NEUROFIBROMATOSIS AND ITS RELATIONSHIP TO SCHOOL PERFORMANCE PROBLEMS, LEARNING DISABILITIES, HYPERACTIVITY, AND INTELLIGENCE

A Thesis

Presented to

the Faculty of the Department of Psychology
University of Houston

In Partial Fulfillment

of the Requirement for the Degree

Masters of Art

Ву

Sherrie Coleman

Spring, 1987

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ABSTRACT

Reports from professionals suggest that Neurofibromatosis (NF) is associated with school performance problems and learning disabilities. The 92 children studied, ages 6 to 16, were participating in the Baylor NF Program and were representative of gender and race of the general population. A follow-up study involved a subset of 23 children. There were six significant findings: (a) children with NF scored significantly lower than expected on the Wechsler Intelligence Scale for Children- Revised (WISC-R) and Wide Range Achievement Tests (WRAT), (b) children with NF have a higher incidence of learning disabilities than the general popultation, (c) correlations using a cross-sectional population suggests the IQ's of children with NF decreased with the age, (d) IQ was related to severity average, (e) parents and teachers rated child behavior as significantly different on the Child Behavior Profile, and (f) disfigurement correlated with parent behavior ratings and attitudes on the Parental Attitude Research Instrument.

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LIST OF ACRONYMS

Acronym Stands for

BNFP Baylor College of Medicine

Neurofibromatosis Program

CEP Child Behavior Profile

CLS Cafe-au-lait Spots

CNS Central Nervous System

CRPBI Child's Report of Parental

Behavior Inventory

FSIO Full Scale IQ

Learning Disabilities

NE Neurofibromatosis

PAR! Farental Attitude Research Instrument

PIQ Performance IQ

VIQ Verbal IQ

WISC-R Wechsler Intelligence Scale for

Children-Revised

WRAT Wide Range Achievement Test

Neurofibromatosis and Its Relationship

to School Performance Problems, Learning Disabilities,

Hyperactivity, and Intelligence

Neurofibromatosis (NF), an autosomal dominant genetic disease, affects approximately one in every 3000 individuals. Although genetic, approximately one-half of all index cases, that is cases which bring a family to the physician's attention, have no family history of NF. These sporadic cases are believed to be the result of a new mutation. However, once present, NF may pass from a parent of either sex to a child of either sex. If one parent has NF, a child has a 50 percent chance of inheriting the condition (Fienman & Yokovac, 1970; Riccardi, 1381b). NF is frequently said to be associated with mental retardation and school performance problems, which include learning disabilities (Carey, Laub, & Hall, 1979; Fienman et al., 1970; Holt, 1978). Parents of children with NF often mention that their children tend to be unruly and noncompliant (Riccardi, personal communication, Aug. 10, 1983). At the present time there is no literature concerning these problems in the population of children with NF. The purpose of this proposal is to examine the occurrence and specific patterns of school performance problems and hyperactivity in children with NF. In order to explore these problems, three bodies of literature will be examined. The areas of literature to be examined include (a) symptoms and complications of NF, (b) hyperactivity and school performance problems, and (c) the effects of chronic illness on a child and his or her family.

Neurofibromatosis

NF is characterized by (a) cafe-au-lait spots, (b) iris Lisch nodules, and (c) cutaneous neurofibromas.

Patients with NF manifest one or all of these three to a widely varying degree. Most individuals will have all three characteristics. The neurofibromas increase in number and size at puberty and with pregnancy.

The first characteristic is the cafe-au-lait spot (CLS). CLS are birthmarks that are the color of coffee-with-milk. CLS are usually present at birth or within 12 months from birth. They are variable in size

and in number and may appear on any part of the body except the scalp.

The second characteristic is the iris Lisch nodule. Lisch nodules are small tumors which appear on the iris of the eye, but do not compromise the function of the eye. Though Lisch nodules may be present at birth, they occur most commonly after the age of six.

The third characteristic is the neurofibroma.

Neurofibromas are normalignant cutaneous or subcutaneous tumors which may not appear until after puberty. If these tumors are present at birth, they often indicate the potential for serious complications. These complications result from plexiform neurofibromas which may cause airway and/or cardiovascular compromise.

Plexiform neurofibromas with overlying diffuse hyperpigmentation (darker skin coloration) may suggest that the tumor is more extensive within the chest or abdomen. If hyperpigmentation crosses the midline of the body, central nervous system involvement is likely with the attendant problems caused by neural damage.

Neurofibromas that are deeper than the skin may cause functional compromise of different organ systems

(Riccardi, 1980).

In general, NF is characterized by variability.

Seven or more different forms of the disease have been described. The most frequently occurring group is NF-I, with 85 to 90 per cent of all NF patients falling in this group. The various forms are:

- (a) NF-I is characterized by the presence of CLS, neurofibroma, and Lisch nodules,
- (b) NF-II is recognized by a few CLS and a high frequency of acoustic neurofibromas
- (c) NF-III consists of a mixture of NF-I and NF-II symptoms,
- (d) NF-IV is characterized by CLS and neurofibromas diffusely present,
- (e) NF-V is limited to one single region of the body,
- (f) NF-VI occurs when symptoms do not include neurofibromas but may be limited to CLS
- (g) NF-VII is the occurrence of symptoms later in life than childhood, and
- (h) NF-NOS is any case which can be classified as NF without falling into one of the above categories.

NF is not only variable between families, it is also variable within a particular family. The various forms of NF (NF-I to NF-VII) do, however, breed true in families. Furthermore, NF varies with respect to time. The presence of one symptom does not guarantee the development of another symptom nor the lack thereof (Riccardi, 1982a). In this paper, NF will refer to NF-I, which constitutes 85% of the NF cases reported.

Symptoms that may be present in NF-I include macrocephaly, short stature, delayed language development, constipation, segmental hypertrophy, premature or delayed puberty, pruritus, and pheochromocytoma, among others. NF also carries an increased risk of malignancies. Malignancies that may be present include neurofibrosarcoma, neuroblastoma, Wilms tumor, rhabdomyosarcoma, and leukemia.

Disfigurement and handicaps may be the result of kyphoscoliosis (curvature of the spine), pseudarthrosis (which may result in surgical amputation of a limb), and orbital neurofibroma (a growth around the eye which can result in blindness) (Riccardi, 1981a, 1981b, 1982b).

Central nervous system involvement is also present in

NF. During the first decade of life, CNS tumors may develop. Tumors are suspected when a child complains of seizures and/or headaches. However, seizures and headaches may both be present when no evidence of CNS tumors can be found. Optic glioma, a tumor on the optic merve, may cause blindness, and auditory nerve tumors may cause deafness.

Symptoms such as headaches, seizures, and hyperactivity may suggest that CNS damage is present even when no other evidence of CNS damage can be found using modern diagnostic techniques. This has led some researchers to believe that the damage may be at the microscopic level (Crowe, Schull & Neel, 1956). As evidence for their belief, Crowe, et al., (1956) cite the high incidence of microscopic changes in the brains of victims of NF. These researchers suggest that these changes in the brain may result in mental retardation. It is unclear at the present time whether reported school performance problems and hyperactivity (Carey, et al., 1979; Fienman, et al., 1970; Holt, 1978) are associated with microscopic CNS damage or are associated with sociological factors (e.g., rejection of the child

by a parent or society) or associated with both.

Furthermore, school performance problems, learning
disabilities, and hyperactivity are problems commonly
associated with NF, although at the present time, there
are no studies specifically relating these problems to
the disease. As a result, the extent to which these
problems are present in the populations of individuals
with NF is unclear. Furthermore, it is unknown if NF is
associated with a specific type or subset of learning
disabilities, school performance problems, or
hyperactivity.

Hyperactivity and School Performance Problems

Publications discussing hyperactivity and its diagnosis indicate that the condition is not clearly defined, leaving research studies subject to personal biases as to what types of individuals are to be included (Barkley, 1981; Loney, 1981; Whalen, 1983).

Four Kinds of behavior appear to be related to the condition: (a) activity, (b) attention span, (c) aggression, and (d) achievement in school (Loney, 1981). It is still indefinite as to which types are antecedents of the condition, which areas are causing the observed

effects in other areas, and which types, if any, are necessary and sufficient.

Many people believe the basic problem with hyperactive children is their excessive motion. In some situations, by some measures, children who are hyperactive will be different in their activity level from children who are normal. Other research suggests that these two groups of children, normal and hyperactive, are not consistently distinguishable in activity levels. Barkley (1981) suggests that problems with hyperactivity differ in expression, severity, and frequency from one situation to another. Hyperactive boys are more likely to display problems when they play with other children, when their parents are on the phone, and when they are in public places. They are least likely to display problems when playing alone, when taking a bath, and when their fathers are home.

The second characteristic of hyperactivity is altered attention span. Children who are diagnosed as hyperactive tend to be distractible; they have problems with sustained attention and with impulsiveness. They also have a tendency to be sensation or stimulus

seekers. Many researchers believe that this aspect of hyperactivity is the most important. This is reflected in the labeling of the condition in the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-III; APA, 1980). The DSM-III diagnosis which replaces hyperactivity is "Attention Deficit, with or without Hyperactivity".

The third area associated with hyperactivity is aggression. A high percentage of children who are hyperactive also demonstrate conduct disorders; however, many researchers argue that hyperactivity with aggression is a different syndrome from hyperactivity without aggression, particularly in the area of concurrent behavior patterns and long-term outcomes.

The fourth behavior associated with hyperactivity is poor achievement. Children with hyperactivity tend to be "underachievers"; that is, they do not perform in school at the level expected, given their IQ levels. A high percentage of these children also have school performance problems and learning disabilities. In a review of the literature, Whalen (1983) concludes that learning disabilities and hyperactivity are different

syndromes with similar behavior consequences. In another review, Barkley (1981) suggests that while each child with hyperactivity may have a specific deficit, no specific deficit characterizes the whole group.

Some researchers argue that to maintain the cohesiveness of the hyperactivity diagnosis, certain subpopulations of children should not be diagnosed as hyperactive. These subpopulations include the mentally retarded, the psychotic, and children with CNS damage. Some individuals also believe that children whose hyperactivity is due to Known antecedents, e.g., a parent losing their job, or their parents obtaining a divorce, should not be included.

Factors which are also related to hyperactivity include the sex of the child, the parental Socio-economic Status (SES), and a family history of hyperactivity and other psychological problems (Barkley, 1981; Loney, 1981). There is a higher frequency of hyperactivity in males than in females. Some evidence suggests that hyperactivity in females leads to symptoms different from those seen in males. Girls appear to have more problems in mood, affect, and emotional

liability. A second factor associated with hyperactivity is familial SES. Whalen (1983) disagrees with the assertion that there is a meaningful relationship between low SES and hyperactivity, though she does suggest that factors associated with low SES may be important to the development of hyperactivity, which is more common and tends to be more severe in the lower SES. Another related factor of hyperactivity is the presence of hyperactivity and other psychological problems in family members of the hyperactive individual. Female relatives of children diagnosed as hyperactive have a higher incidence of hysteria. hypochondriasis, and depression. Male relatives are more likely to evidence conduct disorders. Siblings of children with hyperactivity are also more likely to be diagnosed as hyperactive.

At the present time it is unclear if children with NF should receive the diagnosis of hyperactivity even if their behavior appears to be similar to behavior of children who are considered to be hyperactive. For example, one group of children which many researchers believe should be excluded is children with CNS damage.

This presents a diagnostic dilemma for the placement of children with NF. Some the children with NF have demonstratable brain lesions, some have symptoms that suggest some form of CNS damage but the damage cannot be documented (e.g., seizures or headaches), and some have only soft signs which might suggest CNS damage.

This discussion has concentrated on hyperactivity. Children with NF also have school performance problems. In a discussion of school performance problems, Kinsbourne and Caplan (1979), suggest that there are two basic types. One is a cognitive power disorder and the other a cognitive style disorder. A cognitive power disorder is basically a learning disability; i.e., "either they are not performing up to their potential (underachievement) or their potential for learning is abnormally limited (cognitive disorder)* (Kinsbourne & Caplan, 1979, p 45.) Underachievement includes school performance problems resulting from cultural deprivation, from general limited mental abilities (e.g., mental retardation), and from emotionally based problems (e.g., anxiety, school phobia, and adverse family situations). In contrast, a cognitive disorder

as such usually refers to a specific cognitive function (e.g., a problem with reading or a problem with mathematics). However, a cognitive disorder may also refer to the child's inability to perform up to his or her intellectual potential when there is no discernible reason for the child's poor performance. Often a child's school performance problems are not the result of a defect in a specific area of academic achievement, but the result of the child's orientation to the world. A child may be either underfocusing or overfocusing. A child who underfocuses is often considered hyperactive. Such children have a short attention span, have generally widespread academic problems, often do not complete assignments, display attention seeking behavior, and are frequently discipline problems. A child who is overfocused tends to be extremely slow at shifting attention. As a result, they also show widespread academic problems but, unlike the underfocusing child, they are not discipline problems. They tend to turn in completed assignments and display very few attention seeking behaviors.

