CHARACTERISTICS OF FAMILIES WITH A CHILD WITH MENTAL RETARDATION IN YUCATAN, MEXICO

by

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An Abstract

Of a thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Education (Rehabilitation Psychology) in the Graduate College of The University of Iowa

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CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

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A model inspired by Boss' contextual framework of family stress was used to investigate environmental and familial factors influencing the family adaptation to child disability.

Ethnic and socioeconomic factors, characteristics of family members and family resources, as well as parental beliefs, attributions and expectations were investigated in 50 families with both a child with mental retardation and able children.

Except for the Mayan ethnic background prevalent in Yucatan, these families showed characteristics similarly described for other families in Latin America. These were mostly Catholic extended families living in poor socioeconomic conditions. Parents exhibited well defined gender roles, low levels of education, and labor related jobs. At a familial level, extended family relatives constituted the family support network.

Results suggest that parental characteristics such as expectations of child independence, degree of religiosity, and level of education are factors associated with adaptation, as measured by the degree of family esteem.

It is suggested that theoretical models from the field of family research can be successfully incorporated into the study of disability. Family adaptation to the presence of

disability is a phenomenon difficult to study due to the complex psycho-social relationships between family and disability. Thus, the use of family research models in the study of mental retardation facilitates the identification, analysis, and conceptualization of family factors and dynamics present in families facing disability.

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CHAPTER I

INTRODUCTION

This study describes the influence of intra-familial and environmental features on the family's capacity to adapt to the presence of a child with mental retardation. Families in the state of Yucatan, México, were studied with the purpose of identifying some of the factors involved in the family's ability to achieve adaptation when facing the potential stressor of having a child with mental retardation. The Yucatan is one of the 33 federative states of México. A uniqueness of this region is the influence of the Mayan civilization, an ethnic group which developed in the south east of México. This study attempts to gather a preliminary base of data for future research about family and disability in the state of Yucatan. In addition, results are expected to lead to the development and improvement of services to families affected by disability in this region.

Rationale for the study

The family, as the basic unit of the social system, is a powerful force in the determination of human behavior. The family is an important environment in which children with disabilities develop and grow. Hence, it is fundamental to understand how the family adapts to the presence of

disability and how it influences the habilitation of children with disabilities. Buscaglia (1975) observed, "...the family will have more poignant, influential, lasting and significant effects on the disabled person than all the professionals that work with the individual" (p. 119).

In spite of the importance attributed to the family, the current empirical knowledge on how families in different economic and cultural contexts adapt to disabilities is limited. In addition, few investigators have studied the effects of disability in developing countries. In particular, research on the relationship between family and disability in Yucatan is practically non-existent. Indeed, there is no empirically based information on how the presence of a child with mental retardation impacts family functioning in the Yucatan and how families in this region adapt to the presence of a child with mental retardation.

Knowledge about current and potential involvement of Mexican families in the habilitation of their children with mental retardation is needed in order to develop and improve services such as special education programs, family guidance, and vocational training. In addition, there is a great need in México to establish a research base in the field of disability. Thus, information about families in the Yucatan with children with mental retardation may be highly useful in providing the professional in México with a frame of reference that takes these families' ethnic and socioeconomic characteristics into consideration when

planning intervention. Knowledge about specific intra-familial factors affecting Mexican families' adaptation to disability may enable the professional to identify available family resources.

Mental retardation has been described as a condition with great impact on the family's unity, economic survival and mental health (Combrinck, 1989). Due to the potentially stressing effects of mental retardation on the family, the study of this disability seems to be a particularly important first step toward a systematic description of family adaptation to disability in the Yucatan. Empirical information about environmental and intra-familial variables is essential for planning services in the Yucatan. When only limited economic resources are available, as in this region, professionals need to develop solutions which use existing resources and prevailing norms. Powers and Thorwarth (1988) noted, "...the therapist's ignorance of the prevailing ethnic context and its implications for family behavior with a child with a disability may result in mislabeling otherwise normal family processes as psychopathological" (p.36).

Importance of the study

Research on families in the Yucatan with children with mental retardation is important in the implementation of special education practices, since such practices are an early stage of the rehabilitation process. Wright (1980) stated, "...rehabilitation is concerned with the nature of

the family, its developmental role and its influence on handicapped members" (p.583). Results from this study are expected to be useful both in México and the United States. In México, documented results about how family resources and views promote adaptation to the presence of disability may lead to improved educational practices that take family values and strengths into consideration. They may also provide a frame of reference to judge what research-based knowledge produced in the United States can be transferred to the Latin American context. In the United States knowledge about how Mexican families adapt to disability may lead to improved services for many Hispanic families. These families are a rapidly growing social group in the United States, that exhibit characteristics similar to those found in families in the Yucatan. In sum, by understanding how contextual and intra-familial variables interact to facilitate family adaptation to mental retardation in the Yucatan, professionals may be in a better position to incorporate the full potential of family resources in promoting the best possible development of the child.

Theoretical framework

Stoneman (1991) reviewed the existing research literature about mental retardation and the family. She proposed that a theoretical void exists in this field due to the complexity of the conceptual relationship between family and disability. The use of theoretical models may be helpful

in assisting investigators to describe how the family adjusts to the potential stress of the presence of a child with mental retardation.

Hill's (1949) ABCX model of family crisis has been used widely in family theory to explain a family's reaction to stressful situations. This model focuses primarily upon pre-crisis variables that account for differences in the family's capability to cope with the impact of a stressing event. Hill presented a framework for family stress theory that includes the following ABCX variables: A, the provoking event or stressor; B, the resources or strengths the family has at the time of the event; and C, the meaning that the family attaches to that event. The X factor is defined as the degree of crisis or stress impacting the family.

A later modification of the ABCX model, focusing on family adaptation rather than on crisis -the double ABCX model- was later proposed by McCubbin and Patterson (1983). The double ABCX model identifies those psychological and social factors called upon by a family in crisis and the processes and outcomes related to a stressful situation. Three units of analysis were proposed: individuals, the family as a unit, and the community. This model added 4 post-crisis variables to the original ABCX model: family adaptation (xX), accumulative family demands or pile up effect (aA), existing family resources (bB), and the dynamic meaning of the condition for the family (cC). The double ABCX model focuses on the ability of the family to achieve

adaptation, searching for the specific dimensions of family life that are likely to shape the course of family adaptation over time.

Boss (1987) further elaborated on the original ABCX and double ABCX models. She proposed a third more comprehensive model of family stress adaptation, a contextual ABCX model that considered the influence of environmental factors on the ABCX variables. According to Boss, two sorts of contexts need to be considered in family stress. The external context is a social context comprising factors such as economic, religious, and ethnic values. The internal context is a context within the family that includes factors such as the sociological and psychological configuration of the family as well as the original ABCX intra-familial factors.

From Boss' perspective, stressors such as the presence of disability in a family member are seen as acting indirectly in the family system. Thus, family adaptation to the presence of a child with mental retardation would be viewed as mediated by the effects of internal and external contexts. In the present study, a model inspired by Boss' contextual ABCX model of family stress (Figure 1) will be used in an effort to organize and interpret information from families in Yucatan with children with mental retardation. This proposed framework calls upon factors at three levels of analysis: external context, internal context, and intra-familial factors (ABCX variables).

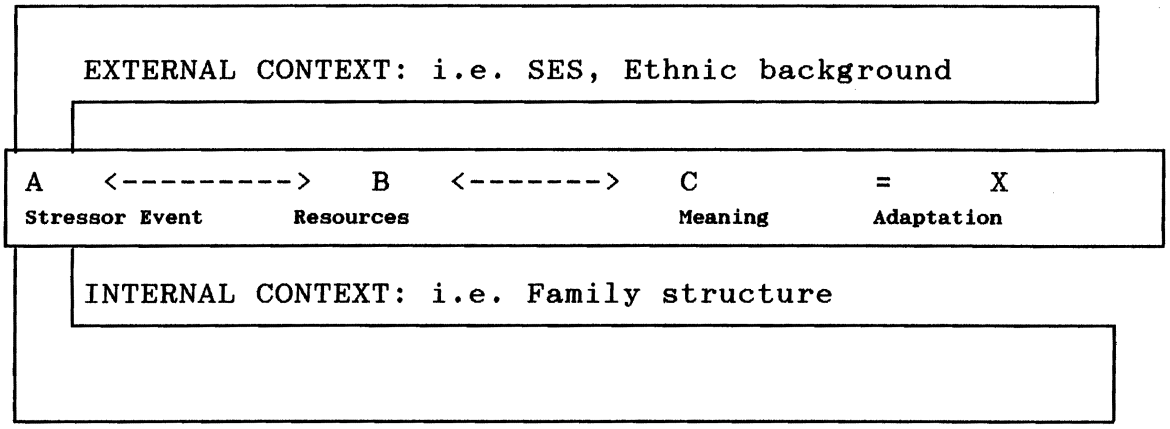


Figure 1. Contextual model of family stress (Adapted from Boss, 1987).

These factors and their corresponding variables will be described in the following section.

ABCX-contextual family stress model

This section lists the components of Boss' family stress model. Variables considered in the present study are identified and paired with model factors which are operationally defined. General external and internal context factors are described followed by more specific ABCX intra-familial factors.

External context variables

Boss' (1987) contextual model considers the external context as comprised of six dimensions: historical, socioeconomic, developmental, constitutional, religious, and cultural. In particular, socioeconomic conditions and

cultural factors such as ethnicity are important social forces in shaping family resources and perceptions of disability. MacGoldrick (1982) asserted that ethnic patterns play important roles in determining how we think and behave, relax, celebrate life transitions, and how we respond to physical illness and psychological distress. In addition, poverty, a pervasive condition in Latin-America, may influence the meaning of disability for the family. A family's socioeconomic status and ethnic background are important factors influencing adaptation to the child's disability and of the family's acceptance of particular intervention methods (Powers, 1986). These two factors of the external context of the family will be specifically addressed.

Socioeconomic status

A family's socioeconomic status (SES) is composed of the economic conditions or wealth of the family, as well as by the perception of its members of their social class or economic status in society. In this study the wealth of the family is measured by the possession of appliances in the household. The family's perception of social class was also estimated and considered an indicator of SES.

Ethnic background

The ethnicity of a social group is an important factor to consider when describing the cultural characteristics of a group. In this study, the ethnic background of the family

was determined by the degree of Mayan influence. The most important ethnic group in the Yucatan is the Mayan. To measure the degree of Mayan influence, the number of Mayan last names in the family and the number of family members that speak the Mayan language were counted. It has been argued in the literature of rehabilitation that families from different ethnic groups may vary in their perceptions of disability (rf. Correa & Weismantel, 1991). Hence, it is important to consider a family's ethnic background when studying children with disabilities.

Internal context variables

Boss (1987) suggested that the internal context of the family in stress is comprised of three dimensions: the sociological, the psychological and the philosophical. These are broad dimensions which are impossible to study simultaneously. Hence, this study focused on the sociological dimension, specifically on family members' characteristics and the family structure.

Characteristics of family members

The description of the major demographic characteristics of parents and their children is useful in understanding available resources and constraints for the functioning of the family. Aspects such as parental level of education, occupation, religiosity, and age may influence the ways these families perceive and adapt to disability (Powers, 1986).

Family structure

Family structure refers to the number and type of relationships of family members participating in the family's daily life. It is important to establish whether families in the Yucatan exhibit the extended family structure previously described for Mexican families (Bridges, 1980). Extended families have been characterized as cooperative, interdependent and involving relatives in the normal functioning of the family.

Bridges (1980) described Mexican families as large social units that frequently include extended family members who are expected to contribute to the welfare of the group. Reliance on family members in a crisis situation, and the help relatives provide to meet the needs of children with disabilities needs to be better understood. Family structure is an important factor to consider in evaluating family resources, in particular the development of a support network within the family.

ABCX factors and variables

A-factor: The stressor

A stressor is an event that is capable of causing change and stress. Boss (1987) defined stressor as "...a stimulus or force that has an impact on the individual or family and that may or may not produce stress every time, depending on the individual's or family's perceptions, resources and context" (p.698). Thus, stressor is not

synonymous with crisis. In this study the stressor which is under study is the condition of mental retardation.

Mental retardation

Literature about children with disabilities and their families has accentuated the negative consequences of having a child with a handicap in the family (Schild, 1971). Lyon and Preis (1983) asserted, "...one of the most frequently discussed areas pertaining to the families of severely handicapped children has been the psychological or emotional impact upon the family" (p. 215). Research results indicate that the family as a unit may incur important social and psychological costs. According to Farber and Ryckman (1965), "...one of the most consistent research findings is the limitation of participation of parents of severely retarded children in extra-familiar relationships, such as organizational membership or recreation" (pp. 7-8). Several authors have defended the position that rearing a child with mental retardation may be burdensome, stressful, alienating and frustrating for the family (Schilling, Gilchist, & Schinke, 1984). In this study, the condition of mental retardation was assessed and empirically supported by the scores of adaptative behavior yielded by the Vineland scale.

<u>B-factor: Family resources</u>

Family resources are those sociological, economic, psychological, emotional and physical assets on which family members can draw in response to a single stressing event or

accumulation of events. Boss defined the B factor as "...the family's coping resources, individual and collective strengths at the time the stressing occurs" (p.702). The family support network is the B factor under study here.

Family support network

Family support-network refers to the assistance in various dimensions (i.e. emotional, economic, instrumental, educational) that relatives, provide to a particular member of their family in order to adapt successfully to life demands. Cooke, Rossmann, McCubbin, and Patterson (1988) defined social support-network as "...a unit of social structure and ties of emotional support which connect the individuals to groups" (p. 212). In this study, the support network is described in terms of the frequency with which assistance is provided to the parents. Nimkoff (1965) suggested that the support network in a family may be determined by establishing the residential proximity, frequency of contact and economic interdependence of extended family members. Considering these factors, the family's support network was assessed by parents' estimates of the amount of help provided by relatives.

C-factor: Meaning of the stressor

McCubbin and Patterson (1983) suggested that the meaning of a stressor is "...the family's subjective definition of the stressing, accompanying hardships, and their effect on the family" (p. 18). Boss (1987) asserted

that because the study of the meaning of the stressor implies the use of qualitative variables, researchers have focused very little in this area. She claimed that, "...clinicians, however, know at least intuitively that a family's perception of the situation is critical to how they will react and cope with stress" (p. 708).

Describing the meaning of mental retardation in the family is both conceptually and methodologically difficult because of the complexity and subjective nature of family members' perceptions of the significance of the presence of mental retardation in the family. Hence, the meaning of the presence of child disability in the family must be inferred from relevant family characteristics.

In this study the following three indicators of the meaning of the presence of mental retardation were considered: (1) Beliefs about the management of a child with mental retardation; (2) attributions about the origin of the child condition and about the incidence of mental retardation in some families; (3) expectations parents have toward their children with and without disabilities.

Parental beliefs

In this study, parental beliefs about the management of a child with mental retardation refers, , to the ideas parents reported about what is best to do in managing the care of a child with mental retardation. Parents were asked

to state the actions they recommend to help a child with mental retardation achieve a productive life.

Attribution of disability

Attribution refers to the parent's imputed origin of their child's condition. Holtzman, Diaz-Guerrero, and Schwartz (1975) reported that Mexicans tend to attribute outcomes to destiny or fate. It was important to establish whether parents in the Yucatan exhibit a similar attribution about the origin of their own child's condition or to the presence of a child with mental retardation in other families.

Parental expectations

Parental expectations were defined in this study as the parents' estimate of the occurrence or duration of an event in their children's life. Parents hold expectations about a number of aspects of their child's future. Expectations of occupation, marriage, happiness and health are common parental expectations that may influence the meaning parents ascribe to the presence of mental retardation in the family. For example, parents expecting their child to excel academically may be more affected by knowing that their child has mental retardation, than parents expecting their children to fulfill basic duties at home. Lavelle and Keogh (1980) suggested that parents' expectations of their children with disabilities were related to the attribution they attach to their child's disability. Wright (1960)

suggested that expectations mediate behaviors and they are important components of attitudes.

In this study, three major areas of parental expectations were explored: (1) Parental life-expectations, referring to how many years parents expect their child to live; (2) parental expectations of well being, referring to parental estimate of how happy, healthy and secure their children will be when adolescents and adults; (3) parental expectations of independence, referring to the expectations parents hold about their child's degree of economic, emotional, and social autonomy in the future.

X-factor: Family adaptation

The X factor is seen as a continuum of outcomes reflecting family efforts to achieve a balance of functioning. The positive end is called adaptation or 'bonadaptation' and the negative end is called maladaptation or crisis (McCubbin & Patterson, 1983). Adaptation is achieved through reciprocal relationships where family demands are met by resources from the environment, and environmental demands are met by family resources (McCubbin, Cauble, & Patterson, 1982). To achieve adaptation, families have to reorganize their functioning to cope with the stressor. Boss (1987) described coping as the cognitive and affective processes by which families adapt rather than eradicate stress. Thus coping may be conceptualized as a pre-requisite necessary to achieve adaptation.

In this study, family adaptation to the potential stress of a child with mental retardation refers to the parents' reported degree of family esteem. The concept of family esteem as used in this study is described below.

Family esteem

McCubbin and Patterson (1983) described crisis or maladaptation as the family's failure to reorganize and restore some functional stability. In this study it was assumed that families in the sample maintained some degree of functional relationships and family boundaries, given they have been able to preserve the integrity of the traditional family despite disability and other hardships. To provide a quantitative measure of family adaptation (X-factor) it was necessary to develop an indicator based on the parents' perception of the family as compared to others: the family esteem. The family's esteem was assessed by estimating how parents perceive their family as compared to others on the following dimensions: happiness, respect, worth, luck and amount of problems. Although the construct of family esteem has not been explored before in the research on family and disability, this may be a promising concept in assessing the impact of disability.

Assumptions of the study

Four major assumptions were made in this study. First, it was assumed that the presence of a child with mental retardation is a potential stressor for the family system.

Second, it was assumed that these families exhibit a certain degree of adaptation. Third, it was assumed that the degree of adaptation (X-factor) was related to the family resources (B-factor) and the meaning (C-factor) members ascribe to the presence of mental retardation (A-factor) in the family-system. Lastly, it was assumed that family resources, beliefs and attributions about mental retardation are influenced by external and internal contextual variables. Thus, this work assumes the validity of the proposed model in understanding the phenomenon of family adaptation to mental retardation as well as the necessity of considering this model in light of contextual and intra-familial characteristics.

Research questions

I. Considering the external context, What are the socioeconomic and ethnic characteristics of the sampled families in the Yucatan?

II. Considering the internal context, What characteristics describe the parents and children, as well as the structure of these families?

III. Considering factor-A, the stressor: What are the adaptative-functional levels of mental retardation present in these families?

IV. Considering factor-B, family resources: What is the nature of the support-network available in these families?

IV. Considering factor-C, the meaning of having a child with mental retardation: What are the parental beliefs, attributions, and expectations of these families?

VI. Considering factor-X, level of adaptation: What is the degree of adaptation in these families as measured by the family-esteem?

VII. Which intercorrelations between the quantitative variables in this study are significant in predicting family adaptation?

Limitations of the study

This study included complete family units. Thus, non-traditional families with children with mental retardation were not included in the sample (i.e. single parent families).

Caution must be exercised in interpreting the results because most the measures used were assumed valid and reliable without empirical evidence. Due to the lack of instruments available in Spanish or validated with this specific Mexican population, four of the instruments were specifically designed by the investigator for this study. Similarly, the limitation of using the Vineland Scale, a test developed in the United States in México deserves some consideration. Figueroa (1989) claimed:

> It is not a difficult task to translate a test. Perhaps, for this reason it has always been a favorite solution in the assessment of linguistic minorities. However, as early pioneers in this effort found, it is exceedingly difficult, if not impossible, to translate the psychometric properties from one language to another (p.145).

Thus, the reliability and validity of this scale for children in the Yucatan needs to be established before conclusive statements can be made.

Finally, given the voluntary nature of family participation, the assumption that this sample was representative of all families with children with mental retardation enrolled in special education programs in the Yucatan may not be warranted.

Summary

The importance of the family as a context to better understand the phenomenon of disability was recently emphasized by the National Council on Disability, which in August of 1989 organized a national conference entitled "Disability: A family affair". The conference highlighted the roles of the family as an agent of change, as well as a support group. Information about the structure and functioning of the family with a child with mental retardation in the state of Yucatan may be useful in understanding how the family perceives and adapts to disability in this specific context.

