To the Graduate Council:

I am submitting herewith a dissertation written by John L. Hawley, Jr. entitled "A Descriptive Study of Adolescent Home-Reared Down's Syndrome Children and Their Families in East Tennessee." I recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.

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3

A DESCRIPTIVE STUDY OF ADOLESCENT HOME-REARED DOWN'S SYNDROME CHILDREN AND THEIR FAMILIES IN EAST TENNESSEE

A Dissertation

Presented for the

Doctor of Philosophy

Degree

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John L. Hawley, Jr.

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ABSTRACT

The purpose of this study was to obtain useful information on adolescent home-reared Down's Syndrome (DS) children and their families. The subjects for this study were an exhaustive sample of the DS children, ages 12 through 16, and their families who were or had been patients at the Birth Defects Evaluation Center of the University of Tennessee Center for the Health Sciences, Knoxville.

The study was descriptive in nature and involved the collection and descriptive reporting of data as it occurs on the DS children in their natural environments. The families and children were interviewed and observed in their homes to obtain information on the adaptive functioning of the individual DS child and to obtain information on the programs, activities, interactions, and family and community involvement of the DS child and his/her respective family. Specific behavioral information concerning the adaptive functioning of the DS children was obtained by the administration of the AAMD Adaptive Behavior Scale for each child.

The results were reported in a descriptive manner and synopses of the families' experiences and the DS children's adaptive functioning were presented. The synopses provide useful normative data that can be applied by families of DS children and professionals who work with DS children and their families. The synopsis of the children's adaptive functioning is particularly useful as a guide for parents to indicate what specific adaptive behaviors and skills their DS child may be able to master.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

FIGURES Page

CHAPTER I

INTRODUCTION

A. AREA OF THE STUDY

Down's Syndrome (DS) is a genetically determined disorder that affects physical, intellectual and social functioning. The clinical manifestations of DS usually allow for a diagnosis at birth and developmental delays are often apparent within the first few months of life. DS results in mild to severe mental retardation, with most DS individuals functioning in the moderate range of mental retardation. While some DS children are institutionalized at birth, more and more families are selecting to rear their children at home. It is generally agreed that home-rearing is more beneficial for the child than institutionalization, and typically the home-reared child functions better overall than his institutionalized counterpart.

Despite recent trends in mental health and mental retardation for "mainstreaming" and "de-institutionalization", there is a paucity of research in the literature on home-reared DS children and their families. The need for research in this area is clear. Parents who are raising their DS children in the home are asking professionals questions such as what can we expect from our child, what will he/she be able to do, what programs will be useful for our child, what can we do to improve his/her functioning, and what effect will he/she have on the rest of the family. Due to the lack of research,

professionals often answer these questions with the prevalent but often inaccurate folklore or with a well intentioned guess that nonetheless can prove to be counterproductive.

The purpose of this study was to gain useful information on home-reared DS children and their families. Specifically, the study was concerned with the social and adaptive functioning of adolescent DS children, the activities and programs they have been involved in, and the relevant activities and interactions of the families of these DS children.

Adolescence was targeted for study because it is a time when the DS children's social and adaptive behavior are most fully developed, they have been involved in the greatest number of different activities and programs, and the families have had the most experience with them all prior to the DS children reaching adulthood when some of them may leave their homes and families for other placements.

The level of social and adaptive functioning of a retarded individual largely determines how well that person is able to function in society; the more advanced are the social and adaptive behaviors, the more the person is capable of appropriate, rewarding, autonomous living. While DS individuals are a relatively homogeneous group in that they manifest a specific genetic disorder resulting in characteristic attributes, they seem to display variation in their social and adaptive skills; there are common limitations but there also are individual differences. This study attempted to

elucidate and specify the level of social and adaptive functioning of home-reared adolescent DS children and note common abilities and skills as well as differences.

Families of DS children approach the special demands of a retarded child in different ways and they often have little guidance as to how to raise their child and what activities and programs may be beneficial for their child or themselves. Some families seem to be actively and aggressively involved in their child's development and training and others seem less so. Those families also seem to differ in their overall involvement and visibility in the community. This study attempted to elucidate and specify what activities and programs that home-reared adolescent DS children have been involved in, how involved the parents have been in the training and development of their children, and the extent of the families involvement and visibility in their communities. The study also attempted to note any relationship between the level of social and adaptive functioning of the children and the activities, interactions, and involvement of the families.

In short, the objectives of this study were:

1. To obtain information on the social and adaptive functioning of home-reared adolescent DS children.
2. To obtain information on the programs, activities, interactions, and involvement of home-reared adolescent DS children and their families.
3. To note any relationship between the level of social and adaptive functioning of home-reared adolescent DS

children and the activities, interactions, and involvement of the families.

B. THE DESCRIPTIVE APPROACH

The approach to this study was essentially "non-experimental", in the traditional sense of psychological research. There were no elaborate and sophisticated experimental/statistic designs, no formal hypotheses testing, no dependent and independent variables, and no control groups. The approach to the study of these home-reared adolescent DS children and their families was "descriptive" instead. The need and purpose of this descriptive approach to psychological research is, perhaps, best described by Roger Barker (1968) in a discussion of his ecological psychology:

> Psychology has been predominately an experimental science. The first psychologists were experimenters who worked in laboratories. Even clinical and industrial psychologists have, in their research, usually worked as experimenters, arranging and varying the conditions of behavior in order to test hypotheses and hunches. The descriptive natural history, ecological phase of investigation has had a minor place in psychology, and this has seriously limited the science. Experimental procedures have revealed something about the laws of behavior, but they have not disclosed, nor can they disclose, how the variables of these laws are distributed across the types and conditions of men. Psychology knows how people behave under the conditions of experiments and clinical procedures, but it knows little about the distribution of these and other conditions, and of their behavior resultants, outside of laboratories and clinics.

This study was primarily concerned with gathering information on the social and adaptive functioning of DS children, and the

activities and interactions of these children and their families. As such, traditional experimental methods were determined to be of less value than description and report of naturally occuring behavior. Manipulation of events and conditions may have yielded more scientifically pure and exact data, but it would not have answered the question of what DS children and their families do in their everyday lives in their everyday environments. Clearly, the best way to learn about DS children and their families is simply to look at and talk with DS children and their families. These families have had a wealth of experiences with DS children and this is useful information that can be tapped and added to the body of knowledge of the science of psychology. The imposition of "scientific method" can not improve upon this direct natural experience.

Verplanck (1970) comments on the necessity for descriptive research in psychology:

> We [Psychology] have tried . . . to bypass the critical first stage in the development of every science,--the period of observation and description. . . . . .
>
> It is about time more of us started on the straightforward job of developing a descriptive methodology. The job of recognizing that observing and reporting upon the functioning of an individual, of individuals in groups, of groups, and of social method constitute research and yield scientific data and statements. . . . . .
>
> Observational and descriptive research is not solely "acceptable,"--it is indispensable.

The purpose of this study was not to formally test hypotheses or to assess the effects of imposed conditions, but rather to observe and describe, and thus learn more about the functioning of DS children and their families in their natural environments. This research was an attempt to report on data as they naturally present themselves--the "critical first-stage" that Verplanck speaks of. Like a large portion of the scientific literature of psychology, basic descriptive information on DS children and their families is seriously lacking and sorely needed.

In short, from both a research perspective and a practical perspective, a descriptive study of adolescent home-reared DS children and their families is both necessary and useful. The scientific literature is lacking in basic, descriptive information--the "critical first-step"--on what DS children can do and what goes on in their families. There is a need to fill this research void, not with elaborate experiments but with the collection and classification of naturally occuring data that can lead to a basic foundation of information. This information will not only add to the body of knowledge of the science of psychology, but will also prove useful to professionals who work with DS children and their families. The intent of the present study was to observe, describe, and report on the functioning of DS children and their families, an area of research that is lacking and needed in the science of psychology.

CHAPTER II

REVIEW OF THE LITERATURE

Down's Syndrome (DS) is a genetically determined disorder that affects physical, intellectual and social functioning. Polani (1976) speculated that DS has always existed in the human species, and cited evidence of a skull of a DS child found during excavation of a ninth century monastery. Zellweger (1968) described a 1618 painting by the artist Jacob Jordaens that shows a middle-aged woman holding a child with distinctive DS features. Beidleman (1945) reported that in the early 1800's the French physician Sequin described features of "idiocy" that later would be subsumed under DS.

It was not until 1866 when the British physician John Langdon Haydon Down wrote his three page hospital report "Observations on an ethnic classification of idiots" that DS--earlier called mongolism, a term that would not fall into disuse until the 1960's--became a recognized clinical entity. In a discussion of Down's work, Howard-Jones (1979) stated that Down's intention was to construct a more satisfactory classification of "feeble-mindedness" and thus proposed a "natural system" achieved by "arranging them around various ethnic standards." Howard-Jones reported that Down devoted the bulk of his report to a description of the "Mongolian type of idiocy" and attributed tuberculosis in the parents as the cause of this entity.

Over the years since Down's report, there have been a number of explanations regarding the cause of DS. Polani (1976) noted that early researchers found a relationship between maternal age and incidence of DS and thus concluded that DS was the result of "wearing out or aging of the womb." Beidleman (1945) discussed various theories of etiology and noted that tuberculosis, alcoholism, syphilis, mental stress, defective sperm, increased amniotic pressure, and chemical contraceptive agents were all proposed as causes of DS. While genetic explanations of DS had been suggested, it was not until 1959 that the French geneticist Lejeune identified the chromosomal aberration responsible for DS (Lejeune, 1963).

DS is the result of trisomy of chromosome 21 (Polani, 1976; Heller, 1969). Whereas normally human beings have one pair each of 23 chromosomes, in DS there is an additional chromosome 21 resulting in 3 (a "trisomy 21") rather than the normal pair of chromosome 21. There are three subtypes of DS: primary (or standard), translocation, and mosaicism. Primary (or standard) trisomy 21 is the most common subtype of DS and it is estimated that up to 97% of DS individuals are of this type. Primary trisomy 21 individuals have an extra chromosome 21 and their total chromosome count is 47 rather than 46. Translocation trisomy 21 is rare and it is estimated that less than 3% of DS individuals are of this type. In translocation trisomy, the extra chromosome 21 is attached or "translocated" onto another chromosome resulting in a trisomy 21, but only 46 total chromosomes. Mosaicism is very rare and it is estimated that about 1% of DS individuals are of this type.

Mosaicism results from faulty cell division of the developing embryo, after the initial division of the zygote, so that some cells have the normal 46 chromosomes and some have 47 chromosomes with trisomy 21. All three subtypes display the clinical manifestations of DS and the particular subtype can only be determined by chromosomal analysis.

A. THE CHARACTERISTIC BEHAVIORS AND LIMITATIONS OF DS CHILDREN

DS is a genetically determined disorder that is not uncommon. Estimates of incidence are typically about 1 per 780 live births (Zarfas & Wolf, 1979) and the percentage of DS among all mental retardates is about 17% (Heller, 1969). Despite their frequency and the definite etiology of DS, there have been relatively few studies in the literature concerning the characteristic behaviors and limitations of DS children. Some of the folklore, much of it of doubtful validity, concerning the abilities of DS children still persists in informally written "guides for parents," but surprisingly little systematic, thorough work has been done on DS children.

DS affects the intellectual, physical, and social functioning of children with this disorder. The clear genetic etiology results in a fair amount of commonality of characteristic behaviors and limitations. Since the majority (97%) of DS children are primary trisomy 21 subtypes, most investigators study this population.

Intellectual Development, Limitations and Behaviors

The rate of intellectual development of DS individuals is slower and the level of intellectual functioning attained is not as high for DS individuals as for their normal counterparts. Ross (1961) in a cross-sectional study of 319 DS individuals ages 1 to 66 established a mental growth curve for DS and compared it to a normal growth curve. He observed that mental age for DS individuals, while lower than the corresponding attained age for normals, "increases relatively rapidly for the first 15 years and then more slowly at least between 15 and 40." He concluded that the mental growth curve for DS individuals is essentially the same shape as a normal mental growth curve but only about 25% as high at each chronological age. In a longitudinal study of DS infants, Dameron (1963) found that by 6 months of age mental retardation is evident, and that there is "a trend of increasing deviation from normals at later ages." Dicks-Mireaux (1966) in a longitudinal study concured with Dameron that DS children show "a gradual and steady discrepancy from normal development with increasing age" but observed that intellectual development for DS infants is already below average at 3 months of age. She further observed that the rate of development for DS infants is faster between the ages of 3 and 9 months than between 9 and 18 months. In a similar study, this time with normal controls, Dicks-Mireaux (1972) again concluded that DS infants are below average at 3 months and show a slower rate of mental development than normals. She further asserted that the DS infants'

slower rate of mental development shows progressive deterioration. Thus, not only do DS individuals develop mentally at a slower rate, there is a continual leveling off of the rate of mental development. As the DS individual increases in age, there is a decrease in the level of intellectual functioning when compared with normal development. In short, as age goes up, IQ goes down.

Share et. al. (1963) addressed this issue of the seeming regression in development for DS children. In a longitudinal study they noted the slower rate of mental development and the decreasing IQ's of DS children from 2 months to 60 months of age. They observed that while IQ's decreased with age there was still definite, steady mental development, albeit not at the rate of normals. They concluded that this apparent progressive retardation is an artifact of the IQ formula which is largely the relationship between maturity age and chronological age. Silverstein (1966) in a cross-sectional study of 256 DS individuals ages 4 years to 40 years proposed a "mongoloid quotient" as a substitute for the misleading IQ that appears to decrease with age. He found that by using a logarithmic derivation of chronological age and a mental age estimate, a more accurate appraisal of the mental development of DS individuals can be obtained. The "mongoloid quotient" circumvents the appearance of declining mental development of DS individuals when compared to normal development.

While mental retardation is a characteristic of DS, there is some variation as to the level of intellectual functioning that is achieved. Dundson et. al. (1960), in an attempt to establish the

upper limit of intelligence, studied 44 DS individuals ages 5½ to 18½ years old. These 44 subjects were considered to be the highest functioning of an original sample of 390 DS individuals by virtue of their being assessed educable and subsequently placed in schools. Less than 10% of these high functioning DS individuals had IQ's above 55, with the highest IQ being 68. The authors concluded by estimating that only 1-2% of the DS population have IQ's above 55 and by suggesting that an IQ in the region of 70 represents the upper limit of intelligence for DS. Kousseff (1978) presented a case study of a DS girl (where chromosomal analysis confirmed the diagnosis of trisomy 21) who apparently demonstrated low average intelligence. Formal psychological testing with different instruments over several years placed this girl's IQ from 69 to 83. Thus, at least in isolated cases, the upper limit of intellectual functioning for DS individuals can be as high as the low average range. Typically, however, intellectual functioning is considerably lower.

There is some disagreement as to the effect of the intellectual and educational level of parents on the intellectual functioning of their DS children. Fraser and Sadovnick (1976) correlated the IQ's of both institutionalized and home-reared DS children with the IQ's of their parents and siblings. They found that home-reared DS children's IQ's correlate significantly with their parents and siblings while the IQ's of institutionalized DS children do not display this familiar relationship. While the authors noted that the relationship between home-reared DS children's IQ's and the IQ's of parents and siblings is the same as for normal families, they do not speculate as

to genetic or environmental factors. Clements et. al. (1978) examined the relationship between DS children's IQ and their parents' educational level. They found that "a small positive relationship exists between the number of years of formal education of parents and the IQ's of their DS children." The authors suggested that genetic and/or environmental factors could account for this relationship but did not speculate further. Bennett et. al. (1979) also studied the relationship of DS children's IQ with their parents' educational level. They found "no correlation or trend toward higher (for age) IQ scores in those children whose parents had higher educational attainments." The authors further suggested that children who experience early continuous stimulation programs also have higher IQ's. They conclude that, "measurable intelligence in DS seems to be influenced by a complex interaction of genetic and environmental factors and not reliably predicted by parental intellectual status alone."

Physical Development, Limitations and Behavior

As DS is a genetically determined disorder, there are associated characteristic physical features and limitations. Breg (1977) in a comprehensive review discussed the physical stigmata of DS. He noted that DS children are typically of small stature with a mean height and weight 2 to 4 standard deviations below normal. They tend to have small skulls with prominent foreheads and oblique palpebral fissures ("slanting eyes"). They usually have short,

narrow hard palates and manifest dental irregularities. Their extremities are short, with the fifth digit curving inward and they often have a single transverse palmar crease ("simian line"). While very young, DS children manifest muscular hypotonia and later still typically display hyperflexibility of joints.

Not all DS children manifest the same physical stigmata, and there is variation in the severity of the different stigmata. Thus some DS children can appear to manifest more signs of DS than others. Baumeister and Williams (1967) examined the relationship of physical stigmata to intellectual functioning in DS. While citing earlier methodologically flawed studies as well, the authors concluded that "the evidence regarding a relationship between IQ and number of stigmata is equivocal." A greater number of physical stigmata of DS does not necessarily indicate more severe mental retardation.

