child, he feels that the handicapped child can play a positive role in the family's emotional system. His handicap hurts, but it can also bring to his parents, depending on different situations, the secondary benefits of possession and indefinitely prolonged help towards the child that is a painful but real form of fight against aging. The modifications of the original but often fragile familial equilibrium make the handicapped child into the

revealer of pre-existing family interactions (conflict or solidarity in the parental couple), but not their protective agency, contrary to what is still often said. The stereotypes of rejection and overprotection are no longer valid after a review of such studies.

WATSON and MIDLARSKY (1979) shed a completely new light on overprotection, they studied 38 mothers of mentally deficient children and 70 mothers of normal children and observed their attitudes and opinions on mental deficiency, as well as their image of social reaction. Mothers of mentally deficient children have a more positive attitude towards mental deficiency, but expect a negative attitude from the community. This leads the authors to conclude that the "overprotective" attitude of mothers seems linked to their negative image of social reaction. They attempt to protect their handicapped child from rejection by a society of which they most likely feel a part.

*To conclude.* Recent studies and research on reciprocal adaptation of parents and handicapped children, whether or not they focus on patterns of communication, for the most part suggest the need for a "third person" as mediator - the presence of the father between mother and child, availability of a friendly, social or professional environment - in order to fight isolation, the major "surhandicap" of families.

## **ROLE OF PARENTS TOWARDS THEIR DISABLED CHILD**

For a long time the role of parents towards their disabled child was neglected. Then it came to be interpreted either as pathogenic (see discussion of psychosocial factors in the genesis of handicaps above); or as a means of replacing the professionals.

Here I will analyze the role of parents of disabled children as parents. How do they behave? What do they wish? What influence do they have as parents on the development of their child?

### **Parents talk about their role towards their disabled child**

Testimonies written by parents - almost exclusively by mothers - describe without theorizing their role of daily support of their child.

HERBAUDIÈRE (1971), for instance, describes the everyday life of her autistic child in the family and illustrates the complexity of the parental role. In this case it is primarily the mother, but also the father and brother of Cati, who act at every level in response to the needs of the child:

providing care and security to this autistic child who often endangers her own life;

trying to understand her unpredictable behavior where acting out plays the role of language;

begging from professionals, sometimes in vain, explanations, concrete help, comfort, and an educational framework.

HERBAUDIÈRE does not understate the pain, fatigue, discouragement,

anger and even aggressiveness triggered in the family by such a heavy load. One can understand why the parental role can so frequently become more technique-oriented. Although professionals or parents' isolation might lead to this, emphasis on techniques nevertheless remains a defense mechanism.

Other mothers describe the hindrances to their performing their parents' role: GIRÓN (1978), with the significant title, *The Hindered Mother*, shows how erroneous medical diagnoses and the absence of "insight" about the psychological trauma she experienced at the birth of her child kept her from performing her role as mother for a long time. FREDET (1979) recounts the painful experience of being denied recognition by professionals as the mother unless she was willing to accept the responsibility of the handicap. Again, the title of her book, *But, Madam, You are the Mother*--- is revealing.

Two other documents actually show parents addressing professionals while remaining in their parents' roles. For example, a group of parents (*Parents Speak* 1978) speak out against professionals about the legitimacy of behavior modification therapies, not for theoretical reasons or for educational efficiency, but for the sake of their children's physical safety, which falls indeed in the realm of their responsibility. Other (UNAFAM, 1979) parents of mentally disturbed, institutionalized adults, demand to talk with the nurses about physical care and everyday life activities of their children about which they are better informed than anyone.

### Parental Influence

The mechanism of parental influence on the disabled child is highlighted by AJURIAGUERRA and ABENSUR (1972) concerning the deaf child. They base their work on prior work by REFOND, PINTER and MEADOW who demonstrated that children born deaf of deaf parents are better adapted than those born of hearing parents. They suggest that this evolution towards a better social autonomy takes place through a positive identification of the child with his parents who use the same language, i.e., sign language. Deaf parents can convey to their deaf child a better self-image.

The SANDOW and CLARCKE (1978) study of severely handicapped children (Down's Syndrome, I.M.C. - central motor handicapped) confirms that a positive parental self image has a strong influence on the disabled child. They compare, a posteriori, the development of 32 children distributed in two groups according to the frequency of the help applied for by parents and given in their homes during the first three years. They observe that children who received more frequent professional help in their first year developed more rapidly for a while, then stagnated, and finally, at age 3, performed less well than the others. This could mean, according to the authors, that parents who depend less on care services may be more stimulating for their child.

KASUO-NIGURA and MEYERS-MINK (1980) studied the relationship between the role of the family and the role of the social environment on the

development of the mentally deficient child living at home. They observed two groups of children: 114 severely deficient children (TMR) and 152 mildly or moderately deficient children (EMR) from underprivileged social milieus. They learned that familial and social factors act in the same direction on the child's development. If the family is in harmony with its social environment, it can help the child develop harmoniously. But if there are conflicts between the family and its social environment, or within the family, the disabled child is less tolerated. These observations are true for the two groups of children (TMR and EMR).

When children are "institutionalized," the role of parents remains important. VILLECHEOUX-BONNAFE (1974) showed that the links between parents and children persisted, provided the institution permitted parents to visit their children. Parents had an indirect impact on their institutionalized child's development because those who took care of the child in the institution provided him with differential care based on the image they had of the family. For instance, educators can help the child progress only if they are convinced that parents wish the child to progress and care that they are separated from their child.

ANDERSON and co-authors (1976) have studied factors effecting the linkage between parents and an institutionalized child. They isolated six variables enabling them to predict rare visits:

- Concerning the child: a visible handicap and a low intellectual level;
- Concerning the parents: geographical distance, socio-cultural difficulties and separation followed by second marriage in the couple;
- Concerning the institution, the authors considered only one factor - that *medical care was free*, but it seems to us that other more influential factors on parents' visits might be the rigidity towards parents, the size of the institution, its accessibility, and the quality of services.

### Examples of programs that respect the natural parental function

K.P. MEADOW and L. MEADOW (1971) recognize, as I do, a dual function for parents of handicapped children: a technical function of rehabilitation and education, and an affective function ("expressive role"). They view them as always intertwined and believe that the parents must be taught their parental roles.

I would prefer to give here a few examples of experiments and services that respect the natural parental function:

The most famous of all is reported by WINNICOTT (1980). The story of "little Piggie" is a unique instance of psychoanalytical treatment of a little girl "during which therapy sessions took place on an irregular basis, over a long period of time, not frequently, and always at the request of the parents who, during the intervals, relayed the voice of the child and of the therapist, while keeping their role as participating parents, translating into everyday activities

the new needs of the child as they perceived them." Parents themselves expressed that it was most valuable to them to be allowed to take part in a growth and repair process. This way avoided having parents feeling left out in the cold, or competitive toward or envious of the therapist (as well as envious of the child). Otherwise, in order to avoid such painful feelings and potential obstructive behavior, they run the risk of withdrawing from a living relationship with the child and just "giving him away" to an authority figure endowed with technical know-how and knowledge.

Indeed, this experiment involved Winnicott and his incredible talent at individualizing each therapy and at communicating, and included particularly enlightened and available parents. One would wish that this unique experiment could become a model.

I retained here four examples of services providing parents of very disabled children with help "on demand" which would respect the natural parental function:

- In France, the CESAP (1974), a regional service for multiplyhandicapped children offers, when families demand it, concrete and educational help to severely handicapped children. In this type of service, a family helper and a technical educator can take over from the mother, allowing her to regain some of her freedom for her role as a wife, a woman, a mother of the other children, a participant in social life, without being denied her role as mother to the handicapped child. In addition to the benefits to the mother, all the children can benefit from the more equally distributed attention provided by the helper.

- The program TEMPO (HORSE, 1979) in the U.S. appears to have similar goals and is currently being evaluated.

- In the U.K. (RAYNER, 1978) and in Sweden EVANS,(1978), flexible and diversified programs are being implemented, where, upon parents demand, different forms of respite are provided: help in the home, temporary stays in apartments, vacation places, and "foster homes" for the child with or without his mother. These programs never eliminate the mother's role whose choices and decisions are respected.

To conclude: testimonies, studies and research of the 70's have led to a better knowledge of the specific role of parents which will most likely allow us in the future to avoid two possible risks: turning parents into professionals and actual denial of the parental role.

## **CHILDREN IN FAMILIES WITH DISABLED PARENTS**

### **Emotional disturbance in parents**

An analysis of works concerning the repercussions of emotional disturbances of parents on their performance of the parental role and on the development of the child proved difficult because limits on what to include were hard to set.

In the area of mental health (of adults as well as children) classification that makes a clear cut distinction between normal and pathologic conditions has not been accepted either in research or in practice for the last ten years. This is a very positive development with regard to respect for individuals and dynamic treatment, but makes the results of evaluation studies difficult to interpret.

Furthermore, even within the framework of mental pathologies considered, the classification of psychoses is defined in much wider terms in the U.S. than in France, and the intensity of parents' disturbances is rarely specified in studies of the last ten years.

We became aware of this in the quite recent study by DAVID (1981) on the "danger of early relationship between the infant and his psychotic mother: an attempt at responding." Her very precise description of interactions between mother and child allowed her to evaluate the gravity of the mother's psychosis.

EGGERS (1973) conducted a 30 year longitudinal study on the evolution of 52 young schizophrenics. For 29 of them, various psychopathic disturbances were observed in parents (eight were psychotic, three were mentally deficient), but most of these disturbances seemed to be *in reaction* to the child's handicap, positive and negative evolutions of the young schizophrenic were equally distributed between disturbed families and those who were not. The same held true for a control group of 14 youngsters who had been initially diagnosed psychotic in error. The author concludes that what matters most when making a prognosis on young schizophrenics is not the mental health of the family, but the onset of the child's disturbance. This has been confirmed by other very recent clinical studies.

Five other clinical studies concern psychotic mothers and deal with the psychological evolution of the child and the specific help he requires. ANTHONY (1980); BOURGEOIS (1974), MANZANO (1979); MASSON (1976), and RUTTER (1980) deal primarily with young children of schizophrenic mothers. Concerning the child, clinical observations are very detailed and in agreement for the most part. Most authors mention:

- the frequency of somatic disturbances in early childhood;
- the precocious psychomotor development with interpretation that the child is behaving as if he can feel that he must become autonomous soon.

These two traits lead specialists to the concept of early maturity and "parentification" of the child.

At first sight, it seems that the child's personality in his first years develops without pathologic signs. Only a keener observation with a longer scope reveals a definite frequency of defense mechanisms of a neurotic type: obsessional and ritualistic behavior (ANTHONY, BOURGEOIS). The actual frequency of clinical psychosis is around 15 to 20 percent for these children, and that of children who will remain hyperadapted and "invulnerable" is around 5 to 10 percent.

## Prognosis

The prognosis depends largely on the quality and stability of the remaining parent who supports and relieves the inadequate mother (RUTTER). It depends also on the style of the family and how open or closed it is with regard to receiving help from the community.

Finally, a good prognostic factor seems to be the possibility of a supportive educational program for the child geared at giving him structure, according to Piaget's theories (permanence of objects, time-pace structuration).

## Impairment in Parents

Few references were available concerning situations where a parent had such diverse disabilities as deafness, progressive neurological disorders, or the residual effects of traumatic accidents.

## Other Studies Relating to Potentially Disabling Conditions in Parents

ANTHONY (1974) reviewed studies on *children of the holocaust*. They show that, despite that indelible trauma experienced by parents, and despite some idiosyncracies in their behavior (like overfeeding the children), children showed no evidence of specific developmental disorders. This group had been considered a high risk one, but in this case as well as in others, there is no distinct psychopathology. Child development is related to the two parents' personalities and the equilibrium of the couple.

SERRANO (1980) studied in immigrant families the disturbances provoked in parents by social and cultural uprooting, loss of identity, devaluation, and confusion experienced in time and space structures. (Don't these difficulties exist also for the disabled adult at a physical and psychological level? It would be interesting to study it). In any event, SERRANO shows the impact on the parental function of immigrants who often end up renouncing their parental power in an ambivalent way. Values and distance between generations are reversed and, here again, the child often is "parentified."