The present chapter presented the need to investigate, in a preliminary and systematic fashion the nature of family

adaptation to the presence of a child with mental retardation in the Yucatan. A contextual model based on family stress theory was proposed to delineate the variables which are pertinent for this study. Factors in this model were subsequently outlined, defined and explained, and the research questions were stated considering the assumptions and limitations of the study. The following chapter examines relevant concepts in the literature regarding mental retardation and family adaptation as a basis for the design and interpretation of this research.

CHAPTER II

REVIEW OF LITERATURE

Although the literature about family and disability is vast, the existing research about Mexican families with mental retardation is limited. Few studies have described the characteristics of Mexican families and empirical information about Mexican families with children with mental retardation is unavailable in main stream journals. Hence, literature about Hispanic families and more general research about families and disability is called upon in guiding the research about the families in the Yucatan.

Two trends can be identified in the existing research about the relation between family and disability. Investigators have focused on how the presence of a disability affects the functioning of individual family members (Wilson, Blacher & Baker, 1985; Handleman & Harris, 1985), and how disability affects the family as a social unit (Farber & Rickman, 1965). How the family influences the processes of rehabilitation and education, and how family members can be better provided with effective services, has been the concern of professionals in the fields of rehabilitation and special education (i.e. Bubolz & Wiren, 1984).

Among the various disabilities that affect the family, mental retardation is probably the condition most frequently studied (Prout & Prout, 1991). Stoneman (1990), in her comprehensive review of the conceptual relationships between existing research of family and mental retardation, identified three research goals: 1) To understand general family processes; 2) to understand the impact of mental retardation on families; and, 3) to use family research as a means to better understand mental retardation.

Stoneman (1991) further indicated that research on the family and mental retardation has relied on theories developed by family sociologists and stress researchers focusing on mediators of family adaptation. She claimed, "These models have successfully guided research that has increased our understanding of stress and coping in families with mentally [retarded] members" (p. 192). Stoneman noted that this research has proven useful in expanding family theory. However, its usefulness in expanding our knowledge about mental retardation has been disappointing: "For family research to increase our understanding of mental retardation, models must be created to directly relate specific aspects of mental retardation to family processes and outcomes across the life-span" (p.192). The following section discusses the application of family research models in the field of disability, with a specific emphasis on how these models may enrich our understanding of family and disability.

Family and disability

According to Gartner, Lipsky and Turnbull (1991), "the family's role in the development of a child with disabilities has gained increasing attention, as well as a changing focus" (p. 65). Much of the current research about family and disability is based on family system theories. Harris (1983) suggested that the family facing disability should be conceptualized within a systems model. Gallagher and Bristol (1989) identified current trends in research on disability that focused on "the surrounding relationships within the family system" (p. 295). Similarly, Fine (1991) encouraged the use of a family system model when approaching disability in the family, and the importance of understanding the reciprocal impact of persons within the family. He asserted that the presence of stress in the family does not necessarily constitute maladjustment. Adaptation is determined by the manner in which the family organizes itself to adapt to stressful events (McCubbin & Figley, 1983; Seyle, 1974; Fine, 1991).

From a rehabilitation perspective, family research must emphasize strengths, coping capacities, assets and adaptation, rather than deficits and vulnerability (Boss, 1987; Wright, 1980). Longo and Bond (1984) asserted that practitioners and investigators often falsely assume that a major family problem exists when, in fact, many families cope successfully with members with disabilities.

A family's response to disability can range from positive adjustment to distressed maladaptation (Seligman & Darling, 1989). Hence, it is important to investigate which strengths, capacities and assets allow the family to be incorporated into the process of rehabilitation. Trute (1990) reported that marital satisfaction is a strong predictor of parental adaptation to child disability. Naseef (1988) concluded that family unity and stability were associated with adaptation in families with children with mental retardation. Taylor (1989) demonstrated that social support and problem solving abilities were significant moderators of stress in families with children with mental retardation. Blacher (1984) suggested that a pattern of adaptability in the family with a member with mental retardation does exist. McCubbin & Huang (1989) claimed:

> Families who manage the lifetime care of a handicapped child are faced with unique stressors. However, these families also develop resources and capabilities to manage the day to day care of the child. These critical family strengths have become the focus of more recent family and health research in an attempt to elucidate what characteristics of the family system play a major role in buffering the ongoing stresses associated with rearing a handicapped child and also foster adaptation and promote positive health outcomes for the child (p. 436).

Spaniol & Lipple (1988) asserted that a rehabilitation perspective should focus on helping families develop more effective coping strategies, and stress the need for cooperation among family members. Family research models,

such as the one used in this study, which focus on family processes leading to adaptation, are suitable for incorporation into the research of mental retardation.

In the following section, literature about the family will be reviewed focusing on the experience of Mexican and Hispanic families with disability.

The family

This section defines some of the basic concepts necessary to understand the family as a social unit and describes the characteristics of families with disabilities. The importance of considering the diverse contexts in which a family functions is highlighted.

The nuclear family is the smallest unit of social organization and is composed of parents and their offspring. The extended family is formed by adding kin such as grandparents and other relatives or by adding marital units when a family member marries (Henslin, 1989). Building on this, family structure refers to the configuration of units comprising the family. Family functioning connotes the ways the family behaves. Family organization refers to the interrelationships between family members and family units (Nimkoff, 1965).

The nuclear family has been characterized as independent, molar, and typical of industrialized societies. Sussman (1988) claims that existing patterns of occupational and social mobility in the United States demand an

independent and flexible family unit. Members of nuclear families are typically emotionally and financially independent of their extended families, have a residence distant from their kin, and exhibit limited family ties.

In contrast, the extended family has been described as the typical social structure of many Latin-American countries. Salient anthropological characteristics associated with the extended family are the economic interdependence of the members and their strong sense of familism (cf. Nimkoff, 1965). Familism is a concept referring to the economic support and emotional ties among kin. A highly familistic group is one in which there is much cooperative activity and group loyalty (Bardis, 1959). In the economic domain, employment is encouraged on the basis of family connections rather than merit, and the family income of all working members contributes in the maintenance of all.

The literature about extended families and disability is scarce. Handleman and Harris (1986) point out that there are few research studies that can help us understand the reactions of the extended family to a child with disabilities. They assert, "...extended family members are very important to the child with a developmental disability and to the child's family" (p. 105). Wright (1982), with regard to the extended family and disability, stated:

> Children all helped, as did impaired and aged kinfolks: there was work for the retarded cousin, the aged grandmother and the alcoholic uncle. Able members of the family accepted the responsibility for dependent members (p.583).

Thus, members of an extended family have been characterized as cooperative and interdependent. When facing disability, the whole family is mobilized to promote the normal functioning of the family. In theory, decisions are made in light of what is best for the family, not for the individual.

The family, whether nuclear or extended is not an isolated social unit. Thus, information about the context in which a family is imbedded is necessary to explain the family's reaction to disability.

Families are rooted in customs and traditions (Fine, 1991), and families in different cultures vary in their perceptions of disability. Thus, the impact of disability on the family may be different in diverse social contexts. Kurtz (1977) suggested that it was possible that in cultures which do not emphasize success as strongly as the American culture, parents might not be as severely affected emotionally by the arrival of a child with mental retardation. Edgerton (1970), reviewed studies comparing families with members with mental retardation in different cultural contexts. He concluded that, in general, the arrival of a child with mental retardation has stressing effects on the family, and children with mental retardation in less developed countries are subject to pity and have

less educational and work opportunities than in the United States.

Comparative studies have focused on diverse ethnic groups. Ethnicity, as part of the family's cultural background, needs to be considered in the description of family and disability. For example, white American families have been described as more dependent on community and public resources than Chinese (Wu & Retish, 1989), Indian (Black, 1976), or Mexican families (Zuñiga, 1988).

Correa & Weismantel (1991) asserted:

> ...Cultural and ethnic backgrounds are important aspects of how a family conceptualizes, understands and reacts to having a child with a disability, with implications in terms of the extended family's (a) acceptance and support, (b) willingness to acknowledge disability, and (c) perceptions and responses to agencies and mental health professionals (p. 83).

Thus, families with children with disabilities cannot be studied in isolation from their social context. In the following section, literature describing Mexican families will be reviewed, providing a general picture of the social context in which Mexican families are imbedded.

The family in México.

The trend toward the small, contained and isolated nuclear family in the United States contrasts sharply with the more traditional, rural, extended family model prevalent in México. Holloway, Gorman and Fuller (1987) considered the Mexican society as, "...an interdependent social structure

in which each individual is likely to recognize that his or her actions are dependent on the needs and actions of other family members" (p. 501). Bridges (1980) described Mexican families as large social units that frequently included extended family members. In Mexican families all members are expected to contribute to the welfare of the group. For example, young children often care for younger siblings and perform duties to contribute to the family income and well being. Zayas and Palleja (1988) asserted that familism is a high value in most Hispanic groups, and that family centered members feel an obligation to relatives and a duty to help in times of need.

Finley and Lane (1971), reported that parents in Mexico tended to nurture cooperative rather than competitive competences. In Mexican families, mothers are the primary care-takers of the children (Marcenko & Myers, 1991). Holtzman, Diaz-Guerrero, and Schwartz (1975) reported that Mexican mothers consider the development of social concern and obedience more important than mothers in the US. Mexican mothers place more emphasis on fostering curiosity and independence than fathers.

In addressing the literature of Mexican families, it is important to recognize some limitations. For example, literature on Mexican families has failed to differentiate which family characteristics are best explained by psychological or sociological theories. For example, Ramirez and Castañeda (1974) suggested that the Mexican's

sensitivity to others and the desire for a collective harmony, depended on specific psychological traits such as higher levels of field dependence and lower levels of internal locus of control. However Holloway, Fuller and Gorman (1987) failed to confirm the hypothesized relation between higher levels of efficacy and external attribution. Cooperative behavior in family members was thus attributed to ideological values, rather than to personality traits.

Marín and Triandis (1985) in a sociological view, suggested that Latin-American countries had a trend toward a collectivism that emphasizes the values and goals of the group, as opposed to developed societies which are oriented toward individualistic values. From a psychological view, Holloway et. al (1987) suggested that Mexican families exhibited behaviors directed to the development of cooperative skills fostering group sensitivity rather than independence and assertiveness. Considering these different perspectives of similar family traits, identifying which characteristics of the Mexican family are best explained by sociological or psychological perspectives would be useful.

A number of attributes have been discussed in relation to Mexican families. In general, attitudes of family members have been described as fatalistic, due to the general belief in this population that what happens is predetermined, a matter of one's destiny, and must be accepted (Holtzman, et al., 1977; Harward, 1969). It is also important to consider the attitudes of mistrust toward agencies and institutions

described for Mexicans and Mexican-Americans. Correa and Weismantel (1991) characterized Mexican-American attitudes toward special education as, "secondary to the family's hope of a cure for the disabled child" (p. 88). Shapiro & Tittle (1990) warned that family members in Mexican families even take pride in their resistance to seek help from outsiders. Rivera (1983) claims Mexicans rely on the family when seeking social support.

In sum, Mexican families have been characterized by a great sense of familism, high levels of cohesion, and economic interdependence. Literature about attitudes of Mexican families has identified attitudes of fatalism and resistance to institutional attendance.

Mental retardation

Both previously described concepts about the family and information about the disabling condition itself are necessary to fully understand the relationship between the family and mental retardation. This section addresses the concept of mental retardation.

There is a lack of a clear and unequivocal definition of mental retardation that is generally accepted by health professionals and special educators throughout the world. Controversy persists about the criteria to diagnose an individual as having mental retardation without giving sufficient consideration to the context within which the individual develops. For many, mental retardation is a

function of the individual's ability to adapt and respond to the demands of their particular environment (rf. Doll, 1965).

According to the American Association of Mental Deficiency (AAMD) an individual is considered to have mental retardation if there is a significant sub-average general intellectual functioning associated with concurrent impairments in adaptive behavior and manifested during the developmental period (Grossman, 1983). The first part of this definition refers to IQ levels of 70 or below as measured by individual standardized tests of intellectual functioning. The second part requires evidence of reduced levels of adaptive behaviors as manifested by delays and deficits in acquiring personal independence and social responsibility expected within age and cultural groups. Distinguished from IQ scores, diagnosis of mental retardation as a function of adaptive behavior may be determined by clinical assessment as well by standardized tests. The ability of the clinician to determine adaptive functioning in the absence of suitable psychometric data may be the most significant factor related to a diagnosis of mental retardation.

In the absence of adequate psychometric procedures to obtain IQ scores, social incompetence becomes the major criteria to attribute the diagnosis of mental retardation to an individual (Nihira, 1969). Actually, a trend toward conceptualizing mental retardation in terms of social

competence is evidenced in recent efforts to redefine the condition of mental retardation. Social competence or adaptive behavior can be thought of as, "the person's ability to cope with the social demands of his or her environment" (Patton, Payne, Bernie-Smith, 1986, p. 130). The activities and demands required by the environment vary widely across settings. For example, self-dressing abilities are more demanding during the winter in northern latitudes, than in tropical countries; similarly, a person's transportation skills need to be more sophisticated in large urban centers than in the rural areas. From a psychometric perspective, valid instruments assessing adaptive behavior should list activities which are essential to the individual's age and daily life demands.

For a more reliable diagnosis of the condition of mental retardation, the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R, 1987), establishes the following diagnostic criteria: (1) Significantly sub-average intellectual functioning; (2) significant deficit or impairments in adaptive functioning; (3) onset before the age of 18 (cf. p. 28). This study based the identification of mental retardation on the levels of adaptive functioning of children sampled in special education centers in the Yucatan.

Mental retardation and the family

Previous sections have addressed general concepts about the family and the definition of mental retardation. This section considers the specific effects of the presence of mental retardation in the family and identifies relevant family factors to consider when explaining family adaptation to the potential stress of a child with mental retardation.

The literature about children with disabilities and their families has accentuated the negative consequences of having a child with a handicap in the family (Schild, 1971). One of the most frequently discussed areas pertaining to the family is the potential psychological or emotional impact of mental retardation on the family. Kanner (1953), for instance, identified three types of parental reactions to children with disabilities: acceptance, concealment and denial. Rosen (1955) suggested that parents exhibit predictable stages of psychological adaptation: awareness, recognition, search for a cause, seek cure, and acceptance. In general, parents in families with children with mental retardation have been depicted as suffering "guilt, ambivalence, disappointment, frustration, anger, shame, and sorrow" (Schild, 1971, p. 434). Similar notions have been reported with respect to siblings (Ferrari, 1982; Seligman 1983; Treviño, 1979) and grandparents (Harris, Handleman, & Palmer, 1985).

At a social level, research results indicate that the family as a unit incurs important social and psychological

costs. For example, Farber and Ryckman (1965) pointed that a consistent research finding is the limitation of participation of parents of children with mental retardation in recreational activities. Kurtz (1977) suggested that this limited social interaction was probably related to difficulties in finding baby-sitters, and to the child's behavior in public places. Similarly, Tizard and Grad (1961) reported that families with a child with mental retardation had comparatively less social contact with others, and Culver (1967) concluded that the presence of a child with mental retardation had depressing effects on the family's social mobility. In sum, several authors have defended the notion that rearing these children can be socially burdensome, and psychologically stressful, alienating and frustrating for the family (Schilling, Gilchist, & Schinke, 1984).

In spite of such a clear emphasis on the negative consequences of having a child with mental retardation in the family, research in this area has not produced compelling evidence to support the generalized assumption that a child's mental retardation is a *necessary and sufficient* condition for family dysfunction.

In contrast to the emphasis on the negative effects of mental retardation in the family, investigators have shifted focus toward researching factors associated with family adaptation to the presence of mental retardation. DeMyer (1979) asserted that the family may still be a functional

unit in spite of disability. Gath (1978), reported that families with children with developmental disabilities do not suffer from more severe psychopathology than other families. Cadwell and Guze (1960) found no evidence of negative impact on siblings of children with mental retardation raised at home; and, Combrinck (1989) asserted that most families with exceptional challenges affecting its members do adapt.

Jacobson and Humphrey (1979) criticized the literature on disability and the family concluding that: (1) Negative effects of children with disabilities on the family have been overstated; (2) positive aspects have been ignored; and (3) many other family variables have been neglected in scientific study. As Zucman (1982) inferred: the mental retardation literature does not lead to the conclusion that the presence of a severely handicapped child results in necessarily negative or harmful effects on parents. Handleman and Harris (1986) stated:

> Indeed, some parents report that they are stronger for the experience of raising a disabled child, some couples indicated that their marriage has been enhanced by sharing the challenge of the child's needs, and some siblings regard themselves as better people for having learned to respond with compassion (p. 107).

Hence, it is important to identify which family factors are related to family adaptation to the potential stress given a child with mental retardation. Boss' (1987) contextual ABCX model, provides a framework for the

identification of some of the relevant factors that may influence the family's capacity to achieve adaptation. For example, factors in the external context of the family may influence the resources a family draws upon given the demands of a child with mental retardation. In Boss' model, both family resources and the meaning of the stressor are seen as intra-familial factors that impact adaptation. The research model for this study argued for considering a variety of family influences when analyzing the extent of family adaptation to a child with mental retardation.

Among the factors delineated in the model used in this study are: Ethnicity, socioeconomic status, family support network and parental expectations. These factors will be discussed in the following sections.

Ethnic and socioeconomic factors

The literature has generally distinguished ethnicity as an important indicator of the family's cultural milieu. Hawkins (1984) studied the population of some regions in Guatemala and differentiated culture from ethnicity in a way that helps us to clarify the concept of ethnicity as handled in this study. Hawkins defined culture as "the ideology prevalent in a particular region" (p.6); and ethnicity as the perception and symbolism of the influence of the Mayan culture in the family's origin.

Ethnic values may affect the way families adapt to different stressors. Boss (1987) argued that belief-systems

associated with different ethnic groups, have prescriptive effects on the family's choice of coping mechanisms. For example, she suggested that, when a flood is fatalistically perceived by a given ethnic group as a message from god, "families coped passively in the belief that nothing could be done about the imminent destruction" (p. 717). Thus, it is important to identify the contribution of the ethnic background in explaining the ways a particular family perceives disability. This study specifically focuses on the Mayan background as a particular ethnic group to analyze the impact of ethnicity considering adaptation to disability in families.

There is a lack of information about specific factors related to disability in this ethnic group. Nonetheless, it remains important to explore if families with a strong Mayan ethnic background react to disability differently than other families in the Yucatan.

Socioeconomic conditions associated to particular ethnic groups may be major factors which account for differences in a family's reaction to disability. Most ethnic groups are associated with certain socioeconomic conditions. Chan and Rueda (1979) stressed the need to separate the effects of socioeconomic factors from the essence of ethnicity. However, ethnic and socioeconomic factors are so closely interrelated that a clear-cut differentiation is difficult.

Socioeconomic status refers both to external social (class or social status) and economic characteristics of the family. Hence, to determine the socioeconomic status it is necessary to identify the economic resources of the family as well as its perceived social class, and how these factors independently or combined relate to the family's capacity to adapt to disability.

In terms of economic conditions, poverty is an important concept to consider when describing the economy of the Yucatan. Poverty refer to the scarcity of economic resources in the larger context. In this economic domain, poverty is a pervasive condition in México that conveys complex social and psychological implications. For example, Capper (1990) described barriers to the implementation of services in special education in poor settings.

Poverty as an economic phenomenon is more likely to affect the resources available for the family, regardless of the individual's perception of social position within the society. However, identification with certain social class is more likely to influence expectations, motivation or the sense of self-efficacy. In a psychological perspective, Maslow (1975) suggested that when the person's primary needs are not met, that person must spend more time and energy trying to meet them. Thus, it may be suggested that within conditions of poverty, parents may be more concerned with the immediate satisfaction of basic needs: food, shelter, and the preservation of health than with the inability of a

child to perform well in school or the inability to understand complex instructions.

In terms of social status, determining the relative status families children with mental retardation occupy in the society is fundamental in understanding the dynamics of the external family context and disability. In conditions of poverty, children with mental retardation may have the same status in the family as their able siblings. Black (1977) reported, for instance, that parents in Bangladesh did not consider children with mental retardation to be handicapped. Parents reporting a higher social status may have higher expectations for their children, thus they may be at a greater risk of frustration given the limitations of their child with mental retardation. Mercer (1968) suggested, "From a social system perspective, mental retardation is not viewed as an individual pathology but as a status which an individual holds in a particular social system, and a role which he plays as an occupant of that status" (p. 383).