In addition to physical appearance DS children are affected by a number of other physical limitations. Breg (1977) noted that DS children have a marked increase in the frequency of congenital heart defects and congenital abnormalities of the gastrointestinal tract. They have a susceptability to upper respiratory infections and infections in general. The incidence of leukemia is also greater in DS children than in the general population.

Other specific physical limitations of DS children have been mentioned by researchers. Clausen (1968) observed that DS children are more impaired in visual and auditory acuity than their normal counterparts. He also noted that DS children seem to be

slower in perceiving stimuli than normals. Pesch et. al. (1978) reported that there is a high incidence of visual defects among DS children including Brushfield spots nystagmus (rapid involuntary eye oscillation) and pathological myopia. Evans (1974) found that DS children have a very high incidence of significant hearing loss. He also noted that DS children, particularly boys, have a high incidence of disfluent speech.

Several researchers have speculated that a motor disability accounts for specific deficits in DS. Greenwald and Leonard (1979) found that DS children rely more heavily on hand gestures in their communication than their normal counterparts. The authors suggested that type of communication may be related to the level of sensorimotor development, which lags behind in DS. Dodd (1975) found that DS children perform worse on a word reproduction task than their intellectually matched normal counterparts. She hypothesized that this articulatory deficit in DS children "is part of a general motor disability due to a difficulty in preprogramming sequences of movements." In essence DS children have difficulty using learned sequences of articulation movements and can not easily construct the necessary sounds to produce words. Frith and Frith (1974) produced similar results for motor tasks. They observed that DS children unlike normals, did not improve on a motor tracking task after rest and were abnormally slow on a tapping task. The authors speculate that these deficits in DS children are the result of the difficulty "in using long term motor programs" and

the dependence instead "on simple feedback processes to perform motor tasks."

Social Development, Limitations, and Behaviors

DS results in retardation of social functioning as well as intellectual functioning. Griffiths (1976) noted that DS children have delays in motor development, sensory development, language, and emotional and social development. She mentioned, however, that the DS children's social adaptibility "may mask their lack of attainment of other skills." In this regard, there is some evidence to suggest that DS children's social functioning may be higher than their intellectual functioning. Cornwell and Birch (1969) found that IQ in DS children decreased, while a measure of social functioning "did not decline as systematically" with age. They suggest that there is a greater correspondence of social age to chronological age than there is to mental age to chronological age in DS children. They also observe that "there is both a developmental lag and an arrest of certain psychological and social capacities" in DS children.

Melyn and White (1973) collected developmental data over a period of 20 years on 612 DS children and subsequently produced developmental norms for home-reared DS children. Their norms are limited to a few gross motor skills, toilet training, and speech milestones, but represent one of the very few attempts at normative data for DS children. Of particular importance they established that DS boys walk unassisted at 26 months while girls walk earlier at 23 months, they both are toilet trained at 35 months, boys speak

their first word at 27 months while girls are at 22 months, and they both speak their first sentence at 52 months.

It is often stated that institutionalized DS individuals do not function as well socially as those that remain in their homes. Menolascino (1974) investigated the social behavior of 72 older DS individuals ages 25 to 45 years old. He found 75% could walk freely and unassisted, 79% could feed themselves completely, 64% could dress and undress themselves with only minor help, a large percentage could adequately complete personal grooming such as washing, brushing teeth, etc., and 66% could toilet themselves as well as an average normal adult. Ross (1971) suggested that mental age is a better indicator of the level of social functioning than is chronological age or years of training for institutionalized DS individuals. In a study of 187 institutionalized DS individuals ages 5 to 50 years old he found a higher correlation between mental age and self help skills than chronological age and self help skills. Thus, regardless of chronological age there is a definite relationship between mental abilities and social functioning.

Social functioning, other than self help skills, is affected by DS. In a longitudinal study of 14 DS infants Cichetti and Sroufe (1976) found that affective development tended to parallel cognitive development. The authors noted affective expression and development is appropriate and consistent with cognitive and motor development and delays for DS infants and the authors suggested that this is evidence of "the organized nature of retarded development."

An indication of the social functioning of DS children in the classroom was given by Blessing (1959). In a survey of 23 teachers of trainable retardates the author had teachers rate 83 DS children. The satisfactory aspects most frequently mentioned were: amenable, good-natured; gay, happy, cheerful; and obediant, docile. The satisfactory aspects least frequently mentioned were: good communication; and special talents in music, art. The problems most frequently mentioned were: short attention span; poor communication; and stubborn. The problems least frequently mentioned were: self, egotistical; perseverates; and hyperactive. The teachers reported that the most satisfying aspects of working with DS children were their "warm, happy, good-natured sense of humour" and that they were "affectionate, lovable and demonstrative on impulse."

Another indication of the social functioning of DS children in a class or group setting was offered by Schlottmann and Anderson's (1973, 1975) investigations. They found that DS boys tend to be more greatly influenced by the sex of the individual that they are interacting with socially than DS girls. They also found that DS girls tend to be more sedentary in their play activities than DS boys. Further they observed that DS boys tend to be more sociable and gregarious than their nonDS-retarded counterparts and thus "support the stereotypic conception of mongoloids (DS)."

In regards to the "stereotypic conception" of DS children, several researchers have tested out the accuracy of the stereotype concerning the social functioning of DS children. Brink and

Grundlingh (1976) compared the performance of DS children to nonDS-retarded children on two projective techniques. They found that the DS children had a better self concept and were more affectionate and cooperative in keeping with "the traditional stereotype of the person with DS." Silverstein et. al. (1979) examined whether DS individuals "are outstanding in their mimicry" as a popular stereotype suggests. In comparing DS individuals with subjects matched for sex, age, and IQ they found no difference in the groups' verbal and nonverbal imitative behavior. The stereotype of DS individuals being great mimics and imitators is not supported. Peters (1978) presented three separate case studies to refute the stereotype that DS individuals do not show sexually motivated behavior. The author described three adolescent DS males, institutionalized and home-reared, who have had long histories of frequent sexual behavior. He suggested that sexual behavior for retardates is normal and that "the stereotype of DS children as little angels who never do 'such nasty things' often sets up an unrealistic attitude of the parents in the face of basically normal sexual behavior."

B. PROGRAMS FOR DS CHILDREN

Given the prevalence of the disorder, surprisingly few programs for DS children have been reported in the literature. Of those that are published, few report results concerning the program affectiveness. Programs for DS children can be loosely categorized as institutional, parent education, early stimulation, and specific language and academic skills programs.

Institutional Programs

One type of comprehensive program for DS children is residential placement or institutionalization. Residential placement does not necessarily mean that a child will be placed in a stereotypic bleak, spartan institution that offers only custodial care. While there is little doubt that such places still exist, there have been several residential programs reported in the literature that are refreshingly different from the stereotype of an institution for the mentally retarded.

Kugel (1970) described an experimental residential program that "provided three ingredients generally lacking in an institutional setting: a homelike atmosphere, enough staff to allow each child to be assigned a 'substitute mother', and continuous stimulating and physically strengthening experiences for each child." The author conducted an 18 month pilot study of 7 DS children ages 4 to 17 months. While he did not report empirical results, Kugel asserted that this radically enriched institutional program allowed the children to make greater gains than they would have had they been in a traditional institutional setting.

Aronson and Fallstrom (1977) described a program where 16 DS children ages 2 to 6 years received special training in "1) sensory functions 2) natural body functions 3) mental endowment functions 4) motor functions 5) memory functions 6) emotional functions 7) social functions 8) energy functions." This training was in addition to the regular institutional program and was conducted twice weekly in individual and group sessions. The authors reported that the

special training program children showed a greater increase in mental age than the controls who had only the regular institutional program.

Stedman and Eichorn (1964) described an enriched institutional setting where infants were individually held for feeding, placed no more than two to a room, had access to a brightly decorated nursery with a variety of toys and where the adult--child ratio was 1 to 5. Despite the enriched environment, the authors reported that the institutionalized DS infants and children lagged far behind their home-reared counterparts in a number of measures of growth and development.

Stimson et. al. (1968) examined the effects of early institutionalization on growth and development of DS children. Not surprisingly they found large differences between home-reared and institutionalized DS children. While identifying the adverse effects of institutionalization, the authors acknowledged that there are circumstances where institutionalization is the only option. They described a program where a DS child is accepted as a guest to an institution for a short period of time, rather than for permanent placement, when the child's presence in the home is contraindicated due to health or family discord.

Parent Education

Several programs for DS children are geared not to the child but to the parent. Often this involves a group approach in either

parent support or parent education. Murphy et. al. (1973) described a parents support group for parents of DS children that allowed the expression of common concerns and the sharing of information. Atwood (1979) described a time limited 10 week workshop for parents of DS children conducted by a multi-disciplinary team of professionals. Topics included: the child at school, communication and the development of language, practical help with delayed language, frustration and boredom, difficult behavior, initiative and independence, and dental care.

Sinson (1978) reported on a group for parents of DS children. Like Atwood's group this group was to be time-limited and conducted by an interdisciplinary team. The original intention was for the formal group meetings to be replaced by several informal parent self-help groups. The author reports that the parents found the time-limited group so helpful that they elected to stay together as one group and formed a quasi-society for DS children.

In parent groups, parents of DS children are often instructed in specific techniques to use with their children. Gath (1979) commented on parents serving as therapists and suggested that the DS child, the parent, and the family all seem to benefit from this approach. Several researchers have reported results of parents being educated in particular techniques. Frederick et. al. (1971) described a program where parents of DS children were educated in behavior modification principles and techniques. The authors noted that not only were the techniques subsequently administered by the parents successful for the DS children but were useful for their

normal siblings as well. Cheseldine and McConkey (1979) described a program where parents of DS children were educated in regards to their children's language development. Following the parent education program, the parents were able to increase their DS children's expressive language. The authors noted that education concerning general principles without accompanying specific technique, was sufficient to affect change.

Early Stimulation Programs

A number of programs for DS children have been proposed that involve the early and continuous sensory and physical stimulation of the DS infant to assure that the child reaches his full potential of physical, intellectual, and social functioning. Many of these programs are home-based and involve a professional coming to the home and working with the parents and DS child. Banning (1979) described the qualities that are useful for a worker to have to work in a home-based infant stimulation program. Key et. al. (1979) described a home-based stimulation program and suggested that videotape was useful to note progress and to give feedback to the parent. Beare (1979) offered an overview of a home-based infant stimulation program involving a health visitor and suggested various techniques for the visitor to model for the parents.

Other early stimulation programs for DS children involve more traditional office consultation with the professional. York-Moore (1976) described both the necessary attitude and qualities of the therapist and a series of specific exercises to stimulate the DS child

physically to encourage proper physical development. Brinkman (1975) described the early stimulation that he used on his own DS daughter. In addition the author cited empirical support for the effectiveness of a similar early stimulation program.

Several researchers have proposed multidisciplinary infant stimulation programs. Harris (1980) described an interdisciplinary team approach for early stimulation where all team members have a working knowledge of the others' discipline and where one professional coordinates the intervention with the parent and child. The author listed six proposed goals for the program consistent with a multidisciplinary approach. Connolly and Russell (1976) described an interdisciplinary early intervention program for DS children and reported empirical support for the effectiveness of this program. The authors concluded that "early intervention helps the DS child in earlier attainment of many developmental tasks."

Another type of early stimulation program for DS children is drug and vitamin therapies. Share (1976) reviewed a number of drug and vitamin programs for DS children. He concluded that "there have not been any drugs that have demonstrated remarkable improvement in the status of DS individuals."

Programs for Specific Language and Academic Skills

A number of specific programs have been proposed for DS children to improve language and academic skills. The majority of these programs involve behavioral principles and techniques. MacCubrey (1971) described an operant conditioning program to

increase expressive language in DS children. Using both social and tangible reinforcement, verbal production was encouraged. Shaping, imitation training, and chaining increased both the frequency and complexity of expressive language. The author reported significant empirical results concerning effectiveness of this program. Hyde (1974) reported a single case study in which similar operant techniques were used to increase the expressive language of an older DS girl who was virtually mute. Using shaping and modeling techniques with social reinforcement, the author encouraged any vocal production to improve this girl's expressive skills. The author described significant gains but did not offer empirical support.

Glovsky (1972) described a language program for DS children in residential placement. The program involves stimulating the children with soothing pleasant voices and recordings of a variety of different sounds, encouraging vocal productions, and modeling appropriate expressive language, and using labeling and association techniques. The author did not report results concerning effectiveness of the program, or any of its parts, but did assert that "programs have to maintain elasticity" to offer assistance to DS children with language problems.

Pothier et. al. (1974) explored the effects of a receptive language training program on both receptive and expressive language. Using operant techniques, DS children were trained in language comprehension. The authors reported that this training

program resulted in significant improvement of not only receptive language but expressive language as well.

Several programs have been proposed to improve reading skills in DS children. Folk and Campbell (1978) described a program that teaches "functional reading" to DS children. Different from traditional reading programs, functional reading involves overlearned associations of specific written words to spoken sounds, and thus the repertoire of specific nouns, verbs, and adjectives is limited. The authors reported significant results for 3 DS children and suggested that functional reading skills can be taught to DS children by classroom teachers without such sophisticated methods as teaching machines.

Sidman and Cresson (1973) described a program to introduce severely retarded DS children to simple reading skills. Similar to the method reported by Folk and Campbell, the authors taught the children to match printed words to their corresponding pictures and then to speak the word. They reported significant results and concluded "that a practical method and an effective teaching sequence are available for introducing severely retarded children to reading."

A program that produces overall improvement in the academic performance of DS children was reported by Dalton et. al. (1973). The authors described a token economy program that reinforced correct responses to a variety of academic tasks. The authors found that the program significantly improved the academic

performance of DS children and these gains were maintained at a one year follow-up.

Farb et. al. (1978) described a training program to improve memory in DS children. Using a single case study, the authors reported that reinforcing correct repetitions of word and number lists resulted in general memory improvement. The authors concluded that operant techniques can improve memory performance.

C. THE EFFECTS OF DS CHILDREN ON THEIR FAMILIES AND THEIR INTEGRATION IN FAMILY AND SOCIETY

DS children have definite limitations in their physical, intellectual, and social functioning and, as such, their presence in the home must have an impact on their families and communities. However, this area apparently has been largely ignored by researchers because there are very few studies in the literature that investigate DS children and their families and even fewer (virtually none) that investigate DS children and the community.

Many parents choose to raise their DS children at home but institutionalization is an option taken by a number of parents of DS children. There is evidence, however, that indicates that DS children reared at home function better than their institutionalized counterparts. Centerwall and Centerwall (1960) compared home-reared and institutionalized DS children and found the home-reared DS children superior in physical, social and mental capacities and functioning. Shotwell and Shipe (1964) reported similar findings and concluded that "institutional placement during the earliest years

of life adversely affects the development of the mongoloid (DS) child."

Despite evidence that institutionalization adversely affects DS children, parents continue to place their children. Wolf and Whitehead (1975) investigated parents' decisions to institutionalize and found that the "amount of disruption perceived by the family as caused by the child" largely determined whether a DS child was institutionalized or not. The authors also noted that DS boys were placed more often that girls. Stone (1967) also examined parents' willingness to place DS children and found that those parents with the poorest socio-economic conditions and the worst family relationships and adaptation were the ones most willing to place their child. The author also noted that "active participation in parents' organizations was associated with both accurate knowledge about mongolism (DS) and willingness to care for the retarded child at home."

While institutionalization may adversely affect DS children, occasionally parents elect a course of action for their child that at best can be described as total nonacceptance and rejection. Gustafson (1973) reported a case study of parents of a newborn DS infant who refused to give permission for a corrective operation of little risk for the infant's intestinal blockage. Without the operation the infant would (and subsequently did) die. The mother's stated reason for allowing the otherwise healthy DS infant to die was "It would be unfair to the other children of the household to raise them

with a mongoloid." Will (1980) reported a similar case of parents who refused to grant permission for heart surgery that would save the life of their 13 year old DS boy. Further aspects of the case, including the boy's life long institutionalization, suggests that the parents' concern for their DS child's life is questionable at best. Clearly, not all DS children are accepted by their families.

Given the limitations of DS children and the extreme reactions of some parents to these limitations, one might assume that home-reared DS children would have a negative impact on their families. The literature, however, does not support this assumption. Carr (1976) investigated the effects of DS children on their families and found that very few parents reported any unusual difficulty in the areas of family adjustment, social isolation, or problems of everyday life. She concluded that "the effects of a DS child on his family have not been found as serious as had been accepted."