Populations of children with NF are reported to

have school performance problems. However, it is unclear what school performance problems these children display and whether there is a specific pattern of problems found among individuals with NF. For example, school performance problems might be the result of a specific deficit in math or reading, or the result of anxiety caused by rejections of a child by his or her classmates or the result of the child's inability to sit still and finish his or her work.

Chronic Illness in Children

Individuals with NF must also deal with psychological burdens that would accompany any chronic illness. Since there are currently no published reports dealing with NF specifically, problems which accompany childhood chronic illness in general will be examined.

Chronic illness in children often promotes problems in two areas. These areas are scholastic achievement and social behavior (Eiser, 1982). Children with chronic illnesses appear to have a disadvantage at school when compared to their peers. For example, Eurton (1975) reported on a group of children with cystic fibrosis who were still behind in school

although, as a group, they had an average IQ of 104.

Most of the group were twelve or more months behind

school achievement expectations. Other examples of low

scholastic achievement in cases of chronic illness in

children included reports of those with hemophilia

(Olch, 1974) and physical disability (Allen, 1974). In

a study on children with diabetes, Gath, Smith and Baum

(1980) reported that over one third of 76 subjects were

a year or more behind in school. In another study, one

fourth of 32 school age children with cystic fibrosis

had failed one grade. These academic problems did not

reflect cognitive-based learning disabilities (Drotar,

1978). Lower scholastic achievement has also been

reported in children with epilepsy (Green & Hartlage,

1971, 1972; Rutter, Graham & Yule, 1970).

Frequently mentioned reasons for the delay in academic achievement included loss of time at school due to frequent and/or long hospital or bed stays, and problems caused by parents being overly protective. Another reason frequently cited for delayed scholastic growth in children with chronic illness is medical complications due to the disease, or to side effects of

medication; e.g., drousiness, exhaustion (Burton, 1975; Eiser, 1982; Pless & Roghmann, 1971).

Burton (1975) suggests that some children may have problems with their school work due to anxiety caused by lack of acceptance by their peers.

NF appears to cause school performance problems other than those associated with the emotional aspects of coping with the disease. Many children are first diagnosed with NF only after they have started school and are already experiencing problems in school. Frequently these children are placed in special classrooms prior to diagnosis (Riccardi, personal communication, August 1982).

The second area in which children with chronic illness are believed to have problems is in social behavior. However, several problems exist in many of the relevant studies. The major problem is that "...most of the studies in the current literature were based on assumptions, clinical impressions, subjective evaluations or abbreviated projective techniques, [and thus] the findings should be considered tentative and largely speculative "(Tavormina, Kastness, Slater and

Watt, 1976, p. 101).

In recent years, there has been an attempt to remedy the lack of objective data on children with chronic illness. Pless and Roghmann (1971) reported that children with chronic illness tended to display more behavior problems at school and more psychiatric disturbances when compared to normal peers. Tavormina, et al. (1976) studied a group of 144 chronically ill children with either diabetes, asthma, cystic fibrosis, or hearing impairment. In general, these children's scores did not deviate significantly from the published norms on measures of locus of control and personality. On a measure of self-concept the mean score for the chronically ill children was higher than reflected in published norms; that is, the chronically ill children had a higher self-concept than published norms. When scores were examined in relationship to the chronic disease entities, hearing-impaired children scored significantly lower than published norms and lower than the other chronically ill children. Boys were reported to have more problems than girls. Also, younger children tended to differ from the older children on

responses to personality inventories. Younger children (5-10) were less stable and less conforming, while older children (14-19) were more alienated, less sociable and made more socially desirable responses. In another study, chronically ill children who had a physical handicap, diabetes or hemophilia were compared to a control group of healthy children (Steinhausen, 1981). The children with either hemophilia or diabetes did not differ from the control group. However, the children with a physical handicap tended to be less extroverted than the control group.

A child's ability to cope with chronic illness obviously depends on many factors (Lipowski, 1970). Disease-related factors which appear to be important in a child's ability to cope with NF include the severity of the disease, the visibility of the condition and the child's age at diagnosis. Another factor which is important to the child's ability to cope is parental reaction to the child's condition.

The severity of the disease appears to affect a child's adjustment in a curvilinear fashion (Eiser, 1982). A child who is more severely disabled appears

more likely to accept his or her handicap and less
likely to compete in the ordinary world. This has been
demonstrated for patients with hemophilia (Bruhn,
Hampton & Chandler, 1971), and for children with
congenital heart conditions (Garson, Benson, Ivler &
Patton, 1978).

Another set of disease-related variables which affect NF individuals includes the visibility of the handicap, and the type of handicap. In a study of boys with hemophilia, Steinhausen (1981) reported that patients with hemophilia who suffer from limitations in joint mobility in more than one major joint were more likely to evidence personality problems than boys with only minor loss of joint mobility. In another study (Richardson, Goodman, Hasdorf and Dornbusch, 1961), children rated the acceptability of handicaps in the following order: (a) a child with no visible handicap, (b) a child with crutches and a leg brace, (c) a child in a wheelchair, (d) a child with a missing hand, (e) a child with a facial disfigurement, and (f) an obese child.

The children rated the handicaps by picking from a

set of standardized pictures the child they most wanted as a friend. The child with the crutches was the most acceptable as a playmate while the obese child was least acceptable. Girls tend to rank children with cosmetic handicaps lower, while boys tend to rate children with functional disabilities lower. This factor may play an important role in the child's acceptance by society since children with NF tend to exhibit a wide range of physical disabilities including the loss of limbs or facial disfigurement.

In a review of physical appearance and its effect on development, Hildebrandt (1982) reports that children older than Kindergarten tend to agree on rankings of disabilities. It is suggested that as children grow older, they prefer children with handicaps located farther from the face.

An intrapersonal factor which may affect the child's ability to cope is the age at diagnosis. Since the only visible sign of NF in many children prior to puberty is CLS, many individuals are not diagnosed as having NF until at or beyond puberty. The child who is diagnosed early in life might be expected to show more

problems than those who are diagnosed later in life if their parents' inability to cope with the disease was causing hyperactivity and school performance problems. However, a child with a family history of NF (i.e., one parent has the disease) may be diagnosed as having NF with only CLS at birth. Therefore, these children are expected to be diagnosed earlier in life than children without a family history of NF. Children who do not have a family history of NF and are diagnosed early in life may have more severe problems since these problems would tend to draw attention to the child's condition.

A child's ability to cope with the disease is related to the parents' reaction to the child's condition (Drotar, 1978; Friedrich, 1977; Garson et al., 1978; Satterwhite, 1976). Parents of children who are chronically ill are frequently described by the terms guilty, denying, and rejecting. When a parent feels guilty, he or she may be more likely to be overprotective and not allow the child full freedom to grow and develop. Children whose parents deny or are unwilling to talk about the child's condition, often experience excessive anxiety. These children may also

have problems in complying with their medical regimes.

Emotional trauma frequently accompanies the rejection of the child by a parent. Fathers are reported to be more likely to reject than mothers (Friedrich, 1977).

Study's Furpose

The purpose of this study is to describe a population of children with NF in terms of (a) intellectual strengths and weaknesses, (b) academic achievement, (c) behavior at home and at school, (d) personality factors, (e) the child's perception of parental behavior, and (f) parental attitudes toward the child. The relationship of these six factors to demographic data (e.g., age, sex, SES, and race) and to medical data (e.g., severity of condition, age at diagnosis, presence of a family history of NF, specific symptoms, and degree of disfigurement) will be explored.

The lack of research in this field gives no basis for hypotheses concerning this study; therefore, hypotheses for this study would be based soley on conjecture. At the present time, there is not sufficient scientific Knowledge in this area (school performance problems and hyperactivity in individuals

with NF) to even warrant stating hypotheses. This study is to serve as a foundation for further research in this area. The results of this study will also serve as a screening device for future studies. In serving as a screening device, it is hoped that the results of this study will allow researchers to to target fruitful areas of research with a minimal amount of time and effort.

METHODS

Subjects

Subjects for this study were school age children, ages 6 to 16, who had been diagnosed as having NF-I. These children were a part of the Baylor College of Medicine's NF Program (BNFP). Subjects for BNFP were referred by physicians and social agencies who suspect a patient of having NF. By accepting referrals from many specialties, BNFP attempted to have a representative sample of patient's symptoms and background demographic data. In the first part of the study, 92 subjects met the criteria for participation.

Criteria for the second or follow-up portion of this study were as follows: having met criteria for part one and with ages between 6 and 17 at the outset of the second phase. There were 68 subjects who qualified for part two. Eighteen of the subjects who did not qualify were too old, while three subjects had died due to complications of NF. Three of the families were out of the country and unavailable.

In the second part of the study, 28 subjects did not respond to the letter and were not available for

telephone contact. Efforts were made to discover the new residence of many of the subjects who had moved. These efforts included review of BNFF files of family members, periodic review BNFP correspondence while the study was in progress, and use of the telephone information services. Two families refused to participate. Both of these families cited personal problems as the reason for not participating. Ten families, when contacted by telephone, stated that they were interested in participating, but never returned the consent forms. A total of 28 families returned the consent forms. Of these 28, 22 returned a portion of the packet. Six of the families did not return the packet. The reasons given for not returning the packet included losing the packet and that the packet been mailed but not received by the investigator. Three teachers did not return their portion of the study. more than one teacher returned questionnaires on a particular child then the results were averaged to give one number per child.

Families who participated in the follow-up portion of the study where significantly different in several

ways than those that did not participate. The families who participated were better educated ($\frac{2}{2}$ (1, N = 83) = 11.13, p>.001), had children who had higher Full Scale IQs ($\frac{1}{2}$ (83)=-2.61, p>.01) and had children whose NF was the result of a spontanous mutation ($\frac{2}{2}$ (1, N = 92) = 5.88, p>.02). Families were not different in terms of age of diagnosis ($\frac{1}{2}$ (84)=0.95, p>.34), severity average ($\frac{1}{2}$ (90)=0.85, p>.40), race ($\frac{2}{2}$ (1, N = 92) = 0.18, p>.68), sex($\frac{2}{2}$ (1, N = 92) = 0.20, p>.65), disfigurement ($\frac{2}{2}$ (1, N = 93) = 0.08, p>.78), and maximum severity ($\frac{2}{2}$ (3, N = 92) = 2.15, p>.54).

Measures

1. The Child Behavior Profile (CBP; Achenbach, 1966, 1978; Achenbach & Edelbrock, 1979) assesses parental perceptions of a child's behavior. The CBP consists of two parts, social competence and a behavior problem checklist. In the social competence section, parents or parent surrogates provide information related to social involvement, participation in organizations, and contact with friends. The second part consists of a behavior problem checklist to which the parent answers 'not true', 'somewhat true', or 'very true' concerning

behaviors of their child. Norms are provided for three age groups, 4 to 5, 6 to 12, and 12 to 16. Norms are also provided for each sex within the three age groups. Results yield first order factors which are similar for each age group and each sex. Second order factors are the same for each age group and sex. The second order factors are Internalizing and Externalizing. Factors are based on factor analytical studies. This test has good reliability and validity.

2. A modified version of The Child's Report of
Parental Behavior Inventory (Schaefer, 1965) developed
by Burger and Armentrout (1971) provided information on
the child's perceptions of parental behavior (see
Appendix C). The scale yields two major orthogonal
dimensions designated as love-hostility and
autonomy-control. The modified version consists of six
scales. These scales are acceptance, childcenterednes,
control through guilt, nonenforcement, lax discipline
and instilling persistent anxiety (see Appendix D for
items on the scales). The modified questionnaire
consists of one 16-item scale and five 8-items scales.
Internal-consistency reliabilities for the original

range from .84 to .66 for median reliabilities of the four molar dimensions. Discriminative ability for the original was demonstrated by the scales ability to discriminate between a group of normal boys and a group of delinquent boys. The modified version of the CRPBI uses the two best scales for each of the three factors. These scales were selected using regression.