In sum, the external context of the family focuses on a social perspective of mental retardation that allows examination of the differential effects of ethnic and socioeconomic values in the family's capacity to adapt to the disability of their child within their own family context. Although it is difficult to dissect the effects of ethnicity from the effects of socioeconomic factors, research has successfully addressed this problem. For example, Lesser, Fifer, and Clark (1965) investigated mental

abilities of children of four different ethnic groups: Chinese, Jewish, African-American, and Puerto Rican. Each group was divided into lower and upper socioeconomic status. They concluded that each ethnic group appeared to have a particular pattern of abilities, and that SES did not alter this pattern of abilities. Lower SES was associated with about the same amount of reported deficit for each ethnic group.

Family support network

This section explores the types of support families provide to its members focusing on the support available among Mexican family members.

The Mexican family has been previously described as an extended social structure imbedded in conditions of poverty, having a support system which is qualitatively different from nuclear families. For example, different psychological events (i.e. emotional attachment, sense of security) may be expected from children under the care of professionals working in state agencies as contrasted to children attended by extended family members. Powell (1980) identified a tendency in the literature to refer to a person or family's relations with relatives, friends, neighbors, co-workers and other acquaintances, as the personal support network. House (1981) identified four broad areas of social support: emotional (care, empathy), instrumental (financial, labor), informational (advice, direction), and appraisal (feedback,

self-evaluation). Gotlieb (1983) defined a social support network as "... verbal and/or non- verbal information or advice, tangible aid, or action that is profited by social intimates or inferred by their presence and has beneficial effects on the recipient" (p. 28).

Schilling, Gilchist, and Schinke (1984) identified three levels of social support available for an individual. Nuclear family members, close friends and relatives, and other significant persons are often the most basic, enduring and immediate sources of social support. A second level of support includes neighbors, more distant friends and relatives, and certain professionals and service providers. A third level of support rests on social institutions. Different social institutions may be available for the family with a child with mental retardation.

In México, schools are institutions that play an important supportive role for a family with a child with mental retardation (Cantón, 1991). Martinez (1988) claimed that schools were viewed as formal support systems for Mexican-American families. He concluded that Mexican-American families should be seen as ecological systems which support parents and are considered the primary educators of their children.

Bayley (1973) described the help and support provided by neighbors, siblings and relatives of poor families with children with disabilities in London. He reported that tolerant neighbors were important for the family. In

general, fathers and siblings participated in the care of the child, and the help relatives was important for the family. He concluded "...an important factor in the amount of help anyone, whether a relative or a friend, could give was the proximity. The families who received the strongest support were generally those who had relatives living close at hand" (p. 297).

The significance of the support network is acknowledged by numerous authors in the field of disability. Bristol (1984) suggested that research evidence indicates that the presence of a social support network is related to more positive adaptation outcomes in families with children with disabilities. Bronfenbrenner (1986) emphasized the importance of a support network for children with mental retardation and their parents. Cochram & Bassard (1979) claimed that the quality of parent-child interaction and child-care may relate to the parental support network. Marcenkco and Myers (1991) concluded that social support is positively associated with family adaptation, greater maternal life satisfaction, and better parent-child interaction.

In order to better understand the support available for children with mental retardation and their families, it is important for investigators to describe the sources and kinds of support available in these settings. The assessment of a social support network involves the identification of the various kinds and sources of help available to the

family. House (1981) indicated that a support network is effective only to the extent that assistance is perceived to be available by the person. Thus, the reported reliance of Mexicans on family members identifies the family support network as one of the major resources in adapting to the presence of disability. Shapiro and Tittle (1990) reported that Mexican mothers with a strong support network exhibited positive adjustment to their children with disabilities.

Parental expectations

The meaning a family ascribes to the stressor (i.e. mental retardation in this study), may be the most important factor determining adaptation (Boss, 1987). However, there are important difficulties in identifying, describing, and evaluating which factors are relevant to establish the meaning a disability has for the family. Variables related to the perception and meaning of the stressor to the family are usually subjective in nature and empirically difficult to support.

In this study, parental expectations are proposed as one of the primary indicators of the meaning of mental retardation for the family. Jensen and Kingston (1986) asserted that parental expectations were important in providing a structure in the family suitable for a healthy growth climate. Parents hold expectations of occupation, marriage, happiness and health for their children. Thus, the importance of parental expectations for the future

development of a child with a disability needs to be considered. Lavelle and Keogh (1980) noted:

> Despite some uncertainty about the functional processes that characterize the interaction between parent and child, an extensive clinical literature argues for the importance of parental attitudes and expectations in the development of young handicapped children (p.2).

Levine (1980) suggested that parents share some common, and universal goals for their children with disabilities. For example, they seek the physical survival and health of the child, his or her economic self-maintenance, and the promotion of their child's achievement of a culturally valued role in their community. These goals are similar for all children.

The impact of specific parental expectations needs to be explored, since Wolfensberger (1975) a noted authority, asserted that the negative impact of a child with mental retardation on some parents was due to the demolition of their expectations, when they learned about their child's condition, they lost "hope" for the future. Lavelle and Keogh (1980) suggested that parents' expectations toward their children with disabilities were related to the attribution they made about their child's disability. When a disability was perceived as internal and stable, expectations were likely to be low and intervention efforts tended to be more maintaining than remedial. Lavelle and Keogh (1980) further differentiated parental expectations from parental demands on various grounds. They claimed that

parental demands are to be met immediately, and they are less conducive to the development of freedom and trust than parental expectations.

Among the set of expectations parents hold toward their children, parental expectations of child independence in the US and western societies have been highlighted as important in families with children with mental retardation (Yanok & Deruberty, 1989). Independence has been a value of paramount importance in special education practices. Thus, considering parental expectations of future independence may be a useful indicator for determining the acceptance and outcome of special education and vocational intervention from a parental vantage point.

The future independence of children with developmental disabilities has been reported as a common parental concern. Birenbaum (1971) claimed that while mothers of able children may look forward to the eventual departure of their offspring, mothers of children with mental retardation must change their expectations in response to a reality of the continuing dependency of the child. Fewell & Gelb (1983) claimed, "...uncertainty is the bane of parents thoughts about the future" (p. 183). Clearly, when a child has a major disability, parents are often unable to predict future outcomes and their ambivalences can be very anxiety-producing for the family.

Independent living is an outcome recognized by disability legislation in the United States (Wright, 1980),

and a social status which is fostered by US social values. Independent living is a common expectation for children and a desirable trait for most adults in the American society and independence is seen as a sign of maturity in the young adult (Stassen, 1984). However, emphasis on independence may be less important in societies in which prolonged emotional and economic interdependence of the family is a common parental expectation. For example, Holloway et. al. (1987) suggested that in Mexican families the maintenance of harmonious relations and interdependence among family members are highly valued expectations. It seems logical to explore how such different views of independence may show themselves in Mexican families with children with mental retardation.

In sum, parental expectations are important because of their powerful mediating effects on parental behavior and subsequent child rearing practices. Expectations depend on factors such as parental perception of the capacities of the child, his/her appearance and demonstrated potential. For example, if a mother believes that her child with mental retardation is capable of doing a task, she will encourage the child to learn the abilities necessary to perform this task. Farber (1960) suggested that crisis, as a reaction to a child's disability, was more likely among parents who held high occupational and status expectations for their children. Fewell and Gelb (1983) claimed, "...parental realization of cherished goals can be thwarted by social

obstacles as well as by disability itself" (p. 178). Ethnic and socioeconomic factors are important ecological influences on the development of parental expectations of independence and subsequent child rearing practices. Mercer (1966) reported that parents from lower socioeconomic status (SES) were aware that their child with a disability would continue to be dependent, but that they were willing to accept this dependency, and favored institutional discharge. On the other hand, parents from upper SES indicated that nothing could be done to improve their child's condition. In general, parents of low SES were more optimistic about intervening on behalf of the child. Thus, the value of independence for a family with a child with mental retardation in the context of socioeconomic and ethnic niche needs to be considered and understood when planning and developing special educational and rehabilitation goals.

Summary

This chapter reviewed concepts about mental retardation and the family. Basic terms in studying the family were explained as means to approach the problem of mental retardation in the family context focusing on the literature that describes Mexican and Hispanic families.

Research about families facing children with mental retardation was reviewed to provide a theoretical background for this study. Literature about the following factors delineated by the research model used in this study was

reviewed: Socioeconomic status and poverty, ethnic background, family support network, and parental expectations.

The present literature underscores the scarcity of information currently available about Mexican families facing the disability of mental retardation. This study aims to provide some of the information needed to fill this gap.

CHAPTER III

METHOD

Introduction

The purpose of this study is to describe the characteristics of intact family units in the Yucatan. The study was designed to include families that had a child with mental retardation and at least one able child. Information about these families was collected from both parents. This chapter describes the procedures and instruments used to gather information. In addition, the variables, indicators, and data analysis procedures are described for each one of the research questions.

Procedures

Data for this study were collected through a personal interview with parents of families having a child with mental retardation attending a special education center in the five biggest cities of the state of Yucatan: Mérida (pop. 1,000,000), Valladolid (pop. 275,000), Tizimin (pop. 250,000), Progreso (pop. 220,000), and Motul (pop. 190,000). These were all the centers providing special education services to children with mental retardation in Yucatan at the time of the study. The centers only differ in the way

they are administered and financed, either by federal, state, or private funds.

Selection criteria were developed in order to establish those family characteristics to be considered when generalizing results from this study. Families were included in the study if they met the following selection criteria: (a) Families had a child from 6 to 12 years old with mental retardation who was enrolled in one of the above special education centers in the state of Yucatan; (b) both natural parents lived in the same household; (c) there was another child in the family of either gender, but within the same age-range (between 6 and 12 years old), who was enrolled in a regular elementary school; and (d) parents consented to voluntarily participate in this study.

State and federal educational authorities in the Yucatan were contacted in order to secure the permission and cooperation of the different local school authorities to conduct this study. A meeting with the principals and teachers of each one of the schools targeted for the study (Table 1, p.53) was arranged with the purpose of clarifying the objectives and procedures of the study. In addition, information was provided to the principals on the selection criteria, the approximate length of the interview, and the voluntary and confidential character of the study.

Teachers in each of the schools helped in contacting parents. Invitations were made both verbally and in written form. A letter (Appendix A) introducing the investigators

and stating the purpose of the study was sent to all families that could potentially be included in the study. The letter requested parents either make an appointment at the school or set a time when an interviewer might visit the family in their home. This letter requested the parents' signature as demonstration of their willingness to participate and their informed consent.

A total of fifty families meeting the selection criteria participated in the study. Thirty six families (72%) lived in urban areas, and 14 (28%) families in rural towns. Participating families represented approximately 18 percent of the families with children with mental retardation in these schools. Data about the families contacted that did not participate was unavailable. It was impossible for the investigator to differentiate between families refusing to participate and those not meeting the selection criteria.

Table 1 (p. 53) describes the type of schools, location, number of pupils, and number of families per school interviewed for the study.

This study focuses on family and disability. Thus, the most important inclusion criterion was the presence of a child with mental retardation in these families.

Information about the condition of mental retardation was obtained from school files as well as from the interview with the parents. Such information was difficult to obtain because most of the school files were incomplete.

Table 1. Cities, schools and families sampled

School Name	Type of school	City	Students enrolled	# of fam. sampled
Escuela Yucatan	Federal	Mérida	73	14
Centro Multiple	Federal	Tizimín	48	6
Centro Multiple	State	Motul	37	5
Centro Multiple	State	Valladolid	55	10
Escuela Especial	State	Progreso	22	5
CETEDUCA	Private	Mérida	39	10

For example, these files lacked psychometric assessment data, particularly intellectual evaluations and medical information. School principals acknowledged this limitation arguing that special education centers in Yucatan lack sufficient resources to assess the child with MR in depth. Therefore, there is a general lack of adequate instruments and personnel to evaluate this population. Incomplete school files made it difficult to establish the origin of the condition of mental retardation in some cases.

Considering the lack of information available in the files, classification about the origin of the child's condition could only be made according to whether genetic or environmental factors were associated with the etiology. Sixteen of the fifty children with mental retardation included in the sample had a primarily genetic disorder: 15

children had Down's syndrome and one had Rubinstein's disease. In twelve cases there was a clear pathogenic causal event, usually a perinatal disease or accident (e.g. anoxia, fetal distress), or poorly treated or complicated infectious or metabolic diseases during early childhood.

Most genetic disorders were detected during the first year of life by physicians, mostly by general practitioners; whereas, many cases of mental retardation of unknown etiology were detected when children entered the school system. In seventeen cases teachers referred the child to the special education center when they perceived learning difficulties or other problems that made them suspect mental retardation. For sixteen of these children, parents had not noticed a deficit or a 'problem' in their children before they were faced with the demands of the school.

Data collection

In addition to the principal investigator, three research assistants from the College of Education of the Autonomous University of Yucatan (UADY) and two psychologists from the Federal Office of Education in Yucatan were trained to collect data. All of the assistants had completed their undergraduate college education (licenciatura) and had basic training in research methods.

Training for this study consisted of a four-hour structured session held at the College of Education of the UADY. Activities in this session included clarification of

purposes, procedures and methods; rehearsal of interviewing skills through role playing; and filling in practice questionnaires. Appendix B contains the outline and topical content of the session. The major purposes of the training session were: (1) To standardize the administration of the instruments; (2) to achieve uniformity in the strategy of the interview; and (3) to facilitate the collection and coding of responses.

Data were collected through a semi-structured interview with both parents present at the same time. Interviews lasted approximately 60 to 75 minutes. Interviewers completed a checklist to ensure that the interviews were conducted in the same step-wise sequential order (Appendix C).

The following instruments were used to collect information during the interview: (1) Family Composition Questionnaire (Appendix D); (2) Care of the Exceptional Child (Appendix E); (3) Parental Expectations for Children's Independence (Appendix F); (4) Parental Perception of Family Esteem (Appendix G); and (5) the Spanish version of the Vineland Adaptive Behavior Scale (Appendix H).

The first four instruments were designed by the investigator specifically for this study. The Vineland scale is a commonly used standardized scale to measure adaptive functioning in the United States.

Family composition questionnaire (FCQ)

This instrument requests information about demographic characteristics of the family, family structure, and the family support network. The FCQ is similar in format to other reported instruments for family survey such as the McMaster Family Assessment Device (Epstein, Baldwin, & Bishop , 1983), and The Social Support Inventory (Cooke, et al. 1988), but it was specifically designed to fulfill the purposes of the present research.

The introductory section inquires about the family names, address, and number of relatives that speak the Mayan-language. Following this, the FCQ consists of three parts. The first part collects information about members of the family living in the same household, their age, occupation, and level of education. The second part describes the living relatives of both parents, their location, frequency which they are contacted, and parental estimate of how helpful they are for their family. The third part inquires about the family's socioeconomic status (SES) and religious practices. Two criteria are used to describe SES with the first being the parent's own perception of their economic status. The second follows a more objective criterion that lists the appliances existing in the house. Possession of appliances has been demonstrated as an appropriate indicator of socioeconomic status for the Yucatan (Sánchez & Canto, 1985). This section also inquires about the religious denomination of the family, parental

perceptions of the family's religiosity and the frequency with which they attend religious services.

Care of the Exceptional Child (CEC)

The CEC is comprised of fifteen open-ended questions which investigate a number of issues related to how the family provides care for the child with mental retardation and his/her siblings. It also examines parents' perceptions about the origin and significance of this condition. Interviewers were required to ask questions orally and to record parents' responses. This instrument yields information about the following aspects of the family: (a) Care provided for the child with mental retardation and his/her siblings; (b) parental knowledge and beliefs about mental retardation; (c) parent's attributions about the origins of the condition of mental retardation and their experience with disability; (d) family members reactions to the presence of a child with mental retardation; and (e) parental expectations toward their children in the domains of longevity and well-being (i.e. happiness, security, health).

Parental expectations of children's independence (PEI)

Due to the lack of a standardized instrument to measure parental expectations of independence, a questionnaire was designed to evaluate parents' expectations about their children's independence when adults. This instrument contained 12 items describing parents' expectations about

their child's future independence in three domains: independent living, independent decision-making, and independent social life. To compare expectations in México and the US, an effort was made to describe behaviors that are generally expected for adults in the US (e.g. ability to travel with friends). The PEI required parents to estimate the probabilities of their children behaving in certain ways or doing specific activities when they reach 25 years of age. This age was chosen as a reference point after consulting teachers in the Yucatan concerning the age at which most parents consider their children to be fully grown adults (Cantón, 1991).

Items are framed in a Likert scale ranging from 1 (Unlikely) to 5 (Very likely). Items 1,4,7 and 10 evaluate expectations of independent living. Items 2,5,8 and 11 evaluate expectations for independent social life. Items 3,6, and 12 evaluate parental expectations of independent decision-making. The instrument as a whole had a composite scale from 12 to 60. Maximum independence was reflected by higher scores.

Two forms of this instrument were presented to each parent. One with respect to the child with mental retardation and the other in reference to the able sibling also included in the study.

Parental perception of family esteem (PFE)

The PFE was designed to assess parental perceptions of family esteem. It was assumed that parents who reported a higher perception of their family's esteem have been better able to adapt to the presence of a child with mental retardation. The PFE was designed with the idea that parents' perception of the family esteem may be explored by establishing how parents view their own family as compared to others. Parents completed a Likert scale format estimating their perceptions of their family as compared to others on the following dimensions: happiness, problems, luck, unity and respectability. Scores for each of the items were added to consolidate a single scale with scores ranging from 5 to 25. Higher scores represented higher family esteem.

Vineland Adaptive Behavior Scale

The Spanish version of this instrument includes 297 items that provide a general assessment of adaptive behavior (Sparrow, Balla & Cicchetti, 1984). The instrument is administered by a trained interviewer to a parent or guardian in a semi-structured interview that typically lasts between 20 and 60 minutes. Norm-referenced information is based on the performance of representative standardization samples of about 4,800 individuals in the United States. Norm referenced information is available for American children and adults with and without disabilities. This

instrument consists of four sub-scales: communication, daily living skills, socialization, and motor skills. However, the motor skills domain was not included in this study since it does not apply for children older than 5.9 years old. This instrument provides standard scores for each of the sub-domains and yields a composite score of adaptive behavior with a mean of 100 and a standard deviation of 15.

Validity of the instruments

Four of the questionnaires were designed by the author for the purpose of the study. A major problem in this work was the lack of previous experience with these instruments, and the lack of piloting, re-testing, and refinement of the questionnaires. Hence, there is not sufficient information to clearly establish their consistency, reliability, and external validity. However, instruments were assumed to possess face validity based upon their operational definitions. The investigator also has previously designed similar research instruments for use in this region.

In addition to the lack of previously validated instruments for family research in the Yucatan, some of the limitations described for testing minorities in the United States may be extended to the testing process in this study. Duran (1988) claimed that the primary limitations in existing testing practices with Hispanic students were: (1) The validity and reliability of the test may be reduced because of factors such as limited language proficiency (in

the language of the test) and lack of familiarity with the content of the test's items; (2) the lack of social and cultural sensitivity on the part of the test administrator; and (3) the respondent's lack of familiarity with test taking strategies.

In this study there was an effort to achieve clarity of language during the interview. Interviewers demonstrated competencies related to paraphrasing and clarifying questions during the training session. In addition, the risk of lack of cultural sensitivity was potentially reduced by the fact that all interviewers were from the Yucatan and had a reasonable degree of practical experience interviewing people.

It has been previously argued that the psychometric properties of a test are seldom transferable to other populations. Hence, a general caution must be exercised when interpreting results from the Spanish translation of the Vineland Adaptive Behavior Scale because of the lack of information about the cultural appropriateness and content-relevance of the items.

Research questions

External context variables

What are the socioeconomic and ethnic characteristics of the sampled families?

The variables related to this question were defined using the following indicators:

Socioeconomic status

The socioeconomic status of the family was estimated by the parents reported perception of their family as working class, middle class or upper class, and by counting the number of appliances (0-8) available in the household (See: section III- A of FCQ: SES).

Ethnicity

In Mexico persons use both maternal and paternal last names. The establishment of the degree of Mayan ethnicity in the family was determined by adding the number of Mayan last-names in the family. The number of Mayan last names were added to the number of immediate relatives that were able to speak the Mayan language to create a Mayan ethnic background scale with a scale of 0-9 (See introductory section in the FCQ).

Data analysis procedure

To answer the questions related to the external context, frequency distribution of scores along with descriptive statistics (means and standard deviations) were derived for the variables of Mayan background and SES. Information describing the family's external context was organized and reported in Table 3 (p. 72).