This optimistic view of the impact of DS children on their families is supported by two separate single case studies. Butterfield (1961) described a case of a DS male whose mother refused to institutionalize her child and spent large amounts of time training him. Later when the mother had serious health problems, the DS individual not only did not increase family problems but greatly assisted with essential house chores. DeVizia (1974) described a case of a 6 year old DS girl who was being raised by foster parents. He noted that the family reported that the DS child "has enhanced their family relationship because of the greater tolerance needed to cope with (her) seems to have affected all

members of the family." Gilmore and Oates (1977) interviewed the parents of DS children concerning what information their doctors had told them regarding DS and how the parents felt this information should be given. Of interest, the authors found that 46% of the parents "felt that an overly-pessimistic outlook had been given by the doctor."

Several studies have investigated the impact of DS children on their normal siblings. Gath (1972) compared the degree of behavioral disturbance of siblings of DS children to that of siblings of matched normal counterparts. She found no difference between the two groups and speculated that "the affected families were able to develop ways of adapting to the problems arising from the birth and development of an abnormal child" and that "sharing of these problems may have led to a greater sense of purpose and cohesiveness in the family."

In another study, Gath (1974) investigated whether there were any differences in behavioral disturbance between the brothers and sisters of DS children. She found that the frequency of disturbance for brothers of DS children was consistent with that for boys, in general, with similar socio-economic and family size factors. However, sisters of DS children displayed more disturbance as a function of birth order and age in relation to the DS child. The author commented that "the elder sisters of mongol (DS) children in this study can be described as bearing more than their fair share of community care, and the ill effects of this stress will be felt by them and by the community well into the future."

Caldwell and Guze (1960) investigated whether the adjustment of siblings of institutionalized DS children differed from the adjustment of siblings of home-reared DS children. They found no differences between the two groups and noted that both sets of siblings mirrored the respective actual family decision as to what the ideal living arrangements for a DS child should be.

Murphy et. al. (1976) described a group discussion that was held at a clinic for the brothers and sisters of DS children. The impressionistic comments of the authors suggest that these siblings were very concerned and protective of the DS brother or sister and that the siblings had not been adversely affected by the presence of a DS child in the family.

CHAPTER III

METHODS

A. SUBJECTS

The subjects for this study were 12 DS children and their families, ages 12 through 16, who were or had been patients at the Birth Defects Evaluation Center (BDEC) of the University of Tennessee Center for the Health Services, Knoxville. Each DS child had had a chromosome analysis and had been determined to manifest primary trisomy 21. The 12 subjects were an exhaustive sample of the 12 through 16 year old DS children seen by BDEC.

BDEC is a comprehensive, multi-disciplinary evaluation center for physically and mentally handicapped children. It is the only agency of its kind in East Tennessee and it draws its patient population from the eastern third of the state and occasionally from adjoining states. BDEC is well known in the medical community and its referrals come from private physicians as well as from community and state health-related centers. The agency is supported by a number of funding sources and patients are not refused services because of their inability to pay fees. The families of children seen at BDEC cover a range of social, economic and educational levels and live in all parts of the 34 county region that comprise East Tennessee. BDEC also has an active community outreach program and holds evaluation clinics in outposts throughout the eastern

third of the state. While an accurate percentage is unavailable, it is estimated that the large majority of DS children in East Tennessee are seen at BDEC for some type of evaluation or service at some point in their childhood.

The 12 subjects used for this study were all of the available 12 through 16 year old home-reared DS (primary trisomy 21) children who had been seen previously at BDEC. The active BDEC patient list, numbering over 5,000, was referenced for DS and the DS children whose birthdates indicated that they were between the ages of 12 years 0 months and 16 years 11 months were identified. This yielded an initial list of 29 potential subjects. Of the 29, 2 had died, 2 were mosaic rather than primary trisomy 21 DS, 1 had not had a definitive chromosome analysis, 1 was living in a large group home, 6 had moved out of state, and 5 could not be located through normal search procedures (hospital records, other agencies, forwarding addresses, phone directories, directory assistance). This left 12 home-reared primary trisomy 21 DS children ages 12 through 16 that were available for the study. All of the 12 families that were contacted agreed to participate.

B. PROCEDURES

The 12 families were contacted by telephone and asked to participate in the study. No incentives were offered for participation. During the initial telephone contact, the purpose and procedures of the study were explained to the respective families and an interview was scheduled, at the individual family's convenience, to take place

in the family home at a time when most of the family, but especially the father, mother, and DS child, would be present. Interviewing the families in their homes allowed for the observation of the families in their natural environments. Having as many family members as possible present for the respective family interviews allowed for the presentation of varying family perspectives (i.e., parents' and siblings') and also allowed for a greater consensus and reliability to the family's statements.

Having obtained directions from each respective family, the author drove to the family's home on the appointed day for the interview. Driving to the families' homes, demographic variables were noted and recorded for each family. A list of these demographic variables is included in Appendix B. Arriving at the families' homes, the author introduced and properly identified himself. The purpose and procedures of the study were again explained to the families and a signed consent form was obtained. A copy of the consent form is included in Appendix A.

The interviews with the families lasted from two to four hours each, and each interview was taperecorded with the family's permission. The small condenser microphone cassette audio recorder was in a prominent but innocuous place for each interview setting and all persons were aware that they were being taperecorded. Each family was engaged in neutral, nondirective social conversation for approximately 10 to 15 minutes to assist with their adaptation to the taperecorder, prior to the introduction of topic areas pertinent to the study.

Each family was engaged in an informal, conversational, semi-structured interview concerning the DS child's and the family's recent and past activities and interactions, and the experiences of having a DS child in the family. The author served as facilitator of conversation and encouraged individual family members to contribute to the topics discussed. While an attempt was made to keep the interview on a spontaneous level and particular attention was devoted to monitoring smooth topic transitions, there were particular, identical questions asked of each family at some point in their respective interviews. A list of these interview questions asked of each family is included in Appendix C.

Following the family interview, the American Association on Mental Deficiency Adaptive Behavior Scale for Children and Adults -1974 Revision (ABS) was administered for the DS child. The ABS is a behaviorally oriented instrument that assesses the social and adaptive functioning of mentally retarded individuals and yields normative percentile scores for the areas of independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, vocational activity, self-direction, responsibility, and socialization. The ABS was administered and scored according to the explicit instructions given in the detailed ABS manual (American Association on Mental Deficiency, 1975), which involved both using the parents as informants for their child's behavior and directly observing and recording particular behaviors of the child. The ABS items for

"vocational activity" were not administered because none of the DS children performed any work activity.

After the visit to the family home, the taperecorded family interview was transcribed and the descriptive responses to the specific interview questions were extracted from the tapes for each family. Each DS child's ABS was scored and converted to normative percentile scores in accordance to the ABS manual.

C. PRESENTATION OF THE DATA

To allow for a common means of comparison and to preserve the sense of totality for each family, the individual families' responses to the interview questions first are presented in a narrative descriptive fashion for each family. Each DS child's performance on the ABS also is presented individually. This family by family individual narrative case-study descriptive approach best captures the essence of what each individual DS child is able to do and what experiences each individual family has had concerning their respective DS child. Presentation of the information in this fashion preserves the quality of real individuals and real families, yet the common format still allows for individual to individual, and family to family comparison. Each family's case narrative includes a description of demographic variables (questions included in Appendix B), description of interview responses and information (questions included in Appendix C), and a description of the DS child's adaptive behaviors and skills as assessed by the ABS (American Association on Mental Deficiency, 1975). Further, each

DS child's percentile ranks, from the ABS age specified normative sample of mildly to profoundly mentally retarded individuals, is included for the 9 ABS categories or "domains" of independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, self direction, responsibility and socialization.

Following the individual narrative descriptions for each DS child and the respective family, a synopsis of the 12 DS children's adaptive functioning is presented. A synopsis of the families' experiences is also presented. The synopses provide a format to present commonalities and differences among the 12 DS children and their families as a group that the individual narratives do not afford.

Finally, the level of adaptive functioning of the DS children is explored in relation to the experiences of the respective families. Each of the 12 DS children was assigned an ordinal rank of 1 through 12, with appropriate values for tie ranks, for the relative position of their percentile score for each of the 9 ABS domains. The rank values for the 9 ABS domains were then summed for each DS child, and an overall ABS rank was computed for each child within the group of 12. The DS children's rankings affords a means to explore higher versus lower adaptive functioning in relation to the experiences of the respective families. Frequency distributions of the children's rankings by particular family experience variables were subjected to tests of significance by Chi

Square. The familiy variables were also subjected to the MAXR STEPWISE procedure of multiple regressions.

CHAPTER IV

RESULTS

A. DESCRIPTIVE FAMILY NARRATIVES

Family A

A is a 14 year old while male DS child from an intact family. He is the third of three natural children born to Mr. and Mrs. A, a working class couple in their early 50's. A has an older brother age 30 who has not lived at home for the past 10 years, and a 22 year old sister who still lives at home. The A family has lived in their current home all of A's life.

The A family lives in a sparsely populated rural agricultural area of the Tennessee Valley. They live in an older, small, but well appointed single family dwelling in a surrounding neighborhood whose density is less than 6 houses per square mile. The nearest town is 10 miles away and has a population of about 5,100. The nearest major large city is 45 miles away.

The A family first sought out training programs when A was 2 years old. They contacted the local chapter of the Association for Retarded Citizens (ARC) to find that there were no formal training programs available at that time for DS children. The ARC suggested some informal exercises that the family could do at home to improve A's gross and fine motor skills and verbal abilities. The family practiced those exercises, and others that the family devised

on their own, until A entered kindergarten at age 5. The A family believes that the early stimulation activities that they did at home provided A with a needed headstart on his learning. Mr. A states:

> They [DS children] can be helped but it takes a long time. The earlier you start them, the better off they are. We're trying to start in the county now to get them to provide something for these kids from birth to kindergarten.

The A family arranged to send A to a adjoining county to start school, because their own county school system had no programs appropriate for DS children. While he attended school elsewhere for 3 years, the parents worked to have their county institute a special education program, but their efforts were not warmly received. Mrs. A states:

> They [county school board] considered me a trouble maker 'cause I was all the time complaining that he wasn't getting anything. You have to, though; if you sit back and don't complain, then you won't get what these kids deserve. The school won't do it unless you push them.

When A was 8 years old, the county started a special education program with qualified special education teachers. A has attended this school ever since and his parents believe that he has made good progress. A's parents keep close contact with the school and coordinate exercises that A can do at home to improve his abilities and skills. A's older sister has been particularly helpful in working with A individually at home, usually on a daily

basis. Recently, A's parents have been lobbying the school board to institute regular speech therapy in the school program.

A has been involved in structured social activities through a church youth group. A's older sister initiated this contact several years ago and A has been a regular participant in the group's pizza parties, bowling trips and other similar programs. The family believes that this association has been useful in helping to develop A's social skills, especially since there are no children in the family's neighborhood A's age. There are no other social programs, such as scouts, available in the community.

The A family is very family oriented and most activities are done as a family unit. The family keeps fairly regular schedules for meals and times for the family to be together, although there is more flexibility in the summertime. Most trips into the community for routine and special purposes are done as a family unit and A almost always goes along. There are seldom any difficulties in having A out in the community. Mrs. A states:

> A goes everywhere we go, and we treat him like any other child and don't make excuses for him. When we do this, other people see that we do this, so they accept him, too. They know he's different, but not that much different.

The family is very active in the community and has frequent contact with extended family and friends. A is always included in these contacts. The parents are active in church, the PTA, the local chaper of ARC, and a local non-profit workshop for retarded

adults. A has been accepted by all of the family's friends, extended family, and other community contacts.

A's older sister has been a key person in his life. She has taken a special interest in his development since he was an infant. She has worked with him in home-based programs and incorporated him in her social contacts with her friends. Since she has been able to drive, she has taken him on special outings and has sometimes included A in her dates with boyfriends. A has been well received by his sister's friends and the family believes that this has contributed to A's socialization.

Mr. and Mrs. A report very few differences in raising A and raising the two older children. They have treated the three alike and all three have had similar rules, responsibilities, chores, and discipline. Although A has been slower to develop and has had limitations, the A's basic approach to their three children has been the same.

The biggest problem the A family has had raising a DS child has been the lack of accurate advice and appropriate programs. They have had little guidance in trying to provide the best for their child. They credit their family physician as being most helpful in this regard.

The A family has not made specific plans for A's future, largely because there are still few appropriate placements for adult DS individuals. They are working with their local ARC to develop these placements so that by the time A is old enough, something may be available.

The A family advocates that treating the DS child as normally as possible is the best advice for other parents of DS children and professionals working with DS children. Mrs. A states:

> It takes extra time, extra strength, and patience--oh does it take patience--but you have to treat them just as normal as you can. Lots of people will say 'well they're different' and then give in to them. That doesn't do a bit of good, in fact its harmful to the child. You have to let them grow up normal.

A's ABS scores are presented in Table 1. All nine of A's domain scores are above the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. Eight of his nine domain scores are at the median rank or better for the 12 DS children studied. The nine domains are fairly uniformly developed, and A demonstrates no relative substantial deficit in any area when compared with either his normative reference or his peer group of DS children.

Independent Functioning. In regards to eating, A can use knife, fork, and spoon and can drink from a glass held by one hand properly and neatly. He is aware of and usually practices proper table manners. He does not have toilet accidents and he is able to completely and properly care for himself at the toilet. He washes, bathes, brushes his teeth, and shaves without assistance, but does require some prompting. He completely dresses and undresses himself and has no problem with fasteners, buttons, zippers, or laces.

TABLE 1

ABS Scores for Child A

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independant Functioning	64	5
Physical Development	64	3.5
Economic Activity	73	1
Language Development	65	7
Numbers and Time	76	2.5
Domestic Activity	81	6.5
Self-Direction	70	6.5
Responsibility	92	6
Socialization	83	6.5

Physical Development. A has effective use of his limbs and senses and he demonstrates good physical development by balancing on tiptoe, walking down stairs by alternating feet, and throwing a ball overhead.

Economic Activity. While he recognizes various coin demoninations, he can not properly make change. He can shop with some supervision and can make a simple purchase without a note.

Language Development. A can read and write more than ten words and can read simple warning signs. He speaks in complete simple sentences and occasionally can use complex clause sentences.

Numbers and Time. A can perform simple addition and subtraction but not more complex operations. He knows the days of the week and months of the year. He has a basic concept of "hours" and "minutes" but can not tell time.

Domestic Activity. A keeps his own room clean, but does not perform laundry chores. He can set and clean a table and prepare simple foods that require no cooking.

Self-Direction. A initiates most of his own activities and will attend to an activity for more than 15 minutes. He organizes his own leisure time and has several interests and simple hobbies.

Socialization. A participates in group activities and can interact appropriately with others.

Family B

B is a 14 year old white female DS child from an intact family. She is the third of four natural children born to Mr. and Mrs. B, a working class couple in their early 60's and mid-50's respectively. B has an older brother and older sister both in their mid-30's who have lived away from home since B was born. B also has a 13 year old younger brother who lives at home. The B family has lived in their current home for four years; prior to this the family had lived for a long period of time in an older home nearby their present home.

The B family lives in a sparsely populated rural mountainous area of East Tennessee. They live in a new, medium-size, average appointed single family dwelling in a surrounding neighborhood whose density is less than six houses per square mile. The nearest town is 15 miles away and has a population of about 2,600. The nearest major large city is 60 miles away.

B was first involved in a structured training program when she started school at age seven. Prior to this, B had not had any formal or informal community or home based training, other than normal parenting. The family physician, who had provided only medical care, referred the B family to an agency specializing in handicapped children when B started school. This was the first time that the B family received any specific advice on DS or how to assist with a DS child's development. The mother recalls:

> The doctor said she wouldn't learn by booklearning like most people, but would be able to learn by heart from other people. So I'd show her how to do things

> first and she learned that way. She's a fast catcher on-er.

The mother then started what amounts to a modeling behavior program with B, first demonstrating a behavior, such as setting the table, and then practicing the behavior with B. This informal training at home has continued on an almost daily basis to date and the mother believes that this home training alone is responsible for what B is able to do. No other family members have been involved in B's training and B has had no further agency involvement other than for routine evaluations.

B started school when she was seven years old and was placed in a regular classroom, because the school system did not have facilities for handicapped children. The following year, B was placed for home bound instruction, because the regular classroom teacher refused to have a DS child in the class. For two years, a home bound instructor, who had had no training in special education, came to the house twice a week for several hours to tutor B. Mrs. B reports that the home bound instructor was not beneficial for B and Mrs. B consequently removed B from the school system. Since then, Mrs. B has purchased a small blackboard and other school supplies and holds daily school for B. Mrs. B has not followed any particular program, but has tried to teach B basic counting, printing, and word recognition skills. Mrs. B believes that this instruction has been more beneficial for B than her one year of formal schooling and her two years of home bound instruction.