Correlations of the modified scale score with the original scale score ranges from .96 for factor 1 to .86 for factor 2.

3. A modified version of the Parental Attitude
Research Instrument (PARI; Schaefer & Bell, 1958)
developed by Emmerich (1969) was used to assess parental
attitudes concerning their child (see Appendix E).
Emmerich modified the PARI by choosing items which
loaded on three major factors in a study of mother's
attitudes (Zuckerman, Ribback, Monashkin & Norton, 1958)
and in a study of father's attitudes (Nichols, 1962).
The three factors for the mother's PARI were (a)
Authoritarian Control, (b) Hostility-Rejection and (c)
Democratic Attitudes. A high score on Authoritarian

Control reflects authoritarian, suppressive, punitive and restricting attitudes (see Appendix F for items on each scale). Hostility-Rejection is described as hostility toward children and husband and rejection of the maternal role. Democratic Attitudes can be described by the three scales which load on this factor. These three scales are (a) Encouraging Verbalization, (b) Equalitarianism and (c) Comradeship and Sharing. Factors for the father's PARI are similar to factors for the mother's PARI with the exception that factor 2 on the father's seems to have little to do with attitudes concerning child rearing. Instead, this factor seems to reflect complaints and difficulties concerning the wife. Acquiescence-response is controlled for in the modified PARI. Test-retest reliability on the 23 original scales of the PARI after six months varied from .44 for the Encouraging Verbalization Scale to .79 for the Irritability Scale With the exception of the Autonomy of the Child Scale which had a test-retest reliability of .18. Internal consistency as measured by the Kuder-Richardson Formula 20 varied from .54 for the Suppression of Aggression Scale to .84 for the

Intrusiveness Scale.

- 4. The Teacher's Report Version of the Child
 Behavior Profile is similar to the CBP (Edelbrock & Achenbach, 1984). The first part of the profile is concerned with the child's scholastic performance. The second part consist of a behavior checklist to which the teacher answers 'not true', 'somewhat true', or 'very true' concerning behaviors of the child.
- 5. Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974) is an intelligence test for children ages 6-0 through 16-11 years. The test yields results on ten subtests plus two supplementary subtests. The WISC-R provides three IQ scores: a Verbal Scale IQ, a Performance Scale IQ and a Full Scale IQ. Reliability and validity are excellent for this instrument.
- 6. Wide Range Achievement Test (Jastak & Jastak, 1978) is an individually administered achievement test composed of three scales (Arithmetic, Reading and Spelling) measured at two levels. Split-half reliabilities for the three scales vary from .94 to .98. Test-retest reliabilities for two- to twenty-two week intervals varies from .87 to .98. The median

correlations between the WRAT and WISC-R Full scale IQ and the Verbal scale IQ is approximately .60. The Performance Scale of the WISC-R correlates about .40 with the WRAT.

Procedure

All individuals referred to BNFP were initially screened to determine the apparent presence or absence of NF. An individual believed to have NF was encouraged to participate in three days of medical tests at either Texas Children's Hospital or The Methodist Hospital in the Texas Medical Center. These tests were paid for by a research grant or, when available, the patient's private insurance.

All individuals who entered BNFP received a thorough family history interview, a medical history interview, and a medical examination. Additional examination included cranial computerized axial tomography (CAT) scan, electroencephalography, audiometry, radiographic skeletal survey, fasting blood sugar, blood urea nitrogen, complete blood count, routine urinalysis, and intelligence and psychological testing. The intelligence and psychological testing was

performed by one testing center at Texas Children's

Hospital. No attempt was made to Keep the test

administrators blind as to the purpose of the testing.

The results from these procedures were combined to form a severity profile. The severity profile is a series of four numbers reflecting the number of years spent at each of four severity levels. The severity levels were determined by criteria given in Riccardi (1982b) with one minor change (see Appendix A for criteria). Riccardi uses mental retardation, school performance problems, and learning disabilities as criteria. For our present purposes, individuals, placed at a more severe level for these reasons only, were displaced to the next lower level. If an individual was placed at a severity level because of medical complications per se, then the severity level remained unchanged. One individual was placed at a lower severity level as a result of this change in guidelines. Severity average is determine by multiplying each severity level by the number of years spent at that level and then dividing by the total number of years. Maximum severity level is the highest obtained severity

level at the time of testing.

Several variables were determined using information gathered on the demographic sheet and from the child's medical history. These variables were SES, degree of disfigurement, and the child's age at diagnosis. To determine SES, Hollingshead and Redlich's Two-factor index of social position (1957) was used.

Visibility of disfigurement was determined by three factors. These factors were the location of the disfiguring lesions on the body, the size of the disfigurement, and the specific disfigurement. For the purposes of this study, the body was divided in to three areas. According to Hildebrant (1982), disfiguring marks located on the face were judged by children to be less acceptable than disfiguring marks on other parts of the body. Also, head and facial disfiguring lesions were judged by parents to be particular embarassing and to be significant in terms of the child's future. The other two areas of the body are the limbs and the trunk. Disfiguring marks may be concealed if they are on the trunk. It is not as easy to conceal these marks if they occur on the limbs. Neurofibromas and CLS were divided

into three sizes: small, medium and large. It was assumed that large neurofibroma had more visual impact than small neurofibroma. The visibility of disfigurement was determined using the following rating scale:

- (a) 1 was neurofibroma or CLS that are less than Ø.5 cm in diameter and less than five in number on the child's trunk,
- (b) 2 was neurofibroma or CLS that are less than
 Ø.5 cm in diameter and less than five in number on the
 limbs,
- (c) 3 was neurofibroma and CLS on the trunk that are between 0.5 and 1.5 cm in diameter or five to ten in number,
- (d) 4 was neurofibroma and CLS on the limbs that are between 0.5 and 1.5 cm in diameter or five to ten in number,
- (e) 5 was neurofibroma or CLS on the face or neck that are less than 0.5 cm diameter and less than five in number,
- (f) 6 was neurofibroma on the trunk greater than 1.5 cm in diameter or greater than ten in number,

- (g) 7 was neurofibroma on the limbs greater than 1.5 cm in diameter or greater than ten in number,
- (h) 8 was neurofibroma and CLS on the face or neck that are between 0.5 and 1.5 cm in diameter or five to ten in number.
- (i) 9 was a missing or seriously distorted limb or Kyphoscoliosis that is visible to the naked eye, and
- (j) 10 was neurofibroma on the face that are greater than 1.5 cm in diameter or greater than ten in number.

Disfigurement ratings were made by the BNFP nurse who used medical records which included photographs.

These medical records were part of the three days of examinations described previously.

The age of diagnosis was determined by one of two methods. The first method took the age at which a parent either Knew the child had NF or suspected that something was different about the child because of actions or appearance. The second method took the age of diagnosis to be the age at which the child was actually diagnosed as having NF. The earliest of either of these two is used in the study.

This study was comprised of two parts. The first part, the medical examination and the intelligence testing, was conducted over a five year period from 1978 through 1984. A total of 92 subjects between the ages of 6 and 16 were tested during this time. The second part, which included the the CBP, the PARI, and the CRPBI, was conducted by mail.

The parents of the 69 children who participated in the second part of the study were sent an initial letter informing them that someone from BNFP would be contacting them and requesting that they participate in a study. Consent forms for family members to sign were included. These consent forms contained parental consent forms allowing the child's teachers to release information. Each family was then contacted by telephone. If the family agreed to participate in the study, a packet was sent to the family after the consent forms were returned. This packet contained (a) two CBPs (one for each parent), (b) two PARIs, and (c) a CRPBI. The parents were requested to return the information in an envelope which was addressed and stamped. At the same time that the packet was sent to the family, a

letter was sent to the teacher informing the teacher that the student had been selected to participate in a study concerning behavior at home versus behavior at school. To protect the child, no mention of NF was made in the letter.

If the packets or consent forms were not returned within two months, the researcher contacted the families to determine if further assistance was needed. If the packets were not returned a reminder letter was sent after another two months.

RESULTS

10 and Achievement Data

In order to do a comparison of the NF Full Scale IQ (FSIQ) to the general population FSIQ mean, the normative group of the Wechsler Intelligence Scale for Children-Revised (WISC-R) was used as a control group. The normative group was chosen since this study did not include a control group. Information on the normative group was reported in the WISC-R manual as Sum of Scale Scores rather than as FSIQ scores (Wechsler, 1974). Since information on the population of children with NF was reported as FSIQ scores, the mean and standard deviation of the WISC-R scores in the NF group were converted to the Sum of Scale Scores. This conversion produced a mean Sum of Scale Scores of 85 with a standard deviation of 23 for those individuals with NF. The normative group had a mean Sum of Scale Scores of 100.4 with a standard deviation of 21.01. The Sum of Scale Scores for the children with NF was depressed by about 2/3 of 1 standard deviation and was significantly different from the normative group (1(2283) = 6.09, P(.001)).

Information on the Performance IQ (PIQ) and Verbal IQ (VID) of the WISC-R and the subtests of the Wide Range Achievement Test (WRAT) was reported in a form which did not allow for the normative group to be used as a control group, therefore a direct comparison was not possible. The theoretical population mean was 100 and the standard deviation was 15 for PIQ, VIQ, and the three subtests of the WRAT. As seen in Table 1, a comparison of the means of these five test scores with the expected theoretical means suggests that the mean score of children with NF was 2/3 to 1 standard deviation below the theoretical mean for all five scores. This was similar to the results reported above for the FSIO. A comparision of the VIQ and PIQ shows that these means were not significantly different from each other ($\frac{1}{1}$ (168) = 0.91, $\frac{1}{1}$ (.18).

A difference of greater than 15 between VIQ and PIQ was associated with increased learning disabilities

(Kaufman, 1981). An examination of VIQ and PIQ reveals that 11 children had PIQ 15 or more points greater than VIQ while 13 children had VIQ 15 or more points greater than PIQ. This means that 24 children or 28% had one IQ

Table 1 Means and Standard Deviations of Subtests
of the WISC-Ra and the WRATb

Scale	Mean	SD	И	
WISC-R Full Scale IQ	89.00	15.88	85	
WISC-R Performance IQ	90.46	15.89	84	
WISC-R Verbal IQ	88.19	16.80	86	
Information	7.68	2.94	85	
Similarities	8.94	3.37	85	
Arithmetic	7.73	2.77	85	
Vocabulary	8.24	2.99	85	
Comprehension	8.66	3.12	85	
Picture Completion	9.34	3.08	8 6	
Picture Arrangement	9.56	3.67	84	
Block Design	7.97	3.23	85	
Object Assembly	7.68	2.99	85	
Coding	8.19	3.95	83	
WRAT Reading	91.84	15.89	76	
WRAT Spelling	86.07	13.25	74	
WRAT Arithmetic	88.49	15.83	75	

a Wechsler Intelligence Scale for Children-Revised (WISC-R)

b Wide Range Achievement Test (WRAT)

scale 15 or more points higher than the other. This was not significantly different (z = -.60, p(.26) from a population of normal children in which 25% had one IQ scale score 15 or more points greater than the other IQ scale score.

In addition, a comparison of the means of the subtests of the WISC-R (shown in Table 1) show that children with NF score lower than the theoretical mean of 10 on all ten subtests. These subtest means range from 1/4 to 3/4 of a standard deviation of three below the theoretical mean of the normative group.

Performance on the WRAT may also be used to show learning disabilities (Fletcher, 1983). Analysis of WRAT profiles used criteria given in Fletcher (1985; see Appendix E for criteria) modified by use of an FSIQ of 86 rather than an FSIQ of 80. Two children (2%) of those tested with the WRAT were reading and spelling disabled. Seven children (9%) were spelling and arithmetic disabled while six children (8%) were arithmetic disabled only. In addition, one child (1%) was arithmetic, reading, and spelling disabled; that is, the child scored above 86 on the FSIQ but scored below

93 on all three subtests and the child's average on the WPAT subtests was below 91. If the requirement for FSIQ is lowered to 80, then 20 more children were classified as learning disabled. All 20 of these children were classified as arithmetic, reading, and spelling disabled. The overall incidence of learning disabled in this population using FSIQ of 80 was 49%.