Internal context variables

What characteristics describe the parents, children, as well as the structure of these families?

The variables related to this question were described using the following indicators:

Parents' characteristics

Demographic characteristics of the parents were determined by computing their current age, level of education, occupation, and degree of religiosity on Section I of the FCQ.

Children's characteristics

Demographic characteristics of the children were established considering the children's grade, age, and gender as reported by the parents on Section I of the FCQ.

Family structure

The family structure - extended or nuclear- was determined by a content analysis of Section II of the FCQ, considering the following factors: family size, number of members living in the household, location of close relatives, and frequency of contact with relatives.

Data analysis procedure

To answer the questions related to the internal context, descriptive information was organized in separate tables for parents (Table 4, p. 74) and children (Table 5, p.76). Descriptive statistics were reported for age and

levels of education of both mothers and fathers. Parental occupations were analyzed and classified categorically reporting frequencies and percentages. Information regarding the structure of the families, including descriptive statistics, was organized in Table 6 (p. 77).

A-factor variables

What are the adaptative-functional levels of mental retardation present in these families?

To determine the adaptative-functional levels of children with mental retardation in these families, tested outcome levels of behavior were established using the specific scores on the Vineland scale gathered from the parental interview.

Data analysis procedure

The frequency distribution of scores on the Vineland scales were reported providing means and standard deviations for each sub-domain and for the composite scores. This information was organized in Table 7 (p. 78).

B-factor variables

What is the nature of the support network available in these families?

The support network available in these families was determined by a content analysis of questions 7, 9 and 12 of the CEC regarding the persons that parents reported providing the most help with the care of the child with

mental retardation. The "Help scale", a quantitative indicator of family support was created by adding the amount of help parent's rated as being provided by relatives (scale 0-100) in Section II of FCQ.

Data analysis procedure

Care takers of the child with MR and the persons that parents reported providing the most help with the care of the child with MR were identified and reported. The frequency distribution of helpers and the mean, median, and standard deviation of the "Help scale" were reported. Information regarding the family support network was organized in Table 8 (p. 80).

C-factor variables

What are the parental beliefs, attributions, and expectations of these families?

To answer this question, the variables related to this question were analyzed using the following indicators:

Paternal beliefs

Parental beliefs regarding the care of a child with mental retardation were investigated by a content analysis of the parents' answers to the open question: "What advice would you give to another parent who has just recently learned that he/she has a child with mental retardation?" (CEC question #3).

Paternal attributions

Parental attributions about the origin of mental retardation were investigated by a content analysis of the answers parents provided to two open questions: "What caused your own child's condition?", and "In general why do some families have a child with mental retardation and others don't?" (questions 1 and 15 CEC).

Paternal expectations

Three kinds of parental expectations were investigated. Parental expectations of their child's longevity were established by analyzing responses to the question: "How many years do you expect your child to live?".

Parental expectations of well being were investigated by the analysis of parents' estimates of their child's health, happiness and security on a scale from one to ten at different life stages. A composite score for expectations of well being was created by adding the ratings of parental expectations of their child: (1) At the time of the interview; (2) when adolescents; and (3) when adults. The composite scale ranged from 0 to 30. (Refer to questions 14 and 15 of CEC).

Parental expectations of independence were determined by the scores on the PEI. A scale from 12 to 60 was devised. Composite scores were formed by adding the points for each specific item.

Data analysis procedure

Each of the C-factor variables was independently analyzed and reported. Frequencies and percentages of common parental beliefs were reported in Table 9 (p. 82). Frequencies and percentages of common parental attributions about the origins of mental retardation were reported in Table 10 (p. 83).

Means and standard deviations for expectations of well being were organized and reported by disability status and life-stage of assessment in Table 11 (p. 85). Parents expectations of well being for able children were compared to scores for children with mental retardation using a split-plot statistical design considering the dimensions 'time' and 'disability status'. Statistical summaries and results were reported in Table 12 (p. 86).

Regarding expectations of independence, means and standard deviations for composite scores and sub-scales were reported for males and females in Table 13 (p. 88). To control for gender-combination of children within the family, families having both children in the study of the same sex were studied independently. In these families, parental expectations of independence were compared between mothers and fathers and children with and without mental retardation by dependent-measure t-tests. Statistical procedures and results were reported in Table 14 (p. 88).

X-factor variables

What is the degree of adaptation in these families as measured by reported family esteem?

The indicator of the level or degree of adaptation in these families was the score on the PFE (scale 1-15).

Data analysis procedure

Frequency distribution and descriptive statistics (mean, median and standard deviation) for the scores on the PFE were reported in Table 15 (p. 90).

Relationships between model factors

Which intercorrelations between the quantitative variables are significant in predicting family adaptation?

Data analysis procedure

To address this question a matrix of correlations was constructed between all quantitative variables in the study, there as are reported in Table 16 (p. 91).

The theoretical model of this study was evaluated using two criteria. First, external context variables, internal context variables and intra-familial variables were used as predictors of the X-factor family adaptation. Second, a statistical approach was used by considering the highest bi-variate correlations between the variable adaptation and other variables in the matrix. Correlation equations were used to assess the capacity of different factors in the model to predict the degree of adaptation in the family. Variables included in both methods of assessing the model

and statistical summaries for these procedures were organized and reported in Tables 17 (p. 94) and 18 (p. 95).

Summary

Procedures, instruments and methods were described in this chapter. Research questions were stated identifying the variables and indicators pertinent for this study.

Table 2 lists the variables and indicators previously considered as well as other additional variables used in describing these families.

Table 2. Variables and indicators

Variable	Indicator
External context	
SES	- List of appliances - Parents reported social class
Ethnicity	- Mayan-last names - Members of family speaking Mayan-language
Religion	- Denomination
Internal context	
Parental characteristics	- Parents' reported age, religiosity, level of education and occupation
Children's characteristics	- N. of siblings gender, age, disability status

Table 2. continued...

Variable	Indicator
Family structure	- N. of family members; location, and frequency of contact.
ABCX-factors	
A. Adaptive functioning	- Scores on the Vineland scale
B. Family support	- Help scale - Relatives providing help
C. Life expectations	- Parents' estimates over time
C. Expectations of well being	- Parents' estimates over time
C. Expectations of Independence.	- Scores on PEI
X. Family esteem	- Scores on PFE

CHAPTER IV

RESULTS

Introduction

The purpose of this study is to describe the characteristics of families in the Yucatan with children with mental retardation. Data collected from both parents were analyzed using statistical criteria and normative information as available from the literature in this area. Results are presented in this chapter. The first two sections describe the characteristics of the external and internal context of these families. A third section describes the intra-familial ABCX variables: Mental retardation, family support network, meaning of disability and adaptation, separately. The last section presents the interrelationships between the quantitative variables included in the study.

For all sections descriptive data have been organized in schematic tables which are followed by comments about the data and by statistical or conceptual inferences derived from the results. While this chapter focuses on the analysis of the data, the subsequent chapter aims to synthesize the results. Data were analyzed using a statistical package: PC-Statistician (1981).

External context

Three variables describing the external context of families in the Yucatan were considered: Self reported SES, ethnic background, and religion. Table 3 summarizes information gathered about these variables.

Table 3. External context variables

	F	%
SOCIOECONOMIC STATUS		
Self-reported social class		
Working class	35	70
Med-Low	10	20
Med-up	5	10
Upper class	0	0
Number of appliances		
0	17	34
1	18	36
2	3	6
3	3	6
4	6	12
5-8	3	6
ETHNICITY		
Mayan ethnic background scale		
0-1	14	28
2-4	11	22
5-9	25	50
RELIGION		
Catholics	41	82%
Non-Catholics	9	18%

Regarding the indicators of socioeconomic status, fifty percent of the families reported having a washing machine in

the house, 32% a fan, and 24% a phone. Thirty-four percent of these families had none of the listed appliances in their homes. Two-thirds of parents in these families considered themselves to be working class. The Pearson coefficient of correlation between the two indicators of socioeconomic status (self-reported social class and number of appliances) was approximately r=.54, suggesting moderate agreement among these measures.

It can be inferred from these data that families sampled lived in poor socioeconomic conditions. The distribution of SES in this sample is congruent with previously reported distributions of SES for the general population in México (INEGI, 1991).

A second important feature of the external context in the Yucatan was the presence of a Mayan ethnic background which is prevalent in this part of México. Families perceiving themselves as working class tended to have a higher degree of Mayan ethnic background ($F= 3.72$, $p \leq .05$; statistical summary can be consulted in Appendix I).

A third important feature of the external context of the Yucatan is the prevalence of the Catholic religion in this region (82% of the families).

In sum, the external context surrounding families in these sampled families in Yucatan can be characterized by poor socioeconomic conditions, a Mayan ethnic background in many families, and the prevalence of the Catholic religion.

Internal context

The internal context of the families in this study have been described in three tables with information concerning the parents, children, and family structure respectively.

Table 4 provides a description of the demographic characteristics of these parents.

Table 4. Parents' characteristics

		Fathers (n=50)		Mothers (n=50)	
	AGE				
	Mean	38.96*		37.04	
	sd	7.09		5.98	
	RELIGION				
Reported (scale 0-10) degree of religiosity	Mean	6.9		7.06	
	sd	2.5		2.36	
Frequency of church/ temple attendance per month	N	2.32		3.56	
	EDUCATION				
Maximum level of education	Mean	6.12		5.18	
	sd	4.68		3.94	
	OCCUPATIONS	F	%	F	%
Unskilled workers Campesinos, builders		8	16	0	0
Blue collar, drivers		14	28	2	4
Skilled workers carpenters, plumbers		19	38	0	0
Clerks, sales,		6	12	4	8
Professionals, executives		3	6	1	2
Household		0	0	43	86

* in years

Table 4 indicates that the parents participating in this study were, for the most part, middle aged. However, since the mean age of the Mexican population is 16 years (INEGI, 1990), a mean sample age of approximately 39 years might suggest that these were relatively "old" parents.

These parents rated themselves rather high on the religious scale (approximately 7 on a scale of 0 to 10), and self-perceived degree of religiosity was very similar between spouses. However, mothers attended religious services more often than fathers.

The average level of education for both parents in this sample was equivalent to the completion of an elementary education in México. This finding indicated generally low levels of education in these families.

Fathers were mostly unskilled blue-collar and skilled workers (87%). The majority of the mothers were housewives (86%). This finding supports the notion that, regarding work, parents in the Yucatan exhibit traditional gender roles: males are usually responsible for earning money outside the home, and females bear the responsibility of the household.

Table 5 (p. 76) identifies the children in these families by age, ability, and gender. As indicated in this table, the number of males and females with mental retardation is approximately equal (26/24). However, male siblings were slightly over-represented in the sample (31/19).

Table 5. Children in the sample

	MR children		Able children	
	AGE			
Mean	8.68		8.94*	
sd	1.86		2.09	
	GENDER			
	N	%	N	%
Males	26	52	31	62
Females	24	48	19	38
Total	50		50	

* in years

There were no statistically significant differences between the age group means of children with mental retardation and able children. All of the children in this sample attended school.

Table 6 (p. 77) presents characteristics that describe the family structure. Information in this Table suggests that the internal context of the families in this sample is congruent with previous reports characterizing the family in Latin America as an extended social structure with intense participation of relatives in the family's life (Holloway, et al. 1987; Bridges, 1980). As described for other Latin American families, relatives in the families sampled were contacted frequently, on a daily basis in approximately a third of the families. The majority of relatives lived in the same town with many living in the same neighborhood. On the average, approximately 7 persons lived in the household, and parents had between 3 and 4 children.

Table 6. Family structure

Number of people living in the household	Mean	6.46
	sd	1.92
Number of children in the family	Mean	3.52
	sd	1.55

Location of most extended family relatives

	N	%
In the neighborhood	15	30
In same town	19	38
Other towns within the state	7	14
Number of families with an extended family member living with them.	7	14

Frequency of contact with extended family members

	N	%
Daily	15	30
twice a week	14	28
once a week	13	26
Percentage of families receiving some help from relatives	39	78

Intra-familial characteristics

This section describes the intra-familial characteristics of the families sampled. Results of the measures associated with the ABCX factors of the model guiding this study are presented and discussed.

A-factor: Mental retardation

The condition of mental retardation (MR) was supported empirically by scores on the Spanish version of the Vineland Adaptive Behavior Scale. This scale was administered to

determine the current degree of adaptive functioning of the children sampled in relation to their age based upon parental reports. Table 7 summarizes the Vineland data obtained, specifically composite and sub-scale standardized scores.

Table 7. Adaptive behavior in children with mental retardation
(N= 50)

		Vineland standard Scores		
		Males (n=26)	Females (n=24)	Total Sample (N=50)
		COMPOSITES		
	Mean	42.92	43.92	43.42
	sd	11.23	10.44	10.74
		SUB-SCALES		
Socialization	Mean	57.08	59.48	58.28
	sd	19.04	17.09	17.95
Living skills	Mean	44.88	46.12	45.50
	sd	19.46	22.20	20.67
Communication	Mean	42.92	43.92	39.88
	sd	11.23	10.44	9.32

Frequency distributions of composite scores for this sample

Range	F	%
20-30	4	8
31-40	11	22
41-50	21	42
51-60	10	20
60-69	4	8

It can be observed that the mean for the sample (43.42) is below the third percentile of the standardized scale Sparrow, 1984). These results may give the impression that this sample consisted of very low socially functioning children, considering that the third percentile in the Vineland scale is associated with a severe level of mental retardation. These were children with an obvious degree of mental retardation given their placement in a special education center. Some children in the sample had severe mental retardation and very likely validly exhibited poor adaptive functioning. However, it is the investigator's impression, as well as the impression of many psychologists and teachers working in the centers included in this study, that some of these children, despite obvious cognitive and communication deficits, were sociable and functioned relatively well in community and family contexts. Hence, one may suspect that the Vineland scale may underestimate adaptive behavior in this population, perhaps by under-estimating socialization skills.

The above suspicion does not affect the outcome of this study since the Vineland scale was simply used to corroborate the presence of mental retardation in these children. However, it seems necessary to determine the validity of this instrument in assessing this specific population before it can be used for clinical purposes.

A post-hoc examination of this instrument led to the identification of potentially culturally inappropriate

items. For example, Item 51 in the daily living skills domain, 'Makes own bed when asked' makes little sense in a community where most children and adults sleep in hammocks.

In sum, for The Vineland scale to achieve sound clinical utility in the Yucatan, it is essential to identify and modify some of the items according to their cultural adequacy, validity and reliability for this population.

B-factor: Family support network

Table 8 summarizes information related to the support network of these families.

Table 8. Family support network

Help scale:	Mean	sd.	Range
	26.9	24.5	0-99

		%
Main care-takers of the child with MR	Mother	70
	Both parents	22
	Others	8
Persons helping the most with the care of the child with MR	Siblings	26
	Grandparents	22
	Other relatives	10
	Maid	4
Persons that would take care of the child with MR if both parents were to die	Siblings	32
	Grandparents	16
	Other relatives	12
	God parents	6

The help scale was designed by adding the estimated amount of help each parent reported receiving from relatives. The highest score (99) indicated families that

had the greatest amount of family support. It can be observed that this help varied greatly (sd=24.5) between families.

In seventy percent of the families studied, the mother was considered the primary care-taker of children (both able and with MR). Siblings and grandparents were the persons helping the most in the care of children with mental retardation. Siblings, grandparents and even godparents were to bear the responsibility for the child's care in case of parental death.

C-factor: Meaning of mental retardation in the family

Parental beliefs

Parental beliefs were explored by asking parents what advice they would give to other parents who have recently learned that they have a child with mental retardation. Questions were open-ended; thus, responses likely suggest parental priorities and the concerns that may be most immediate for these families. Table 9 (p. 82) summarizes a content analysis of the most frequently expressed beliefs.

It can be observed that parents in this sample most frequently recommended the enrollment of a child with mental retardation in a special education school. Actually, when asked to estimate how beneficial school was for their children, parents estimated school benefitted their child with mental retardation more than their able child (t(49)=

2.11; p= < .05) (see question 10 CEC, and data summary in Appendix I).

Table 9. Parental beliefs

Parents' advice	F	%
Send the child to a special education school	29	58
Take the child for medical attention	24	48
Provide the child with love and affection	16	32
Provide the child with adequate care	12	24
Be patient with the child	7	14
Do not mistreat the child	6	12
Accept the child as is	5	10

Parents also recommended taking the child with mental retardation for specialized medical attention and providing the child with love and the necessary care. In six cases, parents specifically advised not to mistreat the child physically.

Parental attributions

Table 10 (p.83) describes parental attributions about the origin of their own child's condition, as well as parental attributions about the incidence of mental retardation in other families. Parental responses to open-ended questions were content analyzed, classified and summarized.

As shown in Table 10, approximately a third of these parents did not know the specific cause of their child's condition. In three cases, parents attributed their own

child's condition to destiny or God's will. Parents identified drug and alcohol abuse, particularly "the father's drinking", as a major factor associated with the incidence of mental retardation in other families.

Table 10. Parental attributions of MR in "own" child and in "other" families

	F	%	F	%
Attributed cause	Own child		Other families	
Don't know	16	32	6	12
Drug and alcohol abuse	0	0	13	26
Pregnancy accidents and birth defects	10	20	0	0
Disease/accidents during infancy	7	14	0	0
Genetic disorders	6	12	8	16
Parental old age	5	10	6	12
Luck/God's will	3	6	9	18
Contraceptives	0	0	5	10
Marital discord	3	6	3	6

The most common misconceptions about the origins of mental retardation in this sample were the attribution of this condition to marital discord and to the use of oral contraceptives. The parents in nine of these families attributed mental retardation in other families as the result of 'bad luck' or 'God's will'.

Parental expectations

Parental expectations toward both able children and children with mental retardation were investigated in the following domains: life, well being, and independence.

Life expectations

Regarding life expectations, parents were asked: "How many years do you expect your child will live?". Seventy four percent of parents were unable to provide an estimate. Their most common responses can be synthesized as follows: "God knows", "Only God can tell", "Only God gives and takes away life". Cultural factors may have some influence on the difficulties these parents demonstrated in estimating how long they expected their children to live. For example, the general belief of the Mexican population that life and death are pre-determined events may be in part as tenable explanation for this finding (see Holtzman et al., 1975).

Well being expectations

Parents were asked to rate from 0 to 10, how happy, secure and healthy they believed their child was at the time of the interview and how happy, secure and healthy their child would be when a teenager and an adult. Table 11 (p. 85) summarizes the results of parental expectations of both able children and children with mental retardation.

Table 11 shows higher scores for able children than for children with mental retardation. For both groups, scores tend to decrease over time. A composite score of parental expectations of well being was created by adding the three estimates over time. To determine whether these differences between children over time were statistically significant, an AxBxC mixed design (split-plot design) was executed.

Table 11. Parental expectations of well being

			Now	Teen	Adult
MR child	happy	Mean	9.23	8.76	8.73
		sd	1.5	1.35	1.64
	secure	Mean	8.87	8.85	8.89
		sd	1.70	1.49	1.30
	healthy	Mean	8.73	8.79	8.77
		sd	1.51	1.25	1.27
Able child	happy	Mean	9.24	9.12	8.93
		sd	1.30	1.18	1.32
	secure	Mean	9.20	8.96	8.96
		sd	1.35	1.40	1.44
	healthy	Mean	9.12	9.21	9.23
		sd	1.29	1.07	1.04

Table 12 (p. 86) summarizes composite means and test results. As indicated in this Table, the only statistically significant differences found were in regard to the 'time' factor. These parents tend to have lower expectations of the well being of both children with MR and able children as their children grow older. The ability of the child had no statistical effect on parental expectations as tested. It is hypothesized that considering the poor socioeconomic conditions prevalent in this sample, parents may foresee increasing difficulties for both able children and children with mental retardation as they grow older, due to the limited opportunities and economic hardships in this particular social context.

Table 12. Testing differences in expectations of well being

ability\time	NOW	TEEN	ADULT	
MR	8.75	8.37	8.31	8.47
ABLE	8.98	8.76	8.48	8.74
	8.86	8.56	8.40	8.6

SOURCE	SS	df	MS	F
Between S	576.4	99	5.82	
B	5.5	1	5.48	.94
error (b)	570.9	98	5.8	
within S	307	200	1.5	
A	83.7	2	41.9	17.0*
AxB	5.2	2	2.6	1.06
error (w)	487.5	198	2.46	

* $p \leq .001$

Independence expectations

Parental expectations of their children's future independence was measured by the 'Parental expectations for children's independence (PEI)' questionnaire, which was administered to both parents. This instrument yielded information about parental expectations in three domains: independent living, independent social life, and autonomous decision-making. Scores on the PEI may range from 12 to 60 with higher scores reflecting higher expectations of independence. For each child, a composite score of the degree of expectations of independence was formed by adding the scores from the three sub-scales of the PEI. Since a preliminary exploration of the data failed to show any significant differences between mother's and father's estimates, ratings of both parents were combined into a

single estimate of parental expectations of independence per child.