B is not involved in any structured social activities in the community. The family tried to involve B in Sunday school when she was younger but this lasted for only a few months. The other children in the class were verbally and physically cruel to B and the family thought it best to remove B from the class. There are very few other social programs available in the community and the family has been reluctant to involve B in any other social activity for fear of similar consequences.

B has virtually no age appropriate peers or opportunities for informal socialization. There are two much younger children who live nearby that B occasionally plays with and this practically exhausts her social contacts outside of the family.

The B family maintains predictable schedules and always arranges to eat breakfast and dinner together. Mealtimes are central family activities where family members discuss events and plans. The family rarely engages in activities as a unit outside the home, but instead often hosts extended family in the B home. The family is not involved in any community activities or programs, except for occasional church attendance. The B family makes very few special trips into the community and routine trips for shopping are limited to once or twice a week. B usually goes along with her mother for these trips and she is well received by the same limited number of people that she sees on each trip.

B and her slightly younger brother interact well, and he tends to be protective of her. B has limited contact with her older brother and sister who moved away from home before she was born.

Mr. and Mrs. B see little difference in raising B and raising her brothers and sister. They see their children as almost two separate families, their son and daughter in their 30's and the daughter and son in their teens. Despite the age differences, Mr. and Mrs. B have reared the children in similar ways. Mrs. B. states "I treat B just like I'd treat a regular child, but I do watch and make sure no one causes no harm to her."

The B family has not made any precise plans for B's future. The mother has attempted to increase B's self sufficiency by teaching B to cook, clean, sew, and do other domestic activities, in hopes that B may some day be able to be semi-independent. B's older brother and sister have both offered to care for B, should Mr. and Mrs. B become unable to care for her.

Mrs. B sees the lack of accurate advice and assistance as the greatest difficulty in raising B. She states "I didn't know anything about it [DS] and had to find out on my own. But she's mine and I'll do whatever I can for her." Mrs. B has been B's primary caretaker and has been most responsible for B's development. Other family members have had only ancillary involvement with B.

B's ABS scores are presented in Table 2. Six of B's nine domain scores are clustered around the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in her age group, suggesting that most of her adaptive skills are consistently developed. Three of her domain scores are substantially higher and correspond to the three domains where she is at the

TABLE 2

ABS Scores for Child B

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	40	8
Physical Development	43	7.5
Economic Activity	49	9
Language Development	56	8
Numbers and Time	42	8.5
Domestic Activity	97	1.5
Self-Direction	70	6.5
Responsibility	99	2
Socialization	56	8.5

median rank or higher for the 12 DS children studied. B's adaptive functioning in domestic activity, responsibility and self direction are relative strengths for her. She demonstrates no particular relative weaknesses.

Independent Functioning. In regards to eating, B can use knife, fork, and spoon and drink from a glass held by one hand properly and usually neatly. She is aware of and often practices proper table manners. She occasionally has toilet accidents, but she is able to completely and properly care for herself at the toilet. She washes, bathes, and brushes her teeth without assistance but requires prompting. She largely dresses and undresses herself, but requires assistance with fasteners, buttons, zippers and laces.

Physical Development. B has effective use of her limbs and senses and can properly execute gross motor skills such as throwing a ball overhead and walking down stairs by alternating feet. She has some difficulties with fine motor coordination and body balance such as standing on one foot.

Economic Activity. B has no money skills and can not consistently identify various coin denominations. She can shop or make purchases only with close supervision or with precise written instructions to the clerk with accompanying proper payment.

Language Development. B can print her name and a few other words. She recognizes less than ten written words and can not

read warning signs. She speaks in simple but complete sentences but cannot use or understand complex clauses.

Numbers and Time. B can mechanically count, but cannot perform simple addition or subtraction. She has no concept of time.

Domestic Activity. B can properly clean, sweep and dust a room. She can wash, dry, iron and fold clothes. She can prepare, cook, and clean up a simple meal. She can perform gross machine and hand sewing chores.

Self-Direction. B initiates most of her own activities and will attend to an activity for more than 15 minutes. She organizes her own leisure time and has several interests and simple hobbies.

Responsibility. B always takes care of her personal belongings and is always dependable in carrying out requested activities or chores.

Socialization. B avoids participating in group activities and interacts with others only in an imitative fashion.

Family C

C is a 16 year old white male DS child who lives with his mother, a middle class woman in her early 60's. C's father died when C was four years old and his mother has not re-married. C is the second of two natural children born to Mr. and Mrs. C and the fourth of four total siblings that were raised in the C home. C has a natural sister in her early 30's and two adoptive sisters in

their mid-20's. All of C's sisters have married and moved away from home and C has been the only child living at home for the past four years. Within the past year C's oldest sister moved out of state; prior to this, she maintained daily contact with C. The C family has lived in their current home all of C's life.

The C family lives in a suburbanized area of the Tennessee Valley. They live in a fairly new, large, well appointed single family dwelling in a neighborhood whose density is about four houses per acre. They live within the limits of a city with a population of about 14,000 and the nearest major large city is 15 miles away.

C was first involved in a structured training program at the age of six, when his mother arranged for him to attend a private non-profit training center for handicapped children located over 40 miles from the C family home. C attended this center for several months, but the daily commute was too difficult for the C family. Mrs. C then entered C in the public school system where the program for handicapped children was largely custodial in routine. Mrs. C was displeased that C was receiving little beneficial training at school, so she organized a group of parents to lobby the school board for better programs for their children. Two years later, the public school system opened a new special education program for retarded children, due in large part to the efforts of Mrs. C and other parents. C has attended this program since he was eight years old and Mrs. C believes that the quality of the program and staff has afforded C an opportunity to learn and has been very

beneficial for him. Mrs. C has remained involved in the school affairs and tries to coordinate C's home training with his school programs.

C has been involved in several other structured training programs. While C receives speech therapy through school, Mrs. C also has taken C for speech therapy at a speech and hearing clinic since he was 12 years old. She states:

> These [DS] children need speech [therapy] more than anything else, at least twice a week. If they get their speech, a lot of the things will just come natural. They can understand, it's their communication lag.

Mrs. C believes that the added speech therapy has greatly assisted in the development of C's expressive skills. Mrs. C arranged for C to have a private tutor, in addition to his school program, when he was 11 years old. The tutor came to the home twice a week and worked with C on math, writing, reading and spelling skills. While Mrs. C believes that the tutor was very beneficial, C had to withdraw from this program due to financial problems.

The C family has not followed any particular structured home training program for C but they have developed various exercises to assist him with his learning. C's oldest sister started working with C soon after his birth in what amounts to an informal early stimulation program to assist with his gross and fine motor development. She continued to take an active interest in C's learning until she moved out of state last year. Mrs. C has tried to duplicate many of C's school activities at home, and she often

requests from C's teachers exercises that the family can work on at home. At her own initiative Mrs. C has constructed "flash cards" for math, spelling, and work and object recognition skills that she and C practice at home.

Other than through school, C is not involved in any structured social activities. A teacher at C's school arranges a number of social activities such as picnics, camping trips, and trips to the circus and zoo for the special education children. C's mother often attends these events with the children and assists with arrangements and supervision. Mrs. C arranged for C to attend church school when he was much younger but this proved to be counterproductive. C attended for several weeks when he was about ten years old, but refused to go back after he was the object of cruel comments and physical taunts. Mrs. C tried to work through this problem by talking with the parents and church officials, but C refused to go back. Mrs. C states:

> The problem is these retarded children are isolated, and if you don't have one in your own family, then your children have never seen one. So, they just don't know how to act toward one, and that's a shame.

Aside from school, C has little opportunity for peer interaction. There have never been other children his age in the neighborhood and most of his interaction with other children has been limited to his oldest sister's children who are much younger than he is.

Since it has been only Mrs. C and C in the home for a number of years, they maintain very flexible family schedules, but do

almost all activities together. Mrs. C and C make daily trips together into the community for meals out, shopping, or visiting family and friends. These trips are usually positive and without problems, but occasionally C is ridiculed by others because of his physical features or his mannerisms. When this occurs, C refuses to go back to where he was made fun of. Mrs. C holds no malice towards the offending person, but she does wish that the public was better educated and more tolerant of handicapped children. Mrs. C has not been involved in any church or civic activities or organizations since her husband's death 12 years ago.

Mrs. C's basic child rearing techniques have been similar for all four of her children and each has had similar rules, regulations, and privileges. Other than the fact that C was without a father earlier in his development than the others, she sees the only difference between raising C and raising the others as C being slower to learn. She states:

> I've treated him just like a normal child. I think a DS child can learn if someone will take the time to teach them and you push them. But treat them like you would a normal child--don't treat them special because they really can understand.

Mrs. C has not made any definite plans for C's future, although she has arranged for her oldest daughter to care for C should Mrs. C become unable to care for him. Mrs. C expects that C will stay with her for as long as she is able to care for him. She has thought about group homes, but has not made any specific preparations.

C's ABS scores are presented in Table 3. Five of C's nine domain scores are clustered near the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group, suggesting a fair amount of consistency in the development of his adaptive skills. When compared to his normative sample age group he shows relative strength in the areas of responsibility and socialization. He does not show any particular relative weaknesses.

Independent Functioning. C can properly use fork, spoon and knife while eating but has difficulty managing a fork and knife together. He can drink properly and neatly from a glass held by one hand. He is aware of and practices proper table manners. He does not have toilet accidents and he is able to completely and properly care for himself at the toilet. He washes, bathes, and brushes his teeth without assistance or prompting. He completely dresses and undresses himself without assistance or prompting.

Physical Development. C has effective use of his limbs and senses and can properly execute gross motor skills such as throwing a ball overhand and walking down stairs by alternating feet. He has some difficulty with fine motor coordination and body balance such as standing on one foot.

Economic Activity. C recognizes various coin denominations but can not make change. He can make simple purchases unaided provided he has the correct amount of money.

TABLE 3

ABS Scores for Child C

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	49	7
Physical Development	44	5
Economic Activity	52	8
Language Development	68	5.5
Numbers and Time	51	7
Domestic Activity	73	9
Self-Direction	61	8
Responsibility	92	6
Socialization	90	4

Language Development. C can write meaningful simple notes and messages. He can read complete very short simple stories. He speaks in complete simple sentences but does not use complex clauses.

Numbers and Time. C can perform simple single digit addition and subtraction. He has familiarity with time concepts such as "hour" but cannot tell time.

Domestic Activity. C can clean his room, wash dishes and perform several other simple household chores with slight supervision. He can prepare simple foods that do not require cooking.

Self-Direction. C initiates most of his own activities and will attend to an activity for more than 15 minutes. He organizes his own leisure time and has several interests and hobbies that he regularly devotes time to.

Responsibility. C always takes care of his personal belongings and is usually dependable in carrying out requested activities or chores.

Socialization. C interacts appropriately in group activities and is an active participant.

Family D

D is a 15 year old white male DS child from an intact family. He is the ninth of nine natural children born to Mr. and Mrs. D, an illiterate working class couple in their early 60's. D has eight

brothers and sisters ranging in age from their early 20's to late 30's. Only the 20 year old brother and 22 year old sister have lived in the D home over the past five years; the others have married and moved away. The D family has lived in their current home for five years. Prior to this, they had lived in an aging house very close to their current home.

The D family lives in a sparsely populated rural agricultural area of East Tennessee. They live in an old, small, spartanly appointed single family dwelling in a surrounding neighborhood whose density is less than 12 houses per square mile. The nearest town is ten miles away and has a population of about 5,300. The nearest major large city is 40 miles away.

D was first involved in a structured training program at the age of eight years old when he attended a training center for handicapped children. This placement and transportation were arranged by a social worker who handled the D family's welfare case. At the time, Mr. and Mrs. D had not considered any school or training for D, but were agreeable when the placement was arranged. D attended the training center for one year and was then placed, again by the social worker, in the local public school system program for handicapped children. D has attended this program ever since. Mr. and Mrs. D have little knowledge of D's school program and have had minimal contact with school officials. The D family has not been involved in any home based activities or programs for D's training.

D has not been involved in any structured social activities or programs outside of school. His opportunities for peer interaction outside of school are very limited. There is one boy much younger than D in the neighborhood that D occasionally plays with. Most of D's time at home is spent in unsupervised social activities.

The D family does not keep any regular schedules for meals, bedtime or any family activities. The family rarely makes trips into the community other than for necessary shopping. D does not go along for any of these trips. The family does not engage in any activities together other than occasionally watching TV. The D family is not involved in any church or civic activities or organizations. The family rarely has any contacts from friends other than an occasional visit from extended family.

Mrs. D has been the primary caretaker for D and none of D's siblings have been directly involved with his development. D gets along well with his brothers and sisters but their interactions have been limited. Mr. and Mrs. D have raised all of their children in a similar fashion and D has posed no special problems. Mr. D states:

> He ain't no trouble to us, ain't been any more special than the rest of 'em. Weren't much different with him and t'others, 'cept have to take him to the doctors more and can't understand what he says.

The D family has not made any plans for D's future and cannot predict where D will be or what he will be doing in ten years. Several years ago they were contacted by an outreach worker from a large residential state facility for mentally retarded individuals,

but they dismissed any involvement from the worker and stated that they would not place their child outside of the home.

D's ABS scores are presented in Table 4. Most of D's domain scores are below the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. All of his domains are below the median rank for the 12 DS children studied.

Independent Functioning. D can properly use fork, spoon and knife while eating but has difficulty managing a fork and knife together. He cannot drink from a glass held by one hand without spilling. He has little awareness of proper table manners. He does not have toilet accidents and he is able to completely and properly care for himself at the toilet. He washes and bathes without assistance but requires assistance and prompting with teeth brushing.

Physical Development. D has effective use of his limbs and senses and can properly execute gross motor skills. He has difficulty with body balance and cannot stand on one foot.

Economic Activity. D does not use money and does no shopping.

Language Development. D can write his name but cannot recognize any printed words. He speaks in very simple phrases little better than word pairs.

TABLE 4

ABS Scores for Child D

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	23	11
Physical Development	33	9.5
Economic Activity	44	10
Language Development	37	10.5
Numbers and Time	35	11
Domestic Activity	55	10
Self-Direction	52	9.5
Responsibility	59	10
Socialization	48	10

Numbers and Time. D can mechanically count to ten but cannot perform addition or subtraction. He has no concept of time.

Domestic Activity. D performs no cleaning chores. He is able to prepare simple foods but can do no cooking.

Self-Direction. D initiates most of his own activities but relies on extended cues to maintain the activitiy. He can attend to a task for 15 minutes. He has no hobbies and his leisure time is usually spent on simple activities such as watching TV.

Responsibility. D usually takes care of his personal belongings. He is usually not dependable or reliable in carrying out requested activities or chores.

Socialization. D is a passive participant in group activities and he interacts with others only in an imitative fashion.

Family E

E is a 13 year old white male DS child from an intact family. He is the fifth of five natural children born to Mr. and Mrs. E, a middle class couple in their early 60's and mid 50's respectively. E has two older sisters in their early 30's and two older brothers in their mid-20's. E has been the only child at home for the past four years. The E's have lived in their current home for all of E's life.

The E family lives in a suburbanized area of the Tennessee Valley. They live in a fairly new, large, well appointed single family dwelling in a neighborhood whose density is about four

houses per acre. They live within the limits of a city with a population of about 14,000, and the nearest major city is 15 miles away.

Mr. and Mrs. E began searching for structured learning programs when E was an infant, but found nothing available until he was 3½ years old. At that time they became involved in a multidisciplinary training program for handicapped children through a speech and hearing clinic. This program involved the parents and the child and worked on physical, intellectual, as well as language development. The E family participated in this program for four years and believe that it provided E with a headstart in his training and development. While still participating in the first training program, the E family enrolled E in the public schools at the age of six. The parents were disappointed in the custodial care that E was receiving in the multiple handicap class he attended and they began lobbying the school board for better programs for retarded children. Two years later, the public schools opened a renovated school for handicapped and retarded children staffed with special education teachers. E has attended this school ever since. While acknowledging the school's improvement, Mr. and Mrs. E have continued to push for better programs for retarded children.

E has also been involved in a summer training program that uses school facilities to continue physical, language, and intellectual exercises over the summer months. Mr. and Mrs. E believe that this summer program has been very beneficial for E's learning but

they are disappointed that the program will be discontinued due to lack of interest. Mr. E states:

> These children need something just about year round. Problem is we can't get the parents to participate. There are only about four of us families that has to do it all. We need participation more than anything else and we've tried just about evey angle in the book to get the parents actively engaged for their own children.

The E family has been actively involved in home based training programs for E since his birth. After talking with their family physician and researching DS, the E family set up a number of exercises to practice with E on a daily basis. The family's home devised early stimulation was supplemented with other structured activities when the family became involved in the speech and hearing clinic's program. The family has continued these home based exercises to the present and they have made their own "flash cards" to help E with his math and language skills. While the entire family has been involved in these home-based programs, E's oldest sister especially has spent a considerable amount of time with his training.