COSTES (1976) studied with projective methods the parental images of children whose parents had a severe neurological disease (multiple sclerosis). On five children, ages 10 to 16, he found that the sick parent always appears devalued, never idealized. This invalidating of the parent tends to generate guilty aggressivity in the child. All the children showed anguish, but no severe personality disorders.

ANTHONY (1974) recounts a very different type of study on *Reactions of Peruvian families to the father's disability*. This study, already old, shows that disturbances of family dynamics are related not to the type or severity of the father's disability, but to the pre-existing "pattern" of family interactions, i.e., the despotic family, the patriarchal family, the collegial family. The typology is, of course, a function of the ethnic group and the social class. Actually, the father's disability is better tolerated in "collegial" type families, which is an in-



teresting fact for our Latin and Anglo-Saxon cultures.

*Conclusions:* These heterogenous studies on the impact of a parent's disability on the child's development indicate that there are no specific or systematic pathological repercussions. This can be seen as a new evidence of the individual plasticity of each child and of his unique utilization of his milieu's resources. Harmony between the child and a stable person in his environment (e.g., between deaf children and deaf parents, as shown by AJURIA-GUERRA) seems to be one of the best protective factors for the healthy development of the child.

# REPERCUSSIONS OF DISABILITY ON FAMILY LIFE

## TRAUMA OF PARENTS

In France, during the years 1970 to 1980, professionals in the field of rehabilitation became aware of the psychological trauma experienced by parents when informed of their child's disability.

Contributing to this awareness were:

- the influence achieved by the spreading of psychoanalytical concepts in specialized professional circles, e.g., the concept of the fantasized child and the mourning brought on by the actual child (SOULE, 1978).

- the more recent influence of statements published by parents of disabled children. These testimonies are better known by the general public than by professionals.

This new awareness has led to what appears to be paradoxical behavior of professionals:

On the one hand, medical professionals and staff who are not specialists (obstetricians, nurses, pediatricians, midwives) remain insensitive to the severity of psychological trauma parents experience on first learning of the neonates impairment. It is as if they were unaware of this phenomenon or the importance of the first words to parents describing the impairment.

On the other hand, professionals specialized in medical and educational rehabilitation of disabled children (psychiatrists, psychologists, educators), all too aware of the importance of the impact of the parental psychological trauma on the child's development, often have a tendency to make the negative impact stronger, although unconsciously, by encouraging guilt through their own attitudes toward the parents.

## Parents speak

HANNAM (1980), a British educator and father of a child with Down's syndrome, reports on his experiences and those of seven families he interviewed. He describes the violence of the psychological trauma created by the revelation of the disability and of its indelible character, always ready to surface again in the parents' life. He notes how the perfume his wife was wearing at the moment he informed her of the disability of their child still now triggers in him an immediate recollection of that painful moment.

HANNAM explains that at the very moment of the revelation his intense emotional confusion was similar to that he experienced as a child when he felt guilty. Then, as other parents also testify, he had felt like killing the child. One can now understand how the trauma is rooted in an intense guilt feeling. A survey conducted in France by an association of parents of autistic children, (SESAME, 1977) confirms that all parents experience this guilt feeling. But they think that one should not confuse their spontaneous self guilt, which can

be the source of a mobilizing emotional force, with the *added* guilt that some professionals impose, as their silence generates a social pressure that alters the parent's self-image.

HANNAM insists on this self-devaluation and shows how the birth of a disabled child, especially if he is the first born, leads parents to question their own life-giving capabilities, and alters their taste for living - as witnessed in the frequency of subsequent severe and prolonged depressions.

LONSDALE (1978) lets the 60 families that he interviewed speak for themselves. They describe how they were informed of their child's severe disability (Down's Syndrome, C.P. - Spina Bifida). In most cases the information was conveyed to the mother alone - and all considered this to be prejudicial. They describe the successive stages of their experienced trauma as they are aware of it at a conscious level - denial, pain, then the effort to accept, while fear for the future does not disappear. Their confusion is expressed thusly: "Disability forces us into a social game, the rules of which are unknown."

### Contribution of studies on parents' trauma

ROSIN (1977) studied the reactions of families of 24 Israeli adults who were unconscious for a long time following a concussion, usually due to an accident. In these very severe cases (12 died and only 2 have only a mild disability), six dominant reactions were observed: anguish, guilt, denial, adjustment, disengagement, rejection. The author insists on the frequency of denial, which is important for professionals to respect, in order for the family to face the situation. The same holds true for attitudes of partial disengagement whereas rejection, according to the author, implies a complete break-up between the patient and his family, and is prejudicial to the patient whose rehabilitation needs familial support. Rosin thinks that if the medical team can help the family become aware of their own reactions, they will be better adjusted to the needs of the patient.

ANTHONY (1974) reports on a study by FUTTERMAN on the psychological trauma of parents of children with leukemia. It showed the parents of 23 families suffering conflicting forces that led them to accept the prognosis of death, while they kept on hoping. Their adaptation often seemed to go through a specific process of anticipation of the death which provoked a progressive relaxation of their emotional involvement with the child who, at the same time, expressed his intense fear of being abandoned. On the other hand, sustained confidence in life relies on the control of the expression of feelings, then, after the death of the sick child, it is perpetuated through memory.

The psychological trauma of mothers of premature babies has been studied by a Neonatology Center (premature birth) associated with a Child Guidance Center, SATGE (1976). The authors recognize the importance of the very first days when the process of attachment between mother and child is established and the disappointment when the separation occurs; they describe

the chronic secondary emotional attachment, sometimes displaced in time for the mother and for the child.

The disruption of the natural process of attachment can contribute pathological developments in the mother:

- Sometimes the mother tends to request several unnecessary admissions into the hospital for the child;

- The mother may become a "therapist," thereby perpetuating care by herself;

Finally, the authors believe that repressed anger, due to the separation at birth, can explain some cases of "child abuse."

Actually, these disturbances are often avoided by admitting the mothers themselves into the premature birth unit where they can provide their child with maternal care at this earliest stage.

LANDRY and MOTTIER (1977) describe the effects of the parental trauma in 100 families with deaf children. The depression provoked by the revelation is followed by a period of uneasiness that parents resolve by either:

- engaging in "repairing," becoming the educator of their child, becoming actively involved in association work; or

- rejecting the handicap through denial, which does not mean rejecting the child.

The authors note that at the outcome of these long and painful processes, parents sometimes say: "The child made me progress."

HARRISON-CAVELLO and LAIRY (1980) studied the psychological trauma of parents of children born blind. They describe the "normal" stages of development to the anxiety about the future through the relatively protective process of a traumatic neurosis.

They assert that psychotic disorders appear frequently in blind children, thus extending their (the authors') rather pessimistic interpretation of the stages of development in parents' reactions toward having a blind child.

EDME and BROWN (1978) studied the process of adaptation of six families at the birth of a child with Down's Syndrome. They contend that differences are due to the personalities of the parents rather than the severity of the child's condition. Furthermore, their detailed clinical observations of mother/child interactions allowed them to highlight a two-step evolution of the double process of mourning and attachment. Following the initial trauma of disclosure, a second traumatic wave occurs a few weeks later when the child's pattern of smiling and looking around differ from the mother's expectation.

If, however, they are well established, the attachment is reinforced. Once again the authors show that the circular interaction between mother and child is the basis for reciprocal attachment. They also concluded that professionals have a positive role to play by easing the parent's expression of mourning, through an early and continuous listening.

ZUCMAN (1978) describes another aspect of the two-step mourning pro-

cess, as observed in parents of multiply handicapped children. The late revelation of a second handicap (in most cases, the revelation of mental deficiency in a C.P. child) reactivates the initial trauma in parents. The management of this second trauma is sometimes impossible, especially when the revelation of the second handicap is connected with rejection of the child and his family by professionals. The parents often seek refuge by denial of this added difficulty for the child and the resultant pain that they experience themselves. One must respect this denial until the time when parents regain enough confidence in themselves, in their child, and in their capacity to raise a multiply-handicapped child.

### Recent research attempts at elucidating parental trauma

JANSSEN (1976) conducted research with 223 families with severely mentally deficient children in order to define the factors that are instrumental in the success or failure of the parental adaptation to the child's disability.

68 variables were studied, distributed in three groups:

- the child and his disability;
- the way the disability was revealed;
- parents, family, and the social environment.

The study analyzes the principal determinants of eight dimensions of the adaptive behavior of parents. The two most important are:

- "Fretting" about the child's future which occurs most often when the etiology of mental deficiency is unknown, when the child has added disturbances, and when parents have a pre-existing neurosis which interferes with their ability to face reality;

- *The feeling of social isolation* which is due to insufficient help received from the social and professional environment. This feeling of social isolation has a tendency to increase as the child grows older.

Five other variables were found to have a less important impact:

- An unrealistic view of the child's future, often linked with inadequate early guidance.

- Concern about the child's deviant behavior, especially if he is the older child.

- Frustration, which is less important in altruistic parents.

- Stress created for parents by behavior disturbances of the disabled child, especially if these disturbances lead to disruption among siblings.

- Non-acceptance of the disability, not so frequent in parents of children with Down's Syndrome (or whenever the cause for the mental handicap is visible).

Paradoxically, shame and guilt appear to have the *least* impact in parental adaptation. Could it be that these feelings were buried so deeply that they simply did not emerge during the interviews in most of the cases? What the authors did observe was that feelings of guilt and shame came up more often

among uneducated parents unaware of the cause of the child's handicap who had pre-existing neuroses. In those instances they seemed to have a definite impact on the parent's adaptation.

PAQUAY-WEINSTOCK and his collaborators (1978) systematically analyzed the family dynamics of 25 parents of hemophiliac children. Parents were placed in three groups defined by their adaptation to stress, the process of emotional mourning at the revelation, and the style of communication within the family:

-10 families rebuilt themselves into a cohesive and open mode: their mourning process had been loud and intense, their behavior was stable both before and after the discovery of hemophilia, their mode of communication was open and direct.

-8 families rebuilt themselves by shrinking their social, intellectual and affective investments. Their mourning process had been diffuse and insufficient; their communication system was indirect and hidden.

-7 families disintegrated after the stress of hemophilia, they were disturbed before the stress of revelation, their communication system oscillated between rigidity and confusion.

On the other hand, the severity of the condition of hemophilia itself does not appear to me to play a very sharp role. Neither does the age of the child at the time he is diagnosed, nor the presence of other hemophiliacs in the family.

The impact of the "pattern" of intrafamilial communication on their adaptation to stress leads the authors to a recommendation for systematic family therapy.

HOLROYD and MC ARTHUR (1980) measured the impact of stress on parents of children with Down's Syndrome and autistic children. They compared the two groups, and also compared them with a comparison group of parents consulting in the same Guidance Center for other reasons. They reported that parents of autistic children differ from the other two groups (who are rather similar) by displaying a significantly more negative attitude towards the child. The other 14 variables concerning the behavior of parents, the social life or financial resources of the family, and the child's capabilities do not show significant differences among the three groups (except, of course, concerning personality disturbances). The authors speculate as to whether these results should be interpreted according to the psychogenetic hypothesis on the "coldness" of parents of autistic children ("refrigerator parents"), or rather as a defense mechanism towards children whose behavior is very difficult to tolerate. I am inclined, as they are, to accept the second interpretation.

*To conclude:* We propose two suggestions:

One concerns research. A new step could be taken in the understanding of the complex mechanisms of parental trauma if one were to compare the factors at play in parents' adaptation to the occurrence of a terminal disease of a

child and in the disclosures of a congenital handicap. Such research would offer the added advantage of removing disability from a special area. It would show, as this review of recent works did, that several situations are common in the process of adaptation to very different disability situations and that, therefore, all professionals should receive similar preparation in order for them to adapt also to the needs of parents whose child is disabled or terminally ill.

The other suggestion concerns the disclosure of the handicap. We support the same conclusions as LAMBERT (1978) in the study he made of 34 families in Belgium who had a child with Down's Syndrome. He speaks for the parents whose difficulties he analyzed. These difficulties seem greater in underprivileged social classes who are treated with even less respect than others. Parents should be given a "private" disclosure of the diagnosis, to both parents together, by someone who can give them precise information about the causes and consequences of the impairment and what they can do for their child.

## REPERCUSSIONS OF THE DISABILITY ON THE LIVES OF MOTHERS AND THE COUPLE

*The everyday lives of mothers and couples* are as upset by the real constraints they face and the way society regards them as they are by their emotional reactions to the disabling condition.