Table 13 (p. 88) illustrates parental estimates of their children's future independence across gender and disability status.

A review of Table 13 suggests that generally, males were expected to be more independent than females and able children more independent than their siblings with mental retardation. However, to test for statistical significance, it was necessary to account for the effects of gender-combination (e.g. both children males, both children females) in each family. For this purpose, related means t-test comparisons were carried out specifically with families having both children in the study of the same gender. Table 14 (p. 88) describes the data and results.

It can be observed in Table 14 that comparisons using families with children of the same gender were statistically significant. In general parents expected their able children to be more independent when adults than their children with mental retardation. Similarly, parents expected their male children to be more independent than their female children. A closer inspection of the items in the questionnaire suggested that males, regardless of disability status, scored higher on all items except one: Item 10, "When 25 years old, he/she will be able to cook for him/herself".

Table 13. Parental expectations of independence (Independent estimates)

	(range 0-60) N=50		Males n=26	Females n=24
Child with mental retardation	Composite	Mean	37.96	35.1
		sd	6.71	6.1
	Independent living	Mean	12.65	11.60
		sd	2.66	2.8
	Independent social life	Mean	13.37	12.17
		sd	3.05	2.60
	Autonomous decision-making	Mean	11.94	11.3
		sd	2.60	2.9
	(range 0-60) N=50		Males n=34	Females n=16
Able child	Composite	Mean	45.31	42.34
		sd	5.32	10.78
	Independent living	Mean	15.08	14.34
		sd	2.41	3.79
	Independent social life	Mean	16.21	14.61
		sd	2.17	4.10
	Autonomous decision-making	Mean	14.02	13.37
		sd	2.69	3.65

Table 14. Parental expectations of independence (dependent estimates)

	MR	Able	t
	MALES (n=15)		
Mean	37.57	46.61	6.05*
sd	7.56	4.04	
	FEMALES (n=8		
Mean	37.25	44.28	4.27*
sd	7.22	5.03	

* $p \leq .001$

This latter finding further suggests that the presence of traditional gender roles in Latin American homes is evident in this sample. In general, responses indicated that women are expected to be more dependent on parents and to do the cooking and other traditional domestic chores and males are expected to be more independent and detached from the family (see Hawkins, 1984).

To explore whether expectations of independence for Mexican children are different than in the US, the sample mean on the PEI for able children was compared to a norm criterion which was operationally developed as follows: When all the items in the PEI are marked "somewhat probably" a score of 48 is obtained. Considering that items connote behaviors normally expected for US adults, this score may be used as a "population mean", and, thus, compared with the sample mean of 40.38 (sd=8.2). A single sample t-test yielded a significant difference between the assumed mean for the US population and the mean for able children in the sample ($t=37.5$; $p= \leq .001$.). This finding may support the notion that parental expectations for children's independence may be less important in families sampled in the Yucatan than in the US.

X-factor: Adaptation to disability

An estimate of the degree of family adaptation was obtained using the 'Parental perception of the family

esteem' questionnaire. The PFE has a scale range of 10 to 25 with higher scores indicating higher family esteem.

Table 15. Parental perception of family esteem

Mean= 16.28	sd= 2.85	Md= 17
Frequency distribution		
Interval	F	%
10-13	8	16
14-17	26	52
18-21	15	30
22-25	1	2

Table 15 presents the frequency distribution and descriptive statistics regarding PEI scores. It can be observed that variation in this distribution of scores was rather moderate (sd = 2.85). Nonetheless, it appears that this measure of adaptation allows the identification of families with relatively low or high degrees of self-reported esteem. Although low family esteem cannot be attributed to the presence of mental retardation, high or average family esteem may be assumed to indicate some degree of positive family functioning as well as positive adaptation despite the presence of a child with mental retardation.

Relationships between model factors

An attempt was made to look at the relationships between the factors considered in the theoretical model used

in this study. To visualize the inter-relationships among the variables at various levels, quantitative contextual and intra-familial variables were ordered and arranged in a matrix of correlations in external context, internal context, and intra-familial ABCX variables (Table 16, p.92).

It can be noted in Table 16, that the highest correlations obtained were between the parents' level of education, and between parental level of education and SES. This outcome corroborates the reported association between higher levels of education with better socioeconomic levels. Only two variables were correlated moderately high with family adaptation: parents' degree of religiosity (.36) and parental expectations of independence (.31).

Considering coefficients of correlations between external context variables and other variables in this model, the relationships of SES and cultural background was investigated. It was important to separate the effects of poverty, a pervasive condition in Latin American countries as well as in Yucatan, from the effects of cultural values that differentiate ethnic groups, such as the Mayan in regard to disability.

These results suggest that ethnic background may be related to family adaptation in a way that is different than the effects of SES. (continue in p. 93...)

Table 16. Matrix of correlations between quantitative model variables

		External context			Internal Context			ABCX- factors				
		SES	Etn	FEd	MEd	#Child	Prel	A MR	B Help	C Well	C Ind	X Adapt
External Context	SES	-	-	.69	.609	.18	-.039	.08				.149
	Etn	-.334	-	-.31	.53	.14	.05	-.11				.139
Internal Context	FEd			-	-	-	-	.06	-.251	.273	.064	.208
	MEd			.673	-	-	-	-.029	.074	.105	-.054	.087
	#child			.22	-.25	-	-	-.036	.208	-.446	.007	.1027
	Prel			.13	-.17	.06	-	.164	.08-	.280	.20	.359
ABCX factors												
A	MR	.08	-.113					-	.07	.218	.054	.075
B	Help	-.092	.076					-	-	-.224	.224	-.103
C	Well	.118	-.215					-	-	-	.137	.052
	Indep	.02	.163					-	-	-	-	.308

Codes:

Ind: Parental Expectations for Independence.
SES: Socioeconomic status.
Etn: Mayan ethnic background.
Help: Degree of help from relatives.
FEd: Father's educational level.
MR: Degree of MR as indicated by Vineland scores.
Prel: Parental self-rated degree of religiosity.
MEd: Mother's educational level.
#Child: Number of children in the family.
Well: Parental expectations for children future well being.
Adapt: Degree of family adaptation.

For example, SES was correlated with parental occupation, but was unrelated to family adaptation. Mayan background, on the other hand, was associated with family adaptation, and it was inversely correlated with parental education and SES.

It is necessary to acknowledge the independent contributions ethnic and socioeconomic factors play in explaining family adaptation. However, these effects are very difficult to establish because external context factors are mediating variables that are usually highly correlated with each other.

Information on Table 16 was used to consider the relative usefulness of the model developed for this study and to examine the phenomenon of family adaptation. Two kinds of analysis were executed. First, using the model based on Boss' theory of family stress, factors which were delineated in the external and internal context were selected and used as predictors of adaptation. Second, statistical criteria were used to form a prediction model selecting the variables which correlated most highly with the dependent variable: adaptation.

Considering the theoretical framework, three models were evaluated as predictors of adaptation: (1) External context variables (SES, ethnicity); (2) internal context variables (mother's education, father's education, number of children in the family, and parents' religiosity); and (3) ABC-variables (adaptive levels of functioning, family support, parental expectations of independence, and parental

expectations of well being). Multiple-correlation equations were carried out using the factors delineated in the model as predictive variables of the dependent variable "adaptation". Table 17 summarizes the results of these analyses. Data summaries and results can be consulted in Appendix I.

Table 17. Model variables as predictors of family adaptation

Model	r^2	F	p
1) External context variables			
Adapt = f (SES, Etn)	.0629	1.57	.21
2) Internal context variables			
Adapt = f(FEd, MEd, #child, Prel)	.174	2.38	.065
3) Intra-familial variables			
Adapt = f (MR, Help, Wellb, Indep)	.134	1.74	.156

It can be observed that none of the three models accounted for statistically significant ($\alpha \geq .05$) amount of the variations in family adaptation.

According to statistical criteria, independent variables from the model were selected based on the strength of the their association with the dependent variable "adaptation". The following three variables which were correlated the highest with adaptation were included in a prediction model: Parental degree of religiosity (Prel), Parental expectations of independence (Indep), and the level

of father's education (FEd). A multiple-regression equation yielded the results summarized in Table 18 (p.95). Data summaries and results can be consulted in Appendix I.

Table 18. Model considering highest correlations

1) Highest correlated variables			
Model	r^2	F	p
Adapt = ƒ (Prel, indep, FEd)	.20	3.84	.01

This model is statistically significant ($\alpha \leq .05$) and accounted for approximately twenty percent of the variance of family adaptation. However, when considered in isolation, only the independent variable parental religiosity resulted in a significant predictor of the dependent variable adaptation (See appendix I). Nonetheless, it appears that parental degree of religiosity, level of education, and expectations of independence may be factors to consider when examining adaptation to the presence of a child with mental retardation in these families.

Summary

Data collected were presented and analyzed according to the model proposed in this study. The family external context, internal context, and the ABCX-intra-familial variables were described. Results from statistical and content analysis procedures were presented and comments were made about the findings. Inferences from the results were

attempted when possible. The following chapter provides an overview of the results, addresses each one of the research questions of the study, and synthesizes the information obtained in the study.

CHAPTER V

DISCUSSION

Introduction

This study describes the environmental and familial characteristics of intact family units in the Yucatan, that included both natural parents, a child with mental retardation and an able child. This chapter addresses each of the research questions delineated in this study, it synthesizes the information obtained in the survey from the parents and provides integrative comments. Following the model used in the study, questions regarding the external and internal family contexts will be discussed first. Specific intra-familial ABCX factors will be considered second. Third, questions regarding the value and limitations of the theoretical model used in guiding the study will be addressed. This chapter includes recommendations for future research in this area and comments about the implications of the data for family intervention in rehabilitation and special education in the Yucatan.

External context

What are the socioeconomic and ethnic characteristics of the sampled families?

In general, families in this sample reported a relatively low socioeconomic status and some degree of Mayan ethnic background.

Regarding the socioeconomic status, two thirds of the parents reported belonging to working class families. In addition, there was a trend in these families to possess few, if any appliances in the household. Such data supports the general notion in the literature that families in Latin America are surrounded by conditions of poverty (Sterner, 1976). As also reported for most Latin American countries, Catholicism is the prevalent religion in the Yucatan.

The presence of a Mayan ethnic background in the majority of these families was corroborated by the number of families in the sample with Mayan last names and family members who were able to speak the Mayan language. No relationships were found between the degree of Mayan ethnicity in the family and ABCX intra-familial variables.

The above external factors help us understand family adaptation to disability given these factors describe the environment in which the family functions. These results set a base for future research on family and disability in Yucatan. Such research should identify external context factors, including potential resources and social norms, that may influence the family 's reaction to the presence of

disability. For example, the identification of parental acceptance of services available for these children, need to consider the parents' perception of their value in helping their child with mental retardation.

Internal context

What describes the characteristics of parents and children, as well as the structure of these families?

In general, these families had middle aged parents, who had an elementary level of education and generated their economic resources by fathers working in labor, building, and agricultural tasks.

Division of tasks in these families appears to follow traditional Latin American gender-roles patterns. In general, fathers worked outside the home, whereas the majority of the mothers were responsible for the household. Consistently, mothers were considered as the major care-takers of children. Only female children were expected to cook for themselves when adults. These findings suggest that further research is needed to establish the implications of these well defined gender roles for vocational training and other rehabilitation and special education practices with these children.

Children in this sample ranged from 6 to 12 years of age. They were all enrolled in the educational system. Children with mental retardation attended a special

education center, while able children attended the regular school.

The extended family is still the prevalent family structure in the Yucatan as well as in the rest of México. Extended family members lived with the family or nearby, they were contacted often, and they provided help to the family in various domains.

The frequent interaction among family members underlines the importance of assessing the functioning of children with disabilities within the family context. Considering the family internal context, further research in these families is needed to elucidate the ways extended family members specifically contribute to the various needs of children with a disability.

A-factor: Mental retardation

What are the adaptative-functional levels of mental retardation present in these families?

Standardized scores in the Spanish version of the Vineland scale yielded a mean for this sample of 43.42 (sd=10.74). This figure falls below three standard deviations from the mean of this scale for the normal population (X= 100 sd=15). Results indicate that children with mental retardation in this sample presented reduced levels of adaptive behavior expected for their age, thus corroborating empirically one of the major features for the diagnosis of mental retardation.

The description of these children as mentally retarded solely based on their level of adaptive-functioning is very limiting, especially if one considers that very few information about intellectual functioning and medical conditions could be obtained from the files in the special education centers included in the study.

The picture of children with mental retardation in this sample is unclear. For example, the clinical opinion of teachers and psychologists regarding children with mental retardation in these centers, suggests that the Vineland scale may underestimate the adaptive functioning of these children. Thus, it is necessary in future research to explore alternative criteria to describe these children as well as to develop studies directed to establish the validity of the Vineland and other scales for this specific population.

Considering the need for adequate methods of assessment, data-based information about familial and environmental demands on the child with mental retardation is essential, as a first step to develop adequate criteria to evaluate children with mental retardation in the Yucatan.

B-factor: Family support network

What is the nature of the support network available in these families?

Parents reported that they relied upon the help of family members. For example, grandparents, siblings and

godparents in some cases, often helped the parents with the care of the child with mental retardation. Relatives were expected to take care of the child in case of parental death. In general, the extended family was the most immediate source of social support for these parents.

The support provided by extended family members is a resource available for the child with mental retardation. This asset may be incorporated into rehabilitation and special education practices. For example, the availability of extended family relatives to help the child develop social skills, may compensate for the scarcity of public resources for the attention of these children in México.

The development of early stimulation programs in México, similar to the 'Head Start' program in the US, may incorporate family relatives who could spend time helping the children with professionally prescribed tasks and exercises, fostering their development at home.

C-factor: The meaning of mental retardation

What are the parental beliefs, attributions, and expectations of these families?

Parents reported that the best method to improve the condition of children with mental retardation was to assure their enrollment in special education programs, and to provide them with appropriate medical attention. Parents also emphasized the importance of providing emotional

support (love, care, patience and acceptance) to these children.

Mental retardation in the family was most frequently attributed to accidents during pregnancy and birth defects. However, parents attributed the incidence of mental retardation in other families to drugs and alcohol abuse. A third of the families did not know the origin of their child's mental retardation. Investigating this differential attribution of mental retardation in the future, may yield information about the ways parents restructure their ideas about this condition in order to adapt to their child's condition.

Two major misconceptions about the origin of mental retardation held by these families were the attribution of this condition to the use contraceptives (5 families) and to marital discord (3 families).

Parents were unable to state an estimate of their children's longevity. The majority of parents' suggestions and responses to questions regarding the life expectations of their children can be summarized by the following sentence, "only God gives and takes away lives."

Parents had lower expectations for the well being of their children as they grew older. No statistical differences were found between parental expectations of well being between able children and children with mental retardation. This finding may support the notion in the literature reviewed that, in conditions of economic

disadvantage, children with mental retardation may have the same status in the family as their able siblings. Considering external context hardships in the Yucatan, fathers may be concerned about their children's survival equally. In some families, poverty may be more disabling than the presence of a child with mental retardation.

When designing the questionnaire, Parental Expectations of Independence (PEI), behaviors normally expected for US adults were hypothesized and used as normative criteria. Results obtained with the PEI suggest that Mexican parents may have lower expectations of independence for their children when as compared to US parents. Further, statistical procedures indicated that in Mexican families expectations of independence are higher for males than for females. This finding parallels previous characterization of well defined gender roles in Mexican families (Smart & Smart, 1991).

X-factor: Adaptation

What is the degree of adaptation in these families as measured by the family esteem?

The degree of self-reported family esteem was the indicator of family adaptation in this study. The degree of family esteem was determined considered parents' perceptions of: their family problems, luck, respectability, happiness, and worth.

Family esteem was a useful criterion to discriminate between parents who considered their families similar to other families, from those parents who considered their families better or worse.

A major limitation in this study was the difficulty in linking the family esteem, as a measure of family adaptation, to the family's reaction to the stress of the disability. It is impossible to establish cause-effect relationships between disability and adaptation based upon measures of the degree of association between their respective indicators.

Indicators of adaptation such as the family esteem, help identify those families that despite disability are positively functional. However, it is necessary to search for better and more specific indicators of family adaptation, particularly when a family faces disability.

Relationships between model factors

Which intercorrelations between the quantitative variables are significant in predicting family adaptation?

Neither the external context variables, nor the internal context variables delineated by the model used in this study proved to be significant predictors of the level of adaptation, as reported by the level of esteem in these families. Similar non-significant results were obtained when the ABC intra-familial variables were used as the predictors of the X-variable adaptation.

There are various explanations for this outcome. First, the instruments and measures in this study were used in this population for the first time. Limitations regarding their validity and reliability have been previously acknowledged. Second, the variables considered in the model are psychosocial in nature. When these variables are analyzed with quantitative indexes and integrated in statistical models, their mathematical prediction is inexact.

The failure of this model to predict adaptation in this study suggests a need to reconsider both, the measures and the factors targeted. Measures may become more valid as research on the family and disability in the Yucatan evolves. There is a need to develop instruments which are valid for this region. In addition, it is necessary to establish the reliability of these instruments for clinical and research purposes. The relevance of family traits targeted in the study must be judged by the results and by existing literature in this area. For example, literature about Mexican families underlines the importance of the family support network in the family's capacity to adapt to disability. Thus, new ways to explore this feature have to be devised and tested. For example, according to the results, future efforts investigate the roles of parental religiosity and parental expectations of independence in the family's capacity to adapt to mental retardation will be important considerations.

Summary

There is an absence of previously documented research about mental retardation and its impact on the family in the Yucatan. This work represents a basic description of these families, and considered a large number of variables at different levels of analysis (i.e. external, familial and intra-familial). The use of a theoretical model from the realm of family research proved to be useful in organizing variables and guiding the research. Limitations in attributing the outcome of family processes specifically to the presence of disability was acknowledged.

It is suggested that the major advantage of using family models that focuses on adaptation, rather than maladaptation, is in their usefulness for intervention. For rehabilitation professionals, the assets and strengths of individuals with disabilities are more important for intervention than their deficits and limitations. From this perspective, the identification of family resources and strengths appears to have more useful implications for working with families with members who have disabilities.

Recommendations

Further research is needed in the Yucatan to achieve a more comprehensive description of the families that face the potential stressor of mental retardation. The present study represented only a first step in the process of building a body of research that may guide rehabilitation and special

education practices. Specifically this study provided information about the characteristics of families sampled that constitutes a base line for future research.

There is a need to investigate specific family aspects related to the family's capacity to adapt to disability. For example, further research suggested by this study would indicate the effects of the family support network and parental religiosity on the parents' perception of their child with mental retardation. Beyond description, research on family and disability in the Yucatan must identify and explain how specific family factors influence the development of a child with mental retardation. There also is a need to develop instruments which are sensitive to the specific needs of this population and to establish normative information to judge future results, such as the identification of adaptive behaviors which are meaningful for the families in Yucatan, specifically those living in the rural setting. For children of these families, adaptive functioning may consist in: hanging a hammock, seeking the shade, or washing fruits collected before eating.

It is suggested that models from the realm of family research can be successfully incorporated in approaching disability in the family. Stoneman (1991) suggested that the use of theoretical models may enrich and strengthen the research about the family and mental retardation. She asserted, "...Models are needed that simultaneously consider effects on families of societal forces, effects of living

day to day in the same home with a mentally retarded individual, and interactions between these two sources of influence" (p. 174). Stoneman also indicated that little is known about the characteristics of social environments in which persons with mental retardation live. Research models in the tradition of family stress theory, may be useful to elucidate the complex and reciprocal relationships between family and disability.

From an intervention perspective, professionals working with these families must consider family characteristics when planning intervention. For example, the relatively low expectations of independence in these families, suggest intervention priorities such as conflict resolution within the family, and the mastering of family-oriented tasks, rather than the development of independent living skills which are oriented to activities outside the family. In the Yucatan, efforts to promote the child's independence need to emphasize those abilities necessary to function in an extended family setting, in contrast to the development of skills for independent living emphasized in the US.