Correlation of IO and Achievement Data with Age

The existence of a correlation of the WISC-R ten subtest scores with the age at the time of the testing suggested that, in this cross-sectional population, there was a tendency for older children to perform less well than younger children. As seen from Table 2, this correlation was significant for FSIQ and for VIQ, but not for PIQ. These correlations were significant but did not account for a large portion of the varitability. The WISC-R subtests that were significantly correlated with age were Similarities, Arithmetic, Vocabulary and Object Assembly. In addition, all three subtests of the WRAT were significantly correlated with age. Other factors were examined to determine if the significant

Table 2

<u>Relation of Age at Time of IQ Testing</u>

<u>With the WISC-R³, the WRAT^b & Other Factors</u>

Var iable	Correlation
WISC-R Full Scale IQ	23 [*]
WISC-R Performance IQ	18
WISC-R Verbal IQ	29**
Information	12
Similarities	30**
Arithmetic	25*
Vocabulary	33**
Comprehension	21
Picture Completion	~.09
Picture Arrangement	06
Block Design	13
Object Assembly	26*
Coding	21
URAT-Reading	39 ^{***}
WRAT-Spelling	53 ^{***}
WRAT-Arithmatic	43***
Race	08

SES	07
Severity average	.18
Maximum severity	.03
Age of diagnosis	.20
Family history	02
Disfigurement	.31**
CNS tumors, seizures or blindness	09

^{*} p<.05. **p<.01. ***p<.001.

a Wechsler Intelligence Scale for Children-Revised (N = 77)b Wide Range Achievement Test (N = 72)

correlations were caused by correlation with a third variable. For example, age was not correlated with SES, race, presence of CNS tumors, seizures or blindness. Age at the time of testing was also not associated with severity average, maximum severity level, age of diagnosis, or positive family history, but was associated with disfigurement.

Relationship of IO Data and Disease Factors

The relationships of FSIQ to five disease factors of NF (severity average, maximum severity, disfigurement, age of diagnosis and family history) were analyzed using regression. Regression Equation 1 considered average severity level, degree of disfigurement, family history and age of diagnosis. These four factors taken together account for a significant amount of variance in FSIQ scores as shown by testing the significance of the equation (E(4,74) = 4.41, p(.003). The equation was found to be:

+ (.80)DISFIGUREMENT + (-.54)AGE OF DIAGNOSIS

+ (-2.29) FAMILY HISTORY.

The coefficient for the severity average (see Table

3) was significant. The coefficients for disfigurement, age of diagnosis, and family history were not significantly different from zero.

The second regression equation substituted maximum achieved severity level for average severity level. This equation did not account for a significant portion of FSIQ variance (E(4,74) = 1.11, p(.36). The equation was found to be:

FSIQ = 97.75 + (-3.31)MAXIMUM SEVERITY (2)
+ (.19)DISFIGUREMENT + (-.50)AGE OF DIAGNOSIS
+ (-1.96)FAMILY HISTORY.

The coefficients for the Equation 2 were not significantly different from zero (see Table 3).

Children who were Known to have had CNS tumors, seizures and blindness which could lower IQ were removed from the sample population and the analysis was redone.

A total of 10 subjects were deleted.

Equation 3 corresponds to Equation 1 but uses the reduced sample pool. As in the larger sample pool, these four factors were able to predict a significant amount of variance in FSIQ (E(4,64) = 3.13, E(.02) in the smaller population. The equation was found to be:

Table 3

Test of Significance of Beta of Regression

Equations Predicting FSIQ

Variable	Beta	Beta <u>t</u>	Beta	Beta <u>t</u>
	Equation	n 1ª	Equatio	n_3 ^b
Severity Average	-9.81	-3.19 ^{**}	-8.96	-3.19**
Disfigurement	0.80	0.84	0.66	0. 84
Age of Diagnosis	-0.54	-1.45	-0.60	-1.45
Family History	-2.29	-0.65	-2.23	-0.65
	Equation	on 2ª	Equatio	n 4 ^b
Maximum Severity	-3.31	-1.69	-3.97	-1.69
Disfigurement	0.19	0.46	0.39	0.46
Age of Diagnosis	-0.50	-1.38	-0.61	-1.38
Family History	-1.96	-0.54	2.01	-0.54

^{*} p<.05. **p<.01. ***p<.001.

a Children with CNS tumors, seizures & blindness (df = 74)

b Children without CNS tumors, seizures & blindness (df = 64)

- FSIQ = 103.89 + (-8.96)SEVERITY AVERAGE (3)
 - + (.66)DISFIGUREMENT + (-.60)AGE OF DIAGNOSIS
 - + (-2.23) FAMILY HISTORY.

The coefficient for severity average was again significantly different from zero. The coefficients for disfigurement, age of diagnosis and family history were not significant; repeating results from the larger sample group.

Equation 4 used the reduced sample pool as in Equation 3. Maximum severity level replaced average severity used in Equation 3. Taken together maximum severity level, disfigurement, age of diagnosis and family history were not able to significantly predict FSIQ (E(4,64) = 1.24, p(.30)). Equation 4 was found to be:

FSIQ = 98.68 + (-3.97)MAXIMUM SEVERITY (4)
+ (.39)DISFIGUREMENT + (-.61)AGE OF DIAGNOSIS
+ (-2.01)FAMILY HISTORY.

Individually the coefficients for maximum severity level, disfigurement, age of diagnosis and family history were not significant (see Table 3). Thus the reduced sample pool (Table 3, column 2) produced similar

results to the larger sample pool (Table 3, column 1).

Further analysis was conducted using stepwise regression. Once severity average was entered into the equation, the three variables: age of diagnosis, disfigurement, and family history were entered individually to determine if each could account for a significant amount of variance above that accounted for severity average. Once severity average was entered into the equation, the other three variables were individually unable to contribute a significant amount of variance. In addition, the three variables taken together were unable to account for a significant degree of variance. This was true for both the total populations of children with NF and for the population which excluded those with CNS tumors, seizures, and blindness (see Table 4). Since the equations using maximum severity did not account for a significant portion of variance, maximum severity was not included in further analysis.

Results of an assessment of the relationship between the five disease factors using Pearson correlation coefficients may be found in Table 5.

Table 4

Partial Correlation of Disease Factors With IQ

After Accounting for Effects of Severity Average

	Increment	
Variable 	in R ²	Partial E
Children with CNS tumors.	seizures & bli	ndness
Disfigurement	.01	.01ª
Family History	.01	.01ª
Age of Diagnosis	.02	.02ª
Disfigurement, Family His	tory,	
and Age of Diagnosis	.04	.04 ^b
Children without CNS tumor	rs. seizures &	blindness
Disfigurement	.01	.01 ^C
Family History	.01	.63 ^c
Age of Diagnosis	.03	2.34 ^c
Disfigurement, Family His	tory,	
and Age of Diagnosis	.05	3.61 ^d
Probability, <u>p</u> is not less above correlations. <u>Note.</u> IQ is Wechsler Inte: Children-Revised Full Sc: ^a Partial E has <u>df</u> = 1,76 ^b Partial E has <u>df</u> = 1,74	lligence Scale	

 $d_{Partial} = 1,74$

Table 5

Intercorrelations of Disease Factors and IQ

	Disf ^a	Age D ^b	Fam ^C	S Avg ^d	M Sev ^e
FS1Q ^f	03	.12	13	41****	14
Disf	1.00	02	08	.37***	.33**
AgeD		1.00	.05	08	04
Fam			1.00	03	12
S Avg				1.00	.74***

^{*} p<.05. **p<.01. ***p<.001. ****p<.0001.

Note. N = 85

a Disfigurement

b Age of Diagnosis

c Family History

d Average Severity

e Maximum Severity

f Wechsler Intelligence Scale for Children-Revised
Full Scale

Relationships of the disease factors to FSIQ are also presented in this table. Three significant correlations between disease factors were observed. These three correlations were: (a) maximum severity with severity average, (b) disfigurement with maximum severity and (c) disfigurement with severity average. FSIQ was significantly correlated to one factor, severity average. The correlation of FSIQ to severity average remained significant (r (73) = -.35, r (.002) once children with CNS tumors, seizures, and blindness were removed from the sampling population.

Parent and Teacher Behavior Ratings

Table 6 contains means and standard deviations for parent and teacher ratings of child behavior, parental attitude measures, and ratings of the child's perception of parental attitudes. In the NF sample, the mean of the father's behavior rating taken from Achenbach's Child Behavior Profile (CBF) was above the critical level; that is, the mean was above the 98th percentile of the normative group's parental ratings of their child's behavior problems. The mean of the mothers ratings was very close to this critical level though not

Table 6

Means and Standard Deviations of Achenbach
Behavioral Ratings, PARI and the CRPBID

Scale	Mean	SD	Ŋ	Possible Range
Mother ^a	68.68	11.77	19	0-99
Father ^a	70.77	9.86	13	0-99
Teacher ^a	50.89	13.02	18	0-99
Extent of Acceptance ^b	74.75	8.07	19	25-125
Autonomy ^b	34.32	4.90	19	15-60
Firmness of Control ^b	29.47	5.33	19	15-60
Extent of Acceptance ^C	73.20	5.83	15	25-125
Autonomy ^C	36.27	6.71	15	15-60
Firmness of Control ^C	30.67	4.37	15	15-60
Authoritarian Control ^d	29.73	5.76	15	24-72
Hostility & Rejection ^d	36.53	6.25	15	16-48
Democratic Attitudes ^d	36.40	9.48	15	16-48
Authoritarian Control ^e	34.50	9.95	14	24-72
Hostility & Rejection ^e	37.29	6.82	14	16-48
Democratic Attitudes ^e	36.43	7.77	14	16-48

a Achenbach Behavioral Ratings Child Behavior Profile

b Child's Report of Parental Attitude-Mother (CRPBI)

^C Child's Report of Parental Attitude-Father (CRPBI)

d Parental Attitude Research Instrument-Mother (PARI)

^e Parental Attitude Research Instrument-Father (PARI)

above. On the other hand, the mean of teacher behavior ratings of the NF sample was below the 50th percentile for teacher ratings of behavior problems. Possible ranges are given for each scale so the reader can observe where the means and standard deviations fall on the lesser Known scales.

Table 7 contains a graphic display of the number of children who, as a result of mother, father, or teacher behavior ratings on the CBP, had clinical scales above the critical level. Each table value represents the number of mothers, fathers, or teachers rating behavior above the defined critical level on x clinical scales of the CBP where x is given by the column headings in the table.

The relationships between mother, father, and teacher ratings of the child's behavior were examined using the CBP. Parents rated their child's behavior as significantly worse than the teachers' ratings of the child's behavior ($\underline{t}(27) = 3.60$, $\underline{p}(.001)$. Mothers and fathers tended to agree on the severity of their child's behavior as evidenced by the lack of significant difference between the two means ($\underline{t}(24) = -.08$, $\underline{p}(.92)$.

Table 7

Number of Critical Scales as Rated by Mothers. Fathers.

and Teachers on the Auchenbach Behavior Ratings

						
	Number	οf	critical	scales	per child	
	<u>©</u>	1	2	3	4	5
Mother ^a	4	3	2	4	4	2
Father ^a	Ø	4	4	2	1	1
Teacher ^a	14	2	Ø	0	Ø	0

a Achenbach Behavioral Ratings Child Behavior Profile

Teachers' and fathers' behavior ratings were significantly different (\pm (12) = 4.50, \pm (.001) as shown by the means of 50.89 and 70.77, respectively. Fathers' and teachers' behavior ratings were not significantly correlated ($\underline{r}(8) = .64$, $\underline{r}(.12)$. Mothers' and teachers' behavior ratings repeated a similar pattern. Mother's and teacher's ratings were significantly different $(\underline{t}(20) = -2.93, \underline{p}(.01))$ and were not significantly correlated ($\underline{r}(12) = -.18, \underline{r}(.61)$. Mothers' and fathers' behavior ratings correlate significantly ($\underline{r}(13) = .67$, p(.01.) It appeared that the behavior of children with NF was neither internalizing (M = 59.58) or externalizing (M = 59.73) as evidenced by the fact that the means of these two scaled were not significant $(\underline{t}(95) = -.07, \underline{v}(.94)$. Internalizing behavior was defined as behavior which was fearful, inhibited, and overcontrolled, while externalizing behavior was defined as behavior which was aggressive, antisocial, and undercontrolled.

Analysis of correlations of disease factors and behavior ratings (see Table 8) show that mothers rate their children as a behavior problem in proportion to

the child's disfigurement, but inversely related to the child's severity average. Mothers are more likely to rate a disfigured child as a behavior problem and are less likely to rate a child with serious medical problems as a behavior problem. In contrast, teacher's behavior ratings were unrelated to disfigurement and severity average while being significantly related to the child's age of diagnosis. Fathers' ratings did not significantly correlate with any of the five disease factors studied.

Parent and teacher behavior ratings did not correlate with parental atitudes of either parent (see Table 3) nor with the child's perseption of parental attitudes (see Table 10).