### Repercussions of the disability on lives of mothers

- The most simple daily activities appear, through reports of mothers (#18 - #46 - #51 - #60), and through surveys NOUET (1975), studies LEBARBIER (1979), or handbooks CARR (1975) and FINNIE (1975) to meet with many obstacles connected with the home life of the disabled child, his needs, his physical difficulties, and his behavior. Restrictions differ according to age and kind of disability, but they have a strong effect on *all* daily activities nevertheless. Feeding the child, dressing him, toileting him; the child's use of space and everyday objects - all pose problems on a daily basis.

Handbooks such as FINNIE's (1979), written and illustrated for mothers of young CP children, or the one that FREEMAN (1975) wrote for mothers of blind and deaf children show the numerous ways the house and the way it looks changes in order to respond to the specific needs of the child. The necessity for these adaptations, as well as the energy expended, leave virtually no free time for the mother and turn her into a "professional" permanently *on duty* in the house.

This natural isolation is reinforced by practical and social difficulties if she goes out and moves about with the disabled child, and by other problems if she looks for a proper "babysitter" when the child stays at home (WATSON, 1979).

Works of the 70's show a cultural evolution towards a more balanced sharing of daily chores between father and mother. For example VAN NOORDT

(1978) recounts a Canadian experiment where the father sought training in the concrete techniques of education in the daily life of his autistic child.

- *Health of mothers* of disabled children has begun to appear worthy of attention in different studies. LONSDALE (1978); MC ANDREW (1976); SATTERWHITE (1978); and GREGORY (1976) agree on the health risks faced by mothers of disabled or chronically ill children. About one-third of mothers feel depressed and have physical problems. They complain about fatigue, back pains, and sleeping difficulties. These symptoms seem to be related to the extraordinary efforts required in caring for a disabled child.

- *Professional lives of mothers* are also restrained by the child's disability. NOUET (1977) analyzes over 4,000 answers by mothers of disabled children in a survey conducted in France during the "International Year of Woman." She reports that the impact of the child's disability on his mother's professional life (about two-thirds of the mothers work) varies according to her professional category. It is non-existent for two extreme categories, executives and professionals, on the one hand, farm workers on the other hand, kept working, for the most part, after the birth of the disabled child. In most other employment categories, mothers ceased to work. More than one-third of those who continued to work preferred to work part-time.

### **Repercussions of the disability on the lives of the parents, as a couple**

The few works available on this topic concur in emphasizing the mother's isolation in her permanent struggle to organize the child's daily life. Because the mother is so caught up in the needs and demands of the disabled child, she does not even seem to notice when her husband begins to move away from her and the home. A disabled child in the family tends to test the bonds of the couple even beyond the ordinary family situation (HANNAM 1975).

GREGORY (1976) did an in-depth study of the lives of parents of CP and of deaf children. She found that deaf children's fathers help their wives neither more nor less than normal children's fathers. However, fathers of CP children seem to help their wives less.

She also interviewed couples on their sexual lives. Questions as well as answers seem difficult to express and difficult to interpret as well. (The "unspoken" seems to be especially intense here.) About one-fourth of the parents thought that their sexual life had improved after the birth of the child, one-fourth that it had deteriorated, one-fourth that it was no different, the remaining fourth did not answer. These findings are inconclusive.

LONSDALE (1978) interviewed 60 families of very disabled children. Parents acknowledged in 40% of cases that the disability added a burden to their life as a couple, in eight percent of cases, a complete break-up took place.

Break-up rates of six percent in Australia (ANDREW, 1976) and 17 percent in France (NOUET, 1975) are impossible to interpret, since they are not contrasted with the divorce rate for comparable populations during the same



period. However, investigation of this topic suggests that divorces should be viewed as the crystallization of conflicts in the couple prior to the birth of the disabled child. This coincides with clinical observations, but more scientific evidence would be helpful in making any interpretations.

Even more obscure, and more specific at the same time, are the repercussions of the birth of a disabled child on the *desire to procreate*. In all studies already mentioned, self-devaluation, anxiety, and guilt feelings lead couples to give up, at least for a while, having another child. NOUET (1975) observes that out of 4,000 respondents, 40% of mothers do not want another child and use birth-control, 40% desire another child; and 20% will not make a commitment either way. This study did not ask whether they gave up the idea of having sexual relationships altogether.

### Repercussions of the birth of a disabled child on social lives of parents

LONSDALE (1978) interviewed 60 British families and concluded that 50 percent of the fathers had their social and professional lives disturbed.

VOYSEY (1972) studied about 20 families during 18 months and conducted a psycho-sociological analysis of the burden on parents of *Le Regard Des Autres*. (*Les Regard Des Autres* is the title of a great French film of 1980 which shows visually the added handicap of social regard). He analyzed the mechanism by which parents' competence was threatened by the questioning of their traditional educational role. Their doubts about their disabled child's public behavior limited their normal social interplay. They were actually experiencing double doubts. they could not anticipate the public behavior of the child, nor could they anticipate the way that the public would view their disabled handicapped child. Furthermore, they were divided between contradictory desires and needs - their desire that the child would appear "normal" contradicted by the need to secure legal, medical and financial assistance from other human beings - and this assistance is given *only* if the "stigma" of the disability is obvious enough.

VOSEY concluded that reliable information enabled parents to develop their ability for social encounters in other domains outside that of the child's disability. These mechanisms and these solutions apply to the improvement of social interactions of any family as well.

KOCH and DOBSON (1976) examined the *social dimension* of disability, i.e., handicap. According to their work, mentally handicapped persons constitute "a national community of high-risk making social changes possible." In his work one author particularly emphasized the role that social class plays in taking advantage of what assistance is available for everyone with a mentally retarded child.

BOULESTEIX and FALQUE (1979) confirmed that last point. They studied about 200 families with a disabled child. They questioned them about

their difficulties with the bureaucracy when trying to get recognition for their social rights. (The Act of 1975 has established in France very broad social rights for disabled persons.) Thirty to 40% of the parents complained about how slow, confusing and rigid the system still is and about the lack of helpful information and the absence of personal responsibility within the government's administration. Dissatisfied parents are more numerous among younger ones. They usually feel humiliated by the authorities, as if they transferred on to the civil servant who answers their questions, a prejudice that echoes their own deep guilt feeling.

The authors conclude that there is a connection between the attitude of parents towards the disability and their attitude towards the authorities. These parents are a more vulnerable population than other users. Personnel should be prepared to welcome them and understand them. Their conclusions might also apply to other "vulnerable" populations in their contacts with administration services - like older people or immigrants.

*To conclude:* We maintain that a child's disability acts not as the "provocateur" but as the "revealer" of potential abilities as well as difficulties in his familial milieu. Creativity or fragility of the mother, solidity or split in the couple, social ability or withdrawal - all are reinforced for better or for worse after the birth of a disabled child.

## **GRANDPARENTS AND THE DISABLED CHILD**

Despite the apparent clinical importance of grandparents in family dynamics around the disabled child there is a scarcity of personal statements, studies, and research on this subject.

A scientific meeting of the Institute of Child Development of Paris in 1978 (SOULE 1979) was devoted to the theme, "Grandparents in the psychological dynamics of the child." None of the presentations dealt with grandparents of disabled children. Rare were the references to the grandparents' role as custodians of little children whose mother works.

ARIES, the historian, explains this absence by the fact that after the 1920's, solidarity between the three generations disappeared in urban societies, with the result that the two extremes, older and younger ones, were pushed out. Evidence of this social exclusion is found in other well-known works. PRINGLE (1974) barely considers the role of grandparents in his *Needs of Children*. Why, then, devote some space in this monograph to the grandparents of the disabled child?

The first reason comes from daily practice where one realizes how important the grandparents' behavior is to the parents. Many statements from mothers and a few studies, MC ANDREWS (1976), for instance, describe the support and sometimes the avoidance by grandparents. This deep psychological move worsens the narcissistic wound and the distress of both generations. It is probably also the result of an interaction between parents

"guilty" of giving birth to a disabled child and the guilt feelings of their parents toward them. The typical climate of a birth provokes a resurgence of the first bond between the woman who just gave birth and her own mother. The cumulation of such violent affects around the birth of a disabled child is dealt with only by reciprocal avoidance and misunderstanding. The "unspoken" can make this avoidance an everlasting one.

In other cases, however, which were not studied, to our knowledge, a stable supportive relationship is observed between the mother and one grandmother, providing the disabled child with the "holding" he needs. If psychological and social forces involved in this supportive relationship between two generations were better known, it would benefit other parents and grandparents of disabled children. It would undoubtedly be helpful in broader terms in the upbringing of all children. In our urban societies the generation gap does not have to be inevitable, as is suggested by other cultural models, e.g., collaboration between generations as in urban centers in China.

Works by BOSZORMENYI-NAGY (1973) show through the concept of "invisible loyalties" that even if urban society has destroyed social solidarity between generations, the powerful cement of psychological solidarity remains.

Loyalty between generations is defined as an obligation to respond to the expectations of the family group. Even when it appears transgressed by the generation gap, this loyalty, although invisible, continues to work as a force - and then produces guilt and pathological anguish.

The concept of loyalty between generations seems to us capable of explaining the mechanism either of rejection or of supporting behavior which takes place in the families of disabled children as in any others. This field of research, still open for exploration, could lead to ways of preventing the added handicap for families.

## **SIBLINGS OF THE DISABLED CHILD**

### **Problems with siblings**

The disabled child's siblings have been studied widely during the 1980's, but the numerous documents published on this interesting subject are often contradictory. One reason for this contradiction is the diversity of the authors: parents, research people, and professionals do not speak the same language on this subject. But part of the reason may very well be the absence of theoretical and clinical knowledge of the dynamics of siblings in general.

A few questions stand out:

- Parents have a tendency to deny that there are problems among siblings.

- Professionals are of a contrary opinion: MC ANDREW (1976), in his study of 116 families, found that 45 percent of siblings are disturbed (15 per-

cent required therapeutic help); and 50 percent do not get along well with the disabled child. LONSDALE (1978) views these disruptions as much less frequent. He observed only 9 percent behavior disturbances and 13 percent misunderstandings among siblings.

What can be inferred from these contradictory opinions?

HANNAM (1980) implies that it is most difficult on the siblings if a disabled child is the first-born, but that, even though there is some significance to rank order, what is most important is that the disabled child have a "place" among his siblings.

### **Parents' behavior towards siblings**

Parents are aware that they are more tolerant toward the disabled child than toward his siblings.

Adolescent siblings of orthopedically disabled children expressed feelings of injustice, neglect, fear about their own future careers and families, fear of transmitting a physical impairment to their own children. But of most importance to these siblings was the feeling of being over-burdened at an early age with responsibilities, and having to perform the role of second parent to the disabled sibling (Association of Paralyzed Persons of France, 1970).

### **Relationship of the disabled child to his siblings**

There are feelings of jealousy between any and all siblings.

LANDRY and MOTTIER (1977) studied 100 families with deaf children and analyzed the subtle relationship between brothers and sisters. If neglected, the normal child ended up identifying with his deaf brother who receives so much attention from the mother, and for Christmas asked for a hearing aid!

SCHWIRIAN (1976) investigated the impact of the pre-school deaf child on his older brothers' behavior:

He compares 77 siblings of young deaf children with a matched control group. Among the seven variables taken into account, in the studies among the older children were their degree of autonomy, sense of responsibility, and openness of their social contacts. Comparing the two groups, significant differences were not observed in behavior of the older children.

The author concludes that the absence of an apparent impact of the young deaf child on his siblings could be explained by the fact that deafness is a non visible handicap for which the mother would not feel guilt and which does not really restrict practical autonomy. Therefore, excessive help would not be required from the older siblings.

### **What happens to brothers and sisters of the disabled child?**

Distress among siblings exists in connection with the fact that the mother is not available, concretely or affectively, to the "normal" brothers and sisters.

A few studies give details on the mechanism at play:

The BRAUNER's (1978) who, having considerable experience with autistic children and their families, describe the many aspects of the unintentional mismanaging of normal brothers and sisters. They are the ones who are often sent away from the family in order to relieve the mother. Also, to fight the anxiety provoked in themselves by the strange behavior of the autistic child, they try to assert themselves by either hostile behavior or by a devotion that does not fit their age. On the other hand, the autistic child sometimes finds it hard to understand the predictable behavior of the older children or simply the presence of a younger one who takes away from him some of the mother's attention.