E participates in structured social activities through the county's after school and summer recreation program. He has also been involved in church school. The E's believe that both of these programs have been very beneficial for E's social development. There have always been children E's age in the neighborhood and E has been an active participant in the informally semi-organized

activities of the neighborhood children. He plays well with and is accepted by his peers.

The E family keeps regular schedules for meals and other family activities. They have always been very family oriented and often engage in family activities such as picnics, fishing trips, camping trips and others. E is always involved in these activities and there are rarely any associated difficulties. Mr. and Mrs. E make frequent trips into the community, especially since Mr. E retired several years ago, and E always goes along, whether it's a simple shopping trip, visit to a friend, or special church event. E is accepted and well liked wherever his parents take him and only rarely has he been subjected to ridicule out in public. The E family is involved in many community activities, especially church and the PTA. They are also active with a group for parents of handicapped children and with their older son's semi-professional ball team.

Mr. and Mrs. E have raised their children in similar ways and each has had similar rules, limitations, and responsibilities. The main difference they see in raising E is that they have had to fight for appropriate programs for their son. They are disappointed that the government has been lax in providing the necessary resources for handicapped children and even more disappointed that many parents of handicapped children have been unwilling to get involved for their children's benefit. They credit the four year involvement with the speech and hearing center's program as being most helpful in helping to raise their DS child.

Mr. and Mrs. E have been exploring options for E's future but have not made any definite plans. They are hopeful that E can someday have some degree of independence, but in the meantime E's older sister has agreed to care for E should Mr. and Mrs. E become unable to. The E family believes that E has had a positive influence on the family. Mr. E states:

> He has added something to our family. He has brought us closer together and we, I don't know, just seem to have more love than we used to. Cause he's been nothing but love.

The E family advises other families with DS children to get involved in programs for the child, parents, and total family as soon as they can. Mr. E especially stresses the importance for parent involvement in the child's training:

> The parents have to be educated right along with the child. You've got to work along with them and carry it on at home or it's just no good for them. The parent has to be involved.

E's ABS scores are presented in Table 5. All nine of E's domain scores are above the 50th percentile and most are above the 70th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. All nine of his domains are at the median rank or higher for the 12 DS children studied.

Independent Functioning. E can use knife, fork, and spoon and drink from a glass held by one hand properly and neatly. He

TABLE 5

ABS Scores for Child E

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	54	6
Physical Development	99	1.5
Economic Activity	69	3
Language Development	72	2.5
Numbers and Time	72	4.5
Domestic Activity	81	6.5
Self-Direction	83	1.5
Responsibility	99	2
Socialization	83	6.5

is aware of and usually practices proper table manners. He assists with dressing himself but has difficulty with buttons, fasteners, and laces. He washes, bathes and brushes his teeth with only verbal prompting. He does not have toilet accidents and he practices appropriate toilet behavior.

Physical Development. E has effective use of his limbs and senses. His gross and fine motor skills are well developed and he can properly throw a ball overhand and balance on tiptoes for ten seconds.

Economic Activity. E recognizes various coin denominations but cannot make change. He can make minor purchases without assistance provided he has the correct amount of money.

Language Development. E can write forty different words and can read very simple short stories. He speaks in complete sentences and sometimes can use complex clauses.

Numbers and Time. E can perform simple addition and subtraction. He understands basic time concepts but cannot properly tell time.

Domestic Activity. E can clean his room but does not regularly perform any other cleaning chores. He can properly prepare and clean up simple foods that do not require cooking.

Self-Direction. E initiates most of his own activities and requires no external cues to maintain this activity. He can attend to

an activity for more than 15 minutes. He organizes his own leisure activities and he has several hobbies and interests.

Responsibility. E always takes good care of his personal belongings. He is very dependable in carrying out requested activities or chores.

Socialization. E interacts appropriately with others in group activities and he usually is an active participant.

Family F

F is a 15 year old white female DS child from an intact family. She is the second of two natural children born to Mr. and Mrs. F, an upper middle class couple in their early 50's. F has an older sister, age 18, who still lives at home. The F family has lived in their current home for most of F's life.

The F family lives in a suburban section of a large metropoliton area in East Tennessee. They live in a fairly new, large, well appointed single family dwelling in a surrounding neighborhood whose density is about four houses per acre. They live just beyond the city limits of a major large East Tennessee city that has a population of over 180,000.

Mr. and Mrs. F first got F involved in a structured training program when F was five years old. The only program available at that time was a private non-profit school for retarded individuals. F attended this program for two years until Mr. and Mrs. F transferred her to the public school program largely for financial

reasons. The F family believes that the private school, despite its limitations, was very beneficial for F and they regret having to have her removed from that program. The public school program was largely custodial and the F family and other parents lobbied the school board for better programs. Several years later the public schools opened a more complete special education school for handicapped children, and F has attended this school ever since. Mr. and Mrs. F believe that F's years in the original public school were largely wasted but that the new school program is much improved. F has not been involved in any other structured training programs.

The F family did not use any home based training programs with F in her early years. However, in the past five years that F has attended the new public school, the F family has coordinated with the school exercises that the family can practice at home to assist with F's learning. Mrs. F has maintained close contact with F's teachers and actively solicits suggestions that the family can do at home to supplement F's school program. The F family believes that this home practice has helped to expand F's skills.

F has been involved in a number of structured social activities. Mrs. F has actively contacted social agencies trying to find appropriate programs for F. Through Mrs. F's efforts F has been involved in a special church group for handicapped children, a scout troop for handicapped children, a bowling team, a swim team, a ball team, and a recreation program. The F family believes that involvement in these programs has been instrumental in F's social development and has greatly added to her self confidence.

F has had extensive informal interactions with peers. There have always been many children F's age in the neighborhood and F's older sister always insisted that F be included in the neighborhood play activities. There rarely have been any problems and F has been accepted well by her peers. Mrs. F states, "Our yard was always one big playground. We never projected her as being handicapped, retarded, different or anything. She always got along well with the other kids." The F family keeps fairly regular family schedules and engages in a large number of individual and family activities. As the two children have gotten older, the family still goes out together for special occasions, like dinner out, and still takes a special two week family vacation each year. The family also participates in church activities together. F almost always accompanies Mrs. F on her trips into the community, from routine shopping to trips to the neighborhood pool in the summer. Typically there are no associated problems although Mrs. F notes that "Sometimes you'll see people point and whisper. The public needs to be more educated in general."

Mrs. F believes that F's older sister has been the greatest help in raising F. F's sister has devoted much time helping F with formal training exercises as well as assuring F's positive interaction with peers. Mr. and Mrs. F have tried to raise F and her sister with similar rules, limitations and responsibilities but note that they have been slightly easier on F. However, they have tried to treat F as normally as possible. The F family states that the largest difficulty in raising a DS child has been the difficulty in finding

appropriate resources. Mrs. F has considered writing an article or book about how difficult it has been to find programs for a child with special needs.

The F family has explored options for F's future but has not made any definite plans. Mrs. F wants to assure that F has a home like environment where F is with people that she knows. The F family has thought of a community based group home but they intend to keep F at home for an unspecified time.

Mrs. F's advice to other families of DS children is to treat the child as normally as possible from birth. She states:

> You get the diagnosis--my child is this, that, or the other--but they're like any other child; ignore the diagnosis. You take her home and treat her exactly like you would any other, you love them just the same and treat them just the same.

F's ABS scores are presented in Table 6. All of F's nine domain scores are above the 50th percentile and most are above the 80th percentile for the ABS normative sample of profoundly to mildly retarded individuals in her age group. All nine of her domains are at the median rank or higher for the group of 12 DS children studied.

Independent Functioning. F can use knife, fork, and spoon and drink from a glass held by one hand properly and neatly. She is aware of and almost always practices proper table manners. She does not have toilet accidents and she completely and properly cares for herself at the toilet. She washes, bathes, and brushes

TABLE 6

ABS Scores for Child F

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	82	1
Physical Development	99	1.5
Economic Activity	64	6
Language Development	72	2.5
Numbers and Time	72	4.5
Domestic Activity	97	1.5
Self-Direction	83	1.5
Responsibility	92	6
Socialization	94	2

her teeth without assistance or prompting. She completely and properly dresses and undresses herself without assistance or prompting.

Physical Development. F has effective use of her limbs and senses. Her gross and fine motor skills are well developed and she can properly throw a ball overhand and balance on tiptoes for ten seconds.

Economic Activity. F recognizes various coin denominations but cannot make change. She can make minor purchases with slight supervision.

Language Development. F can write forty different words and can recognize and read most major warning signs. She speaks in complete sentences, and sometimes uses complex clauses.

Numbers and Time. F can perform simple addition and subtraction. She understands basic time concepts but cannot properly tell time.

Domestic Activity. F can perform most household chores such as cleaning, doing laundry, washing dishes, and making beds. She can prepare and clean up a simple meal requiring no cooking.

Self-Direction. F initiates most of her own activities and requires no external cues to maintain this activity. She can attend to an activity for more than 15 minutes. She organizes her own leisure activities and she has several hobbies and interests.

Responsibility. F always takes care of her personal belongings and is usually dependable in carrying out requested activities or chores.

Socialization. F interacts appropriately in group activities and is an active participant. She will often spontaneously offer assistance to others.

Family G

G is a 15 year old white female DS child from an intact family. She is the ninth of ten natural children born to Mr. and Mrs. G, a working class couple in their mid-50's and late 40's respectively. G has six brothers and three sisters ranging in age from their early teens to their early 30's. A younger brother age 13 and an older sister age 17 are still living at home; the other siblings have been away from home for at least five years. The G family has lived in their current home all of G's life.

The G family lives in a sparsely populated rural agricultural area of East Tennessee. They live in a fairly new, medium sized average appointed single family dwelling in a very small, isolated subdivision whose density is about one house per five acres. The nearest town is five miles away and has a population of about 5,300. The nearest major large city is about 40 miles away.

G was first involved with a structured training program when she attended a training center for handicapped children at the age of eight years old. This placement was initiated and arranged by an outreach worker from a social agency. G attended this program

for two years until the local public school system opened a new school for handicapped children and G was transferred there by the school system. She has attended the public school ever since. Mr. and Mrs. G have not been involved with G's school programs and have little information as to what G is learning or being trained in at school. The G family has not been involved in any other programs or agencies other than for routine evaluations.

The G family has not formally or informally engaged in any home based training programs for G. She has received the same care as her siblings and has not been exposed to any special exercises, activities, or programs to supplement her routine learning or development. Mrs. G states, "The day I left the hospital my doctor told me to make no more difference in her than the other ones. So I treat her just like the other ones."

G has not been involved in any structured social activities outside of school. There are several children her age in the neighborhood, but her peer interaction has been limited. Most of her social interaction is with her siblings and her older siblings' children.

The G family keeps few regular schedules but does try to eat dinner together. The family engages in very few activities together and each family member practices a high degree of independence. Mr. and Mrs. G make few trips into the community other than for routine shopping. G rarely accompanies her parents on these trips but prefers to stay home instead. The G family is not involved in any church or civic activities or organizations. The G family has

few contacts with friends although the married children from the G family often visit with their own families.

Mr. and Mrs. G have not had any special problems in raising G and they see little difference in raising G and raising their other children. Mrs. G does note "We have to watch out for her a little more, maybe." While all of the children have been raised similarly, G has not been assigned any routine chores or responsibilities like her siblings have.

Mr. and Mrs. G have not made any future plans for G. They have not thought of or explored any options for G's future life and state only that G will stay with her mother.

G's ABS scores are presented in Table 7. Five of G's nine domain scores are below the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in her age group. All nine of her domains are below the median rank or higher for the group of 12 DS children studied.

Independent Functioning. G uses knife, fork, and spoon properly but she has difficulty managing a knife and fork together. She can drink from a glass held by one hand properly and neatly. She is aware of but does not always practice proper table manners. Her toilet behavior is appropriate. She usually needs assistance with washing and bathing but she can brush her teeth by herself. She needs help with buttons, fasteners, and laces while dressing and undressing.

TABLE 7

ABS Scores for Child G

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	31	9
Physical Development	33	9.5
Economic Activity	59	7
Language Development	42	9
Numbers and Time	35	11
Domestic Activity	76	8
Self-Direction	48	11
Responsibility	59	10
Socialization	56	8.5

Physical Development. G has effective use of her limbs and senses although she has some difficulty with balance and motor control. She cannot balance on one foot and cannot walk down stairs by alternating feet.

Economic Activity. G has difficulty recognizing the denomination of coins and she cannot make change. She can make a simple purchase either with a specific written note or with close supervision.

Language Development. G can write her name but no other words. She recognizes fewer than ten words by sight. She speaks in simple sentences, but these are often little more advanced than word pairs.

Numbers and Time. G can mechanically count to ten, but she cannot perform simple addition or subtraction. She has no concept of time.

Domestic Activity. G can tidy up a room but can perform few other cleaning chores. She can prepare and clean up a simple meal that does not require any cooking.

Self-Direction. G initiates most of her own activities but usually requires external cues to maintain these activities. She can attend to an activity for 15 minutes. She organizes her own leisure time on a very simple level such as watching TV.

Responsibility. G usually takes care of her personal belongings. She is usually not dependable in carrying out requested activities or chores.

Socialization. G interacts with others in group activities in a passive fashion. She often avoids social interaction.

Family H

H is a 14 year old white male DS child from an intact family. He is the second of four natural children born to Mr. and Mrs. H, an upper middle class couple in their early 50's and early 40's respectively. H has an older sister age 17 and two younger brothers ages 10 and 11; all of the children still live at home. The H family has lived in their current home for many years.

The H family lives in a suburban section of a large metropolitan area in East Tennessee. They live in a fairly new, large, well appointed single family dwelling in a surrounding neighborhood whose density is about two houses per acre. They live within the city limits of a major large East Tennessee city that has a population of over 180,000.

Mr. and Mrs. H began actively searching for structured training programs when H was an infant but discovered that there was very little available. When H was three years old, he started his first training program through a children's rehabilitation hospital. The program was beneficial for physical training but it was not a comprehensive program. The following year, H started in a private non-profit training program for retarded individuals. This program

was superior to what was offered through the public school system, so H continued with this program for seven years. Four years ago the public school system opened a new comprehensive learning center for handicapped children and H began attending this school. He has attended this program ever since. Mr. and Mrs. H have been very active and verbal in securing the best training programs for H and they have been instrumental in the implementation of appropriate, beneficial, mandatory education for the handicapped in their community.

The H family has been involved in informal home-based training programs for H since his birth. When the parents were informed that H was a DS child, they researched DS at a large academic library for information on how to best raise H. They also became active in their local chapter of the Association of Retarded Citizens (ARC) and various parents groups in order to learn more about retardation and how to best train their DS child. While they have not followed any specific formal home-based program, they have practiced what amounts to early stimulation exercises with H.

H is involved with structured social activities through a community based boys recreation program. This program is not limited to handicapped children and H participates in team sports with his two younger brothers. Mr. and Mrs. H believe that this program has been very beneficial for H and they note that he has been well accepted by the recreation staff as well as by the other children. In addition to the recreation program, H has many opportunities for peer interaction in the community. H's brothers and sister have

integrated H into their circle of peer contacts and H is almost always accepted.

While they do not often keep regular family schedules, the H family is very family oriented and engages in a number of family activities. The family often attends sporting events and other activities associated with the boys recreation program. There are also frequent family outings or special trips. The family makes daily trips into the community and H almost always goes along. H especially likes to go shopping with his mother so that he can "make his rounds" of all the storekeepers that always receive him well.

The H family is very active, visable, and verbal in the community. They have long been involved with the local ARC and have served in executive positions. They have been involved in a non-profit private training center for retarded individuals since its inception and have also served in executive positions. They have been involved with community based committees of a large residential facility for retarded individuals. They have also been involved in PTA, church, and other community organizations not associated with retardation.

Mr. and Mrs. H believe that H's interaction with his siblings has been very beneficial. The brothers and sister have taken some teasing from their peers because of their brother, but the siblings have always defended H. H has been particularly close to his older sister and she has devoted considerable time to H's development and training. Mr. and Mrs. H have tried, whenever possible, to raise

each of their four children with the same rules, limitations, and responsibilities. They note, however, that H's handicap has occasionally made for differential treatment.

Mr. and Mrs. H believe that the most difficult thing in raising H has been the lack of available information and resources. Mrs. H states:

> You're faced with a kid that you know is going to require a lot of help. A lot of it was really quite frustrating because there was no where you could go for somebody to say this is what your child needs.

Mr. and Mrs. H note that the situation now is not as bad as when they first started out with H, but that programs and information for DS children and their parents are still lacking. They also note that professionals working with these people need to be better educated. Mr. H states:

> Physicians ought to get their act together. There are still pediatricians today that will recommend institutionalization for DS children at the first crack of life. If the parents don't somehow by accident get on to someone that knows where to go for help, they can flounder around and God knows what can happen.