Parental Attitudes and Child's Perception of Parental Attitude:

Table 11 contains correlations of the three factors for both mother and father on the PARI. Mothers' and fathers' attitudes significantly correlated on the PARI factor entitled Authoritarian Control and tended to agree on the Hostility and Rejection factor.

Table 12 shows the correlation of the child's

Table 8

Relations of Disease Factors and Behavior Ratings

-	Disf ^a	AgeD ^b	Fam ^C	S Avg ^d	M Sev ^e
Mother	.53*	.29	. 10	50*	31
Father ^f	.18	10	46	.36	.36
Teacher ^f	.02	67**	44	. 25	.40

^{*} p<.05. **p<.01. ***p<.001.

a Disfigurement

b Age of Diagnosis

^C Family History

d Average Severity

e Maximum Severity

f Achenbach Behavioral RatingsChild Behavior Profile

Table 9

Relationship of Parental Attitudes and Behavior Ratings

	PM1ª	PM2 ^b	PM3 ^C	PF 1 ^d	PF2 ^e	PF3 ^f
Mother ⁹	45	.18	21	18	25	24
Father ⁹	12	. 18	20	. 10	49	26
Teacher ⁹	04	.55	.22	.19	.48	.00

Probability, $\underline{\mathbf{p}}$ is not less than .05 for any of the above corelations.

 $[\]underline{n}$ given in the following order Mother, Father, and Teacher.

b PM2 - PARI-Mother's Hostility & Rejection (n=13,11,19)

PM3 - PARI-Mother's Democratic Attitudes (n=13,11,19)

d PF1 - PARI-Father's Authoritarian Control (n=13,9,15)

e PF2 - PARI-Father's Hostility & Rejection (n=13,9,15)

f PF3 - PARI-Father's Democratic Attitudes (<u>n</u>=13,9,15)

⁹ Achenbach Behavioral Ratings

Table 10

Relation of Child's Perception of Parental
Attitudes and Behavior Ratings

	MC1 ^a	MC5 _p	MC3 ^c	FC1 ^d	FC2 ^e	FC3 ^f
Mother ⁹	.02	.02	25	.12	.29	39
Father ⁹	.24	13	36	.34	32	53
Teacher	9 .27	37	.51	.40	21	.52

Probability, \underline{p} is not less than .05 for any of the above corelations.

 $\underline{\mathbf{n}}$ given in the following order Mother, Father, and Teacher.

- b MC2 CRPBI-Mother's Autonomy (n=11, 10, 14)
- $^{\text{C}}$ MC3 CRPBI-Mother's Firmness of Control (\underline{n} =11, 10, 14)
- d FC1 CRPBI-Father's Extent of Acceptance (n=10,9,13)
- e FC2 CRPBI-Father's Autonomy (n=10, 9, 13)
- f FC3 CRPBI-Father's Firmness of Control (n=10, 9, 13)
- ⁹ Achenbach Behavioral Ratings

Table 11

Intecorrelations of Parental Attitudes Using the PARI

	PM1 ^a	PM2 ^b	PM3 ^C	PF 1 ^d	PF2 ^e	PF3 ^f
PM1	1.00	12	24	.54*	.04	07
PM2		1.00	.02	12	.45	31
РМЗ			1.00	. 16	. 10	.37
PF 1				1.00	29	18
PF2					1.00	.03

^{*} P(.05. **P(.01. ***P(.001.

For mothers n=19. For fathers n= 15.

PM1 - Parental Attitude Research Instrument (PARI)-Mother's Authoritarian Control

b PM2 - PARI-Mother's Hostility & Rejection

^C PM3 - PARI-Mother's Democratic Attitudes

d PF1 - PARI-Father's Authoritarian Control

e PF2 - PARI-Father's Hostility & Rejection

f PF3 - PARI-Father's Democratic Attitudes

Table 12

Intercorrelation of the Child's Perception
of Parental Attitudes Using the CRPBI

	MC1ª	MC2 ^b	MC3 ^C	FC1 ^d	FC2 ^e	FC3 ^f
MC i	1.00	00	11	.59*	09	. 10
MC2		1.00	.41	0 8	.67**	.30
мсз			1.00	28	.49	.91***
FC1				1.00	.05	23
FC2					1.00	.37

^{*} p<.05. **p<.01. ***p<.001.

For mothers n=15. For fathers n=14.

a MC1 - Child's Report of Parental Behaviors Inventory (CRPBI)-Mother's Extent of Acceptance

b MC2 - CRPBI-Mother's Autonomy

^C MC3 - CRPBI-Mother's Firmness of Control

d FC1 - CRPBI-Father's Extent of Acceptance

e FC2 - CRPBI-Father's Autonomy

f FC3 - CRPBI-Father's Firmness of Control

Table 13

Relation of Parental Attitudes and the Child's Perceptions of Parental Attitudes

	MC1 ^a	MC2 ^b	MC3 ^C	FC1 ^d	FC2 ^e	FC3 ^f
PM1 ^g	25	.27	.38	48	17	.53
PM2 ^h	44	07	.38	33	.18	.31
PM3 ⁱ	.11	04	. 1 1	06	12	.04
PF 1 ^j	37	23	00	05	36	17
PF2 ^K	39	.17	.72**	22	.38	.73**
PF3 ¹	.06	02	.22	19	26	.28

^{*} p<.05. **p<.01. ***p<.001.

For mothers $\underline{n}=14$. For fathers $\underline{n}=12$. For mother & fathers $\underline{n}=13$.

a MC1 - Child's Report of Parental Behaviors Inventory (CRPBI)-Mother's Extent of Acceptance

b MC2 - CRPBI-Mother's Autonomy

MC3 - CRPBI-Mother's Firmness of Control

d FC1 - CRPBI-Father's Extent of Acceptance

e FC2 - CRPBI-Father's Autonomy

f FC3 - CRPBI-Father's Firmness of Control

⁹ PM1 - Parental Attitude Research Instrument (PARI)-Mother's Authoritarian Control

h FM2 - PARI-Mother's Hostility & Rejection

i FM3 - FARI-Nother's Democratic Attitudes

^j FF1 - PARI-Father's Authoritarian Control

 $^{^{\}rm K}$ FF2 - PARI-Father's Hostility & Rejection

¹ PF3 - FARI-Father's Democratic Attitudes

perception of their parents attitudes as measured on the CRFEI. The correlation of the child's perception of their parents' attitudes with each of the three CRPBI factors was significant.

The correlations of the parents' attitudes and the child's perception of the parent's attitudes was found in Table 13. The child's perception of the Firmness of Control factor for both mother and father correlated significantly with fathers' scores on the Hostility and Rejection factor. No other correlations were significant.

The correlations of the five disease factors with parental attitudes are presented in Table 14. As a child's score in disfigurement increased, their mothers significantly scored higher on the Authoritarian Control factor while their fathers exhibited significantly decreased scores on the Democratic Attitudes factor. In addition, fathers' scores on the Democratic Attitudes factor was significantly related to a positive family history. The child's perception of their parents' attitudes did not appear to be related to the five disease factors (see Table 15).

Table 14

<u>Falation of Disease Factors and Parental Attitudes</u>

	Dis ^a	Age ^b	Fam ^C	SAvg ^d	MSev ^e
PM1 ^f	.55*	18	04	.05	08
PM2 ⁹	06	32	. 00	03	.08
PM3 ^h	01	22	.18	.19	.27
PF1 i	.17	30	18	02	01
PF2 ^j	09	. ø3	.41	17	.ø2
PF3 ^K	58 [*]	23	.66**	30	40

^{*} p<.05. **p<.01. ***p<.001.

n given for mother and father.

a Disfigurement (n = 17, 14)

b Age of Diagnosis (n = 16, 13)

^c Family History ($\underline{n} = 19, 15$)

d Average Severity (n = 19, 15)

e Maximum Severity (n = 19, 15)

f PM1 - Parental Attitude Research Instrument (PARI)-Mother's Authoritarian Control

⁹ PM2 - PARI-Mother's Hostility & Rejection

h PM3 - PARI-Mother's Democratic Attitudes

i PF1 - PARI-Father's Authoritarian Control

j PF2 - PARI-Father's Hostility & Rejection

K PF3 - PARI-Father's Democratic Attitudes

Table 15

Relation of Disease Factors and the Child's

Perception of Farental Attitudes

	Dis ^a	Age ^b	Fam ^C	SAvg ^d	MSev ^e
MC 1 ^f	.02	35	52*	.06	. 14
MC2 ⁹	.00	.22	.31	11	11
мсз ^h	12	43	.19	17	06
FC1 i	04	32	46	02	05
FC2 ^j	09	.21	. 10	49	39
FC3 ^K	. 15	50	.08	20	15

^{*} p<.05. **p<.01. ***p<.001.

n given for mother's and father.

^a Disfigurement ($\underline{n} = 13, 12$)

^b Age of Diagnosis ($\underline{n} = 12, 11$)

^C Family History ($\underline{n} = 15, 14$)

^d Average Severity ($\underline{n} = 15, 14$)

e Maximum Severity (n = 15, 14)

f MC1 - Child's Report of Parental Behaviors Inventory (CRPBI)-Mother's Extent of Acceptance

⁹ MC2 - CRPBI-Mother's Autonomy

h MC3 - CRPBI-Mother's Firmness of Control

i FC1 - CRPBI-Father's Extent of Acceptance

j FC2 - CRFBI-Father's Autonomy

K FC3 - CRPBI-Father's Firmness of Control

DISCUSSION

IQ and Achievement Results

Children with NF scored significantly lower than expected on the Wechsler Intelligence Scale for Children-Revised in comparison with the general population. These lowered scores were seen in both verbal and visual-spatial areas. Achievement test scores were also below average.

In this sample of children with NF, learning disabilities (LD) occurred more often than found in the general population. Although the 28% of children with NF who were found to exhibit a difference of greater than 15 points between PIQ and VIQ was not significantly different from the 25% that Kaufman (1981) found in the general population, the percentage of children who displayed LD based on performance on the Wide Range Achievement Test (WRAT) appeared to be higher than expected (49% versus 10-15%). The lack of a control group limited direct comparisons. Children with NF may have problems at school as the result of a lower than average IQ or they may have a lower than average IQ as the result of LD.

Children with NF and LD showed evidence of several different ability patterns. The largest group of children with LD were the arithmetic, reading and spelling disabled. A large percentage of children with NF also displayed arithmetic disabilities. This in part supports Eliason (1986) findings. Eliason found that a high percentage of children with NF had some form of visual-perceptual disabilities while very few demonstrated verbal disabilities. However, Eliason also found that the mean VIQ was 10 points higher than the mean PIQ. The results of this study were not in accord with the previos study on this finding. An almost equal number of children had PIQ 15 or more points greater than VIQ as had VIO's 15 or more points greater than FIQ's. In addition, mean FIQ and mean VIQ were not significantly different.

It was important to note that the Eliason study and this study differed on selection criteria. Eliason's population was selected from children who were referred because of behavior problems or LD. The primary criteria for inclusion in the study herein documented was the presence of NF-I.

Children who have LD and NF appear to be no different from children who have only LD. Both groups have similar soft neurological signs and have an increased incidence of minor physical anomalies. It is easy to conclude that both populations of children with LD are the same. However, some differences do exist. Children with NF did not respond as well to medication (je., Ritalin; Riccardi, personal communication). addition, the normal association of pre- and perinatal complications with LD is not present in children with NF. There is an increased risk among children with NF for development of CNS tumors. This risk is not present in the general population of children with NF. As a result of the above factors, it is unclear whether typologies of LD that are identified for children without NF will apply to children with NF. For example, treatment and prognosis of certain typologies may not be the same for the two groups.

Correlation of IO and Achievent Data with Age

Older children with NF have lower FSIQs scores than their younger counterparts. The correlations were significant for FSIQ and VIQ. The lower FSIQ's appeared

to be the result of lowered VIQ's. PIQ's did not decrease in the older population. An increase in the child's age did not relate to any disease factors except to disfigurement. As a result, lower IQ scores were not accounted for by the older children having more severe symptoms generally (maximum severity) or specifically (presence of CNS tumors, seizures, or blindness). The significant relationship between age and FSIQ still remained once children with CNS tumors, seizures and blindness were removed from the sampling population. In addition, older children did not appear to have had more severe symptoms for longer periods of time as seen by a nonsignificant correlation with severity average. Furthermore, this reduction in IQ does not appear to be the result of a skewing of parent's SES or child's race. An increase in disfigurement in older children was not unexpected since the appearance of neurofibroma increases with the onset of puberty.