Conclusions

Theories traditionally used in family research, can be successfully incorporated into the field of rehabilitation in order to increase our understanding of the family and disability (Fine, 1991). Family adaptation to the potential stress of the presence of a child with mental retardation is a complex phenomenon that cannot be fully explained without

considering the salient contextual variables that affect the family.

Results from this study suggest that in the Yucatan, factors such as parental degree of religiosity, levels of education, and expectations of independence seem to be associated with family adaptation as measured by the degree of family esteem. The role of these factors in promoting family adaptation needs to be further explored. Similarly, it is important to identify which other observable family traits may be useful indicators of family adaptation.

Integrating information about environmental conditions, such as contextual demands and resources is essential for a complete and adequate assessment of a family coping with the stress of mental retardation and to establish what is the nature of the reciprocal relationship between the family and its social context. Scheerenberger (1983) asserted, "mental retardation is primarily a socio-culturally defined phenomenon" (p.3). As such, family adaptation to the presence of mental retardation is a question of goodness-of-fit between the family and the demands of its social context.

Research on the family and disability in the Yucatan is emerging. Future efforts should be directed toward the refinement of instruments, the expansion of family description techniques, and toward a more detailed analysis of the factors which are considered important in promoting family adaptation. It is suggested, that this research be

guided by theoretical models which consider the complexities of the family and help in organizing and understanding the multiple factors that influence the family's ability to adapt to the stress of disability.

APPENDIX A.- INVITATION LETTER

UNIVERSIDAD AUTONOMA DE YUCATAN
FACULTAD DE EDUCACION

Estimados padres de niño(a) _____

La Facultad de Educación de la Universidad Autónoma de Yucatán y la Universidad de Iowa en los Estados Unidos, están realizando una investigación sobre los niños en educación especial en el estado. Por este medio le invitamos a participar en este estudio. Para esto, tiene usted un hijo(a) que tenga entre 6 y 12 años que NO esté en un programa de educación especial.

Para colectar la información, necesitamos que los DOS padres estén presentes. Prefiere usted:

Venir a la escuela ( ) de 7:30 a 9:00 A.M.

Ser visitado en su domicilio ( ) Escriba su dirección en esta hoja

Por favor escriba el día de la semana y la hora que es mejor para ustedes:

Día _____ Hora _____

La entrevista dura entre 60 y 80 minutos y le explicaremos en detalle en que consiste.

Muy Atentamente

Mtra. Beatriz Celis de J.
Directora del CTEDUCA

Lic. en Psic. Silvia J. Pech Campos
Directora de la Facultad de Educación

FAVOR DE DEVOLVER ESTA FORMA A LA DIRECCION DE LA ESCUELA.

Calle 61 No 525 CP 97000 Apdo Postal 1207 Mérida, Yucatán, Mexico

APPENDIX B.- TRAINING OUTLINE

THE UNIVERSITY OF IOWA

Adaptation in families with a child with mental retardation in Yucatan, Mexico

Topical content, activities and objectives for the training session at the University of Yucatan

Date of the session : May 08, 1991
Place: College of Education, UADY
Instructor: Pedro Sanchez M.Ed.

Activities:

9:00 AM Presentation, dynamic of introduction

9:15 Objectives of the study and description of the methodology.

9:30 Questions and answers

10:45: description of the instruments

10;10 Brake

10:30 Role playing: questions and answers about the instruments and feed-back.

11:45 Clarification and closure.

Objectives:

1) to acquaint interviewers with the instruments
2) to standardize data collection
3) to motivate interviewer for collecting the data appropriately.

Iowa City, Iowa 52242 College of Education Division of Counselor Education N338 Lindquist Center 319/335-5275

APPENDIX C.- ADMINISTRATION CHECKLIST

UNIVERSIDAD AUTONOMA DE YUCATAN
FACULTAD DE EDUCACION

LA FAMILIA DEL NIÑO CON NECESIDADES ESPECIALES EN YUCATAN

Lista de Cotejo

Familia_____ #_____

Entrevistador_____

fecha ____/____/_____

( ) Leer la carta de introducción

( ) Hacer las preguntas de las secciones I, II y III del Cuestionario de Composición Familiar. Escriba los datos en las formas correspondientes.

( ) Dé a los padres las sección IV y supervise sus respuestas.

( ) Haga las preguntas contenidas en el cuestionario 'Cuidado del Niño Excepcional' y escriba las respuestas en las hojas correspondientes.

( ) Haga las preguntas contenidas en el anexo del 'CEC'que se refiere a los hermanos sin RM.

[Randomize el orden de las siguientes dos etapas]
( ) OK?.

( ) Dé a cada uno de los padres el Cuestionario de Expectativas de independencia con el nombre del niño(a) excepcional.

( ) Dé a cada uno de los padres el Cuestionario de Expectativas de independencia con el nombre del niño(a) no-excepcional.

( ) Haga las preguntas necesarias para completar el cuestionario de Adaptación Familiar de Vinelad.

( ) Revise y codifique todas las hojas del cuestionario de la familia, escriba el número de codigo en la parte superior derecha de cada una de las hojas y engrape todas las formas.

( ) Agradezca a los padres su participación y deje el teléfono y los nombres de los investigadores.

Calle 61 No. 525 C.P. 97000 Apdo. Postal 1207 Mérida, Yucatán, México.

APPENDIX D.-FAMILY COMPOSITION QUESTIONNAIRE

The Family Composition Questionnaire

Instructions: Ask the questions necessary to fill sections I, II, and III. When finish, provide the parents with section IV. Respond to any concerns they might have.

1.Family name:_____.

2.Address_____.

3.City of residence_____

Does anybody in the family speak maya language?

grandparents	MM	MF	PM	PF
parents	M	F		
children	Y			

I.Household

Instructions: List the family members living in the household (codes: p-father m-mother, s-sister, b-brother, gp-grandfather, c-cousins, u-uncles, or-other relatives, f-friends, EC: Exceptional child. 0-non elsewhere classified). Write their age, occupation and educational attainment in years of education completed (i.e. 6, 12, 14, etc.)

Name	Code	Age	Occupation	Ed.
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				

Cuestionario de Composición Familiar

Instrucciones: Haga las preguntas necesarias a los padres para responder a las tres primeras secciones de este cuestionario. Al terminar, dé a contestar la sección IV y clarifique cualquiera duda.

1. Familia:_____

2. Dirección_____

2. Ciudad de residencia:_____

4. Marque con un círculo a los siguientes miembros de la familia que hablan (hablaban) la lengua maya:

Abuelos	MM	MF	PM	PF
Padres	M	P		
Hijos	S			

I.Hogar

Instrucciones: Liste a los familiares que viven bajo el mismo techo.[Codificación: p-padre, m-madre, s-hermana, b-hermano, gp-abuelos, c-primos, u-tíos, or-otros parientes, f-amigos, EC: Niño excepcional, 0- no se encontró otra clasificación]. Escriba en le espacio correspondiente la edad, ocupación y grado de escolaridad en años de educación (i.e. 6, primaria, 9 secundaria etc.)

Nombre	Code	Edad	Ocupación	EC
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				

II.Familiares:

Instrucciones: Investigue acerca de cada uno de los familiares de cada padre por separado. Marque con una cruz, si alguno de los progenitores ha fallecido. Solo pregunte por los hermanos(as) vivos(as). Utilice números impares para hermanos y pares para hermanas. Escriba la inicial del nombre del familiar en la primera linea de cada fila.

Codificación:
B. Donde vive?
1.En otro estado 2.En otra ciudad 3.En otra colonia 4.En el vecindario 5.En la misma casa.
C. Cada cuando lo ve?
1.De una a dos veces al año 2.Una o dos veces cada seis meses 3. Una o dos veces por mes 4.Una o dos veces por semana 5.Mas de dos veces por semana 6.Diario.
D. De 0 (para nada) a 10 (muchísimo), Que tanta ayuda es el o ella para su familia?

MATERNO	I	B)DONDE	C)Freq	D)AYUDA
Madre				
Padre				
hermanos(as)				
1.				
2.				
3.				
4.				
5.				

PATERNO	I	B)DONDE	C)Freq	D)AYUDA
Madre				
Padre				
hermanos(as)				
1.				
2.				
3.				
4.				
5.				

II.Relatives

Instructions: Inquire about each of the relatives of each one of the parents. Mark with an X, parents who have died. For siblings, use odd numbers for brothers and even numbers for sisters. Report only those alive. Write the initial of the relative in each line.

Codification:
I. Initial
B. Where does he/she live?
1.Other state. 2.Other city. 3.Other neighborhood 4.In the neighborhood 5.In the same house.
C. How often do you see him/her.
1.Once or twice a year 2.Once or twice every six months 3.Once or twice every month 4. Once or twice every week. 5.More than twice a week. 6. Everyday.
D. From 0 (Not at all) to 10 (very much indeed), How helpful is she/he to you, or to your family?

MOTHER SIDE	I	B)Location	C)Freq	D)Help.
Mother				
Father				
Siblings:				
1.				
2.				
3.				
4.				
5.				

FATHER SIDE	I	B)Location	C)Freq	D)Help.
Mother				
Father				
Siblings:				
1.				
2.				
3.				
4.				
5.				

III.- Características Familiares

A. SES

1. Marque cuales de los siguientes aparatos existen en la casa:

a) Horno de Micro-ondas
b) Aire acondicionado
c) Teléfono
d) Video-cassetera
e) Plato de satélite o servicio de cable
f) Abanicos de techo
g) Reproductora de discos compactos
h) Lavadora

2. Consideran que su familia es de clase:

a) alta
b) media alta
c) media baja
d) clase trabajadora

B. Religión

1. ¿Cual es su religión?_____.

2. De 0 (para nada) a 10 (Muchísimo), ¿Que tan religiosa es su familia?

Padre _____ Madre _____

3. ¿Cuantas veces asistieron a la iglesia/templo el mes pasado?

Padre _____ Madre _____

3

Section III. Family Characteristics

A. SES.

1. Mark the appliances existing in the house:
a) Microwave
b) Air conditioner
c) Phone
d) VCR
e) Satellite dish or cable
f) Ceiling fan
g) DC-player
h) Washing machine

2. Do you consider your family as:
a) upper class
b) middle upper class
c) Lower upper class
d) working class

B. Religion

1. What is your religion:_____.

2. From 0 (Not at all) to 10 (very much indeed), how religious do you think your family is?

Father_____ Mother_____

3. How many times did you go to church/temple during the last month?

Father_____ Mother_____

APPENDIX E.-CARE OF THE EXCEPTIONAL CHILD

Cuidado del niño excepcional
Cuestionario

Instrucciones: Lea a los padres el siguiente párrafo: "Las siguientes preguntas se refieren a su hijo(a) _____. Cualquiera de ustedes puede responder a mis preguntas. Por favor, pidan que les clarifique lo que no entiendan".

1. Como se dieron cuenta que su hijo(a) tenia un problema de desarrollo?

_____

_____

2. Cuando_____ (edad del niño(a)?

3. Saben que causo su condición?

_____

_____

4. Si otra familia les pidiera consejo sobre como cuidar a su hijo(a) con retraso mental, cuales serían las tres cosas principales que ustedes les aconsejarían?

1._____

_____

_____

2._____

_____

_____

3._____

_____

_____

5. Cuales fueron las reacciones de otros miembros de su familia cuando supieron que _____ tenia un problema de desarrollo.
Hermanos:

_____

Care of the Exceptional child
Questionnaire

Instructions: Read to the parents the following statement: "The following questions I will ask, refer to your child _____. Any of you can respond at any time, do not hesitate to ask for clarification when necessary."

1.How did you realize that your child had a developmental problem?

_____

_____

_____

2. How old was your child?_____.

3.Do you know what caused his/her condition?

_____

_____

4.If another family would seek advice from you, on how to take care of their child with mental retardation, what would be the three things you would advice them to do?

1._____

_____

_____

2._____

_____

_____

3._____

_____

_____

Abuelos:

Otros familiares:

6. De 7AM a 7PM, Cuantas horas pasa su hijo(a) en casa?

7. Quién cuida de él/ella en casa?

8. Que esperan que su hijo haga por otros miembros de la familia?

9. Mayormente, Quien les ayuda mas en el cuidado de su hijo(a)?

10. Que tanto le ha servido la escuela a su hijo?
a)Casi nada b)Poco c)Algo d)Mucho.

11. Donde piensan que su hijo estaría mejor:
a)con otros familiares b)en la escuela d)en una institución

5.What were the reaction of other family members when they found out that _____ had a developmental problem.
Siblings:

Grandparents:

Other relatives:

6. From 7 AM to 7 PM, How many hours does she/he spend at home?

7.Who takes care of him/her at home?

8. What do you expect him/her to do for other family members?

9. Who helps you the most to take care of your child?

12. Cuando mueran ustedes, ¿Quién va a cuidar de su hijo?

_____

_____

_____

13. ¿Cuantos años piensan que su hijo va a vivir? _____

14a. De 0 (Totalmente infeliz) a 10 (muy feliz), ¿Que tan feliz...

es su hijo ahora? _____
será cuando sea adolescente? _____
será cuando sea adulto? _____

14b. De 0 (Totalmente inseguro) a 10 (muy seguro), ¿Que tan seguro(a)...

está su hijo ahora? _____
estará cuando sea adolescente? _____
estará cuando sea adulto? _____

14c. De 0 (muy poco saludable) a 10 (muy saludable), ¿Que tan saludable...

es su hijo ahora? _____
será cuando sea adolescente? _____
será cuando sea adulto? _____

15. ¿Porque creen que algunas familias tienen hijos como el suyo?

_____

_____

_____

16. ¿Existen familiares de ustedes que tienen hijos con problemas del desarrollo u otros familiares con minusvalías (silla de ruedas, sordera, seguez, etc.)

NO ( ) FIN, Gracias. SI ( ) continue...

Comente brevemente el problema y como se las ingenian para ayudarlo:

_____

10. How useful has the school been for him/her?

a)little useful b)somehow useful c)useful d)very useful.

11. Where do you think your child would be better off:
a)with family members b)in the school d)in an institution.

12. When both of you die, who is going to take care of your child?

_____

_____

_____

13. How old do you think your child will live? _____

14a. From 0 (very unhappy) to 10 (very happy), How happy do you think your child

is now _____
will be when an adolescent _____
will be when an adult _____

14. From 0 (very insecure) to 10 (very secure), How secure do you think your child

is now _____
will be when an adolescent _____
will be when an adult _____

14. From 0 (very healthy) to 10 (very unhealthy), How healthy do you think your child

is now _____
will be when an adolescent _____
will be when an adult _____

15. Why do you think some families have exceptional children ?

_____

_____

_____

Preguntas para el hermano del niño excepcional

Instrucciones: Los padres deberan contestar a las siguientes preguntas inmediatamente despues de contestar el CEC. Lea a los padres el siguiente enunciado: " Ahora les haré algunas pocas preguntas, pero con referencia a su hijo_____.

1. De 7AM a 7PM, ¿Cuantas horas pasa su hijo(a) en casa? _____

2. ¿Quién cuida de él/ella en casa?

_____

_____

_____

3. ¿Que esperan que su hijo haga por otros miembros de la familia?

_____

_____

_____

4. ¿Que tanto le ha servido la escuela a su hijo?
a)Casi nada b)Poco c)Algo d)Mucho.

5. ¿Cuantos años piensan que su hijo va a vivir? _____

7. De 0 (Totalmente infeliz) a 10 (muy feliz), ¿Que tan feliz...

es su hijo ahora? _____
será cuando sea adolescente? _____
será cuando sea adulto? _____

8. De 0 (Totalmente inseguro) a 10 (muy seguro), ¿Que tan seguro(a)...

está su hijo ahora? _____
estará cuando sea adolescente? _____
estará cuando sea adulto? _____

9. De 0 (muy poco saludable) a 10 (muy saludable), ¿Que tan saludable...

es su hijo ahora? _____
será cuando sea adolescente? _____
será cuando sea adulto? _____

Questions for the sibling of the exceptional child

Instructions: Read the following statement to the parents: " Now I will ask you some questions, but with regard to your child_____.

1. From 7AM to 7PM, How many hours is your child at home? _____

2. Who looks after him/her at home?

_____

_____

_____

3. What do you expect your child do for others at home?

_____

_____

_____

4. How useful do you think the school has been for him/her?
a)Almost nothing b)little c)some d)A lot

5. How many years do you think your child will live? _____

6. From 0 (very unhappy) to 10 (very happy), How happy do you think your child

is now _____
will be when an adolescent _____
will be when an adult _____

7. From 0 (very insecure) to 10 (very secure), How secure do you think your child

is now _____
will be when an adolescent _____
will be when an adult _____

8. From 0 (very healthy) to 10 (very unhealthy), How healthy do you think your child

is now _____
will be when an adolescent _____
will be when an adult _____

APPENDIX F.- PARENTAL EXPECTATIONS OF INDEPENDENCE

Expectativas *Paternales de Independencia*
Cuestionario

FAMILIA _____

MADRE ( ) PADRE ( )

Instrucciones: La siguiente lista contiene enunciados sobre algunas cosas que los padres esperan que sus hijos hagan cuando estos sean adultos. Piense en las probabilidades que tiene su hijo de hacer las cosas que aquí se describen cuando él o ella sea un adulto de 25 años. Califique de 0 (Improbable) a 5 (Muy probablemente), a las probabilidades de que su hijo haga estas cosas a esta edad. No dude en preguntar lo que ud. no entienda al entrevistador.

Piense en su hijo_____

Cuando mi hijo(a) tenga 25 anos, va a...

ayudarme con el quehacer. 1_____

ser capaz de conocer gente nueva. 2_____

tomar sus propias decisiones. 3_____

vivir fuera de casa. 4_____

estar casado(a). 5_____

pedir mi opinión antes de tomar una decisión importante. 6_____

ganar su propio dinero. 7_____

divertirse conmigo tanto como ahora. 8_____

hacer lo que yo diga. 9_____

ser capaz de cocinar para él mismo (ella misma). 10_____

viajar con sus amigos(as). 11_____

ser responsable de sus propias acciones. 12_____

Parental Expectations for Independence
Questionnaire

FAMILY NAME_____

Mother ( ) Father ( )

Instructions: The following list contains statements regarding actions parents sometimes expect their children to do as they grow older. Think about the probabilities that your child has to take these actions when she or he is 25 years old. You are requested to rate from 0 (not likely at all), to 5 (very much likely) to the probabilities of your child doing certain things at this age. Do not hesitate to ask any questions you may have to the person conducting the interview.

Think again about your child_____

When my child is 25 years old, he or she is going to...

help me with the household.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 1_____

be able to meet new people.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 2_____

make his or her own decisions.
1.Not likely at all 2.Somewhat likely 3.Undecided 4.Somewhat likely 5.Very much likely. 3_____

leave the house.
1.Not likely at all 2.Somewhat likely 3.Undecided 4.Somewhat likely 5.Very much likely. 4_____

be married.
1.Not likely at all 2.Somewhat likely 3.Undecided 4.Somewhat likely 5.Very much likely. 5_____

ask my opinion before she or he makes important decisions
1.Not likely at all 2.Somewhat likely 3.Undecided 4.Somewhat likely 5.Very much likely. 6_____

make his/her own money.
1.Not likely at all 2.Somewhat likely 3.Undecided 4.Somewhat likely 5.Very much likely. 7_____

have fun with me as often as he/she does now.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 8_____

do as I say.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 9_____

be capable of cooking for himself/herself.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 10_____

travel with his/her friends.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 11_____

be responsible for his/her own actions.
1.Not likely at all 2.Somewhat unlikely 3.Undecided 4.Somewhat likely 5.Very much likely. 12_____

APPENDIX G.- PARENTAL PERCEPTION OF FAMILY ESTEEM

V. *Cuestionario de auto-percepción familiar*

[Esta sección debe ser contestada por los padres]

Instrucciones: Comente cada pregunta con su esposo(a) y responda de mutuo acuerdo a las siguientes preguntas. No dude en aclarar cualquier duda con el entrevistador.

Los siguientes enunciados se refieren a su familia; marque en el espacio el numero que corresponda con su grado de acuerdo o desacuerdo con el mismo.

¿Que tan feliz es su familia comparada con cualquier otra? ____

¿Que tantos problemas tiene su familia comparada con qualquier otra?__

¿Que tanta suerte tiene su familia comparada con cualquier otra?___

¿Que tan unida es su familia comparada con cualquier otra?___

¿Que tan respetable es su familia comparada con cualquier otra?___

Parental self-perception of the family esteem

Instructions:Discuss each question with your spouse and answer the questions upon mutual agreement. Feel free to ask any questions you may have to the investigator.