The H family has discussed future plans for H and has made some preliminary decisions. They would like him eventually to have the semi-autonomy that a group home affords, but they are not satisfied with any current group homes. They intend to keep H at home and will explore the issue further when H is older.

H's ABS scores are presented in Table 8. All of H's nine domain scores are above the 50th percentile and most are above the

TABLE 8

ABS Scores for Child H

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	68	3
Physical Development	64	3.5
Economic Activity	69	3
Language Development	75	1
Numbers and Time	99	1
Domestic Activity	88	4
Self-Direction	76	4.5
Responsibility	92	6
Socialization	90	4

70th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. All nine of his domains are above the median rank for the group of 12 DS children studied.

Independent Functioning. H uses knife, fork, and spoon properly but he has difficulty managing a knife and fork together. He can drink from a glass held by one hand properly and neatly. His toilet behavior is appropriate. He washes, bathes, and brushes his teeth without assistance. He completely dresses and undresses himself but he has difficulty with laces.

Physical Development. H has effective use of his limbs and senses. His gross motor skills are well developed. He can balance on one foot, but cannot stand on tiptoes for ten seconds.

Economic Activity. H recognizes various denominations but cannot make change. He can make a minor purchase with slight supervision.

Language Development. H can write over ten words and can read very simple short stories. He speaks in complete sentences and often uses complex clauses.

Numbers and Time. H can perform simple addition and subtraction. H can properly tell time.

Domestic Activity. H can clean his room, make his bed, wash

dishes, and perform laundry chores. H can prepare a simple meal that does not require cooking.

Self-Direction. H initiates most of his own activities and does not need external cues to maintain these activities. He can attend to an activity for 15 minutes.

Responsibility. H always takes care of his personal belongings and is usually dependable in carrying out requested activities or chores.

Socialization. H interacts appropriately in group activities and is an active participant. He will often spontaneously offer assistance to others.

Family I

I is a 14 year old white male DS child who lives with his natural mother. He is an only child and his parents have been divorced since he was five years old. Mrs. I is a working class woman in her early 30's. I and his mother have lived with a female friend of his mother's for the past seven years.

The I family lives in a sparsely populated rural agricultural area of East Tennessee. They live in an old, small, spartanly appointed single family dwelling in a surrounding area with a density of about six houses per square mile. The nearest town is five miles away and has a population of about 1,500. The nearest major large city is about 45 miles away.

I was first involved in a structured training program when he was seven years old. I's grandparents used to keep I while Mrs. I worked, and it was the grandparents who enrolled I in a church sponsored children's day care center. The program was not intended for handicapped children and the training that I received there was minimal. Mrs. I had little contact with this program. When I was nine, he entered the local public school system at the initiative of school officials. He has been involved in the public school special education program ever since. Mrs. I has had little contact with I's school but she is displeased with the type of education that he is receiving. She states:

> They [the school] are not doing what they should be doing. They should teach him to take care of himself and tie his shoes--not ABC's and stuff like that. I have to bathe him and wash his hair for him.

I has not been involved in any other training programs. Mrs. I has not been involved in any home-based programs for I's training. Since he was an infant, someone has watched I while Mrs. I works. The babysitters have not engaged in any particular training exercise with I, either.

I has not been involved in any structured social activities outside of school. The school occasionally takes trips for bowling or other similar activities, and I usually attends. I has very little opportunity for interaction with peers because there are no children his age near where he lives. I spends most of his time at home engaged in indoor solitary activities; he avoids going out of doors.

Mrs. I keeps few schedules for family activities such as meals and rarely plans or engages in any family oriented activities or trips. Other than for work or routine shopping, Mrs. I makes few trips into the community. I almost always does not accompany Mrs. I on these trips. Mrs. I is not involved in any church or civic activities or organizations. Most of Mrs. I's interactions with her friends occur at work and the I family has virtually no contact from anyone, other than extended family, at home.

Mrs. I has regular contact from her parents. I is the only grandchild and he receives considerable attention from his grandparents. Visits to and from his grandparents are the extent of I's social contacts outside of school.

Mrs. I states that the most difficult thing in raising I has been accepting his limitations. She states:

> I don't talk about it much, and at times I get to crying spells. It's hard to understand--I just don't know why he is like that. I see him and he won't get married or have children or live like a normal life. It's hard to look at him like that.

Mrs. I has not made any plans for I's future and is afraid of what the future may bring. She does not want I to grow older because he will become more difficult to handle, will require more supervision, and will stand out more in public. She believes that I will be with her for the rest of her life and she does not see help forthcoming from any other source. She states "I've had him all my life and I've had to take care of him by myself. There hasn't been <u>any</u> help from anyone."

I's ABS scores are presented in Table 9. Eight of I's nine domain scores are below the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. All nine of his domains are below the median rank for the group of 12 DS children studied.

Independent Functioning. I can use a fork and spoon properly while eating, but cannot use a knife. He can drink from a glass held by one hand. I has little awareness of table manners. I occasionally has toilet accidents but can completely care for himself at the toilet. I requires major assistance with bathing, washing, and brushing his teeth. He requires major assistance with dressing and undressing himself.

Physical Development. I has effective use of his limbs and senses, but has difficulty with balance and coordination. He cannot stand on one foot, throw a ball overhand, or walk down stairs by alternating feet.

Economic Activity. I does not use money at all and has no shopping skills.

Language Development. I barely speaks in word pairs. He can print his name with assistance but does not recognize letters or words.

Numbers and Time. I can occasionally count to ten mechanically. He has no concept of time.

TABLE 9

ABS Scores for Child I

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	19	12
Physical Development	20	12
Economic Activity	0	11.5
Language Development	9	12
Numbers and Time	35	11
Domestic Activity	42	11.5
Self-Direction	43	12
Responsibility	59	10
Socialization	23	12

Domestic Activity. I can tidy a room if prompted but performs no other domestic chores. Under supervision he can prepare simple foods that require no cooking.

Self-Direction. I initiates most of his own activities, but is dependent on external cues to maintain these activities. He can attend to an activity for fifteen minutes. His leisure time is organized on a very simple level and he typically engages in repetitious behaviors.

Responsibility. I usually takes care of his personal belongings. He is usually not dependable in carrying out requested activities or chores.

Socialization. I rarely responds to others in a socially appropriate fashion. He is a passive participant, at best, in group activities. He does demonstrate some consideration for the feelings of significant people in his life.

Family J

J is a 13 year old white male DS child from an intact family. He is the third of three natural children born to Mr. and Mrs. J, a middle class couple in their early 60's and mid 50's respectively. J has an older brother age 29 and an older sister age 28, both of whom have lived away from home since J was five years old. The J family has lived in their current home all of J's life.

The J family lives in a suburban section of a large metropolitan area of East Tennessee. They live in an older, medium-

sized, well appointed single family dwelling in a surrounding neighborhood whose density is about four houses per acre. They live within the city limits of a major large East Tennessee city that has a population of over 180,000.

Mr. and Mrs. J first got J involved in a structured training program when he was three years old. At that time J was not yet walking, so his parents enrolled him in a physical therapy program through a children's rehabilitative hospital. J attended this program for two years and learned to walk during this time. Mr. and Mrs. J then searched for a more comprehensive training program and enrolled J in a private non-profit training center for retarded individuals when J was six years old. J attended this program for three years and made good progress. When the local public school system opened a new special education center for handicapped children three years ago, Mr. and Mrs. J placed J in this program where he has remained ever since. The J family has been actively involved in securing the most appropriate training programs for J. They have maintained close contact with each program that J has been involved in.

The J family has coordinated home programs and exercises with each training program that J has attended. When J was in physical therapy, Mr. J constructed a ramp and balance bar set-up at home to help J practice gross motor and coordination skills. J's older sister was particularly involved in working with J in this home program. The J's have also implemented home-based academic

exercises that correspond with the activities that J is learning in his formal school training programs.

J has not been involved in any structured social activities outside of school. There are no children in his neighborhood and he has few opportunities for peer interaction. J's only playmate is his older sister's eight year old son that visits J about once a week. J's older sister has encouraged this interaction.

Mr. J retired several years ago so now Mr. J, Mrs. J, and J spend most of their time together when J is not at school. While they spend many hours together, they engage in few family activities. Other than for routine shopping trips, they rarely go out. When they do go out in the community, J always goes along and there are never any associated problems. Most of the family's time together is spent in each member's solitary activities with little actual interaction between the family members. The J family is not involved in church or civic activities or organizations. The family has regular contact with extended family.

Mr. and Mrs. J believe that they have been easier on J than they were in raising their other two children. They cite J's many health problems, special needs, and limitations for the differential treatment. J has been particularly close to his older sister and continues to be even though the sister is now married and has a family of her own. The sister continues to devote special attention to J. J's brother has been more reserved in his interactions with J.

Mr. and Mrs. J have made preliminary plans for J's future. They have explored a placement at a church run group home and believe that this may be the best plan for J's continual need for supervision. While J's sister has offered to care for J, Mr. and Mrs. J are reluctant to do this. They state, "We can't put him off on our daughter, it wouldn't be fair to her."

Mr. and Mrs. J suggest that other parents of DS children be "patient" and "firm" with their children. In regards to discipline they advise, "Just be firm. Just tell them [DS children] 'No!' and they'll listen. But if you bend, they'll push. You can't let them get the best of you."

J's ABS scores are presented in Table 10. Seven of J's nine domain scores are below the 50th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. All nine of his domains are below the median rank for the group of 12 DS children studied.

Independent Functioning. J can use a fork and spoon properly while eating, but cannot use a knife. He can drink from a glass held by one hand. J is aware and usually practices proper table manners. J occasionally has toilet accidents and sometimes need assistance with toilet care. J requires some assistance with washing, bathing, and brushing his teeth. He needs major assistance with dressing and undressing.

Physical Development. J has effective use of his limbs and

TABLE 10

ABS Scores for Child J

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	25	10
Physical Development	28	11
Economic Activity	0	11.5
Language Development	37	10.5
Numbers and Time	42	8.5
Domestic Activity	42	11.5
Self-Direction	52	9.5
Responsibility	50	12
Socialization	42	11

senses, but has difficulty with balance and coordination. He cannot stand on one foot or walk down stairs by alternating feet.

Economic Activity. J does not use money at all and has no shopping skills.

Language Development. J cannot write or read any words. He speaks in very simple sentences.

Numbers and Time. J can mechanically count to ten but cannot perform addition or subtraction. He has no concept of time.

Domestic Activity. J can tidy a room, clean a table, and perform several very simple household chores. He is unable to prepare any food.

Self-Direction. J initiates most of his own activities but often requires external cues to maintain these activities. He can attend to an activity for fifteen minutes. He organizes his leisure time on a simple level.

Responsibility. J usually takes care of his personal belongings. He is entrusted with very little responsibility.

Socialization. J interacts with others in group activities in only an imitative fashion. He is a passive participant in group activities.

Family K

K is a 12 year old white male DS child from an intact family.

He is the third of three natural children born to Mr. and Mrs. K, a middle class couple in their mid-40's and late 30's respectively. K has two older sisters ages 16 and 17 who also live at home. The K family has lived in the same area for all of K's life and has been in their current home for four years.

The K family lives in a suburbanized area of East Tennessee near a large metropolitan area. They live in an older, small but well appointed single family dwelling in a surrounding neighborhood whose density is about four houses per acre. They live within the limits of a city of 7,500 and the nearest major large city is less than 15 miles away.

Mr. and Mrs. K first considered structured learning programs for K when he was four months old. They asked their family physician how to find such a program and were told to wait until K was school age before placing him. The physician advised the K family in the mean time to "treat him just like a normal child." When K was five years old, Mr. and Mrs. K entered him in a Headstart program for handicapped children. This program concentrated on physical and language development. When K was six, his parents managed for him to attend a comprehensive training program for handicapped children at a speech and hearing center. This program required parent participation and Mr. and Mrs. K became very involved. They believe that the Headstart program and the comprehensive program through the speech center were instrumental in the development of K's motor and language skills.

At seven, K entered the local public school system's special education program for handicapped children where he has been ever since. Mr. and Mrs. K were not satisfied with the school's program in its earlier stages and lobbied for improvements through a parents group. They note that the school is much improved and they believe that K is receiving appropriate and useful training.

The K family has been involved in several home-based training programs that have been adjunct to K's formal training programs. Through the training program at the speech center, Mr. and Mrs. K received suggestions for auxillary exercises that they could practice at home with K to further his motor and language development. The K family, K's sisters included, worked intensively with him using these exercises. Also, the family, on their own initiative, has contacted K's teachers at school to obtain exercises that the family can practice at home to assist with his academic and adaptive training. The family believes that home training is essential for K's continuing training and development.

K has been involved in several structured social programs outside of school. His parents have been very active in church and several years ago they helped to develop a special Sunday school class for retarded and handicapped children. K has attended this program which is largely social in nature, but with a distinct religious orientation. K also has been involved with the church's regular youth groups that sponsor community activities and special outings. K has been well received in the church and the family believes that this involvement has greatly increased his social

skills. For the past year K has participated in a cub scout troop sponsored by a community service organization. Although this is a troop for handicapped children, they do the same activities and have contact with the regular scout troop. In addition to his structured and social activities, K has several peers and playmates in his neighborhood that he interacts with well.

The K family is very family oriented and engages in many church and other activities as a family. The family attends church services together several times a week and Mr. and Mrs. K are the counselors for the youth program that K and his two sisters are involved in. Consequently the family is together even during their special church activities such as trips to amusement parks. In addition to their church involvement, the K family tries to schedule frequent special activities such as camping and picnics. When planning these events, they take into consideration K's limitations. Mr. K states, "Even though he's 12½ years old, on a lot of things he's on a four to five year level. We just have to try to gear ourselves down some." The K family makes frequent routine and special trips into the community and they make an effort to almost always include K. Mrs. K states, "We take him with us wherever we go. That's not like twenty years ago when no one ever took retarded people out but kept them at home like closet people." While the family has received occasional stares and comments from people in the community, there have been few problems with having K out in public.

K and his sisters get along well, and the sisters have been very involved with K's home training and social development. While Mr. and Mrs. K have tried to raise their three children in similar ways, they acknowledge that K's limitations have occasionally led to special treatment. However, Mrs. K asserts "I want him to be as average a child as possible." Mr. K offers the same advice to other parents of DS children:

> Treat him like he was just a normal child, try and do everything with him like he was a normal child. Take him to the store with you, take him out to eat with you, take him everywhere. Let your friends and the public get used to seeing him with you and they'll accept him and it will be a lot easier.

The K family has discussed future plans for K but as yet have not made definite arrangements for his future care. They are hopeful that he may be able to hold some type of lower level employment and achieve some degree of autonomy. Mrs. K states:

> If he can learn to do something like work in a grocery store or gas station--I know he'll never work on computers or go to college--but at least if he can do <u>something</u>, that would be a lot better than him growing up and being put in an institution if we die.

If competitive employment is not possible, they would like K to be involved with a sheltered workshop and possibly a group home. They are committed to keeping K at home for the forseeable future.

K's ABS scores are presented in Table 11. All of K's nine domain scores are above the 80th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age

TABLE 11

ABS Scores for Child K

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	66	4
Physical Development	61	6
Economic Activity	68	5
Language Development	71	4
Numbers and Time	67	6
Domestic Activity	82	5
Self-Direction	80	3
Responsibility	99	2
Socialization	96	1

group. All nine of his domains are above the median rank for the group of 12 DS children studied.

Independent Functioning. K uses knife, fork, and spoon properly while eating, but has some difficulty in managing fork and knife together. He drinks properly from a glass held by one hand. He is aware of and always practices proper table manners. He never has toilet accidents and he completely cares for himself at the toilet. He washes, bathes, and brushes his teeth properly and without any assistance or prompting. He dresses and undresses himself but needs assistance with buttons and laces.

Physical Development. K has effective use of his limbs and senses. He demonstrates good balance by being able to stand on tiptoes, but he has problems with coordination and has difficulty throwing a ball overhand.

Economic Activity. K recognizes various coin denominations but can't make change. He can make a simple purchase with a written note or with close supervision.

Language Development. K can print his name and a few other words. He can read most basic warning signs, but little else. He speaks in complete sentences and occasionally can use complex clauses.

Numbers and Time. K can count higher than ten, but cannot perform addition or subtraction. He understands a few basic time concepts but cannot tell time.

Domestic Activity. K can tidy a room, wash dishes, make beds, and perform a few more simple domestic chores. He can prepare simple foods that do not require cooking.

Self-Direction. K initiates most of his own activities and requires no external cues to maintain this activity. He can attend to an activity for more than 15 minutes. He organizes his leisure time on a simple level such as watching TV, but has no hobbies.