A longitudinal study of children with NF and a control group would confirm if the decrement in FSIQ with age were a true finding and if adults with NF tend to score closer to the population mean than children.

In addition, since NF disease characteristics escalate with puberty, follow up studies have the potential to track the relationship between the increased symptoms and decreased IQ. These studies may also demonstrate if both PIQ and VIQ decrease with age or only VIQ as suggested by the cross sectional population.

Relationship of ID and Disease Factors

Severity average, disfigurement, age of diagnosis, and family history taken in combination were significant predictors of FSIQ, while maximum severity, disfigurement, age of diagnosis, and family history taken in combination did not predict FSIQ. Further analysis demonstrates that severity average was the only disease factor to correlate significantly with FSIQ. Severity average was related to IQ after subjects with CNS tumors, seizures and blindness were removed from the equation. This was an important finding ruling out the hypothesis that this correlation was the result of older children having more severe conditions which influenced IQ. This hypothesis would have been further supported if a significant relationship between age and higher severity averages were found. However, FSIQ was not

correlated with age. Furthermore, maximum severity was not related to IQ.

A second hypothesis was the relationship of IQ and severity average could also be accounted for by the use of mental retardation and school performance problems as criteria for placement at the different severity levels. Although many children in this study were given a severity profile based in part upon mental retardation and school performance problems, every child was placed at a severity level for medical reasons other than the aforementioned. In addition, if the relationship between severity average and IQ were the result of selection criteria, one would expect to observe results similar to those found with disfigurement.

Disfigurement, which was also used as criteria for placement at a severity levels, correlated with both maximum severity level and severity average.

In light of the above facts, one may conclude that the relationship between the extent that NF had affected a child's life and IQ may be accounted for by either one of two types of mechanisms. Either (a) a child's disease severity early in life was the cause of factors

which in turn influenced IQ (e.g., decreased parental interaction or increased parental rejection) or (b) those factors which cause or contribute to the disease severity also cause or contribute to a lowered IQ. The lack of a relationship between FSIQ and either disfigurement or age of diagnosis suggested that neither of these two factors play a role.

Parent and Teacher Behavior Ratings

Behavior ratings, parental attitudes, and the child's perception of attitudes were part of a follow-up study. The population of children and their parents who participated in this study was significantly different from the larger population of children and parents with NF. Parents of the children in the follow-up study were better educated as indicated by their higher SES, while the children were more intelligent. In addition, the children were less likely to have a positive family history of NF; that is, their NF tended to be the result of a spontaneous mutation. As a result, it is unlikely that these findings apply to the general population of children with NF. Furthermore, this difference in populations raises questions concerning the extent to

which behavior problems are a function of parental expectations among children with NF. Parents who are better educated may have higher expectations for their children.

The behavior of children with NF cannot be chacterized as hyperactive. Children with NF display both internalizing and externalizing behavior problems, that is, their problem behaviors were both attention seeking and nonattention seeking. Owing to the limited number of returned behavior ratings, it was not possible to determine if children's behavior varied according to age and/or gender of the child.

The findings concerning behavior ratings raise further questions about the roles of parental expectations. Parents and teachers differ dramatically in their discriptions of the child's behavior. Parents and teachers observed the child in different situations. This could easily account for some difference in the ratings. However, it is difficult to believe that a child's behavior could vary as much as these ratings suggest. The results of teachers' ratings suggested the children in this study tended to fall below the mean in

behavior problems, while parents' ratings suggested that their children were extreme behavior problems. The lack of a control group in studies causes some degree of uncertainity in these suggested conclusions.

The effect of NF on the child appears to be similar to effects found in other conditions. Children who were disfigured were rated as behavior problems by their mothers while children who had more severe disease complications through most of their life were rated as less of a behavior problem. These relationships were observed only with the mothers' ratings and not observed with either the teachers' or fathers' ratings. Possible emplanations include (a) the child's condition resulted in adjustment problems, (b) the mothers' perceptions were biased, or (c) a combination of the two factors occurred.

Parental Attitudes and the Child's Perception of Parental Attitudes

Children's perception of their parents attitudes indicated that children see their parents as agreeing amongst themselves. In addition, examination of parental attitudes by parental survey suggested that

parents' attitudes actually do tend to agree. However, it appears that child perception of the parents attitudes was not related to the parents attitudes with the one exception that the fathers' attitude toward hostility and rejection was perceived as firmness of control for both mother and father.

Disease factors generally did not relate to either the child's perception of parental attitudes or parental attitudes. The exceptions observed were an increase in disfigurement was associated with an increase in the mother's attitude toward authoritarian control and a decrease in the father's democratic attitudes.

The lack of significant results with parental attitudes and child perception of parental attitudes may be accounted for in part by the small sample size.

Another factor that might account for the lack of any relationship involving the child's perception of parental attitudes may be the age of the chidren involved. The children ranged from 8 to 16 years in age. Children's perception of the their parents change as the child matures.

Conclusion

In summary, six findings were significant. six findings were: (a) children with NF scored significantly lower than expected on intelligence and achievement tests, (b) children with NF have a higher incidence of LD than the general population, (c) correlations using a cross-sectional population suggested that FSIQ's of children with NF appeared to decrease with age, (d) FSIQ was related to severity average, (e) parents and teachers rated the child's behavior as significantly different, and (f) disfigurement appeared to have some effect on parent and teacher behavior ratings. Further research is warranted in the following areas: (a) longitudinal studies of the development of intelligence in children with NF using a control group, (b) exploration of LD in children with NF through performance on various tasks, (c) reconsideration of the use of mental retardation, school performance problems, and LD in the severity profile in terms of treatment and prognosis, (d) further investigation of child behavior using a more representative sample, and (e) further exploration of

the role of disfigurement in shaping parental attitudes and child behavior.

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Appendix

Appendix A

CRITERIA FOR ASSIGNMENT TO SEVERITY

LEVELS OF NEUROFIBROMATOSIS

1. Minimai

- 1. Unobtrusive cafe-au-lait spots (CLS)
- 2. Up to several inconspicuous cutaneous neurofibromas
- 3. Lisch nodules
- 4. Macrocephaly

II. Mild

- 1. CLS with mild cosmetic impact
- 2. Cutaneous neurofibromas with mild cosmetic impact
- 3. Cutaneous neurofibromas with mild functional impact
- 4. Mild prunitus
- 5. Mild short stature (3 to 10 percentiles)
- 6. Mild school performance problems without mental

retardation

- 7. Mild psychosocial burden
- 8. Asymptomatic EEG abnormalities
- 9. Mild headaches
- 10. Mild hearing loss
- 11. Mild constipation

- 12. Mild scoliosis
- 19. Other

III. Moderate

- 1. "Whole person" (multiple, widespread mild problems)
- 2. CLS with moderate cosmetic impact
- 3. Cutaneous neurofibromas with moderate cosmetic impact
- 4. Cutaneous neurofibromas with moderate functional impact
- 5. Moderate prunitus
- 6. Moderate short stature (3rd percentile)
- 7. Moderate school performance problems, with or without "hyperactivity," and/or minor deficiencies in IQ scores

 (to as low as 80)
- 8. Moderate psychosocial burden, with or without therapy
- 3. Speech impediment
- 10. Seizures controlled with medication
- 11. Moderate headaches
- 12. Moderate hearing loss (with or without hearing aid)
- 13. Moderate constipation
- 14. Moderate scoliosis, with or without surgical correction
- 15. Fseudarthrosis with limited consequences

- 16. Other skeletal involvement
- 17. Asymptomatic paraspinal tumor
- 18. Asymptomatic intraorbital optic glioma
- 13. Viseral neurofibromas
- 20. Benigh pheochromocytoma
- 21. Renovascular hypertension
- 22. Precocious puberty
- 23. Serious aggravation with pregnancy
- 24. Other

IV. Severe

- c)1. "Whole person" (multiple, widespread moderate problems)
- 2. Cutaneous neurofibromas with severe cosmetic impact
- 3. Cutaneous neurofibromas with severe functional impact
- 4. Severe grunitus
- 5. Frank mental retardation
- 6. Severe psychosocial burden
- 7. Seizures not controlled with medication
- 8. Severe hearing loss (not correctable)
- 3. Severe scoliosis
- 10. Fseudarthrosis with severe consequences (eg, amputation)

- 11. Symptomatic (ie. invasive paraspinal tumor(s))
- 12. Intracranial, spinal neoplasm
- 18. Symptomatic optical glioma
- 14. Unilateral or bilateral blindness
- 15. Malignant neoplasia (neurofibrosarcoma, leukemia,
 etc)
- 16. Intractable pain
- 17. Cerebrovascular involvement
- 18. Other

From Riccardi, 1982

Appendix B

CRITERIA FOR DIFFERENT LEARNING DISABILITIES

Patterns based on performance on the Wide Range

Achievement Test (WRAT; Jastak & Jastak, 1978)

Reading-spelling disabled

- 1. Full Scale WISC-R IQ'S greater than 80
- 2. URAT reading and spelling percentile scores below 31
- 3. Arithmetic percentile score above 30
- 4. Arithmetic score one-half standard deviation above reading scores

Reading-spelling-arithmetic disabled

- 1. Full Scale WISC-R IQ'S greater than 80
- 2. Feading, spelling, and arithmetic percentile scores below 31
- 3. Fercentile scores average on the three subtests below 26

Spelling-arithmetic disabled

- 1. Full Scale WISC-R IQ'S greater than 80
- 2. Spelling and arithmetic percentile scores below 31
- 3. Reading scores above 39th percentile
- 4. Spelling and arithmetic scores at least one standard deviation below reading scores

Arithmetic disabled

- 1. Full Scale WISC-R IQ'S greater than 80
- 2. Reading and spelling scores above 39
- 3. Arithmetic scores below 31
- 4. Arithmetic scores one standard deviation below reading score

Appendix C

Parent Behavior Inventory

We are interested in learning more about the different experiences poeple have had in their families. We therefore are asking a number of people to report their experiences during childhood.

If you are under sixteen and have lived at home up to this time, answer the questions as they describe what happens there. If you did not grow up with your real mother or father, but someone took the place of that parent in your life, please describe that person.

Read each item on the following pages and circle that answer that most closely describes the way each of your parents acts toward you. BE SURE TO MARK EACH ITEM FOR EACH PARENT.

If you think the item is <u>LIKE</u> your parent, circle L.

If you think the item is SOMEWHAT LIKE your parent, circle $\underline{\mathsf{SL}}$.

If you think the item is <u>NOT LIKE</u> your parent, circle <u>NL</u>.

FORM FOR MOTHER

- Makes me feel better after talking L SL NL over my worries with her.
- 2. Likes to talk to me and be with me L SL NL much of the time.
- Isn't very patient with me.
 L SL NL
- 4. Is easy with me. L SL NL
- Seems to see my good points more L SL NL than my faults.
- 6. Doesn't let me go places because L SL NL something might happen to me.
- 7. Feels hurt when I don't follow L SL NL advice.
- 8. Usually doesn't find out about my L SL NL misbehavior.
- 9. Worries about how I will turn out, L SL NL because she takes anything bad I do seriously.
- 10. Almost always speaks to me with a L SL NL warm and friendly voice.
- 11. Is always thinking of things that L SL NL

will please me.

- 12. Say's I'm a big problem. L SL NL
- 13. Let's me off easy when I do L SL NL something wrong.
- 14. Understands my problems and my L SL NL worries.
- 15. Forgets to help me when I need it. L SL NL
- 16. Thinks I'm not grateful when I don't L SL NL obey.
- 17. Doesn't pay much attention to my L SL NL misbehavior.
- 18. If I break a promise, doesn't trust L SL NL me again for a long time.
- 13. Enjoys talking things over with me. L SL NL
- 20. Gives me a lot of care and attention. L SL NL
- 21. Sometimes wishes she didn't have L SL NL any children.
- 22. Can't say no to anything I want. L SL NL
- 23. Enjoys going on drives, trips, L SL NL or visits with me.
- 24. Forgets to get me things I need. L SL NL
- 25. Feels hurt by the things I do. L SL NL

L SL NL

26. Doesn't insist that I do my homework. 27. Says someday I'll be punished for L SL NL my bad behavior. 28. Smiles at me often. L SL NL L SL NL 29. Often gives up something to get something for me. 30. Is always getting after me. L SL NL L SL NL 31. Excuses my bad conduct. 32. Is able to make me feel better when L SL NL I am upset. 33. Almost always complains about what L SL NL 1 do. 34. Tells me how much she has suffered L SL NL for me. 35. Doesn't check up to see whether I L SL NL have done what she told me. L SL NL 36. Thinks and talks about my misbehavior long after it's over. L SL NL 37. Enjoys daing things with me. L SL NL 38. Makes me feel like the most important person in her life.