The authors feel that professionals should be aware of the tensions that generate an *added handicap* for all members of the family in order to offer preventive help to brothers and sisters.

LONG and MOORE (1979) found that parents' expectations concerning school success were more positive for their normal children than for the epileptic one. However, despite a positive attitude, 20 percent of siblings are disturbed, but the authors do not say to what other factors these disturbances could be due. Parents' silence concerning epilepsy (the "unspoken" is the rule in one-third of families) can provoke anxiety in the other children.

FOTHERINGHAM (1972) observed 38 families of severely retarded children kept in the home. He analyzes with great precision how the physical health and equilibrium of brothers and sisters is altered. He also describes how the educational attitudes of parents towards them deteriorate and how tensions grow in the parental couple - but does not try to explain the possible interaction of these various factors. On the other hand, in cases where the disabled child is institutionalized, siblings do not seem to improve after the institutionalization; this fact is not clearly explained either.

*To conclude.* These studies can be considered as an initial attempt to explain very complex interactions where siblings of the handicapped child act as a sounding board for the emotional turmoil of parents. They also suggest that a better knowledge of these interactions and better use of existing knowledge would lead to preventive action concerning the mental health of siblings of disabled children and of entire family groups.

## REPERCUSSIONS ON THE FAMILY IN VIEW OF THE SOCIO-CULTURAL CONTEXT

It appears that social class does not influence psychological adaptation and plays a role only on social adaptation. This social adaptation is easier for middle classes than for lower classes since the poorest classes, for instance, find it particularly difficult to exert their civil rights as far as disability is concerned as well as in other domains.

## Does the cultural context play a part in the genesis of disability?

Three studies published in the 70's allow us to think that the cultural context does not play a direct role in the genesis of disability:

KAFFMAN (1972) compared the emotional disturbances of children in Israel raised in kibbutzim with those of the rest of the population. He finds the same rate and the same type of disturbances in the two populations which shows, contrary to BETTELHEIM in *Children of the Dream*, that raising children in kibbutzim does not eliminate the impact of diverse parental influence.

COLLOMB (1977) on the rapid evolution of African cultures and SER-RANO (1980) on immigrant families living in France, lead us to believe that it is not the culture per se but rather the cultural mutation - through disintegration or transplantation - that can play a pathological role in the family group.

## Does the cultural context affect family adaptation to disability?

It is very difficult to delineate the impact of cultural context on family adaptation to the disability of a child:

There is agreement - although never objectively proved - that Judeo-Christian culture reinforces the parental guilt-feeling (SESAME). On the contrary, DARDENNE and his collaborators' (1980) very precise study of the reactions of families from Brittany confronted with a myopathic child found that the psychological trauma annihilates religious faith in this highly Catholic region. A few studies were conducted on the impact of culture on family adaptation to disability. They show that the articulation of factors is a complex one.

Let us recall the research done by CASTRO DE LA MAIA, and recorded by ANTHONY (1974) about the adaptation of Peruvian families to the father's disability. It shows, first, that it is not culture, but cultural sub-groups that play a part, second, that their influence takes place indirectly through different patterns of family authority.

WELLER and his collaborators (1974) conducted research in Israeli families on their perception and acceptance of mental deficiency. They show that the original sub-cultures - Ashkenazic and Sephardic - play no unique part in the perception, the guilt, and the acceptance of mental deficiency. The only social influence they observed was that of the professional category, even though they view it as quite partial. It affects neither the emotional adjustment nor the always intense guilt-feeling. The only point where they observe a difference is that underprivileged social classes have a less acute perception of the child's mental deficiency, but this could be seen as an "artifact" since in such cases the mental deficiency was mild, more difficult to spot - and not just in the eyes of the parents.

FLORIAN and his collaborators (1981) shed a supplementary light which

is so important that we included it in this monograph. They compare the patterns of social adaptation in Israel of 57 Jewish families and of 74 Arabic families, to their CP handicapped children. The differences are considerable. Jewish families, where mothers keep a professional activity, rely on themselves primarily, on the community to a lesser degree, and not all on parent's associations. Arabic families, where mothers do not work, rely on the advice of extended family, on selling family assets or on public help, and are extremely interested in association support. The author discusses these results with fairness by wondering whether these differences are cultural, psychological, or social.

*To conclude.* The debate on the influence of cultural context is still open. The complex factors involved make it entrancing, if difficult to resolve, and suggests prudence and more research in the future. The way professional behavior and care services are affected by socio-cultural environment also needs comprehensive research and study.

## HELPING PARENTS

### PARENTAL GUIDANCE.

All parents of disabled children initially expect that they will receive help. Numerous testimonies bear witness to this (18, 46, 51, 55, 60). But what parents expect overall has changed considerably over the past 30 years (McKenna 1978 (84)). In all developed countries medical care and special education technically should be available. LAMBERT (1978) reports on parents' expectations and needs in England: parental guidance (95%), financial help (95%), other services (80%), parents' organizations (65%). But what *really* matters is to be understood and to be relieved (HANNAM, 1980). "Being understood" implies being listened to, without prejudice, by someone who can hear what is actually said as well as what is behind the words (TOMKIEWICZ, 1978). "Being relieved" implies being helped by professionals in institutions and organizations without being deprived of their parents' role and responsibility. This implies being in control of decisions concerning the child and maintaining or regaining an active role within institutions. It also implies retaining the right to have a say in studies and research works. Several recent works are actually expressing the voices of parents (Parents Speak 1973). These specific expectations are created by the gap that has occurred between professionals and parents. However, most of the studies we analyze show awareness of this in present practices. Indeed, what we now call "Parental Guidance" in France, what in England has the more egalitarian title of "Working with Families," echoes the desire of mutual collaboration between parents and professionals, even when the child is no longer living at home.

#### *Contribution of research to development in practice*

Works of the IVth Convention of the Association for the Scientific Study of Mental Deficiency (MITTLER 1977) illustrates the development of research and practices towards respect and support of the active role of families - especially of mothers - in prevention and action. Furthermore, these works confirm other developments:

Early stimulation programs geared to socially underprivileged and disabled children, i.e., "Headstart" show the basic importance of language stimulation in prevention and early education programs.

- Before entering into a detailed analysis of the different kinds of help of "Parental Guidance," we would like to focus preliminary attention on another aspect of the importance of language. They studied 105 parents of mentally deficient children to establish their understanding of the technical terminology related to disability, their use of it, their judgment of it, when it applies to mental deficiency in general, and to their child in particular. The results show that:

- Parents know and have a better tolerance for scientific words (like



"Minimal Brain Damage") than for those implying a value judgment ("moron", for instance).

- They tolerate better recent scientific words, especially educational ones, rather than medical ones. For instance, "school problem" or "retardation of language acquisition" are better tolerated than "mental retardation."

The authors conclude that parents have a realistic attitude. They accept an objective diagnosis but refuse the "labeling" that implies social rejection.

It also seems to us that this study shows how rapidly words that refer to misfortune become obsolete. Even if semantic wear and tear is inevitable, we agree with the authors that professionals must be careful to avoid using stereotypes and words which invoke value judgments towards children and parents.

### Parental Guidance in out-patient clinics

In France, Guidance Centers are usually Medical, Psychological and Educational Centers (C.M.P.P.), Centers of Early Medical and Social Action (C.A.M.S.P.) or Mental Health Dispensaries (D.M.H.) and sometimes specialized hospital outpatient clinics.

HAYEZ (1978) describes guidance centers for behaviorally disturbed children. He analyzes the many functions of parental guidance. Depending on individual cases and the time of intervention but even more on the background of those who intervene and the objectives of the guidance center, two major types of functions are performed:

- a therapeutic function, that can be a simple echo function, allowing for the unspoken to be verbalized; or,
- a more deeply rooted-in-reality function: guilt-riddance interventions, information-giving direct interventions.

Hayez insists that one should neither rely on a single approach exclusively, nor on an ideology in order to respond with flexibility to the needs of parents.

In the field of mental deficiency, recent works (LAMBERT, 1978; BETTSCHART and collaborators, 1976; AMENTIA, 1980; TURCHIN, 1974) shed new light on the subject. The technical role of parental guidance is only secondary to the importance of relational dynamics. They insist on the following points:

- Discretion is a must in the presentation of the diagnosis and in early prognosis to avoid slowing down the child's development and reinforcing the parents' guilt

Personal humanitarian qualities are expected of professionals. common sense, warmth, balance and self-control

- Parental guidance must be adapted to the age of the disabled child. The problems treated - like sexual life of disabled teenagers - and the words used should not be prescriptive, but must develop along with the teenager and his family.

Early and sensitive parental guidance can be an excellent tool for preventing the child's and his parent's *added handicap*. SOULAYROL (1977) suggested guidelines for those offering parental guidance concerning epileptic children. The therapist must take into account not only the reality of the disease (seizures and their treatment) but also the weight of this reality on the imagination of parents already affected by social prejudices concerning epilepsy. It is not always easy for the therapist to seize the right moment when he can start to talk with parents about something other than seizures.

### **Professional outreach to the home environment**

The development of outreach programs, as organized from out-patient clinics, has been growing, especially in the last ten years. In France, provision of services in the home environment have received a name and official regulation: "The Home Care and Education Services" (S.E.S.A.D.) which were established in 1970.

In the U.S., LEWITT and COHEN (1975) have described and compared programs designed for disabled children and those for underprivileged children. They found the latter more effective.

Among programs for socially underprivileged children MITTLER, GRAY and MONTENEGRO (1977), for instance, show that early stimulation programs have a better and more durable impact on the child when they include home intervention. Such programs endow mothers with a more active and more individualized role, and mothers feel valuable in their own eyes.

Programs destined for severely retarded children (TOWNSEND and FLANAGAN 1976) show that professional outreach helps keep the child in his home and facilitates his development, provided the person in charge does not deal exclusively with the mother, but with both parents, so as to avoid conflicts within the couple. When the home-worker deals only with the mother, she has two reasons for isolating herself with the child to the detriment of familial equilibrium; she feels solely responsible for her child's development, and her excluded husband steps away from her or is antagonistic.

The authors note also that parents do not take advantage of the non-specialized social services offered in their community - this can be taken as a sign of social isolation.

One cannot help but compare that research with the work of FOTHERINGHAM (1972). He compared family equilibrium, depending on whether the severely mentally retarded child was or was not institutionalized (institutionalization being at that time more frequent). The author expected to observe improvement in the year following the institutionalization by comparison with observations of the previous year, using a "scale of family functions." In the group represented by the 38 families with an institutionalized child, he observes no changes over the two years of his research, neither in the child (intellectual functioning) nor in his family. On the other hand, in the matched

group of families with the child still at home, he observed an important deterioration in the physical and mental health of siblings and parents. This led him to regard the absence of movement in the first group as a relative gain.

The results of this research are disturbing, indeed. One cannot hold the presence of even a severely disabled child entirely responsible for the deterioration in the second group. Could there be an artifact created either by the intervention of research, or by the kind of guidance going on at that time or by an interaction of both? This research offers two advantages, though: First, it shows it can be inappropriate to encourage parents to keep a severely disabled child at home (TOWNSEND), therefore, programs of action should aim at development of the child rather than at changing decisions and attitudes of parents. Second, FOTHERINGHAM concluded by pleading for parents to be relieved for variable lengths of time by an array of respite services.

This goal has been achieved to a certain degree in the U.S. in recent years. In France, professional outreach is never offered in isolation, but always in connection with a specialized outpatient clinic. Therefore, the impact of outreach programs cannot be evaluated in isolation either. However, two works are interesting:

- STORK and FOUCHER (1979) conducted an evaluation of preventive action in an Early Medical and Social Action Center (C.A.M.S.P.) working with children under six, in a poor suburb, in complete collaboration with local children's services. In this program the Mother and Child Protection Agency (P.M.I.) contributed by sending infant care specialists and social workers into the homes to help young isolated mothers with children. This kind of "integrated" action in the community, still rare in France, was viewed by families as helping them feel secure and offering no need for unwarranted psychiatric intervention. The long-term results were evaluated with the criterion of prevention of school problems among the children (more than two years behind their age group). Comparing three groups of 100 children, the authors observed that 57 percent of children whose parents did not receive any help did poorly in school while only 20 percent of those who received help, and 14 percent in the general population of the same age had problems.