The following statements refer to your family, mark in the space the number that best represents your thinking.

How happy is your family as compared to any other family?_____

less than other families 2.Slightly less than other families 3.As other families 4.Slightly more her families. 5.Much more than other families

Does your family have as many problems as any other family?_____

less than other families 2.Slightly less than other families 3.As other families 4.Slightly more her families. 5.Much more than other families

Is your family as lucky as any other family?_____

less than other families 2.Slightly less than other families 3.As other families 4.Slightly more her families. 5.Much more than other families

Is your family as united as any other famiiy?_____

less than other families 2.Slightly less than other families 3.As other families 4.Slightly more her families. 5.Much more than other families

Is your family as respectable as any other family?_____

less than other families 2.Slightly less than other families 3.As other families 4.Slightly more her families. 5.Much more than other families

APPENDIX H.- VINELAND ADAPTIVE BEHAVIOR SCALE

APPENDIX I.- STATISTICAL SUMMARIES

VINELAND

ADAPTIVE BEHAVIOR SCALES

Sara S. Sparrow, David A. Balla, and Domenic V. Cicchetti
A revision of the *Vineland Social Maturity Scale* by Edgar A. Doll

INTERVIEW EDITION
Survey Form
Spanish
Record Booklet

ABOUT THE INDIVIDUAL:

Name _____ Sex
Home address _____
Telephone _____ Grade
School or other facility _____
Present classification or diagnosis _____
Race (if pertinent) _____
Socioeconomic background (if pertinent) _____
Other pertinent information _____

AGE: YEAR MONTH DAY

Interview date
Birth date
Chronological age
Age used for starting points
Type (circle one) chronological mental social

ABOUT THE RESPONDENT:

Name _____ Sex
Relationship to individual

ABOUT THE INTERVIEWER:

Name _____ Sex
Position

DATA FROM OTHER TESTS:

Intelligence
Achievement
Adaptive behavior
Other

REASON FOR THE INTERVIEW:

BEFORE BEGINNING ADMINISTRATION, READ THE INSTRUCTIONS IN THE MANUAL CAREFULLY.

General Directions: In each adaptive behavior domain, begin scoring with the item designated for the individual's age. Score each item 2, 1, 0, N, or DK, according to the scoring criteria in the manual (Appendix C). Record each score in this booklet in the designated box. Establish a *basal* of *seven* consecutive items scored *2* and a *ceiling* of *seven* consecutive items scored *0* for each domain.

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

<1	1.	Vuelve los ojos y la cabeza hacia donde provienen los sonidos.
	2.	Escucha al menos momentáneamente cuando le habla la persona que lo cuida todo el tiempo.
	3.	Sonríe respondiendo a la presencia de la persona que lo cuida todo el tiempo.
	4.	Sonríe respondiendo a la presencia de una persona conocida distinta de la que lo cuida todo el tiempo.
	5.	Levanta los brazos cuando la persona que lo cuida le dice: "Ven acá" o "Arriba, vamos."
	6.	Demuestra entender el significado del "no."
	7.	Imita los sonidos de los adultos inmediatamente después de oírlos.
	8.	Demuestra entender el significado de diez palabras cuando menos.
1	9.	Hace gestos apropiados para indicar "sí," "no," y "quiero."
	10.	Escucha atentamente las instrucciones.
	11.	Demuestra entender el significado del "sí" o del "está bien."
	12.	Sigue instrucciones que requieren una acción y un objeto.
	13.	Señala acertadamente por lo menos una parte importante del cuerpo, cuando se le pide.
	14.	Usa los nombres de sus hermanos, amigos, o compañeros, o dice sus nombres cuando se le pregunta.
	15.	Usa frases con un sustantivo y un verbo, o con dos sustantivos.
	16.	Nombra sin que se le pida al menos 20 objetos. DO NOT SCORE 1.
	17.	Escucha un cuento al menos por cinco minutos.
	18.	Indica preferencia cuando se le presenta una opción.
2	19.	Dice cuando menos 50 palabras reconocibles. DO NOT SCORE 1.
	20.	Relata espontáneamente sus experiencias en términos simples.
	21.	Lleva y da un mensaje sencillo.
	22.	Usa oraciones de cuatro o más palabras.
	23.	Señala acertadamente todas las partes del cuerpo, cuando se le pide. DO NOT SCORE 1.
	24.	Dice cuando menos 100 palabras reconocibles. DO NOT SCORE 1.
	25.	Habla con oraciones completas.
	26.	Usa los artículos "uno, una" y "el, la" en frases u oraciones.
	27.	Sigue instrucciones del tipo de "si ... entonces."
	28.	Dice su nombre y apellido cuando se le pregunta.
	29.	Hace preguntas que empiezan con "qué," "dónde," "quién," "por qué," y "cuándo." DO NOT SCORE 1.
3, 4	30.	Dice cuál objeto es más grande de dos que no están a la vista.
	31.	Relata detalladamente sus experiencias al pedírselo.
	32.	Usa las palabras "detrás de" o "entre" como preposición en una frase.
	33.	Usa la palabra "alrededor de" como preposición en una frase.
	34.	Usa oraciones con "pero" y "o."
	35.	Enuncia claramente sin sustituir los sonidos.

Count items before basal as 2, items after ceiling as 0

RECEPTIVE
EXPRESSIVE
WRITTEN
COMMUNICATION DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

<1	1.	Turns eyes and head toward sound
	2.	Listens at least momentarily when spoken to by caregiver
	3.	Smiles in response to presence of caregiver
	4.	Smiles in response to presence of familiar person other than caregiver
	5.	Raises arms when caregiver says, "Come here" or "Up"
	6.	Demonstrates understanding of the meaning of "no"
	7.	Imitates sounds of adults immediately after hearing them
	8.	Demonstrates understanding of the meaning of at least 10 words
1	9.	Gestures appropriately to indicate "yes," "no," and "I want"
	10.	Listens attentively to instructions
	11.	Demonstrates understanding of the meaning of "yes" or "okay"
	12.	Follows instructions requiring an action and an object
	13.	Points accurately to at least one major body part when asked
	14.	Uses first names or nicknames of siblings, friends, or peers, or states their names when asked
	15.	Uses phrases containing a noun and a verb, or two nouns
	16.	Names at least 20 familiar objects without being asked. DO NOT SCORE 1
	17.	Listens to a story for at least five minutes
	18.	Indicates preference when offered a choice
2	19.	Says at least 50 recognizable words. DO NOT SCORE 1
	20.	Spontaneously relates experiences in simple terms
	21.	Delivers a simple message
	22.	Uses sentences of four or more words
	23.	Points accurately to all body parts when asked. DO NOT SCORE 1
	24.	Says at least 100 recognizable words. DO NOT SCORE 1
	25.	Speaks in full sentences
	26.	Uses "a" and "the" in phrases or sentences
	27.	Follows instructions in "if-then" form
	28.	States own first and last name when asked
	29.	Asks questions beginning with "what," "where," "who," "why," and "when." DO NOT SCORE 1
3, 4	30.	States which of two objects not present is bigger
	31.	Relates experiences in detail when asked
	32.	Uses either "behind" or "between" as a preposition in a phrase
	33.	Uses "around" as a preposition in a phrase

Count items before basal as 2, items after ceiling as 0

24 42 0

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

RECEPTIVE | EXPRESSIVE | COMMUNICATION DOMAIN

36 Cuenta un cuento conocido, un cuento de hadas, un chiste largo, o la trama de un programa de televisión
s 37 Recita de memoria todas las letras del abecedario
38 Lee al menos tres señales o letreros
39 Dice la fecha de su cumpleaños cuando se le pregunta
40 Usa plurales irregulares
s 41 Escribe su nombre y apellido en letra de imprenta o en letra manuscrita
42 Dice su número de teléfono cuando se le pide. N MAY BE SCORED.
43 Dice su dirección completa, incluyendo ciudad y estado, cuando se le pide
44 Lee al menos 10 palabras en silencio o en voz alta
45 Escribe de memoria, en letra de imprenta o manuscrita, cuando menos 10 palabras
46 Expresa ideas de más de una manera sin que se le ayude
7, s 48 Escribe oraciones simples de tres o cuatro palabras
49 Asiste a una conferencia de la escuela o pública por más de 15 minutos
50 Lee por iniciativa propia
51 Lee libros por lo menos a nivel del segundo año
52 Arregla cosas o palabras alfabéticamente usando la primera letra
53 Escribe notas o mensajes cortos.
s 54 Da instrucciones complejas a otros
55 Escribe cartas rencillas. DO NOT SCORE 1
56 Lee libros por lo menos a nivel del cuarto año
57 Escribe con letra cursiva la mayor parte del tiempo. DO NOT SCORE 1.
10 to 10+ 58 Usa un diccionario
59 Usa la tabla de contenido en materiales de lectura
60 Escribe informes o composiciones. DO NOT SCORE 1.
61 Escribe la dirección completa en un sobre
62 Usa el índice en materiales de lectura.
63 Lee artículos en un periódico para adultos. N MAY BE SCORED.
64 Tiene metas realistas a largo plazo y describe detalladamente sus planes para alcanzarlas
65 Escribe cartas complejas
66 Lee cada semana libros y revistas para adultos. N MAY BE SCORED.
67 Escribe cartas de negocios. DO NOT SCORE 1.

Count items before basal as 2, items after ceiling as 0

ITEM SCORES
2 Yes, usually
1 Sometimes or part
0 No, never
N No opportunity
DK Don't know

RECEPTIVE | EXPRESSIVE | WRITTEN

34 Uses phrases or sentences containing "but" and "or"
35 Articulates clearly, without sound substitutions
36 Tells popular story, fairy tale, lengthy joke, or television show plot
s 37 Recites all letters of the alphabet from memory
38 Reads at least three common signs
39 States month and day of birthday when asked
40 Uses irregular plurals
s 41 Prints or writes own first and last name
42 States telephone number when asked. N MAY BE SCORED.
43 States complete home address, including city and state, when asked.
44 Reads at least 10 words silently or aloud
45 Prints or writes at least 10 words from memory.
46 Expresses ideas in more than one way, without assistance.
47 Reads simple stories aloud.
7, s 48 Prints or writes simple sentences of three or four words.
49 Attends to school or public lecture more than 15 minutes.
50 Reads on own initiative
51 Reads books of at least second-grade level
52 Arranges items or words alphabetically by first letter
53 Prints or writes short notes or messages.
s 54 Gives complex directions to others
55 Writes beginning letters. DO NOT SCORE 1.
56 Reads books of at least fourth-grade level.
57 Writes in cursive most of the time. DO NOT SCORE 1.
10 to 10+ 58 Uses a dictionary.
59 Uses the table of contents in reading materials
60 Writes reports or compositions. DO NOT SCORE 1.
61 Addresses envelopes completely
62 Uses the index in reading materials
63 Reads adult newspaper stories. N MAY BE SCORED.
64 Has realistic long-range goals and describes in detail plans to achieve them
65 Writes advanced letters
66 Reads adult newspaper or magazine stories each week. N MAY BE SCORED
67 Writes business letters. DO NOT SCORE 1.

Count items before basal as 2, items after ceiling as 0.

1 3 20 46

DAILY LIVING SKILLS DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

PERSONAL | DOMESTIC | COMMUNITY

DAILY LIVING SKILLS DOMAIN

<1	1	Manifiesta anticipación por la comida al ver la botella, el pecho, o el alimento
	2	Abre la boca cuando se le presenta una cuchara con comida
	3	Toma la comida de la cuchara con la boca
	4	Chupa o mastica galletas
	5	Toma alimentos sólidos
1	6	Bebe de un vaso o una taza sin que se le ayude
	7	Come usando una cuchara
	8	Demuestra entender el peligro de las cosas calientes
	9	Manifiesta que tiene los calzoncillos o el pañal mojado o sucio hablando, señalando o jalando el pañal
	10	Bebe usando una pajita (popote, pitillo)
	11	Le permite a la persona que está a cargo de él que le limpie la nariz
	12	Come usando un tenedor
	13	Se quita, sin ayuda, un abrigo, suéter, o camisa que estén abiertos o que se abrochen por delante
3	14	Come usando una cuchara sin derramar nada
	15	Demuestra interés en cambiarse de ropa cuando está muy mojado o enlodado
	16	Orina en el excusado o en una basinica colocada debajo de una silla para este efecto
	17	Se baña con ayuda
	18	Defeca en el excusado o en una basinica colocada debajo de una silla para este efecto
	19	Pide ir al baño
	20	Se pone ropa con elástico en la cintura
	21	Demuestra entender el uso del dinero
	22	Guarda sus cosas cuando se le pide
3	23	No se orina en la cama
	24	Bebe de la llave de agua sin ayuda
	25	Se cepilla los dientes sin ayuda DO NOT SCORE 1
	26	Demuestra comprender la función de un reloj, común y corriente o digital
	27	Ayuda con quehaceres (tareas) adicionales cuando se le pide
	28	Se lava y se seca la cara sin que se le ayude
	29	Se pone los zapatos correctamente sin ayuda
	30	Contesta el teléfono apropiadamente N MAY BE SCORED
	31	Se viste completamente, con la excepción de atarse las cintas de los zapatos
4	32	Pide que pase al teléfono a la persona a quien le llaman, o indica que no se encuentra N MAY BE SCORED
	33	Pone la mesa con ayuda

Count items before basal as 2, items after ceiling as 0

ITEM SCORES
2 Yes, usually
1 Sometimes or parti
0 No, never
N No opportunity
DK Don't know

PERSONAL | DOMESTIC | COMMUNITY

<1	1.	Indicates anticipation of feeding on seeing bottle, breast, or food
	2.	Opens mouth when spoon with food is presented
	3.	Removes food from spoon with mouth
	4.	Sucks or chews on crackers
	5.	Eats solid food
1	6.	Drinks from cup or glass unassisted
	7.	Feeds self with spoon.
	8.	Demonstrates understanding that hot things are dangerous
	9.	Indicates wet or soiled pants or diaper by pointing, vocalizing, or pulling at diaper
	10.	Sucks from straw
	11.	Willingly allows caregiver to wipe nose.
	12.	Feeds self with fork
	13.	Removes front-opening coat, sweater, or shirt without assistance.
3	14.	Feeds self with spoon without spilling
	15.	Demonstrates interest in changing clothes when very wet or muddy.
	16.	Urinates in toilet or potty-chair
	17.	Bathes self with assistance
	18.	Defecates in toilet or potty-chair
	19.	Asks to use toilet
	20.	Puts on "pull-up" garments with elastic waistbands
	21.	Demonstrates understanding of the function of money
	22.	Puts possessions away when asked
3	23.	Is toilet-trained during the night
	24.	Gets drink of water from tap unassisted.
	25.	Brushes teeth without assistance. DO NOT SCORE 1
	26.	Demonstrates understanding of the function of a clock, either standard or digital
	27.	Helps with extra chores when asked.
	28.	Washes and dries face without assistance
	29.	Puts shoes on correct feet without assistance
	30.	Answers the telephone appropriately. N MAY BE SCORED
	31.	Dresses self completely, except for tying shoelaces
4	32.	Summons to the telephone the person receiving a call, or indicates that the person is not available N MAY BE SCORED
	33.	Sets table with assistance

Count items before basal as 2, items after ceiling as 0

50 0 10

Sum of 2s, 1s, 0s page

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

PERSONAL | DOMESTIC | COMMUNITY

34 Se encarga de toda su limpieza personal sin que se le recuerde y sin ayuda DO NOT SCORE 1
35 Mira para ambos lados antes de cruzar la calle o carretera
36 Guarda la ropa limpia sin ayuda cuando se le pide
37 Se suena la nariz solo DO NOT SCORE 1
38 Levanta la mesa, incluyendo cosas frágiles
39 Se seca con una toalla sin que se le ayude
40 Se abrocha todos los broches DO NOT SCORE 1
• 41 Ayuda en la preparación de alimentos que se tienen que mezclar y cocinar
42 Demuestra que no es seguro aceptar de extraños que lo lleven en carro, ni aceptar que le den comida o dinero
43 Se amarra las cintas de los zapatos en un moño sin ayuda
44 Se baña o se da un regaderazo sin ayuda DO NOT SCORE 1
45 Mira para ambos lados y cruza solo la calle o carretera
46 Se cubre la boca y la nariz cuando tose o estornuda
• 47 Usa la cuchara, el tenedor, y el cuchillo competentemente DO NOT SCORE 1
48 Inicia llamadas telefónicas a otros N MAY BE SCORED
49 Obedece semáforos y señales de "Alto" y "Siga" N MAY BE SCORED
50 Se viste completamente, incluyendo el amarrarse las cintas de los zapatos y el abrocharse todos los broches DO NOT SCORE 1
51 Tiende su cama cuando se le pide
52 Dice el día de la semana cuando se le pide
53 Se pone el cinturón de seguridad por su propia iniciativa N MAY BE SCORED
7 54 Indica el valor de las monedas cuando se le pide
55 Usa herramientas básicas
56 Identifica el lado derecho e izquierdo de otros
57 Pone la mesa sin que se le pida
• 58 Barre, trapea, o aspira cuidadosamente los pisos sin ayuda cuando se le pide
59 Usa el número de teléfono de emergencia en casos de emergencia N MAY BE SCORED
60 Pide una comida completa en un restaurante N MAY BE SCORED
61 Dice la fecha del día cuando se le pide
62 Se viste anticipando cambios del tiempo sin que se le recuerde
63 Evita el contacto con personas con enfermedades contagiosas sin que se le recuerde
• 10 64 Dice la hora en segmentos de cinco minutos
65 Cuida de su pelo sin que se le recuerde y sin que se le ayude DO NOT SCORE 1

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

PERSONAL | DOMESTIC | COMMUNITY

34 Cares for all toileting needs, without being reminded and without assistance DO NOT SCORE 1
35 Looks both ways before crossing street or road
36 Puts clean clothes away without assistance when asked
37 Cares for nose without assistance DO NOT SCORE 1
38 Clears table of breakable items
39 Dries self with towel without assistance
40 Fastens all fasteners DO NOT SCORE 1
• 41 Assists in food preparation requiring mixing and cooking
42 Demonstrates understanding that it is unsafe to accept rides, food, or money from strangers
43 Ties shoelaces into a bow without assistance.
44 Bathes or showers without assistance DO NOT SCORE 1
45 Looks both ways and crosses street or road alone
46 Covers mouth and nose when coughing and sneezing
• 47 Uses spoon, fork, and knife competently DO NOT SCORE 1.
48 Initiates telephone calls to others N MAY BE SCORED
49 Obeys traffic lights and Walk and Don't Walk signs N MAY BE SCORED
50 Dresses self completely, including tying shoelaces and fastening all fasteners DO NOT SCORE 1
51 Makes own bed when asked
52 States current day of the week when asked
53 Fastens seat belt in automobile independently N MAY BE SCORED.
7 54 States value of penny, nickel, dime, and quarter
55 Uses basic tools
56 Identifies left and right on others
57 Sets table without assistance when asked
• 58 Sweeps, mops, or vacuums floor carefully, without assistance, when asked
59 Uses emergency telephone number in emergency N MAY BE SCORED
60 Orders own complete meal in restaurant. N MAY BE SCORED
61 States current date when asked
62 Dresses in anticipation of changes in weather without being reminded
63 Avoids persons with contagious illnesses, without being reminded

22 14 24

Count items before basal as 2, items after ceiling as 0

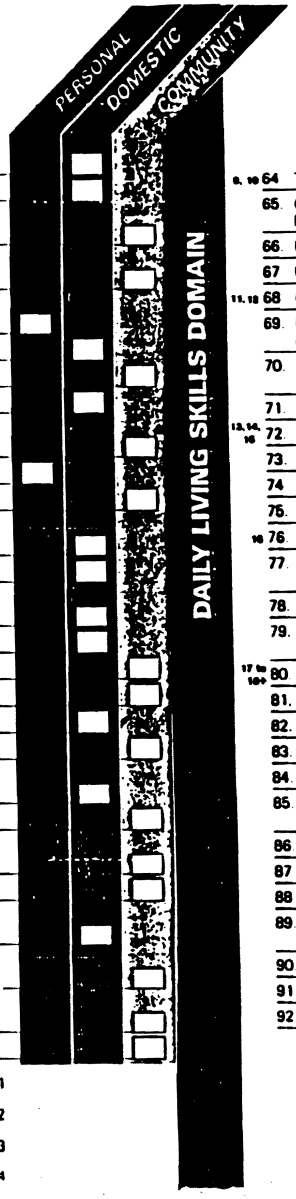
DAILY LIVING SKILLS DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