- 39. Gets cross and angry about little L SL NL things I do.
- 40. Let's me stay up late if I Keep L SL NL asking.
- 41. Enjoys working with me in the house L SL NL or yard.
- 42. Often blows her top when I bother L SL NL
- 43. Says if I loved her, I'd do what L SL NL she wants me to do.
- 44. Seldom insists that I do anything. L SL NL
- 45. Says that some day I'll be sorry L SL NL that I wasn't better as a child.
- 46. Comforts me when I'm afraid. L SL NL
- 47. Enjoys staying at home with me more L SL NL than going out with friends.
- 48. Doesn't work with me. L SL NL
- 43. Does not insist I obey if I L SL NL complain or protest.
- 50. Cheers me up when I am sad. L SL NL
- 51. Doesn't get me things unless I ask L SL NL over and over again.

- 52. Tells me of all the things she has L SL NL has done for me.
- 53. Does not bother to enforce rules. L SL NL
- 54. Thinks that my misbehavior is very L SL NL serious and will have future consequences.
- 55, Often speaks of the good things I L SL NL do.
- 56. Makes her whole life center about L SL NL her children.
- 57. Doesn't seem to Know what I want or L SL NL need.
- 58. I can talk her out of an order, if I L SL NL complain.
- 59. Has a good time at home with me. L SL NL
- 60. Acts as though I'm in the way. L SL NL
- 61. Says if I really cared for her, I L SL NL would not do things that cause her to worry.
- 62. Lets me get away without doing work L SL NL I had been given to do.
- 63. Says that sooner or later we always L SL NL

pay for bad behavior.

- 64. Seems proud of the things I do. L SL NL
- 65. Spends almost all of her free time L SL NL with her children.
- 66. Tells me to quit "hanging around L SL NL the house" and go somewhere.
- 67. Can be talked into things easily. L SL NL
- 68. Isn't interested in changing me, L SL NL but likes me as I am.
- 63. Makes me feel I'm not loved. L SL NL
- 70. When I don't do as she wants, says L SL NL I'm not grateful for all she has done for me.
- 71. Lets me get away with a lot of L SL NL things.
- 72. Will talk to me again and again L SL NL about anything bad I do.

FORM FOR FATHER

1. Makes me feel better after talking	L	SL	NL
over my worries with him.			
2. Likes to talk to me and be with me	L	SL	NL
much of the time.			
3. Isn't very patient with me.	L	SL	NL
4. Is easy with me.	L	SL	NL.
5. Seems to see my good points more	L	SL	NL
than my faults.			
6. Doesn't let me go places because	L	SL	NL
something might happen to me.			
7. Feels hurt when I don't follow	L	SL	NL
advice.			
8. Usually doesn't find out about my	L	SL	NL
misbehavior.			
9. Warries about how I will turn out,	L	SL	NL
because he takes anything bad I do			
seriously.			
10. Almost always speaks to me with a	L s	SL.	NL
warm and friendly voice.			
11. Is always thinking of things that	L S	SL	NL

will please me.

- 12. Say's I'm a big problem. L SL NL
- 13. Let's me off easy when I do L SL NL something wrong.
- 14. Understands my problems and my L SL NL worries.
- 15. Forgets to help me when I need it. L SL NL
- 16. Thinks I'm not grateful when I don't L SL NL obey.
- 17. Boesn't pay much attention to my L SL NL misbehavior.
- 18. If I break a promise, doesn't trust L SL NL me again for a long time.
- 13. Enjoys talking things over with me. L SL NL
- 20. Gives me a lot of care and attention. L SL NL
- 21. Sometimes wishes he didn't have any L SL NL children.
- 22. Can't say no to anything I want. L SL NL
- 23. Enjoys going on drives, trips, or L SL NL visits with me.
- 24. Forgets to get me things I need. L SL NL
- 25. Feels hurt by the things I do. L SL NL

- 26. Doesn't insist that I do my
 L SL NL
 homework.

 27. Says someday I'll be punished for my L SL NL
 bad behavior.
- 28. Smiles at me often. L SL NL
- 23. Often gives up something to get L SL NL something for me.
- 30. Is always getting after me. L SL NL
- 31. Excuses my bad conduct. L SL NL
- 32. Is able to make me feel better when L SL NL I am upset.
- 33. Almost always complains about what L SL NL I do.
- 34. Tells me how much she has suffered L SL NL for me.
- 35. Doesn't check up to see whether I L SL NL have done what he told me.
- 36. Thinks and talks about my L SL NL misbehavior long after it's over.
- 37. Enjoys doing things with me. L SL NL
- 38. Makes me feel like the most L SL NL important person in his life.

- 33. Gets cross and angry about little L SL NL things I do.
- 40. Let's me stay up late if I Keep L SL NL asking.
- 41. Enjoys working with me in the house L SL NL or yard.
- 42. Often blows his top when I bother L SL NL him.
- 43. Says if I loved him, I'd do what he L SL NL wants me to do.
- 44. Seldom insists that I do anything. L SL NL
- 45. Says that some day I'll be sorry L SL NL that I wasn't better as a child.
- 46. Comforts me when I'm afraid. L SL NL
- 47. Enjoys staying at home with me more L SL NL than going out with friends.
- 43. Doesn't work with me. L SL NL
- 43. Does not insist I obey if I complain L SL NL or protest.
- 50. Cheers me up when I am sad. L SL NL
- 51. Doesn't get me things unless I ask L SL NL over and over again.

- 52. Tells me of all the things he has L SL NL done for me.
- 53. Does not bother to enforce rules. L SL NL
- 54. Thinks that my misbehavior is very L SL NL serious and will have future consequences.
- 55. Often speaks of the good things I L SL NL do.
- 56. Makes his whole life center about L SL NL his children.
- 57. Doesn't seem to Know what I want or L SL NL need.
- 58. I can talk him out of an order, if I L SL NL complain
- 53. Has a good time at home with me. L SL NL
- 60. Acts as though I'm in the way. L SL NL
- 61. Says if I really cared for him, I L SL NL would not do things that cause him to worry.
- 62. Lets me get away without doing work L SL NL I had been given to do.
- 63. Says that sooner or later we always | L SL NL

pay for bad behavior.

- 64. Seems proud of the things I do. L SL NL
- 65. Spends almost all of his free time L SL NL with his children.
- 66. Tells me to quit "hanging around the L SL NL house" and go somewhere.
- 67. Can be talked into things easily. L SL NL
- 68. Isn't interested in changing me, but L SL NL likes me as I am.
- 63. Makes me feel 1'm not loved. L SL NL
- 70. When I don't do as he wants, says L SL NL I'm not grateful for all he has done for me.
- 71. Lets me get away with a lot of L SL NL things.
- 72. Will talk to me again and again L SL NL about anything bad I do.

Appendix D

SCALES AND ITEMS OF THE CHILD'S REPORT OF

PARENTAL BEHAVIOR INVENTORY

Factor 1- Extent of Acceptance

Acceptance

- Makes me feel better after talking over my worries with her.
- 5. Seems to see my good points more than my faults.
- 10. Almost always speaks to me with a warm and friendly voice.
- 14. Understands my problems and my worries.
- 19. Enjoys talking things over with me.
- 23. Enjoys going on drives, trips, or visits with me.
- 28. Smiles at me often.
- 32. Is able to make me feel better when I am upset.
- 37. Enjoys doing things with me.
- 41. Enjoys working with me in the house or yard.
- 46. Comforts me when I'm afraid.
- 50. Cheens me up when I am sad.
- 55. Often speaks of the good things I do.
- 53. Has a good time at home with me.
- 64. Seems proud of the things I do.

68. Isn't interested in changing me, but likes me as I am.

Childcenteredness

- 2. Likes to talk to me and be with me much of the time.
- 11. Is always thinking of things that will please me.
- 20. Gives me alot of care and attention.
- 23. Often gives up something to get something for me.
- 38. Makes me feel like the most important person in her life.
- 47. Enjoys staying at home with me more than going out with friends.
- 56. Makes her whole life center about her children.
- 65. Spends almost all of her free time with her children.

Factor 2-Autonomy

Control Through Guilt

- 7. Feels hurt when I don't follow advice.
- 16. Thirks I'm not grateful when I don't obey.
- 25. Feels hurt by the things I do.
- 34. Tells me how much she has suffered for me.
- 43. Says if I loved her, I'd do what she wants me to do.

- 52. Tells me of all the things she has done for me.
- 61. Says if I really cared for her, I would not do things that cause her to worry.
- 70. When I don't do as she wants, says I'm not grateful for all she has done for me.

Lax Discipline

- 4. Is easy with me.
- 13. Let's me off easy when I do something wrong.
- 22. Can't say no to anything I want.
- 31. Excuses my bad conduct.
- 40. Let's me stay up late if I Keep asking.
- 49. Does not insist I obey if I complain or protest.
- 58. I can talk her out of an order, if Icomplain.
- 67. Can be talked into things easily.

Factor 3- Firmness of Control

Monenforcement

- 8. Usually doesn't find out about my misbehavior.
- 17. Doesn't pay much attention to my misbehavior.
- 26. Dowsh't insist that I do my homework.
- 35. Doesn't check up to see whether I have done what she told me.
- 44. Seld:m insists that I do anything.

- 53. Boes not bother to enforce rules.
- 62. Lets me get away without doing work I had been given to do.
- 71. Lets me get away with a lot of things.

Instilling Persistent Anxiety

- 3. Worries about how I will turn out, because she takes anything bad I do seriously.
- 18. If I break a promise, doesn't trust me again for a long time.
- 27. Says someday I'll be punished for my bad behavior.
- 36. Thinks and talks about my misbehavior long after it's over.
- 45. Says that some day I'll be sorry that I wasn't better as a child.
- 54. Thinks that my misbehavior is very serious and will have future consequences.
- 63. Says that sooner or later we always pay for bad behavior.
- 72. Will talk to me again and again about anything bad I do.

Rejection

Rejection

- 3. Isn't very patient with me.
- 6. Doesn't let me go places because something might happen to me.
- 12. Say's I'm a big problem.
- 15. Forgets to help me when I need it.
- 21. Sometimes wishes she didn't have any children.
- 24. Forgets to get me things I need.
- 30. Is always getting after me.
- 33. Almost always complains about what I do.
- 39. Gets cross and angry about little things I do.
- 42. Often blows her top when I bother her.
- 48. Boesn't work with me.
- 5). Doesn't get me things unless I ask over and over again.
- 57. Doesn't seem to Know what I want or need.
- 68. Acts as though I'm in the way.
- 66. Tells me to quit "hanging around the house" and go somewhere.
- 63. Makes me fee! I'm not loved.

Appendix E

INVENTORY OF ATTITUDES ON FAMILY LIFE

AND CHILDREN--MOTHER'S FORM

Read each of the statements below and rate them as follows:

A a d D
strongly mildly mildly strongly
agree agree disagree disagree

Indicate your opinion by drawing a circle around the "A" if you strongly agree, around the "a" if you mildly agree, around the "d" if you mildly disagree, and around the "D" if you strongly disagree.

There are no right or wrong answers, so answer according to your own opinion. It is very important to the study that all questions be answered. Many of the statements will seem alike but all are necessary to show slight differences of opinion.

- A good mother should shelter her A a d D
 child from life's little
 difficulties.
- a. Children should be taught about A a d D sex as soon as possible.

- 3. People who think they can get along A a d D in marriage without arguments just don't Know the facts.
- 4. Parents should not have to earn the A a d D respect of their children by the
- 5. The women who want lots of parties A a d D seldom make good mothers.
- 6. Most mothers are content to be with A a d D children all the time.
- 7. A child has a right to his own A a d D point of view and ought to be allowed to express it.
- If a parent is wrong she should A a d D
 admit it to her child.
- 9. A child should be taught to avoid A a d D fighting no matter what happens.
- 10. Most mothers can spend all day with A a d D the children and remain calm and even-tempered.
- 11. Parent's who are interested in A a d D hearing about their children's

- parties, dates, and fun help them grow up right.
- 12. A child should learn that he has to A a d D be disappointed sometimes.
- 13. It is very important that young A a d D boys and girls not be allowed to see each other completely undressed.
- 14. If a couple really loves each other A a d D there are very few arguments in their married life.
- 15. Parents should adjust to the A a d D children rather than always expecting the children to adjust to the parents.
- 16. A good mother should develop A a d D
 interests outside the home.
- 17. One of the worst things about A a d D taking care of a home is a woman feels that she can't get out.
- 18. Children should not be allowed to A a d D disagree with their parents, even if they feel their own ideas are

better.