- The first "home education action" created in France for multiply handicapped children (their main handicap being severe mental retardation) was studied in 1974 (CESAP, 1974). This qualitative study accurately describes the goals and limitations of that kind of intervention from a diversified team which includes a house helper for practical support to the mother, as well as an educator or a physical therapist. The main advantage is that it breaks up the isolation of mothers by offering them again an interest in expressing themselves, and helps them establish social contacts outside the home. The other objective is to bring educational stimulation and useful care to the child without overloading the mother, by allowing her to be more available to her other children and to her husband. The only limitations are practical ones, e.g.

this action cannot be undertaken on a large geographical scale, as it would be too time-consuming for those involved, and it is too expensive for Social Security. In France *Securite Sociale* is a State health insurance program which pays unlimited medical rehabilitation, as well as health care services. Therefore, it is limited to *three to five hours a week* for each family.

On the other hand, this home educational action creates close relationships, intimate sometimes, between families and team-workers. It needs the permanent support of the multidisciplinary team of the out-patient clinic so that the personal needs and rights of each disabled child, family, and worker, can be respected.

*To conclude:* Workers of the 70's have shown that parental guidance has evolved towards more diversified objectives and means. First, by aiming at preventing psychosocial handicaps as well as compensating for physical ones COWAN and BRENTON (1975); Second, by integrating the different kinds of available help services - out-patient clinics, outreach, prevention programs such as temporary foster homes (RAYNER, 1978 and HORSE, 1979).

## **PARENTS AND PROFESSIONALS: RELATIONSHIPS IN CONFLICT**

### *Professionals become aware of the conflict*

Parents' voices were the only ones heard until recently describing their conflicting relationships with the different professionals working with their children. By the late seventies professionals in France showed concern for this problem, perhaps even earlier in the U.S. The 1975 Act in favor of disabled persons might have been a determining factor in this development in France. The law requires that parents, professionals, and administration services representatives jointly plan goals and financial help for the disabled child and his family. Even if this requirement is not absolutely respected, all concerned persons are aware of it. In some instances it stimulated conflict between parents and professionals, forcing them to think about how to cooperate to attain the purposes of the legal requirement.

DURNING (1980) expressed his surprise at observing "the violence in educational or therapeutic teams' attitudes towards parents." As a linguist, he analyzed semantic expressions of the conflict, e.g., when social workers show an interest in the disabled child's parents, they often speak of working "on" not "with" the family.

LAZAROVICI (1978) speaks in behalf of pediatricians and child psychiatrists of the role that the physician should play, if he were aware of it, in helping prevent the risk of the young child becoming psychotic. He could help reorganize the mother/child relationships if he knew that "sometimes the parents create the psychosis, sometimes they are driven into insanity by the child." This is a first step toward changing the stereotype of the "pathogenic mother."

KEIRN and ANDERSON (1971) in the U.S. in the early seventies studied

one of the parental behaviors which, along with denying the handicap, annoys professionals most - their shopping around for medical advice ("shopping parents"). KEIRN studied 218 parents of mentally deficient children and found that less than 3 percent ask for the advice of more than three different physicians. In some instances the "shopping" was motivated and justified by a vain search for the proper treatment of very severe behavior disorders. He views this so called "shopping" as a stereotype about parental behaviors, symptomatic of the conflict between parents and professionals. ANDERSON believes that the physician's attitudes during the initial consultation may not allow parents to express their pain freely and also may not convey to them that he will be available to them in the future.

BRAUNER (1978) analyzed relationships between parents of autistic children and professionals. He observes that they are more conflicted in France than in the U.S. and that the influence of BETTLEHEIM in France might have something to do with it. Concerning this "shopping" around for physicians, a specifically French development - consulting "quacks" - is discussed in this work.

### **Mechanisms of the conflict**

Misunderstood popularization of the psychoanalytical concepts of "death-giving mother" or "forfeiture of the father's name," is viewed as responsible for the conflict by many French writers. BRAUNER (1978); DURNING (1980).

In other works which explored the conflict:

- HOFFET (1980) studied "interactions between parents and a psychotic child in a day-care hospital" in Switzerland, he analyzes tensions that develop between the "family" group and the "team" group, with the child at stake. The affective rivalry he describes between the two groups sometimes starts with the first contact and is extremely frequent in institutions where the child spends part of his life. This rivalry is reminiscent of "Solomon's judgment" and often leads to rejection or fault finding prejudicial to the child's development.

- SOULE and collaborators (1978) conducted a thorough analysis of the ambivalence of mothers of premature or psychotic children, wishing for amelioration and death at the same time. They observed the same ambivalence in the multidisciplinary teams of institutions such as neonatal hospital centers, or day-care hospitals. They view this "maternalization" of professionals as the source of the conflictual relationship between parents and professionals. The unconscious process of "maternalization" of the professionals tends to be "unspoken" also. This risk points to the need for personal awareness training as part of the training of professionals. (MORVAN, 1977 and ZUCMAN, 1978). Furthermore, the collective work of analysis and control of attitudes by which this "maternalization" could come to the awareness of individuals and teams rarely has been undertaken and done successfully, because it requires such a difficult blending of a psychoanalytic understanding

and a real respect for the persons involved - professionals and parents.

-CAGLAR (1974) and CAHN and collaborators (1974) specifically describe the effects of counter-transference. When it is "uncontrolled," it can lead the therapist to a chronic attitude of superficial support which increases the parents' dependency without actually helping them, or it can lead the therapist to aggressive reactions of fear or rejection and to the break-up of his relationship with the parents.

-CAHN and collaborators describe the frequency of behaviors considered pathogenic in 27 mothers of psychotic children in day-care hospitals. Half of the mothers are seriously disturbed and non-available (whereas fathers are described as simply unobtrusive (10), anxious (7), or occasionally as psychotic (2). Confronted with the severity of the mothers' disorders, CAHN is nonetheless aware of the possible devastating effects of the psychiatrists statements on some parents. He also wonders about the role played by the counter-transference of professionals and attempts to analyze it. He notes that the feelings of professionals are indeed ambivalent and painful. They feel that they are not acknowledged by the disturbed mothers who can be anxious and aggressive; but at the same time, professionals feel attracted by mothers' bizarreness.

*To conclude.* As ROUQUES (1975) proposes, "giving up the will for power" should be an absolutely fundamental objective for professionals and should be emphasized during training as well as in daily practice. This can be accomplished if the professional in training and professional in practice can learn that their exclusion of parents arises from the ambivalence experienced by the professional: the fear of and the desire to regress with the psychotic child, an ambivalence which seems to trigger undefined or even omnipotent attitudes toward parents.

## **PARENTS AND PROFESSIONALS: MUTUAL HELP**

### *Sharing tasks and respecting roles*

EVANS (1978) analyzes the Swedish model of "sharing the caring" between parents and professionals. Children of all ages and with different disabilities are received on a temporary basis, in small groups, in apartments in the city. This relief to the family avoids long institutionalization. This model gives parents an opportunity to modify the choice between their isolation at home and the long institutionalization of their child. This Swedish "experiment," also exists in the U.S. and France. In England, as the HONEYLAND adaptation of this program (RAYNER, 1978) has shown, long stays in institutions are three times less frequent. Both parents and professionals are well satisfied with this flexible and small-scale model of vacation from the family in which the role and place of each are respected.

Mc KENNA (1978) shows that it is possible to respond to the development of parental expectations by encouraging a more active role as soon as early

education programs are set up. He surveys very different types of programs, designed for the physically disabled, the psychosocially disabled, and dyslexics, as well. He insists that the results do not depend only on the quality of parents' initiation to the educational programs in which they will take part, but also, and even to a greater degree, what they will bring back to the therapists about the changes in their own interactions with their child which they are instructed to observe. The active role allows parents to combat the guilt feeling generated in their environment.

During a symposium on *Relationships Between Parents and Professionals* held in Denmark (REAP, 1977), it appeared that appropriate information given to the parents at the time when they were told of the disability of their child was the best guarantee of an active parental role. SCHOLPER (1978) explains also that "a frank sharing of all information with the parents allows them to exercise their responsibilities, whereas secrecy increases their anguish and isolation."

During that same symposium, MAERTEN (1977) confirmed that it was possible to respect the parental function even when the child was institutionalized. With other physicians in France (SATGE, 1976), and VILLECHENOUX-BONNAFE, 1976), he proved that the more parents are involved, physically as well as morally, with the institution, the more favorable to the child the role of the institution.

### Parents as co-professionals? Yes, but to what extent

Many works have been completed or evaluated in England and the U.S. during the seventies which aimed to reinstate parents to the position of responsibility of which they had been deprived. These programs were so successful that "parents as co-therapists" or "educator parents" are now being talked about.

The most interesting programs, from our point of view, reinstated disenfranchised families in the U.S., through programs such as HEADSTART, in their roles as active citizens in their communities. SCHEINFELD and collaborators (1970) found that educational programs tailored around the specific values of the disenfranchised families yielded beneficial results. The benefits extended to the siblings, and even to neighbor families. Such results are due to two specific principles which also inspire the program "Help to All Distressed" geared to the "fourth-world" in France:

- flexibility on the part of intervening professionals so that they can temporarily put the educational program aside in order to resolve concretely a specific crisis;
- individualized action according to each mother's interests, which allows her to be more active and to build her own parental ability and positive self-image

However, "professionalism of parents" should certainly be limited. As

with the "maternalization of professionals" mentioned earlier, the "professionalism of parents" can lead to a confusion in roles.

GATH (1979) reviews the pros and cons of different programs which encourage parents to play an active role. He points out that if programs develop too fast or inadequately, they risk being mimicked by parents as mere "recipes" on which they could become dependent.

DOERNBERG (1978) raises another problem—that of the possible negative effects of excessive therapeutic demands placed on the family by intervening professionals. He describes how perfectionistic professionals who require the mother to focus exclusively on the disabled child may neglect siblings and the family unit. The author suggests that professionals must guard against personal involvement which leads them to provide care for *their own personal satisfaction*. By accepting a technically not-quite-so-perfect result, the cost to the family's well-being might be reduced.

DOMAN (1980) provides an example of what should be avoided. In the first place, he professionalizes the family completely by entrusting them entirely with the implementation of the habilitation program; secondly, he imposes upon them an extremely difficult, if not impossible, program which requires the mother's participation for seven to nine hours a day, with the fallacious hope of curing the brain-damaged child. There is only one explanation for the extraordinary success of this method. The families feel unconsciously that they have to "make up" for having given birth to a disabled child regardless of the personal cost. This is dramatic proof of the strength of "invisible loyalty."

*To conclude.* Collaboration between professionals and parents developed rapidly during the seventies, bridging the conflictual gap that had divided them. This development corresponds with the recent desire of individuals in developed societies to be responsible for their lives—thus, the development of consumer advocacy. However, SCHOU (1977) believes that recent progress does not yet offer a solution to three types of problems:

- Disclosure of the fact of disability (as long as physicians have *not* been trained to listen) in a way which *adds* to the suffering.
- Passage of disabled teenagers into adulthood is often badly handled by parents who are not properly informed and supported (TURCHIN, 1974). It is a time when they relive all their primary anguishes, aggravated by the fear of their own death.
- Aging of parents and their anxiety about dying before their disabled child is the third problem; and the absence of quality services for disabled adults accentuates this last problem.

## FAMILY THERAPY AND PARENTS' GROUPS

Two approaches which, in terms of the involvement of professionals, seem to be in direct opposition to each other both emerged rather recently. Family



therapy, initiated and conducted by professionals, recognizes the family as the important network, however, parents' groups, initiated by parents themselves, see power in the network of a community of people with a common problem.

### Family therapy

In the last ten years much has been written in both French and English about family therapy. Family therapy is based on the concept of the "designated patient" whose role is justification for the disorder in the family system. Does this mean that a child whose disability "designates" him the *revealer* of pre-existing investments and conflicts in the family must *a priori* be "designated patient?" Family therapists need to be aware of the crystalizing function of the disabled child within the family group.

CRAMER (1974) practiced "brief therapeutic interventions with parents and children" offering qualities which, although faded somewhat with the intensive development of family therapies, still have value today. These are: a need to escape analytical purism; the power to prevent distortions in the parent/child relationship, and the double "economical" interest of this type of intervention, due to its brevity and its power to individualize each family member in relation to the others.