	66	Usa la estufa o el horno de microondas para cocinar
	67	Usa apropiada y correctamente los productos de limpieza de la casa
11, 12	68	Cuenta correctamente el cambio de una compra de menos de un dólar
	69	Usa el teléfono para todo tipo de llamadas sin que se le ayude N MAY BE SCORED
	70	Se limpia las uñas sin que se le recuerde y sin ayuda DO NOT SCORE 1
	71	Prepara alimentos que requieran que se mezclen y cocinen, sin ayuda
13, 14, 15	72	Usa el teléfono público N MAY BE SCORED
	73	Arregla su cuarto sin que se le recuerde
	74	Ahorra para comprar y ha comprado al menos algún equipo recreativo de importancia
	75	Se ocupa de su propia salud
16	76	Gana dinero regularmente
	77	Tiende su cama y cambia las sábanas rutinariamente DO NOT SCORE 1
	78	Limpia otro cuarto que no sea el suyo sin que se le pida
	79	Hace reparaciones rutinarias y otras tareas de mantenimiento sin que se le pida
17 to 18+	80	Pone botones, broches, o ganchillos en la ropa cuando se le pide
	81	Hace un presupuesto para sus gastos semanales
	82	Maneja su propio dinero sin que se le ayude
	83	Planea y prepara la comida principal del día sin ayuda
	84	Llega a tiempo al trabajo
	85	Se ocupa completamente de su ropa sin que se le recuerde DO NOT SCORE 1
	86	Le avisa a su supervisor si va a llegar tarde al trabajo
	87	Le avisa a su supervisor cuando va a faltar al trabajo por razones de salud
	88	Hace un presupuesto para sus gastos mensuales
	89	Sube los dobladillos de su ropa o le hace otros arreglos sin que se le pida y sin ayuda
	90	Obedece los límites de tiempo en el trabajo designados para tomar café o para almorzar
	91	Lleva responsablemente un trabajo de tiempo completo DO NOT SCORE 1
	92	Tiene una cuenta bancaria y la usa en forma responsable

Count items before basal as 2, items after ceiling as 0

1
2
3
4



ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

9, 10	64	Tells time by five-minute segments
	65	Cares for hair without being reminded and without assistance DO NOT SCORE 1
	66	Uses stove or microwave oven for cooking
	67	Uses household cleaning products appropriately and correctly
11, 12	68	Correctly counts change from a purchase costing more than a dollar
	69	Uses the telephone for all kinds of calls, without assistance N MAY BE SCORED
	70	Cares for own fingernails without being reminded and without assistance DO NOT SCORE 1
	71	Prepares foods that require mixing and cooking, without assistance
13, 14, 15	72	Uses a pay telephone N MAY BE SCORED
	73	Straightens own room without being reminded
	74	Saves for and has purchased at least one major recreational item
	75	Looks after own health
16	76	Earns spending money on a regular basis
	77	Makes own bed and changes bedding routinely DO NOT SCORE 1
	78	Cleans room other than own regularly, without being asked
	79	Performs routine household repairs and maintenance tasks without being asked
17 to 18+	80	Sews buttons, snaps, or hooks on clothes when asked
	81	Budgets for weekly expenses
	82	Manages own money without assistance
	83	Plans and prepares main meal of the day without assistance
	84	Arrives at work on time
	85	Takes complete care of own clothes without being reminded DO NOT SCORE 1
	86	Notifies supervisor if arrival at work will be delayed
	87	Notifies supervisor when absent because of illness
	88	Budgets for monthly expenses
	89	Sews own hems or makes other alterations without being asked and without assistance
	90	Obeys time limits for coffee breaks and lunch at work
	91	Holds full-time job responsibly DO NOT SCORE 1
	92	Has checking account and uses it responsibly

Count items before basal as 2, items after ceiling as 0

1	Sum of 2s, 1s, 0s
2	Sum of 2s, 1s, 0s
3	Sum of 2s, 1s, 0s
4	Number of Ns
5	Number of DKs

78 42 64
SUBDOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

	1	Mira a la cara de quien lo cuida
	2	Responde a la voz de quien lo cuida o a la voz de otra persona
	3	Distingue a la persona que lo cuida de otras personas
	4	Muestra interés en gente o en objetos nuevos
	5	Expresa dos o más emociones reconocibles tales como placer, tristeza, miedo, o aflicción
	6	Muestra anticipación de que lo cargue la persona que lo cuida
	7	Muestra afecto hacia gente conocida
	8	Muestra interés en otros niños aparte de sus hermanos
	9	Estira los brazos hacia una persona conocida
	10	Juega con un juguete u otro objeto ya sea solo o con otros
	11	Juega juegos muy sencillos de interacción con otros
	12	Usa objetos comunes de la casa para jugar
	13	Muestra interés en las actividades de otros
	14	Imita movimientos sencillos de los adultos tales como el aplaudir o el decir adiós con la mano, respondiendo a un modelo
	15	Rie o sonríe apropiadamente respondiendo a cosas positivas
	16	Se dirige por nombre propio al menos a dos personas conocidas
	17	Muestra deseos de complacer a quien lo cuida
	18	Participa por lo menos en un juego o en una actividad con otros
	19	Imita una tarea relativamente compleja varias horas después de que otra persona lo haya hecho.
	20	Imita frases de adultos que ha oído anteriormente
	21	Se ocupa en actividades elaboradas imaginarias solo o con otros
	22	Muestra preferencia por algunos amigos sobre otros
	23	Dice "por favor" cuando pide algo.
	24	Puede decir cuando se siente feliz, triste, con miedo, o enojado
	25	Identifica a la gente por otras caracteristicas además de su nombre, cuando se le pide
	26	Comparte sus cosas o sus juguetes sin que se le recuerde
	27	Nombra un programa o más de televisión que son sus favoritos, cuando se le pregunta, y dice en que días y a que horas los pasan N MAY BE SCORED
	28	Sigue las reglas en juegos sencillos sin que se le recuerde
	29	Tiene un amigo favorito de cualquier sexo
	30	Sigue las reglas de la escuela o institución
	31	Responde verbal y positivamente a la buena suerte de otros
	32	Se disculpa por errores cometidos sin querer
	33	Tiene un grupo de amigos
	34	Sigue las reglas de la comunidad
	35	Juega más de un juego de mesa o de cartas que requieran habilidad y toma de decisiones
	36	No habla con la boca llena
	37	Tiene un "mejor" amigo del mismo sexo
	38	Responde apropiadamente cuando lo presentan a un desconocido

INTERPERSONAL RELATIONSHIPS
PLAY & LEISURE TIME

SOCIALIZATION DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

	1	Looks at face of caregiver
	2	Responds to voice of caregiver or another person
	3	Distinguishes caregiver from others
	4	Shows interest in novel objects or new people
	5	Expresses two or more recognizable emotions such as pleasure, sadness, fear, or distress
	6	Shows anticipation of being picked up by caregiver
	7	Shows affection toward familiar people
	8	Shows interest in children or peers other than siblings
	9	Reaches for familiar person
	10	Plays with toy or other object alone or with others
	11	Plays very simple interaction games with others
	12	Uses common household objects for play
	13	Shows interest in activities of others
	14	Imitates simple adult movements, such as clapping hands or waving good-bye, in response to a model
	15	Laughs or smiles appropriately in response to positive statements
	16	Addresses at least two familiar people by name
	17	Shows desire to please caregiver
	18	Participates in at least one game or activity with others
	19	Imitates a relatively complex task several hours after it was performed by another
	20	Imitates adult phrases heard on previous occasions
	21	Engages in elaborate make-believe activities, alone or with others
	22	Shows a preference for some friends over others
	23	Says "please" when asking for something
	24	Labels happiness, sadness, fear, and anger in self
	25	Identifies people by characteristics other than name, when asked
	26	Shares toys or possessions without being told to do so
	27	Names one or more favorite television programs when asked, and tells on what days and channels the programs are shown N MAY BE SCORED
	28	Follows rules in simple games without being reminded
	29	Has a preferred friend of either sex
	30	Follows school or facility rules
	31	Responds verbally and positively to good fortune of others
	32	Apologizes for unintentional mistakes
	33	Has a group of friends
	34	Follows community rules
	35	Plays more than one board or card game requiring skill and decision making
	36	Does not talk with food in mouth
	37	Has a best friend of the same sex

Count items before basal as 2, items after ceiling as 0

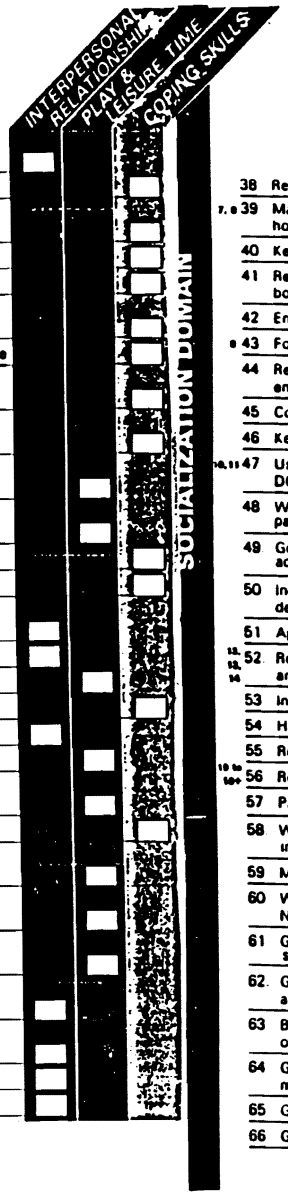
INTERPERSONAL RELATIONSHIPS
PLAY & LEISURE TIME
COPING SKILLS

40 24 18

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

7, 8	39	Hace o compra regalos pequeños para quien lo cuida o para miembros de la familia en las fiestas especiales, por su propia iniciativa
	40	Guarda secretos o confidencias por más de un día
	41	Devuelve juguetes, cosas, o dinero que ha pedido prestado a sus compañeros, o devuelve libros que ha sacado de la biblioteca
	42	Termina una conversación de manera apropiada
9	43	Sigue los límites de tiempo establecidos por la persona que lo cuida
	44	Se abstiene de hacer preguntas o decir cosas que puedan avergonzar u ofender a otros
	45	Controla su enojo o resentimiento cuando no puede hacer lo que quiere
	46	Guarda secretos o confidencias por tanto tiempo como sea apropiado
10, 11	47	Tiene buenos modales en la mesa sin tener que recordarle. DO NOT SCORE 1
	48	Ve televisión o escucha radio para informarse sobre un tema de particular interés. N MAY BE SCORED
	49	Asiste en la noche a funciones escolares o de otra institución con amigos, cuando los acompaña un adulto. N MAY BE SCORED
	50	Evalúa las consecuencias de sus actos antes de tomar una decisión
	51	Se disculpa por errores cometidos por falta de juicio
12, 13, 14	52	Recuerda los cumpleaños o aniversarios de miembros de la familia o de amigos cercanos
	53	Inicia conversaciones sobre temas de particular interés para otros
	54	Tiene un pasatiempo recreativo
	55	Reembolsa dinero prestado de la persona que lo cuida
15 to 16+	56	Responde a insinuaciones o indirectas en la conversación
	57	Participa en deportes fuera de la escuela. N MAY BE SCORED
	58	Ve televisión o escucha radio para obtener información diaria. N MAY BE SCORED
	59	Hace y cumple sus citas
	60	Ve televisión o escucha radio independientemente para oír las noticias. N MAY BE SCORED
	61	Asiste en la noche a funciones escolares o de otra institución con amigos, sin la supervisión de un adulto. N MAY BE SCORED
	62	Asiste en la noche a eventos no escolares con amigos sin la supervisión de un adulto
	63	Pertenece a algún club organizado, grupo de interés, u organización social o de servicio para jóvenes mayores
	64	Sale con una persona del sexo opuesto a una fiesta o evento público donde hay mucha gente presente
	65	Sale en grupos de dos o tres parejas
	66	Sale solo/a con un/a joven

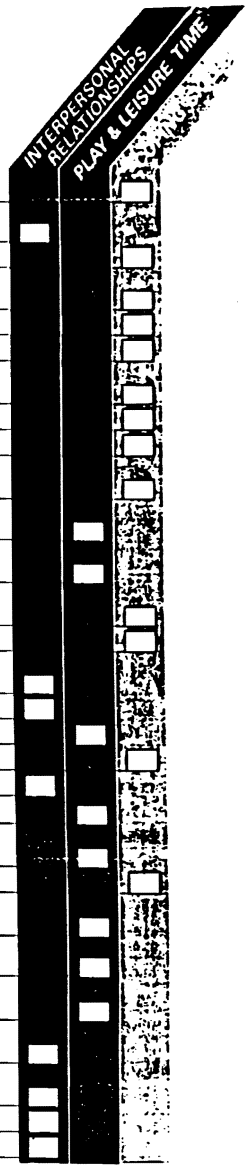
al as 2, items after ceiling as 0



ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

	38	Responds appropriately when introduced to strangers
7, 8	39	Makes or buys small gifts for caregiver or family member on major holidays, on own initiative
	40	Keeps secrets or confidences for more than one day
	41	Returns borrowed toys, possessions, or money to peers, or returns borrowed books to library
	42	Ends conversations appropriately
9	43	Follows time limits set by caregiver
	44	Refrains from asking questions or making statements that might embarrass or hurt others
	45	Controls anger or hurt feelings when denied own way
	46	Keeps secrets or confidences for as long as appropriate
10, 11	47	Uses appropriate table manners without being told. DO NOT SCORE 1
	48	Watches television or listens to radio for information about a particular area of interest. N MAY BE SCORED
	49	Goes to evening school or facility events with friends, when accompanied by an adult. N MAY BE SCORED
	50	Independently weighs consequences of actions before making decisions
	51	Apologizes for mistakes or errors in judgment
12, 13, 14	52	Remembers birthdays or anniversaries of immediate family members and special friends.
	53	Initiates conversations on topics of particular interest to others.
	54	Has a hobby
	55	Repays money borrowed from caregiver
15 to 16+	56	Responds to hints or indirect cues in conversation
	57	Participates in nonschool sports. N MAY BE SCORED
	58	Watches television or listens to radio for practical, day-to-day information. N MAY BE SCORED.
	59	Makes and keeps appointments
	60	Watches television or listens to radio for news independently. N MAY BE SCORED
	61	Goes to evening school or facility events with friends, without adult supervision. N MAY BE SCORED
	62	Goes to evening nonschool or nonfacility events with friends, without adult supervision
	63	Belongs to older adolescent organized club, interest group, or social or service organization
	64	Goes with one person of opposite sex to party or public event where many people are present
	65	Goes on double or triple dates
	66	Goes on single dates.

Count items before basal as 2, items after ceiling as 0



Vineland Adaptive Behavior Scales: INTERVIEW EDITION Survey Form

Individual's name — Chronological age

Date of interview — Supplementary norm group (if applicable)

Before beginning the score summary, read Chapter 5 in the manual.

SCORE SUMMARY

SUBDOMAIN	Raw Score	Standard Score (M=100, SD=15) Tables 6.1 and 6.2	Band of Error (90% Confidence) Table 6.3	Percentile Table 6.4	Stanine Table 6.4	Supplementary Norm Group Table Form Table 6.5	Adaptive Level Tables 6.6 and 6.8	Supplementary Norm Group Adaptive Level Table 6.7 and 6.9
Receptive								
Expressive								
Written								
Personal								
Domestic								
Community								
DAILY LIVING SKILLS DOMAIN SUM								
Interpersonal Relationships								
Play and Leisure Time								
Coping Skills								
(For ages 0-0 to 5-11-30) Gross								
(For ages 0-0 to 5-11-30) Fine								
MOTOR SKILLS DOMAIN SUM								
SUM OF DOMAIN STANDARD SCORES								
ADAPTIVE BEHAVIOR COMPOSITE								

SCORE PROFILE

(See Chapter 5 in the manual to graph scores.)

Standard Score / Band of Error

COMMUNICATION DOMAIN

DAILY LIVING SKILLS DOMAIN

SOCIALIZATION DOMAIN

MOTOR SKILLS DOMAIN

ADAPTIVE BEHAVIOR COMPOSITE

20 30 40 50 60 70 80 90 100 110 120 130 140

Percentile Ranks 1 2 5 9 16 25 37 50 63 75 84 91 95 98 99

-4SD -3SD -2SD -1SD MEAN +1SD +2SD

OPTIONAL

MALADAPTIVE BEHAVIOR DOMAIN

(Administer for ages 5-0-0 and older)

	Raw Score	Maladaptive Level: Table 6.12	Supplementary Maladaptive Le
Part 1			
Parts 1 and 2			

Additional interpretive information (see Chapters 5 and 6 in the manual)

Recommendations

AGS

1. ANOVA: Cultural background by perceived socioeconomic status.

Groups:	Working class	Lower Mid-class	Upper Mid-class
n	34	11	5
Mean	4.56	3.45	1.6
sd.	2.8	2.84	2.61

SOURCE	SS	df	MS	F	p
treatment	60.57	2	30.28	3.72	.038
error	382.3	47	8.13		

Neuman Keuls Test

	MedLow	MedHigh
Poor	1.18	3.17
MedLow		1.99

2. t-TEST: VALUE OF SCHOOL FOR CHILDREN MR vs. ABLE

	MR N=50	ABLE N=50	
X	3.91	3.68	t(49)= 2.115
sd	.41	.84	p = .040

2. MULTIPLE REGRESSION:

VARIABLES

Y factor	Adaptation
Mean	17.08
sd	3.56

External context variables

	SES	Culture
Mean	1.56	4.02
sd	1.93	2.945

Internal Context variables

	Fed	Med	#Child	Relig
Mean	6.120	5.180	3.520	6.98
sd	4.68	3.93	1.5	2.5

ABCX-intra-familial variables

	A(MR)	B(Help)	C(wellb)	C(indep)
Mean	43.42	25.5	24.26	36.02
sd	10.74	14.57	6.07	6.25

A) TESTING THE MODEL ACCORDING TO CONCEPTUAL LOGIC.
External context variables

SOURCE	SS	df	MS	F	p
Regression	39.258	2	19.62	1.57	.215
Residual	584.42	47	12.43		
Total	623.68	49			

Squared Multiple correlation = .0629 (.2509)

Standard Error = 3.52

Variable	coefficient	t-ratio	standard error	p	semipartial r2
SES	0.4067	1.476	0.2756	.1431	.0434
Culture	0.2588	1.426	0.1815	.1572	.0405
Constant	15.4052				

Internal context variables

SOURCE	SS	df	MS	F	p
Regression	108.924	4	27.231	2.381	.0651
Residual	514.756	45	11.439		
Total	623.68	49			

Squared Multiple correlation = .1746 (.4179)

Standard Error = 3.382

Variable	coefficient	t-ratio	standard error	p	semipartial r2
Fed	0.0929	0.621	0.1495	.5434	.0071
Med	0.093	0.519	0.1798	.6052	.0049
#child	0.3049	0.945	0.3226	.350	.0164
Relig	0.5026	2.398	0.2096	.0197	.1054
Constant	11.4468				

ABCX-intra-familial variables

SOURCE	SS	df	MS	F	p
Regression	83.695	4	20.924	1.744	.1564
Residual	539.985	45	12.0		
Total	623.680	49			

Squared Multiple correlation = .1342 (.3663)

Standard Error = 3.464

Variable	coefficient	t-ratio	standard error	p	semipartial r2
A(MR)	0.0263	0.552	0.0476	.5858	.0059
B(help)	-0.0498	-1.366	0.0364	.1757	.0359
C(Wellb)	-0.0349	-0.399	0.0874	.6646	.0031
C(Indep)	0.2043	2.460	0.0828	.0167	.1172
Constant	10.6949				

B) TESTING THE MODEL ACCORDING TO BI-VARIATED CORRELATIONS.

SOURCE	SS	df	MS	F	p
Regression	125.128	3	41.709	3.848	.0153
Residual	498.552	46	10.838		
Total	623.680	49			

Squared Multiple correlation = .2006 (.4479)

Standard Error = 3.292

Variable	coefficient	t-ratio	standard error	p	semipartial r2
Fed	0.12	1.183	0.1014	.2414	.0243
Indep	0.1265	1.613	0.0783	.1091	.0454
Relig	0.3941	2.001	0.0783	.0487	.0696
Constant	9.0369				

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