Responsibility. K always takes care of his personal belongings and is very dependable and almost always carries out assigned activities and chores.

Socialization. K interacts appropriately in group activities and is usually an active participant. He often will spontaneously offer assistance to others and is aware of others' feelings.

Family L

L is a 15 year old white male DS child from an intact family. He is the second of four natural children born to Mr. and Mrs. L, a working class couple in their early 40's. He has an older sister age 20, a younger sister age 14, and a younger brother age 11; all of the children live at home. The L family has lived in their current home all of L's life.

The L family lives in a suburban section of a large metropolitan area of East Tennessee. They live in an older, medium sized, average appointed single family dwelling in a surrounding neighborhood whose density is about four houses per acre. They

live within the city limits of a major large East Tennessee city that has a population of over 180,000.

L first entered a structured learning program when he was four years old. His parents had been advised to institutionalize L, but Mr. and Mrs. L were determined to keep L at home. They actively searched for programs for L and enrolled him in a private non-profit program for retarded individuals that was run in the community. The L family believed that this program was superior to the public school program, so they elected to keep L in the private program when he turned school age. During the six years that L was in this program, his parents were very active in the management and curriculum of the center to insure that their son's education and training were appropriate and beneficial. When the local public school system opened a new special education learning center for handicapped children four years ago, the L family transferred L to this program. L has been in this program ever since. Again, the L family has been very active with the school and school board to insure the quality of L's education and training. Mrs. L states, "They [public schools] are supposed to provide a program for him to develop to his fullest limitation - that's the law. And I intend to see that they do."

The L family has been involved in informal home-based training programs for L since he was an infant. They have had little advice from professionals and have had to implement their own early stimulation type of exercise and design their own training programs. Mrs. L states:

> The doctor said he wouldn't be able to do much, but we've set sort of high expectations for him and followed through on training him. We try to make him do things, but at the same time we don't keep on him so much that he gets frustrated.

The entire family worked with L from an early age and Mrs. L believes that this was very beneficial for his current functioning. "If they get the early training, they can grow up to do better."

L has not been involved in any structured social program outside of school. He has had a great deal of informal interaction with his neighborhood peers and his siblings' peers. He is well accepted in the neighborhood and plays on an informal ball team, goes to the pool, and attends his siblings' sporting events. L's siblings, particularly his older sister, have been very involved with L and integrate him with their friends.

The L family maintains flexible family schedules, due to the large number of activities that different family members are involved in. The family engages in frequent family oriented activities such as camping, swimming, and visits to relatives. The L family makes frequent trips into the community and L is almost always included. Mrs. L states, "The other kids don't like to do anything where they have to leave him [L] home." The L family maintains close frequent contact with extended family and L is well accepted. The L family reports that there are very rarely any associated problems with involving L in family and community activities.

Mr. and Mrs. L have tried to raise L and his siblings with similar rules, limitations and responsibilities. L has assigned

chores like his siblings and he rarely receives differential treatment from his parents. The L family describes some typical sibling difficulties, but overall L and his siblings interact well.

Mrs. L has been an active crusader for better programs for the retarded. In addition to her lobbying efforts with the schools, she has been actively involved in the local Association for Retarded Citizens and with a half-way home for retarded individuals. She also has been involved in different formal and informal parents groups for parents of retarded children.

The L family has discussed plans for L's future and have made some preliminary arrangements in this regard. They would like him to have some degree of autonomy and hope that he will be able to live in a group home in the community and work at a sheltered workshop.

L's ABS scores are presented in Table 12. Eight of L's nine domain scores are above the 60th percentile and five are above the 70th percentile for the ABS normative sample of profoundly to mildly retarded individuals in his age group. Eight of his nine domains are above the median rank for the group of 12 DS children studied.

Independent Functioning. L uses knife, fork, and spoon properly and he drinks properly from a glass held by one hand. He is aware of and practices proper table manners. His toilet behavior is appropriate. He washes, bathes and brushes his teeth without assistance. He completely dresses and undresses himself, but occasionally has problems with laces.

TABLE 12

ABS Scores for Child L

Domain	Percentile Score From ABS Normative Sample	Rank Within Group of 12 DS Children
Independent Functioning	71	2
Physical Development	43	7.5
Economic Activity	69	3
Language Development	68	5.5
Numbers and Time	76	2.5
Domestic Activity	91	3
Self-Direction	76	4.5
Responsibility	92	6
Socialization	90	4

Physical Development. L has effective use of his limbs. He has some visual difficulties and wears thick corrective lenses. His gross and fine motor development is good but he has difficulty with balance and cannot stand on tiptoes.

Economic Activity. L recognizes various coin denominations but can't make change. He can make a minor purchase with slight supervision.

Language Development. L can write ten words and can read various simple warning signs. He speaks in complete sentences and can occasionally use complex clauses.

Numbers and Time. L performs simple addition and subtraction. He understands basic time concepts but cannot tell time.

Domestic Activity. L can clean a room, perform laundry chores, wash dishes, and do most household chores. He can prepare simple foods but he does no cooking.

Self-Direction. L initiates most of his own activities and does not need external cues to maintain these activities. He can attend to an activity for 15 minutes. He organizes his own leisure time and he has several hobbies and interests.

Responsibility. L always takes care of his personal belongings and is usually dependable in carrying out requested activities or chores.

Socialization. L interacts appropriately in group activities and is an active participant. He will often spontaneously offer assistance to others.

B. SYNOPSIS OF THE 12 DS CHILDREN'S ADAPTIVE FUNCTIONING

The 12 DS children studied have commonalities and differences in their adaptive functioning. Table 13 is a compilation of the 12 DS children's percentile scores for the nine domains of the ABS and the children's intellectual level.

As a homogeneous group the DS children's adaptive functioning was compared to the adaptive functioning of the retarded population in general. Tabulating the frequency of the 12 DS children scoring above the 50th percentile for each of the nine domains allowed a ready comparison of the DS sub-group to the ABS normative sample of profoundly to mildly mentally retarded individuals. The frequency of the 12 DS children scoring above the general retarded population mean for each domain is as follows: Independent Functioning - 6, Physical Development - 5, Economic Activity - 8, Language Development - 8, Numbers and Time - 7, Domestic Activity - 10, Self Direction - 10, Responsibility - 12, Socialization - 9. Three of these frequencies are significant: Domestic Activity (χ^2 = 5.33 df = 1 $\rho < .05$), Self Direction (χ^2 = 5.33 df = 1 $\rho < .05$), and Responsibility (χ^2 = 12.0 df = 1 $\rho < .001$). As a sub-group of mentally retarded, DS children function better adaptively than the general mentally retarded population in the areas of domestic activity, self direction,

TABLE 13

DS Children's ABS Percentile Scores for Each of Nine Domains and Indication of Level of Intellectual Functioning

Domain	DS Child A	B	C	D	E	F	G	H	I	J	K	L
Independent Functioning	64	40	49	23	54	82	31	68	19	25	66	71
Physical Development	64	43	44	33	99	99	33	64	20	28	61	43
Economic Activity	73	49	52	44	69	64	59	69	0	0	68	69
Language Development	65	56	68	37	72	72	42	75	9	37	71	68
Numbers and Time	76	42	51	35	72	72	35	99	35	42	67	76
Domestic Activity	81	97	73	55	81	97	76	88	42	42	82	91
Self Direction	70	70	61	52	83	83	48	76	43	52	80	76
Responsibility	92	99	92	59	99	92	59	92	59	50	99	92
Socialization	83	56	90	48	83	94	56	90	23	42	96	90
Intelligence	M	M	M	S	M	S	S	M	S	S	M	M

M = Moderate Mental Retardation

S = Severe Mental Retardation

and responsibility. Only these three areas significantly depart from the general population of profoundly to mildly retarded individuals.

Within the group of 12 DS children, there are differences and commonalities in adaptive functioning. While Table 13 numerically displays these differences and commonalities, it does not describe the actual abilities and functioning of the group. The following discussion describes the adaptive functioning, in synopsis form, of the 12 DS children studied and can serve as normative information for home reared adolescent DS children.

Independent Functioning. Of the 12 children, four can use knife, fork, spoon and drink from a glass properly, six have difficulty managing knife and fork together, and two cannot use a knife at all. Of the 12, ten are aware of and eight usually practice proper table manners, while two have little awareness of table manners. Of the 12, 11 completely care for themselves at the toilet and nine never have toilet accidents. In regards to washing, bathing, and teeth brushing, five of 12 require no assistance or prompting, four require verbal prompting, and three require assistance. In regards to dressing and undressing, four of the 12 can completely dress themselves, five require assistance only with buttons, fasteners, or laces, and three require major assistance in putting on clothes.

Physical Development. All 12 of the DS children have effective use of their limbs and only one has major visual problems. In regards to coordination, nine of the 12 can properly throw a ball

overhand and walk down stairs by alternating feet. In regards to balance six of the 12 can balance on one foot and four of the 12 can balance on tiptoes.

Economic Activity. None of the 12 can properly make change, but nine of the 12 properly recognize various coin denominations. In regards to shopping, seven of the 12 require only slight supervision for a simple purchase, two require either a written note or close supervision, and three can do no shopping at all.

Language Development. In regards to reading, seven of the 12 recognize fewer than ten words, one reads 10 to 40 words, and four can read very simple complete short stories. In regards to writing, seven of the 12 can write fewer than ten words, three can write 10 to 40 words, and two can write meaningful short messages. In regards to expressive speech, two of the 12 talk in very short simple phrases only, four speak in complete sentences only, and six speak in complete sentences and occasionally can use complex clauses.

Numbers and Time. In regards to number concepts, one of the 12 has no counting skills, four can only mechanically count, and seven can perform simple addition and subtraction. In regards to time, four of the 12 have no concept of time, seven understand some time concepts but cannot tell time, and one can properly tell time.

Domestic Activities. In regards to maintenance chores, two of the 12 can perform no chores at all, six can perform only simple chores such as tidying a room or making beds, and four can perform complex chores such as washing, drying, and ironing clothes. In regards to cooking, one of the 12 cannot prepare any foods, nine can prepare simple foods requiring no cooking, and two can properly cook foods on a stove.

Self Direction. All 12 children initiate most of their own activities and can attend to an activity for at least 15 minutes. Of the 12, four require external cues or prompts from others to maintain the activity, while eight do not need the external cues. Of the 12, five organize their leisure time on a very simple level such as watching TV while seven organize their time on a more complex level by maintaining specific hobbies and interests.

Responsibility. In regards to care for their personal belongings, eight of the 12 always (95% of time), and four usually (50-95% of time) take good care of their belongings. In regards to carrying out assigned chores or activities, three of the 12 always (95% of time), six usually (50-95% of time), and three rarely (less than 50% of time) are dependable.

Socialization. Of the 12 children, two avoid participation in group activities, four are passive participants, and six are active participants. In regards to social interaction, two of the 12 avoid interaction, three interact in a simple imitative fashion, and seven

interact with others appropriately. In regards to consideration, four of the 12 children will spontaneously offer assistance to others of their own accord and initiative.

Visual inspection of Table 13 indicates that each child's nine domain scores tend to vary together. Table 14 is a correlation matrix for the nine domains. Each of the nine domains correlated positively with the other eight domains; all correlations were significant at the $\rho<.05$ level. Thus, a DS child's adaptive functioning will tend to be consistent; higher functioning in one area suggests higher functioning in other areas of adaptive behavior, as well.

The consistency of ABS scores across domains for each child, as indicated by Table 13 and 14, suggests that within the group of 12 DS children there are differing overall levels of adaptive functioning. Simply put, some children's adaptive behaviors appear better developed than others. Table 15 is a list of the rank within the group of 12 for each child's nine ABS domain scores, a summation of all nine ranks, and a computed average rank. Table 15 also includes the overall rank within the group for each of the 12 DS children for adaptive functioning. Visual inspection of the ABS percentile scores and the ranks within the group for each domain (Tables 13 and 15) suggests that the overall rank for each child is a simple, yet accurate, indication of the different level of adaptive functioning for the 12 DS children.

Adaptive Functioning and Intelligence. It has been suggested

TABLE 14

Matrix of Correlation Coefficients for ABS Domain Scores of the DS Children

	Independent Functioning	Physical Development	Economic Activities	Language Development	Numbers and Time	Domestic Activity	Self Direction	Responsibility	Socialization
Independent Functioning	1.0	.76	.78	.88	.87	.80	.90	.80	.92
Physical Development		1.0	.66	.75	.69	.64	.85	.69	.72
Economic Activities			1.0	.67	.85	.75	.75	.76	.85
Language Development				1.0	.80	.82	.90	.85	.96
Numbers and Time					1.0	.61	.81	.69	.80
Domestic Activity						1.0	.81	.84	.77
Self Direction							1.0	.89	.85
Responsibility								1.0	.82
Socialization									1.0

TABLE 15

Ranks Within the Group of 12 for Each Child's Nine ABS Domain Scores, Summation of Ranks, Computed Average Rank, and Determined Overall Rank for Each Child

ABS Domains	DS Child A	B	C	D	E	F	G	H	I	J	K	L
Independent Functioning	5	8	7	11	6	1	9	3	12	10	4	2
Physical Development	3.5	7.5	5	9.5	1.5	1.5	9.5	3.5	12	11	6	7.5
Economic Activity	1	9	8	10	3	6	7	3	11.5	11.5	5	3
Language Development	7	8	5.5	10.5	2.5	2.5	9	1	12	10.5	4	5.5
Numbers and Time	2.5	8.5	7	11	4.5	4.5	11	1	11	8.5	6	2.5
Domestic Activity	6.5	1.5	9	10	6.5	1.5	8	4	11.5	11.5	5	3
Self Direction	6.5	6.5	8	9.5	1.5	1.5	11	4.5	12	9.5	3	4.5
Responsibility	6	2	6	10	2	6	10	6	10	12	2	6
Socialization	6.5	8.5	4	10	6.5	2	8.5	4	12	11	1	4
Sum of Ranks	44.5	59.5	59.5	91.5	34	26.5	83	30	104	95.5	36	38
Average of Ranks	4.9	6.6	6.6	10.1	3.8	2.9	9.2	3.3	11.6	10.6	4.0	4.2
Overall Rank	6	8	7	10	3	1	9	2	12	11	4	5

that the level of adaptive functioning of a retarded individual is related to intellectual level. To assess for a relationship between adaptive functioning and intelligence, the 12 DS children's performance on each of the nine ABS domains was correlated with their intellectual level. Table 16 lists the point-biserial correlation coefficients for the nine domains of adaptive functioning.

Figure 1 presents the relationship between the children's overall rank for adaptive functioning and intellectual level. All of the domains were positively correlated with intellectual level, however, only the coefficients for Language Development and Responsibility were significant. The frequency distribution of intellectual level by overall adaptive functioning level, while perhaps suggesting a trend, was not significant. The current data cannot assert a significant relationship between intelligence and adaptive functioning, but visual inspection of the results suggest that intellectual level and level of adaptive functioning may tend to somewhat covary.

C. SYNOPSIS OF THE 12 FAMILIES' EXPERIENCES

The twelve families studied have had commonalities and differences in their experiences with their DS children.

Structured Training Programs. All twelve DS children have been involved in some type of structured training program, but there are differences in the number and types of programs and how they became involved in these programs. The 12 DS children have

TABLE 16

Correlation Coefficients for Adaptive Functioning and Intellectual Level

Domain	r	Significance Level
Independent Functioning	.41	non-significant
Physical Development	.28	non-significant
Economic Activity	.49	non-significant
Language Development	.58	$\rho<.05$
Numbers and Time	.53	non-significant
Domestic Activity	.53	non-significant
Self Direction	.47	non-significant
Responsibility	.68	$\rho<.05$
Socialization	.47	non-significant

Overall Adaptive Functioning Rank

Intellectual Level	1	2	3	4	5	6	7	8	9	10	11	12
Moderate Mental Retardation		X	X	X	X	X	X	X				
Severe Mental Retardation	X								X	X	X	X

Figure 1. Distribution of DS Children's Intellectual Level by Overall Rank of Adaptive Functioning

all attended their local public schools, 11 in a special education setting and one in a regular classroom, but only two of the 12 started their initial training in a public school. Of the other 10 DS children's initial training program: one was at a Headstart pre-school program for handicapped children, one was at a regular children's day care center, three were at a regional comprehensive training center for handicapped children, two were at a private non-profit school for retarded individuals, two were at a physical development program through a children's rehabilitative hospital, and one was at a comprehensive training program for handicapped children through a speech and hearing clinic. Other structured training programs that these DS children have been involved in include private speech therapy, private tutoring, and public school sponsored home-bound instruction. Eight families have involved their child in two different programs, three families have involved their child in three different programs and one family has involved their child in four different programs.