WALKROND-SKINNER (1980) clarifies the bases of family therapy that could interest all professionals concerned about parents of disabled children:

- Family therapies are grounded in psychoanalysis and in general systems theory which emphasize the importance of "feedback" in interactions (implicit in the relational impact of a disability).

- The therapist, with his personality and responsiveness, is *part* of the group he treats.

Although WALKROND-SKINNER insists the therapist must "make good use of oneself," she knows how difficult it is to "make flexible and mobile use of one's personality." She indicates that the presence of a "third observing party" protects this mobility, just as a third-party is needed to protect the family of the disabled child from the risk of rigid or symbiotic relationships.

The original concept of "intergovernmental loyalty" - BOSZORMENYI-NAGY (1973) is helpful in better understanding the interactions which take place around the disabled child. It could help professionals free themselves, and free the parents, from the stereotyped dialectic of "reject/overprotection."

The work of FRENCH (1977) is a good example of the difficulties encountered when trying to give family therapy an objective methodology; these same difficulties are actually encountered with all other types of interactional therapies. The model proposes four criteria (anxiety, ability to change, designated support of the symptom, power) for the analysis of the interactions in the family group, it also could probably be applied to other types of conflicts. Unfortunately, we doubt, as the author does, that it could become part of the

daily practice of therapists who are concerned, with good reason, about their own ability to mobilize and change.

## Parents' Groups

PARFIT (1971) selected 30 of 100 experiments conducted with groups of English parents. From his synthesis of studies of these groups of parents of disabled or chronically ill children he drew several conclusions.

What emerges is that the help available in these groups is flexible and fulfills the objectives:

- an "economical" distribution of technical and psychological help is useful to parents.

- the creation of interparental solidarity can prepare them for associations.

PARFIT also emphasizes the great potential that parent groups hold for groups of adoptive parents, to "foster homes," to socially disadvantaged families, as well as to parents of young delinquents or of children with personality disorders.

JEAMMET (1980) observed an open group of parents of adolescents with anorexia nervosa. He found group support develops through the different following stages: First, there is a distribution of roles in the group, then, parents recognize one another in a mirror-like structure, and this helps improve intrafamilial relationships. Finally, they give each other support, acting in some way as each other's therapists.

DUNST (1976) compared the outcomes of homogenous and heterogenous groups of parents and children. He found that disabled children and their parents develop more strengths when they are mixed with non-disabled members. This study confirms our reservation toward all educational or medical structures limited to one condition for the sake of homogeneity.

Three other studies concerning groups of parents of mentally deficient children, each dealing with a specific aspect, are of interest:

- BIDER and collaborators (1975) compared two samples of mothers of Down's Syndrome children, ages 1 to 3. One of the groups received help from an educational guidance program with discussions about techniques and family interactions. Mothers derived personal well being from the discussions and their expectations towards the child were modified. The Down's Syndrome children made significant progress in language acquisition and body image, although no improvement was observed in their sociability. Such encouraging results led to the idea of extending this program to C.P. children in the hope of making up for the lack of educational settings for these pre-school disabled children.

ATTWOOD (1978) shows that groups of parents can fulfill three objectives. they allow their children to improve and the parents to adjust better, besides, they put them in a better position to take advantage, of their own ini-

tiative, of the services available in their community.

To conclude. Families, therapies and groups of parents stem from a similar objective, to improve relationships and the well-being of families. They are quite different forms of assistance and should not be confused with each other.

## ROLE OF PARENTS' ORGANIZATIONS

Most of the parents' organizations evolve from the initiative of parents rather than from that of professionals. Some authors observe that when parents become involved in developing parents' organizations, it increases their social competence and this may be a factor in influencing the disabled child's sociability (SINSON, 1978 and BIDDER, 1975).

### Successes and problems of the activities of parents' organizations

The basis for this analysis will be the studies published by the three main French associations:

- The Association of Paralyzed Persons of France (1970) was created in 1933. It has 80,000 members, mostly adults whose disability is the result of an accident. It manages 112 institutions.

- The National Union of the Associations of Families and Friends of Mentally Disturbed Persons (U.N.A.F.A.M. #123) was created in 1963. It has 6,500 members, mostly parents of psychotic adults. It does not manage any institution directly.

- The National Union of the Associations of Parents of Disabled Children (U.N.A.P.E.I. 1975 #124) was created in 1960. It has 62,000 members; the majority are parents of severely retarded children. It manages directly many educational and vocational institutions (about 1,300); parents help to originate these centers. Parents, members of U.N.A.P.E.I. created most of the private specialized educational and vocational day-care centers for children and teenagers in France. The sheltered workshops and residential houses were built for adults.

These three large national associations plus about 25 others created more recently for other disabilities (blindness, deafness, C.P., spina bifida) and other chronic diseases (diabetes, congenital cardiopathy), federate their local and regional associations. They share successes and difficulties about which they speak with a great concern for objectivity.

Their effectiveness is recognized at the collective and individual levels as well. Collectively, they are regular speakers to government and public institutions. Starting with the 1970s, parents' opinions, as expressed through these associations, have been taken into account in the National Disability Act legislation. Some would view this success as that of political power.

Their individual efficiency is seen in mutual help and solidarity. At the most difficult moments (revelation of the disability, passage to teen-years or

adulthood, decisions about institutionalization) there are things which are said better, and accepted better, between parents, than if they came from a professional, no matter how sensitive. Also, association life gives every parent the opportunity to go beyond his *own* suffering while attempting to restore his own self-image.

Difficulties arising from diverse individual association actions remain important, in the collective and individual realms as well:

- Each association is specialized, up to now, around a single type of disability. This is divisive and can be especially detrimental to parents whose children have an unspecified disability, or whose children eventually show signs of a second disability.

- Excessive association proselytizing sometimes leads parents to "professionalization" or to being unavailable to themselves, their spouses, and their disabled child and his siblings - and this is detrimental to familial equilibrium.

- Finally, relationships between parents involved in the association and professionals are often controversial. In their functions as managers, parents are often criticized by professionals for their lack of objectivity and for influencing the organization of the institution they manage according to the specific needs of their own child. On the other hand, parents often feel that the institution which their association created betrays its goals because of the now overwhelming influence of professionals. This creates a smokescreen between themselves and their child.

HUDSON (1978) conducted a very interesting sociological study of the functioning of an American parents' association, with 1,500 members and an annual budget of \$300,000. Its goal is to provide volunteer help in the homes of families with mentally deficient children (respite care). The author defines the criteria by which parents were able to retain initiative and active behavior and avoid being dominated by a few leaders. Their success is due in part to the following factors:

- Parents make decisions regarding admissions.

- Salaries are not proportional to the amount of work performed.

- These services are not intended to last forever, but must be taken over by the community as soon as possible.

An organizational model such as this seems to allow for a better integration in society of the parents and their disabled child, and the author suggests that it could be valid for other kinds of actions.

### **Parents' Associations and Information**

It has been noted several times in this analysis that lack of information makes the anxiety and isolation of parents of disabled children worse. Therefore, it seems natural that parents' associations concentrate their action on the development of information in France and abroad. There are numerous ways of enhancing the dissemination of information:

- Meetings and committees are organized on a local, regional or even national scale.

- A specific publication by each type of association serves as a link between its members and provides an avenue for reporting one's experiences, feelings, and reflections. Such publications are useful to professionals too. They contain practical information on legal rights of disabled persons, on ways to create institutions or services, and they describe the activities, background and working conditions of the association's employees.

- "Handbooks" which are very useful to isolated parents are often published and distributed. An example is the *Guidebook of Disabled Persons and Their Friends* by LEIBOVIGI (1978), the director of U.N.A.P.E.T. (National Union of the Associations of Parents of Disabled Children). The same parents' association asked two physicians R. and O. SÅLBREUX (1979), to write a handbook for their medical colleagues to try to fill the gap in training French physicians about problems raised by *Mentally Disabled Persons, Others and Us* (1979).

- "Training" parents for interparental support. This action is very careful to avoid "professionalization" of parents, but rather tries to make them aware of risks inherent in interparental action - for themselves (power, projection) and for the young parents they address (identification, dependency).

- Training new categories of intervening professionals: auxiliaries, volunteers offering help at home, medical and psychological helps for daily life in institutions.

*To conclude.* Parents' Associations seem to perform a regulatory role in the system of help to disabled persons.

On the one hand, they emphasize problems unresolved or poorly resolved. Presently in France they play precisely this stimulating role about multiply handicapped children, mildly deficient teen-agers, and all disabled aging persons.

On the other, by the very virtue of their numbers, they remind everyone that even if professionals are always desired and always desirable "third parties" for helping the child evolve and his parents retain a social life . . . conversely parents must remain the always present "third parties" in their real as well as imaginary parental function, for the child and the professional as well, so as to avoid a second "maternalization" (turning professionals into mothers, in a negative sense), just as painful as the first one.

## CONCLUSION

At the moment of concluding this critical analysis (admittedly somewhat dense), of some works published during the seventies about "Disability and the Family," I would like to propose some possible answers to my working hypotheses and suggest fields for future research.

## ANSWERS TO WORKING HYPOTHESES?

- *The very existence of an added handicap for the family has been confirmed by a number of French and foreign works: the violence of the revelation, the solitude of families, their social isolation, all add suffering.* However, parents and professionals have grown more aware of the repercussions of this *added handicap* on the development of the disabled child; they also have become convinced that it does not have to be so. Indeed, flexible and diversified collaboration between parents and professionals is becoming more efficient in the prevention and treatment of the added handicap, and in the prevention of psychological and social risk as well.
- *Did "theory" slow things down? Has it evolved?* It seems to me that this analysis offers a positive answer to these two preliminary questions. The misuse of certain psychoanalytical concepts has indeed slowed things down, this is a known fact; and it seems that this hindrance can be avoided.
- *Do cultural factors play a part in the impact on the family of a disabled child and in the attitudes of professionals?* My reading of some works referring to the cultural context, allowed me to realize how imprudent, even impudent, an oversimplified question as this one can be. "Culture" certainly cannot be reduced to one entity, and the infinitude of its ethnic, religious, historical, and economic... elements cannot be mastered by a non-specialist such as me. However, from these readings I retain the impression that *this unresolved question remains a very stimulating one* - its many aspects in my daily practice bears witness to this impression - it might be that differences are at play in educational values and the concept of the family group, but the impact of these differences on parents and professionals is in any case probably less important than.
  - the impact of an underprivileged social situation
  - the impact of the personality of each involved partner
  - the impact of the unyielding *violence* imposed by the disability

## FIELDS OF FUTURE RESEARCH

The analysis of some works published during the seventies, suggests many questions that many medical and research professionals are already investigating. We will limit ourselves to listing a few of these questions, following the outline of our analysis:

### PARENTAL ATTITUDES AND CHILD'S DEVELOPMENT

- Can the concept of invisible loyalty be applied to interactions between parents and disabled children, to interactions between siblings, as well as to interactions between generations?

- Is it possible to prove that disturbances connected with a maternal deprivation can be reversed?
- What immediate and long range future possibilities lie ahead for children of disabled parents (motor handicapped, psychotic or mentally deficient parents)?

### *REPERCUSSIONS OF THE DISABILITY ON FAMILY LIFE*

- How can the "added handicap" caused by the disclosure, be avoided? - e.g., study of the training of hospital staff and professionals
- Looking at reasons for resistance to information. - Organization and control of information networks in the hospital
- What are the repercussions of the child's disability on his parents' sexual and emotional life?, e.g., - Analysis of resistance to Genetic Counseling
- What is the importance of the "unspoken" that surrounds disability its mechanisms, its familial and social impact?
- What is the role of prevention played by the social "third-party."
- What could be and what is actually the role of grandparents? e.g., - Advantages and limitations of intergenerational loyalty and solidarity.
- What are the repercussions of the disability on siblings? e.g., prevention, importance of the rank order of the disabled child among his siblings, "differential vulnerability," educational function of the peer group and its influence on future social integration, for the disabled child and his siblings?
- What are the repercussions of poverty on access to legal rights, medical care and education, for the disabled child and his family?