- 13. It's best for the child if he never A a d D gets started wondering whether his mother's views are right.
- 20. A child should be taught to fight A a d D their own battles.
- 21. Children will get on any women's A a d D nerves if she has to be with then all day.
- 22. Children would be happier and A a d D
 better behaved if parents would
 show less interest in their affairs.
- 23. A child should be protected from A a d D
 jobs which might be too tiring or
 too hard for him.
- 24. Sex play is a normal thing in A a d D children.
- 25. Sometimes it's necessary for a wife A a d D to tell off her husband in order to get her rights.
- 26. Children should learn to compromise A a d D and adjust to the demands of their

parents.

- 27. Too many women forget that a A a d D mother's place is in the home.
- 28. Most young mothers don't mind A a d D spending most of their time at home.
- 23. A child's ideas should be seriously A a d D considered in making family decisions.
- 30. A child should be encouraged to A a d D
 look for answers to his questions
 from other people even if the
 answers contradict his parents.
- 31. Children should not be encouraged A a d D
 to box or wrestle because it often
 leads to trouble or injury.
- 32. Raising children is an easy job. A a d D
- 33. If parents would fun with their A a d D children, the children would be more apt to take their advice.
- 34. Children have to face difficult A a d D situations on their own.
- 35. Sex is one of the greatest problems. A a d D

to be contended with in children.

- 36. Almost any problem can be settled A a d D by quietly talking it over.
- 37. There is no reason parents should A a d D have their own way all the time, any more than that children should have their own way all the time.
- 38. A mother can Keep a nice home and A a d D still have plenty of time left over to visit with neighbors and friends.
- 33. One of the bad things about raising A a d D children is that you aren't free enough of the time to do just as you like.
- 40. Children should be discouraged from A a d D telling their parents about it when they feel family rules are unreasonable.
- 41. The child should not question the A a d D thinking of his parents.
- 42. It's quite natural for children to A a d D hit one another.

- 43. Mothers very often feel that they A a d D can't stand their children a moment longer.
- 44. Laughing at children's jokes and A a d D telling children jokes usually fail to make things go more smoothly.
- 45. Children should be Kept away from A a d D

 all hard jobs which might be

 discouraging.
- 46. Children are normally curious about A a d D sex.
- 47. It's natural to have quarrels when A a d D
 two people who both have minds of
 their own get married.
- 43. It is rarely possible to treat a A a d D child as a equal.
- 43. A good mother will find enough A a d D social life within the family.
- 50. Most young mothers are pretty A a d D content with home life.
- 51. When a child is in trouble he ought A a d B to Know he won't be punished for

talking about it with his parents.

- 52. A good mather can tolerate critism A a d B of herself, even with the children are around.
- 53. Most parents prefer a quiet child A a d D to a "scrappy" one.
- 54. A mother should Keep control of her A a d D temper even when children are demanding.
- 55. When you do things together, A a d D children feel close to you and can talk.

INVENTORY OF ATTITUDES ON FAMILY LIFE AND CHILDREN--FATHER'S FORM

Read each of the statements below and rate them as follows:

A a d D
strongly mildly mildly strongly
agree agree disagree disagree

Indicate your opinion by drawing a circle around the "A" if you strongly agree, around the "a" if you mildly agree, around the "d" if you mildly disagree, and around the "D" if you strongly disagree.

There are no right or wrong answers, so answer according to your own opinion. It is very important to the study that all questions be answered. Many of the statements will seem alike but all are necessary to show slight differences of opinion.

- A good father should shelter his A a d D
 child from life's little
 difficulties.
- 2. Children should be taught about sex A a d D
 as soon as possible.
- 3. Feople who think they can get along A a d D in marriage without arguments just

don't Know the facts.

- 4. Parents should not have to earn the A a d D respect of their children by the way they act.
- 5. A man can't do a father's job and A a d D have an active social life too.
- 6. Most fathers are content to be with A a d D children in their spare time.
- 7. A child has a right to his own A a d D point of view and ought to be allowed to express it.
- 3. If a parent is wrong he should A a d D admit it to his child.
- 3. A child should be taught to avoid A a d D fighting no matter what happens.
- 10. Most fathers could spend all day A a d D with the children and remain calm and even-tempered.
- 11. Parent's who are interested in A a d D hearing about their children's parties, dates, and fun help them grow up right.

- 12. A child should learn that he has to A a d D be disappointed sometimes.
- 13. It is very important that young A a d D boys and girls not be allowed to see each other completely undressed.
- 14. If a couple really loves each other A a d D there are very few arguments in their married life.
- 15. Parents should adjust to the A a d D children rather than always expecting the children to adjust to the parents.
- 18. A good father should develop A a d D interests outside the job and home.
- 17. Settling down to family life is A a d D hard for a man because it means giving up so many other things.
- 18. Children should not be allowed to A a d D disagree with their parents, even if they feel their own ideas are better.
- 13. It's best for the child if he never A a d D

gets started wondering whether his father's views are right.

- 20. A child should be taught to fight A a d D their own battles.
- 21. It's no wonder men reach the A a d D boiling point when they come home and run immediatly into family problems.
- 22. Children would be happier and A a d D better behaved if parents would show less interest in their affairs.
- 23. A child should be protected from A a d D
 jobs which might be too tiring or
 too hard for him.
- 24. Sex play is a normal thing in A a d D children.
- 25. Sometimes it's necessary for a A a d D husband to tell off his wife in order to get his rights.
- 26. Children should learn to compromise A a d D and adjust to the demands of their parents.

- 27. Too many men forget that a father's A a d D place is in the home.
- 28. Most fathers don't mind spending A a d D most of their time at home.
- 23. A child's ideas should be seriously A a d D considered in making family decisions.
- 30. A child should be encouraged to A a d D
 look for answers to his questions
 from other people even if the
 answers contradict his parents.
- 31. Children should not be encouraged A a d D
 to box or wrestle because it often
 leads to trouble or injury.
- 32. Raising children is an easy job. A a d D
- 33. If parents would fun with their A a d D children, the chidren would be more apt to take their advice.
- 34. Children have to face difficult A a d D situations on their own.
- 35. Sex is one of the greatest problems A a d B to be contended with in children.

- 36. Almost any problem can be settled A a d D by quietly talking it over.
- 37. There is no reason parents should A a d D have their own way all the time, any more than that children should have their own way all the time.
- 38. A father can be a family man and A a d D still have plenty of time left over to visit with neighbors and friends.
- 39. One of the bad things about raising A a d D children is that you aren't free enough of the time to do just as you like.
- 40. Children should be discouraged from A a d D telling their parents about it when they feel family rules are unreasonable.
- 41. The child should not question the A a d D thinking of his parents.
- 42. It's quite natural for children to A a d D hit one another.
- 43. There are times when a father feels A a d D

that he can't stand his family a moment longer.

- 44. Laughing at children's jokes and A a d D
 telling children jokes usually fail
 to make things go more smoothly.
- 45. Children should be Kept away from A a d D all hard jobs which might be discouraging.
- 45. Children are normally curious about A a d D sex.
- 47. It's natural to have quarrels when A a d D
 two people who both have minds of
 their own get married.
- 48. It is rarely possible to treat a A a d D child as a equal.
- 49. A good father will find enough A a d D social life within the family.
- 50. Most young fathers are pretty A a d D content with home life.
- 51. When a child is in trouble he ought A a d D to Know he won't be punished for talking about it with his parents.

- 52. A good father can tolerate critism A a d D of himself, even with the children are around.
- 53. Most parents prefer a quiet child A a d D
 to a "scrappy" one.
- 54. A father should Keep control of his A a d D temper even when children are demanding.
- 55. When you do things together, A a d D children feel close to you and can talk easier.

Appendix F

SCALES OF MODIFIED PARENTAL ATTITUDE

RESEARCH INSTRUMENT

FACTOR I- Authoritarian Control

Fostering Dependency

- (+) 1. A good mother should shelter her child from life's little difficulties.
- (-) 12. A child should learn that he has to be disappointed sometimes.
- (+) 23. A child should be protected from jobs which might be too tiring or too hard for him.
- (-) 34. Children have to face difficult situations on their own.
- (+) 45. Children should be Kept away from all hard jobs which might be discouraging.

Suppresion of Sexuality

- (-) 2. Children should be taught about sex as soon as possible.
- (+) 13. It is very important that young boys and girls not be allowed to see each other completely undressed.
- (-) 24. Sex play is a normal thing in children.

- (+) 35. Sex is one of the greatest problems to be contended with in children.
- (-) 48. Children are normally curious about sex.

Setlusion of the Mother

- (+) 5. The women who want lots of parties seldom make good mothers.
- (-) 16. A good mother should develop interests outside the home.
- (+) 27. Too many women forget that a mother's place is in the home.
- (-) 38. A mother can Keep a nice home and still have plenty of time left over to visit with neighbors and friends.
- (+) 49. A good mother will find enough social life within the family.

Excluding Outside Influences

- (-) 8. If a parent is wrong he should admit it to his child.
- (+) 13. It's best for the child if he never gets
 started wondering whether his mother's views
 are right.
- (-) 30. A child should be encouraged to look for

- even if the answers contradict his parents.
- (+) 41. The child should not question the thinking of his parents.
- (-) 52. A good mother can tolerate critism of herself, even with the children are around.

Suppression of Aggression

- (+) 3. A child should be taught to avoid fighting no matter what happens.
- (-) 20. A child should be taught to fight their own battles.
- (+) 31. Children should not be encouraged to box or wrestle because it often leads to trouble or injury.
- (-) 42. It's quite natural for children to hit one another.
- (+) 53. Most parents prefer a quiet child to a "scrappy" one.

Factor II- Hostility & Rejection

Marital Conflict

(+) 3. Feople who think they can get along in marriage without arguments just don't Know the facts.

- (-) 14. If a couple really loves each other there are very few arguments in their married life.
- (+) 25. Sometimes it's necessary for a wife to tell off her husband in order to get her rights.
- (-) 35. Almost any problem can be settled by quietly talking it over.
- (+) 47. It's natural to have quarrels when two people who both have minds of their own get married.

Rejection of Homemaking Role

- (-) 6. Most mothers are content to be with children all the time.
- (+) 17. One of the worst things about taking care of a home is a woman feels that she can't get out.
- (-) 28. Most young mothers don't mind spending most of their time at home.
- (+) 33. One of the bad things about raising children is that you aren't free enough of the time to do just as you like.
- (-) 50. Most young mothers are pretty content with home life.

<u>Irratibility</u>

(-) 18. Most mothers can spend all day with the

children and remain calm and even-tempered.

- (+) 21. Children will get on any women's nerves if she has to be with them all day.
- (-) 32. Raising children is and easy job.
- (+) 43. Mothers very often feel that they can't stand their children a moment longer.
- (-) 54. A mother should Keep control of her temper even when children are demanding.

Factor III- Democratic Attitudes

Equalitariasm

- (-) 4. Parents should not have to earn the respect of their children by the way they act.
- (+) 15. Parents should adjust to the children rather than always expecting the children to adjust to the parents.
- (-) 26. Children should learn to compromise and adjust to the demands of their parents.
- (+) 37. There is no reason parents should have their own way all the time, any more than that children should have their own way all the time.
- (-) 48. It is rarely possible to treat a child as a equal.

Encouraging Verbalization

- (+) 7. A child has a right to his own point of view and ought to be allowed to express it.
- (-) 18. Children should not be allowed to disagree with their parents, even if they feel their own ideas are better.
- (+) 29. A child's ideas should be seriously considered in making family decisions.
- (-) 40. Children should be discouraged from telling their parents about it when they feel family rules are unreasonable.
- (+) 51. When a child is in trouble he ought to Know he won't be punished for talking about it with his parents.

Comanadeship and Sharing

- (+) 11. Farent's who are interested in hearing about their children's parties, dates, and fun help them grow up right.
- (-) 22. Children would be happier and better behaved if parents would show less interest in their affairs.
- (+) 33. If parents would fun with their children, the

children would be more apt to take their advice.

- (-) 44. Laughing at children's jokes and telling children jokes usually fail to make things go more smoothly.
- (+) 55. When you do things together, children feel close to you and can talk.

ticte. Flus signs and minus signs indicate direction that item is scored.