### *HELPING PARENTS*

- Is there a real change of objective? Does present help avoid dismissal of parents and offer support instead?
- Study of the "maternalization" of professionals (mechanisms, dangers)
- Roles, self-images, attitudes. their impact on the parents/professionals' exchanges.
- How can parental help be adapted to the passing of time. what becomes of the disabled adult; the aging parents of a disabled child?
- What are the mechanisms of interparental help? (Contributions and limitations of the professional in preparing and providing support)
- Study of the information on disability for parents and professionals. its use, its rejection and perversion. How can general information and respect for individuals be combined? How can specialized vocabulary be protected from wear and tear?
- How should training programs for professionals and non-professionals be modified (specific training, basic training, continuing education,

multidisciplinary training, technical training, personal training)?

Some of these subjects have already been dealt with in the works we analyzed. Others seem more novel, most are multidisciplinary. All seem important if one wishes to see families and professionals engage in harmonious, helpful relationships which will lead to the well-being of the disabled child or adult.

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## COMMENTARIES: U.S. PERSPECTIVES

### COMMENT ON CHILDHOOD DISABILITY AND THE FAMILY, BY DR. ELISABETH ZUCMAN

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I am pleased to have the opportunity to comment on Dr. Zucman's fine monograph which pulls together many interesting resources and ideas on the topic of disability and the family. We in the United States have too few contacts with our fellow professionals in Europe and too little information about their work.

My comments will be focused primarily on the third and final section of the monograph, "Helping Parents." My own experience comes mostly from contacts with deaf children and their families. Their situation has both similarities and differences to families whose children have different kinds of handicaps. However, one thing which does cut across disabilities, I believe, and which makes parents' response to the diagnosis of the handicap very difficult, is the broad area of ambiguity existing in the recognition and diagnosis of childhood disability. Where deafness is concerned, the ambiguities lie in the extent of residual hearing, in the child's frequent response to vibrations that mask inattention to sound, and to the inability of very young children to give information to diagnosticians. These ambiguities frequently contribute to parents' uncertainties in dealing with professionals, and to their "shopping" during the prediagnostic period (Meadow, 1968; 1980). Freeman (1977) reports an average diagnostic delay of almost ten months for profoundly deaf children and more than sixteen months for children with lesser hearing losses. Parental "shopping" becomes more understandable in the context of such extensive ambiguity.

Dr. Zucman's comments on the need for mutual sharing of tasks and respecting of roles between parents and professionals are particularly cogent. The dangers of "professionalizing" families, thereby denying them their rights to *enjoy* their children are certainly rife in our experiences with parents of deaf children (Schlesinger & Meadow, 1976). Sometimes the seeming resistance of parents to the introduction of rehabilitative mechanisms is a reflection of continuing mourning of the loss of the desired "normal" child. We have come to believe that the cognitive abilities of hearing parents for learning sign language are not fully available until they have been helped to come to terms with the grief and sorrow around the diagnosis of deafness.

Dr. Zucman discusses a variety of "agents" who can be involved to help parents in their adjustment to the child's handicap, and in learning about how



to cope with it. One group that might be added to the list is that of adults who have themselves dealt successfully with their disability. Utilization of such individuals can be helpful to professionals as well as to parents, enabling them to avoid some of the pitfalls described by Dr. Zucman. For example, including disabled adults in meetings of parents of disabled children insures that the meetings will be "accessible" to the disabled parents, and sensitizes both parents and professionals to the use of language. It is necessary to use care in selecting disabled adults for this role, however, since the progression of parents from one phase of acceptance to another is sometimes slow and painful. Insensitive persons can accelerate parents' feelings of being inadequate to the task of helping a handicapped child, sensitive persons can demonstrate the possibilities as well as the problems that await a young child with a disability.

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## BETWEEN EARTH AND SKY: COMMENTARY ON CHILDHOOD, DISABILITY AND THE FAMILY

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Dr. Zucman merits our congratulations. Her review of the literature is always humane, insightful, and intelligent.

Dr. Zucman also merits our thanks. She explores a section of the terrain of French psychology, psychiatry, and psychoanalysis - a terrain sometimes profoundly unfamiliar to Americans. The French tradition she presents and through which non-Gallic pieces are refracted is different in sensitivity and emphasis from what may be our habit. She takes these works seriously; serious attention, if not acceptance, is obligatory on all concerned parties.

Dr. Zucman, then, is to be congratulated and thanked. Hopefully, she will

be read as well.

However, or so it seems to me, Dr. Zucman's descriptive program has certain inadequacies. Let me attend however briefly to one of them.

One of Dr. Zucman's goals is to improve the interactions between professional and patient. One wonders whether this goal is well served by studies of the sort that she reports,

Admittedly there are psychological nuances. Admittedly too, in certain instances, nuance can dominate. Yet, or so it seems to me, certain mundane facts must be attended to before psychological soaring.

For example, there are just twenty-four hours in a day. Further, the order of events is critical. The family with a handicapped child is more pressured by the time and sequencing of society than are many other families. Appointments are set at the convenience of the professional, sequencing defined by professional authority, and issues recognized as problematic in the first place only with professional endorsement. If time and sequencing have contributed to the distortion of all families, warping them ever more to the psychological, legal, and professional, then can we not expect the warping of a family with a handicapped child to be, at least as profound?

Money and power are certainly relevant. In general, the family of a handicapped child is likely to have less than the professional. But, this is to distort the point, which is whether the money and power possessed by the individual family exceeds that of professionalism. The answer must surely be no. Even in cases where money and power are at a level sufficient to command, services and resources rather than treatment or program are rare.

Consequences follow. The primary work of the parent is to be a parent. To the extent that the parent is regarded and treated as an infant, patient, or troublesome, how is the handicapped child to regard that parent? To the extent that the handicapped child is monoteknically treated as patient, childhood is inevitably diminished. To the extent that the professional isolates the situation of handicap from society, meaningful participation in society is reduced. The medical dictum, "Do no harm.", of half a century ago is still applicable to the situation of the handicapped child.

The concepts "professionalization" and "maternalization" are interesting and meritorious. But almost certainly they lend themselves to abuse. Although there are distinctions between a maternalized professional and a caring one, it is dangerously easy to confuse the two. What holds with professionals holds doubly with patients. American experience at least has shown that in order to be simply a parent, the parent of a handicapped child must frequently become something of a professional in medicine, education, etcetera.

Indeed, social advances in the situation of handicap are linked with the thought, action, and power of parents, handicapped people, friends, professionals who have changed it in no small measure by changing public policy. In the United States, one thinks of Section 504 and Public Law 94-142.

Dr. Zucman suggests that similar thought, action, and power have affected French policy, which, in turn, has effected the situation of handicap in France. And in the same decade that it was happening here! It is easy to understand the diffusion of blue jeans and the events of the Sixties, it is another matter to comprehend how perhaps similar diffusions occur in the domain of disability.

Psychological refinements are very nice. Further, they may be necessary to comprehend the situation of handicap. Yet, as matters stand now, they are in fierce danger of being abused. It is usually not to the psychology, prejudice, nor ineptness of either parent or professional that we owe the painfulness of their interaction. In some significant measure this interaction is rendered difficult by the social situation in which both parent and professional are embedded. Matters of social situation are frequently quite mundane. It is no small part due to the realization of mundane matters like those sketched above that the situation of parents with disabled children is changing for the better.

While admiring the soaring of the Concorde; let us not forget the earth. It is between the earth and the sky that families with disabled children live.

## COMMENTARY ON CHILDHOOD DISABILITY IN THE FAMILY: THE "ADDED HANDICAP"

Gaston E. Blom, Martha Karson and Marsha Worby\*

The monograph, *Childhood Disability in the Family* by Elisabeth Zucman, addresses the psychological experiences, problems and needs of families with children disabled by a variety of impairments. Common issues for these families are organized into three major themes: 1) parent behavior in relation to child development, 2) repercussions of disability on family life, and 3) helping parents. In addition, a central feature for the family is its relationship with professional helpers, particularly physicians and educators. Zucman examines this feature as a potential "added handicap" when a psychological gap exists between parents and professionals. The gap is created by those professionals who negatively stereotype parents as rejecting or overprotective, who disclose and withhold information from them without sensitivity, and who either over-professionalize parents or compete with their parenting functions.

Zucman shows a sensitive concern for consumer interests with professional providers and alerts us to the theoretical frameworks and traditional practices which bias the professional negatively towards parents. She points out that a "third person" can be an important mediator and source of support

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and information to the family and its handicapped member. This third person can be a professional, a family member or a non professional outside the family. Parent associations can assist in these functional roles.

Disability in the family can be understood and approached professionally from different yet overlapping levels of analysis. 1) individual intrapsychic perspective, 2) dyadic interpersonal relationships and 3) a total family system view. All these levels interact with and influence the social system. Caregivers in the society need to be sensitive and aware of the difficulties at all these levels. We should also attend to the interaction between the care given and the handicapped person and her/his family and to the need for appropriate advocacy. But we must also go further and find ways to enhance the quality of life for the total family.

A family systems view of disability invites attention to how family members influence and are influenced by the behaviors and disability of any member as well as the behaviors of professionals and social institutions that interface with the family. For example, a family with a parent having multiple sclerosis is often referred to by a professional as a multiple sclerosis family, fostering a handicapped family identity. Furthermore, adults and children with disability are frequently not talked to directly by others for information and requests, a spouse, parent or other able bodied family member may be spoken to instead and may often inappropriately speak for the family member who is disabled.

In a family system perspective, a three-generation view should be reflected in professional practice since reactions to a previous disability in a grandparent may be relevant in the parent generation as they relate to their own child with a disability. Family reactions to disability are also influenced by the age and developmental stage of individual and family life when the disability occurs. Reactions are typically re-opened and re-settled with movement through the life cycle.

In the Zucman monograph, some discussion is focused on children in families with disabled parents. This phenomenon, while insufficiently studied, is receiving some attention as society attempts a more adequate response to the civil and developmental rights of persons with disability. By developmental rights one would include sexual expression, marriage and the bearing and rearing of children. However, when concern is expressed about the psychological gap between professionals and parents of disabled children, then that gap is further widened when the parents have disabilities themselves or were disabled children and are now adults who have, care for and rear children. The gap is fostered by a professional bias of pathology-seeking and finding in reports on both the children and their parents with disability.

Zucman reviews a limited and selected number of published studies on children born of parents with disabilities such as serious emotional disturbance, physical impairments and conditions such as immigration and ex-

perceiving the Holocaust. She concludes that no specific or systematic pathological influence on a child's development and adjustment appears to result from a parent's disability. Rather, she is impressed with the strengths from the resilience and plasticity of children, their utilization of positive family and environmental resources and the harmony achieved between children and stable parents who have a disability.

However, without a pathological bias one can usefully examine the psychological influences and effects on the child of parent disability factors. Issues of time or occurrence and the extent and type of physical and psychological dysfunction and limitation are important. There are also additional family system variables such as the developmental stages of individuals, couple and family.

In assessing the impact of parents with a serious emotional disturbance on their children, it is important to recognize that the parents are not psychologically upset twenty four hours a day, seven days a week, for twelve months a year. The idea exists that, when somebody is evaluated who is seriously disturbed, this represents their usual way of behaving and relating in all situations. When people with disorganized behaviors are observed naturalistically, they are not disorganized all of the time. They have areas and times of adequate adaptation and may function well as parents with their own children. Some spare their children from being recipients of their disturbed behaviors. These phenomena do not go unnoticed by children who can make use of their own reality testing of their parents' reasonableness and emotional accessibility. A child may act as a parent towards his/her own parent, i.e. parentify, and gain strength thereby. In fact, Garnezy, Bleuler and Mednick have found in longitudinal studies of children with schizophrenic parents that the great majority of such children adjusted well in both later childhood and adult life.

The few studies of children with parents having severe visual impairment, deafness or motor disability do not point to parental inadequacies and child maladjustment as the literature of opinion militates. What is needed is reassurance to parents from professionals that their disability will not adversely affect their parental competence and their child's development. Children also need information and opportunities to talk about their parent's disability. Again, professionals need to consider family system issues. This is specifically illustrated by Zucman's report of a study from Peru of different family reactions to motor disability in parents. The nature or severity of the disability did not seem to matter, while the typology of family interaction did. Three types were identified: despotic, patriarchal and democratic. The democratic typology was associated with better tolerance of the disability.

In spite of social progress in the civil and developmental rights of disabled persons and of the few positive outcome studies of families with disabled parents, views on the negative influence of disability in parents on children are prevalent. Professional prejudice tends to support the opinion that adults with

disabilities should not have children, or if they do, they are not adequate to care for and rear them without negative influence. This prejudice is related to the "added handicap" of the professional-family gap which results in unfavorable repercussions of disability on family life. Fortunately, social trends are in the direction of active respect and support for families with disabled children. These trends are not only human, but decent and just.

## **The Summer Family Conference: An Adventure in Counseling Families with Handicapped Children**

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Since 1968, United Cerebral Palsy (UCP) of New York City, Inc., has conducted a Summer Family Conference for members of families with young handicapped children living in the New York City area. The purpose of this conference is to provide an orientation and counseling session for families who are just beginning to face the lifelong problems of caring for a disabled child in the home. Each year approximately 25 to 30 families representing between 150 and 175 family members attend this conference from all sections of New York City. Conducted on the campus of Monmouth College in West Long Branch, New Jersey, the conference has proven to be a most outstanding and effective counseling program for families of the handicapped.

Families and children in the largest city in the United States find unrelenting circumstances battering their lives on a daily basis. Economic, racial, and complex social problems are a constant backdrop to life in this metropolis. In addition, a large percentage of the population do not speak the English language and are from alien cultures. These circumstances compound the already existing problems of families with handicapped children. How do the families of handicapped persons link up with a community agency and the essential services it provides? How can a family know what it must do in the home to provide the optimum environment for the development of the handicapped child? Is it just mother, or do other family members have a role to play in the adjustment of a handicapped child in the home? These are but a few of the many questions which must be faced as families of young handicapped children prepare to help the child. Maintaining any kind of normalcy under these circumstances is difficult at best.

In 1970, a significant program was undertaken by UCP of New York City, funded through the U.S. Office of Education. This was a project to develop a demonstration "Early Education Program" for preschool handicapped children. It was one of three such demonstration programs in the country and

was designed to experiment with techniques leading to more suitable education for young handicapped children. Early in the project the question of how the family should be involved was raised. What initial steps should be taken to provide for family orientation and subsequent involvement in the rehabilitation process? Experience had taught us that holding monthly meetings among interested parents was too limited. Often, more questions were raised than were answered and parents found that the subjects were not appropriate to their particular circumstances. Because so many families came from poor economic situations which included inadequate housing, the idea of a "retreat" had great appeal. Such a retreat in the country, in a setting that was conducive to learning, was viewed as a family holiday. The setting of a college campus in a rural atmosphere seemed to offer the most ideal location for the initial parent conference. The selection of Monmouth College in West Long Branch, New Jersey, was extremely fortunate, since this campus offered available facilities for conferences of this type when regular college classes were not in session. The arrangement of dormitory space where families could live as a unit, and where appropriate services could be provided for young children, was quite ideal.

It was decided that a general theme for these conferences should be "All Barriers Down." Barriers of language, dress, and social strata had to be eliminated as we addressed ourselves to learning how to more effectively care for the handicapped in the home and the community. Informal dress was encouraged and staff members were not distinguished by clothing or appearance. Perhaps rapport with parents would be better if such barriers were eliminated. The first conference in the summer of 1970 proved this to be correct. A general atmosphere of informality developed along with a great interest in learning. Parents were at a teachable stage with their young children and they wanted to know what they could do to help their children in the home. The staff members of United Cerebral Palsy became both partners and learners in an intensive three-day experience.

### Format for Learning

It was decided that this conference must do everything possible to strengthen the family unit as well as provide a good educational experience. Families lived together and husbands and wives jointly attended lectures and discussion groups while children mingled freely with other children in organized and supervised day time activities, returning to their families in the later afternoon and evening. The format for learning was well thought-out and provided practical seminars and lectures each morning. These lectures concentrated on primary subject areas, such as, "What can I expect from the medical profession in the future?" "What is different about learning and educational programs for the brain injured child?" "What things can I do in the home that would be most helpful?"

From the very beginning the emphasis was on demonstration and practical "how to" activities presented in simple nontechnical language. Each morning a session was led by a physician, an educator, or a team of therapists who demonstrated simple assistive devices that could be used in the home. This format proved to be effective and has generally been repeated each year. We found that parents were quick to raise questions in this informal atmosphere. Discussions ensued among parents on how their children behaved in various circumstances and how they, as parents, were coping with individual problems.

In subsequent years a special session on the specific resources of United Cerebral Palsy was presented. This theme provided assurance that a community agency would be there to share the burden with them as long as they lived. It was made clear that there were no "cut-off points" when a child reached age 21 or when the financial fortunes of the families rose or fell. Many parents spoke candidly of the positive effect this had on reducing their anxiety. These general sessions revealed many interesting sidelights. The hostility and resentment toward organized medicine was immediately apparent. No doubt this related to "blaming the doctor" for their having a child with cerebral palsy. It was also apparent that parents often had unrealistic educational goals for their limited children. Frank discussions of educational objectives and techniques tended to make them more realistic.

Informal group discussions were held each afternoon in sheltered areas under the trees. Parents from the same neighborhoods (called boroughs in New York City) met together in discussions led by a social worker and psychologist. Parents were encouraged to express their feelings about having a handicapped child and to explain their practical techniques of handling the child at home. Questions about the relationship of the child to other children in the family and the neighborhood were frankly discussed. It was in these sessions that the real feelings of the parents were most effectively voiced. Group leaders with great sensitivity and skill encouraged parents to openly express their feelings without guilt or shame. It was not unusual to hear a husband and wife openly admit that they had never heard the feelings of their spouse expressed before this time. Likewise, a self-teaching attitude developed among the parent groups so that they were soon counseling one another. This highly therapeutic atmosphere has prevailed in virtually every conference. For several years meetings were held among the brothers and sisters of handicapped to encourage a similar type of discussion. Teenage brothers and sisters spoke about what it meant to have a handicapped brother or sister living in the home, how this affected their friendships, and so on. For the most part these sessions were not entirely successful and were abandoned after a period of time. The large age span, plus educational and cultural differences, made such discussions too difficult to conduct productively.

Probably the most effective part of the conference came from the infor-



mal and unscheduled discussions held with the staff members. With a highly experienced staff serving as conference faculty, parents were able to openly discuss any issue relating to care in an informal and relaxed atmosphere. It was encouraging to see how easily parents spoke of their problems when they were at the dining room or the beach. Questions came up which would never have been posed in the formidable environment of the doctor's office.

Children attending the conference were grouped according to age and participated in a day-camp experience. With competent group leaders these children enjoyed a variety of recreational activities and were treated to an interesting outdoor summer experience. City youngsters enjoyed exploring the wonders of the country and many developed new friendships that have lasted over the years.

We soon realized that in the recreation program the children were really being introduced to middle-class American standards. For the first time, many Puerto Rican and black children from the poverty areas of the city were exposed to the way college students lived on a college campus. One young boy was heard to say as he entered the bus to return home, "I would like to come to this college someday."

Afternoon and evening periods during the conference were times for recreational activities and relaxation. Trips to the oceanfront (just a mile away) were provided regularly and group evening activities planned for those who wished to participate. The most popular of evening activities was the square dance program which had wide participation by both families and children. One was quick to observe that many families with handicapped children had simply not learned how to play. It was a revealing experience to see parents and other adults enjoying group activities of this kind for the first time in many years.

Baby-sitters were provided for parents with young children in the evenings so that they might have some opportunity to be off by themselves if they wished. The nearby oceanfront boardwalks and recreation opportunities provided an incentive to get away from the college campus for brief periods of time.

## Conclusions

Where an organization, community, or group of parents can institute a similar type of parent activity, it is evident that the effectiveness is far-reaching and can provide the instruction and practical guidance that parents of young handicapped children are looking for. Followed up by meaningful program services, this type of parent conference and orientation readily becomes an effective instrument for developing meaningful relationships between agency personnel and families of the handicapped. The unqualified success of this conference program is best seen in the responses from those who

answered questionnaires relating to their experiences over the past eight years.

### **Parent Conference Survey**

In 1977, a total of 191 questionnaires were mailed to families who had participated in the conferences since 1970. The returns brought back 75 completed questionnaires, with 51 returned "address unknown." The remaining 65 did not respond, or responded too late to be tabulated.

From all completed questionnaires, the statements rated as "extremely helpful" by more than 50 percent of the participants included: knowledge of other parents sharing similar problems, better understanding of cerebral palsy as a condition; ability to speak to others about the child's condition, helping the child's educational progress and considering future needs of the child, encouraging the child's independence, and using methods learned at the conference for feeding and dressing the child.

The survey indicated that conference objectives had been translated into meaningful behavioral changes within the homes of the children represented. Subsequent interviews with parents revealed that no counseling experience with physician, educator, or clergyman was as meaningful in total understanding of and orientation to the problem as was this experience.

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### **SPECIAL COMMENTARY BY:**

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### **Disability in the Family. The Relation between Parents and Professionals.**

In her paper Dr. Elizabeth Zucman addresses herself to a very important issue: the effects of disability on the family. Based on her study of recent literature and her own experiences, she discusses the intricate relation between the professionals, the experts, and the parents, who at least in the initial stage of being parents of a handicapped child, are not experts or feel as such.

Although the importance of involving parents in the treatment of their

handicapped child is acknowledged by all professionals working with disabled children, very little is known about how to secure this crucial involvement. Research addressed to this question has been sparse. However, an increasing number of studies, especially about early intervention programs have been published describing various models for professional-parent interaction. Also a growing interest in research on infancy is spreading rapidly in the United States.

Dr. Zucman's paper points to a similar interest reflected in the French professional literature, which once again demonstrates how similar trends and interests become of concern to the professionals in different parts of the world at the same time without a direct exchange of information.

While professionals agree that parents should be involved, less agreement is found, when the question is asked how? with what responsibilities? with what focus? Carol Carwright (1981) presents the following list of parent roles currently in use, generally arranged from least to most involved:

- parents as an audience
- parents as supporters and references
- parents as learners
- parents as teachers for their children
- parents as therapists
- parents as decision makers, policy makers, and advisors

One addition should be made to this list: - parents as parents - Based on what is now known from research on the process of attachment, professionals might come to regard the development of maternal/paternal attachment as the most significant contribution of parents in any early intervention program and give high priority to help parents develop such attachment. As part of a study I have extracted 200 different statements made about "key" factors in early intervention programs from 20 randomly selected references. (table 1) The majority of the statements made by professionals are "technical" describing various models for parent infant programs organization of different professionals involved, etc.

The parents have different priorities. They are more concerned about their ongoing relationship and interaction with the professionals. The majority of the parents' statements concerned different aspects of the painful diagnostic process and of the related "breaking of the news".

Anyone who works with or knows parents of a handicapped child will realize the enormous importance of how information about the child's problem is first related to the parents, particular of what is said, how it is said, and what is left unsaid (the unspeakable!).

In spite of this many parents of newly identified handicapped children still tell about experiences that are unnecessarily painful, often cruel in the way they are handled. I totally agree with Zucman that such negative interactions often produce an "added handicap" and certainly an extra burden on the family.

Some important criteria that should be met to secure better interaction

between professionals and parents include:

- parents are given *accurate information* about the nature of their child's handicap
- information is supplied by a *knowledgeable* person who has sufficient *time*
- information includes description of what can be done for the child immediately, and what services are available *now* and for *later need*
- an individual act as *contact person* in obtaining information and services
- *communication between professionals* take place
- *medical professionals take responsibility for referring* children to proper, non-medical programs and *vice versa*
- *such programs*, especially for early infancy, are *developed*

From Zucman's comprehensive study and from all other studies I know of, from recent years, I would venture to conclude that most parents of handicapped children are willing and able to meet the basic needs of their handicapped child for good, stable human relationship, provided they are supported by knowledgeable, caring professionals. Parents seem to be rather modest in their expressed need for practical and economical support, but psychological support, acceptance and understanding from professionals with time to listen, are for many unmet, strongly felt need.

Professionals have the theoretical knowledge to avoid the often mentioned failures and to meet most of the needs and wishes expressed by parents provided a change in attitude will bring increase of respect for the skills and knowledge of other professionals as well as increased respect for an understanding of parents' strengths and resources as parents.

Zucman's paper represents an important step toward such change of attitude. It is important that someone from the medical profession is making such clear statements about the importance not only of the medical aspect of the particular handicap - but also of the influence of the disability on the family.

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