The age at which the DS child started his/her first structured training program varies. Three started at age three, one started at age four, three started at age five, one started at age six, two started at age seven, and two started at age eight; or in short, seven of the DS children started a program before age six and five started a program at or after age six. The person(s) who initiated the DS child's first training program also varies. Eight of the twelve families initiated their DS child's first training placement, and four were initiated by outside sources such as school officials

or social outreach workers. Four of the five children who started their first placement at or after age six were from families where an outside source initiated the DS child's placement.

A common complaint among the families was in regards to the too few programs available for DS children and the relatively poor quality of the programs that are available. This criticism was especially leveled at the public school systems, particularly as they existed prior to the mid-1970's when federal directives and court rulings forced mandatory education for the handicapped. Eight of the twelve families actively searched for the most appropriate training program for their DS child by contacting more than one professional or community agency. These same eight families also actively tried to bring improvement to their DS child's public school program by lobbying their respective school board, forming parent alliances and PTAs, and in at least three cases planning, but not filing, lawsuits. Four families accepted the training placement for their DS child arranged by an outside source. Three of these four have had no complaints with their DS child's respective placements and have little awareness of the quality of the program. The other one of these four families has had complaints with their DS child's arranged placement and decided to withdraw their child from all programs.

Home-based Training-Programs. Nine of the twelve families have involved their DS child in some type of home-based training program on a regular basis. None of the families followed a formal

infant early stimulation program, but three of the families developed their own exercises that they practiced with their DS child regularly (at least twice a week) during the child's infancy. Each of these three families had consulted with their family physician or other professionals for advice but essentially designed their own informal early stimulation program. Eight families, including the three involved with the early stimulation programs, have involved their DS child in home-based training exercises and programs that have been coordinated with the child's formal outside school and/or training program. Each of these eight families has initiated contact with the child's training program to obtain exercises that can be practiced at home, that will supplement and strengthen the formal learning at school. These home based exercises have included physical exercises, self-care exercises, academic drills, and social tasks. One of the twelve families removed their DS child from all formal outside training programs after two years and has relied on their home based programs for all of the child's training. The mother of this DS child holds daily school lessons and adaptive training programs of her own design for her child at home. Three of the twelve families have not been involved in any home-based training programs other than routine child rearing.

Social Activities. Five of the twelve families have involved their DS children, on a regular basis, with community based structured social activities and programs. Two of the twelve families have tried a program for a very brief period of time but

withdrew their DS child when they encountered problems with acceptance. Five of the families have not attempted to involve their DS child in any social programs. Social programs that these DS children have been involved in include special church groups for handicapped children, regular church youth groups, scouts, regular youth county recreation programs, and special bowling, swim and ball teams for handicapped children. Not all of these programs are available in every community, and a common complaint from the families is the limited social activities available for their DS children. However, only one of the five families who have not had their DS child involved in a social program voiced this complaint.

Peer Interaction. Five of the twelve families live in areas where their DS child has had extensive opportunities for interaction with peers outside of school. These five children have been well accepted by and frequently interact with their normal peers. Two of the twelve families live in situations where the only opportunities for social interaction with age appropriate peers outside of school have been with members of the extended family such as cousins, nieces, and nephews. Five of the twelve DS children have had virtually no opportunities for social interaction with age appropriate peers outside of school.

Family and Community Involvement. Five of the twelve families of DS children engage in virtually no family activities other than eating together. Seven of the twelve families engage in frequent

family-oriented activities such as regular family entertainment and special family outings.

Six of the twelve families have been actively involved with more than one community activity or organization such as church, PTA and civic organizations. Six of the twelve have had virtually no involvement with their community.

Seven of the twelve families make frequent (more than twice a week) trips into the community and their DS child almost always goes along. Two of the twelve families make infrequent (less than once a week) trips into the community and their DS child almost always goes along. Three of the families make infrequent trips into the community and their DS child almost never goes along.

Eight of the twelve DS children have had a particular older sibling who has devoted a large amount of time, energy, and attention to the training and development of their DS sibling.

Future Plans. None of the twelve families have made definite plans for their DS child's future. Three families have not discussed the issue at all. Three families are totally deferring the issue until the child is older, but have made contingency plans for a family member to provide care for the DS child should something happen to the parents. Six families hope that their DS child can enter a community based group home at some unspecified point in their adult life. These six familes have gathered preliminary information on group homes but have not made any definite arrangements.

D. RELATIONSHIP OF DEMOGRAPHIC AND FAMILY EXPERIENCE VARIABLES TO LEVEL OF ADAPTIVE FUNCTIONING

There appears to be some relationship between the DS children's level of adaptive functioning and various events, exercises, and experiences of the respective families. The following is a discussion of these variables.

Geographic Location. Seven of the 12 families live in suburban areas near large cities, while five of the families live in rural sparsely populated areas. Figure 2 lists the geographic location for each child. Figure 2 also displays the relationship between the children's overall adaptive functioning rank and geographic location. Most of the children with ranks indicating higher adaptive functioning live in surburban areas, while most of those with ranks indicating lower adaptive functioning live in rural areas. This frequency distribution was statistically significant at the $\rho<.10$ level ($\chi^2 = 3.08$ df = 1) but not at the $\rho<.05$ level. It appears that there is some relationship between the geographic location of the family and the level of the DS child's adaptive functioning.

Age Started First Program. Seven of the 12 children started their first structured training program before age six, the typical age at which children start school. The other five children started at age six or later. Figure 3 lists the age range that each child started his/her first training program. Figure 3 also displays the relationship between the age at which the children first started a

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Suburban			X		X	X		X		X	X	X	7
Rural	X	X		X			X		X				5

A. Geographic Location of Families of DS Children

Adaptive Functioning	Geographic Location: Suburban	Rural
Ranks 1-6	5	1
Ranks 7-12	2	4
TOTAL	7	5

B. Frequency of Geographic Location by Overall Adaptive Functioning Rank

Figure 2. Distribution of DS Families by Geographic Location

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Before Age 6	X				X	X		X		X	X	X	7
Age 6 or Older		X	X	X			X		X				5

A. Age DS Child Started First Program

Adaptive Functioning	Age Child Started First Program: Before Age 6	Age Child Started First Program: Age 6 or Older
Ranks 1-6	6	0
Ranks 7-12	1	5
TOTAL	7	5

B. Frequency of Age Child Started First Program by Overall Adaptive Functioning Rank

Figure 3. Distribution of DS Children by Age at Which They Started Their First Program

structured training program and the children's overall adaptive functioning rank. Most of the children with ranks indicating higher adaptive functioning started their first program before age six, while most of those with ranks indicating lower adaptive functioning started at age six or later. This frequency distribution was statistically significant at the $\rho<.10$ level ($\chi^2 = 8.57$ df = 1). There appears to be a relationship between the age at which a DS child starts his/her first structured training program and the level of the child's subsequent adaptive functioning.

Who Initiated Program. Eight of the 12 families initiated and arranged the first structured training program placement for their DS child, while the other four families waited until they were contacted by school officials or other professionals before placing their child. Figure 4 lists whether the parent or someone else initiated each child's respective first placement. Figure 4 also displays the relationship between who initiated the program and the children's overall adaptive functioning rank. Most of the children with ranks indicating higher adaptive functioning had parents who intiated the children's first training program, while most of those with ranks indicating lower adaptive functioning had families who waited for others to initiate the placement. This frequency distribution was statistically significant at the $\rho<.10$ level ($\chi^2 = 8.00$ df = 1). There appears to be a relationship between who takes the initiative for placing the DS child in the first training program and the level of the child's subsequent adaptive functioning.

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Parent(s)	X		X		X	X		X		X	X	X	8
Other(s)		X		X			X		X				4

A. Who Initiated DS Child's First Program

Adaptive Functioning	Who Initiated Program: Parent(s)	Who Initiated Program: Other(s)
Ranks 1-6	6	0
Ranks 7-12	2	4
TOTAL	8	4

B. Frequency of Who Initiated Program by Overall Adaptive Functioning Rank

Figure 4. Distribution of DS Children by Who Initiated The Child's First Program

Parents Lobbied for Programs. Eight of the 12 families were actively involved in lobbying for improvements to their respective child's training programs, while four families were not involved. Figure 5 lists whether the families lobbied for improvements or not. Figure 5 also displays the relationship between the parents that actively lobbied for program improvements and the children's overall adaptive functioning rank. Most of the children with ranks indicating higher adaptive functioning had parents that actively lobbied for improvement to the children's programs, while those with ranks indicating lower adaptive functioning had parents who were not involved in lobbying efforts. This frequency distribution was statistically significant at the $\rho<.01$ level ($\chi^2 = 8.00$ df = 1). There appears to be a relationship between the families that were actively involved in trying to obtain improvements to their child's training program and the level of the child's subsequent adaptive functioning.

Involved Home-based Programs. Nine of the 12 families have involved their respective DS child in a home-based training program, while three families have not. Figure 6 lists whether the families have been involved in such programs or not. Figure 6 also displays the relationship between the families' involvement in home-based training programs and the children's overall adaptive functioning rank. All of the children with ranks indicating higher adaptive functioning have been involved in home-based programs, while half of those with ranks indicating lower adaptive functioning

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Parent(s) Lobbied	X		X		X	X		X		X	X	X	8
Parent(s) Did Not Lobby		X		X			X		X				4

A. Did Parent(s) Lobby for Program Improvements?

Adaptive Functioning	Parent(s) Lobbied for Programs: Parent(s) Lobbied	Parent(s) Lobbied for Programs: Parents Did Not Lobby
Ranks 1-6	6	0
Ranks 7-12	2	4
TOTAL	8	4

B. Frequency of Parent(s) that Lobbied for Programs by Overall Adaptive Functioning Rank

Figure 5. Distribution of DS Children by Whether Parents Lobbied for Program Improvements

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Involved	X	X	X		X	X		X		X	X	X	9
Not Involved				X			X		X				3

A. Has the Child Been Involved in a Home-Based Training Program?

Adaptive Functioning	Involved In Home-Based Program: Involved	Involved In Home-Based Program: Not Involved
Ranks 1-6	6	0
Ranks 7-12	3	3
TOTAL	9	3

B. Frequency of Child Being Involved in a Home-Based Program by Overall Adaptive Functioning Rank

Figure 6. Distribution of DS Children by Involvement in Home-Based Training Programs

have not been involved in such programs. This frequency distribution was statistically significant at the $\rho<.05$ level ($\chi^2 = 4.0$ df = 1). There appears to be a relationship between involvement in home-based training programs and the level of the child's subsequent adaptive functioning.

Involved Structured Social Programs. Nine of the 12 families have involved their children in structured community-based social programs outside of school, while three have not been involved in such programs. Figure 7 lists whether the families have involved their children in these programs or not. Figure 7 also displays the relationship between the children's involvement in social programs and the children's overall adaptive functioning rank. Most of the children with ranks indicating higher adaptive functioning have been involved in structured social programs, while most of those with ranks indicating lower adaptive functioning have not been involved in such programs. This frequency distribution was statistically significant at the $\rho<.01$ level ($\chi^2 = 8.57$ df = 1). There appears to be a relationship between involvement in structured community-based social programs and the level of the child's subsequent adaptive functioning.

Opportunity for Peer Interaction. Five of the 12 children have had access to and frequently interact with age appropriate peers in their neighborhood, while the other seven have not had this opportunity for interaction. Figure 8 lists whether the children have had this opportunity for peer interaction or not. Figure 8 also

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Involved	X				X	X		X			X		5
Not Involved		X	X	X			X		X	X		X	7

A. Has the Child Been Involved in a Structured Social Program?

Involved In Structured Social Programs

Adaptive Functioning	Involved	Not Involved
Ranks 1-6	5	1
Ranks 7-12	0	6
TOTAL	5	7

B. Frequency of Child Being Involved in a Structured Social Program by Overall Adaptive Functioning Rank

Figure 7. Distribution of DS Children by Involvement in Structured Social Programs

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Opportunities					X	X		X			X	X	5
No Opportunities	X	X	X	X			X		X	X			7

A. Has the Child Had Opportunities for Peer Interaction?

Adaptive Functioning	Opportunities for Peer Interaction: Opportunities	No Opportunities
Ranks 1-6	5	1
Ranks 7-12	0	6
TOTAL	5	7

B. Frequency of Child's Opportunities for Peer Interaction by Overall Adaptive Functioning Rank

Figure 8. Distribution of DS Children by Their Opportunities for Peer Interaction

displays the relationship between opportunity for peer interaction and the children's overall adaptive functioning rank. Most of the children with ranks indicating higher adaptive functioning have had opportunities for peer interaction, while most of those with ranks indicating lower adaptive functioning have not had this opportunity. This frequency distribution was statistically significant at the $\rho<.01$ level ($\chi^2 = 8.57$ df = 1). There appears to be a relationship between opportunity for peer interaction and the level of the child's adaptive functioning.

Family Oriented Activities. Seven of the 12 families frequently engage in activities as a whole family such as entertainment out, while the other five rarely, if ever, engage in family activities. Figure 9 lists whether the families frequently or rarely engage in family oriented activites. Figure 9 also displays the relationship between involvement with family oriented activities and the level of the children's overall adaptive functioning rank. Most of the children with ranks indicating higher adaptive functioning are from families that frequently engage in family oriented activities, while most of those with ranks indicating lower adaptive functioning are from families who rarely engage in such activities. This frequency distribution was statistically significant at the $\rho<.01$ level ($\chi^2 = 8.57$ df = 1). There appears to be a relationship between the families' involvement in family oriented activities and the level of the child's adaptive functioning.

Family's Community Involvement. Six of the 12 sets of parents

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Frequent	X		X		X	X		X			X	X	7
Rare		X		X			X		X	X			5

A. Occurrence of Family Oriented Activities

Occurrence of Family Oriented Activities

Adaptive Functioning	Frequent	Rare
Ranks 1-6	6	0
Ranks 7-12	1	5
TOTAL	7	5

B. Frequency of Occurrence of Family Oriented Activities by Overall Adaptive Functioning Rank

Figure 9. Distribution of DS Children by Occurrence of Family Oriented Activities

and/or families have been very active in two or more community activities, while the other six families have had virtually no involvement with community activities. Figure 10 lists whether the families have been involved with community activities and organizations or not. Figure 10 also displays the relationship between the families' community involvement and the children's overall adaptive functioning ranks. All of the children with ranks indicating higher adaptive functioning are from families that are actively involved with community organizations and activities, while all of the children with ranks indicating lower adaptive functioning are from families that have had no such involvement. This frequency distribution is statistically significant at the $\rho<.001$ level ($\chi^2 = 12.00$ df = 1). There appears to be a relationship between the family's involvement with community activities and the child's level of adaptive functioning.

Trips into Community. Seven of the 12 families make frequent trips into the community for routine and special purposes and the DS child is always included, while the other five families make infrequent trips and the DS child may not always be included. Figure 11 lists whether the families make frequent or infrequent trips into the community. Figure 11 also displays the relationship between the families' trips into the community and the children's overall adaptive functioning ranks. All of the children with ranks indicating higher adaptive functioning are from families that make frequent community trips, while most of those with ranks indicating

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
2 or More Activities	X				X	X		X			X	X	6
No Activities		X	X	X			X		X	X			6

A. Extent of Family's Community Involvement

Extent of Family's Community Involvment

Adaptive Functioning	2 or More Activities	No Activities
Ranks 1-6	6	0
Ranks 7-12	0	6
TOTAL	6	6

B. Frequency of the Extent of the Family's Community Involvement by Overall Adaptive Functioning Rank

Figure 10. Distribution of DS Children by Their Families' Community Involvement

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Frequent Trips	X		X		X	X		X			X	X	7
Infrequent Trips		X		X			X		X	X			5

A. Occurrence of Child's Trips into the Community

Occurrence of Child's Trips into the Community

Adaptive Functioning	Frequent Trips	Infrequent Trips
Ranks 1-6	6	0
Ranks 7-12	1	5
TOTAL	7	5

B. Frequency of the Occurrence of the Child's Trips into the Community by Overall Adaptive Functioning Rank

Figure 11. Distribtuion of DS Children by Frequency of Their Trips Into the Community

lower adaptive functioning are from families that make infrequent community trips. This frequency distribution is statistically significant at the $\rho<.01$ level ($\chi^2 = 8.57$ df = 1). There appears to be a relationship between the family's frequency of trips into the community and the child's level of adaptive functioning.

Involved Older Sibling. Eight of the 12 children have had a particular older sibling that has devoted special time and attention to the child's development and training, while the other four have had no such sibling. Figure 12 lists whether or not the children have had an involved older sibling. Figure 12 also displays the relationship between having an involved older sibling and the children's overall adaptive functioning. All of the children with ranks indicating higher adaptive functioning have had an involved older sibling, while most of those with ranks indicating lower adaptive functioning have had no such sibling. This frequency distribution is statistically significant at the $\rho<.01$ level ($\chi^2 = 7.00$ df = 1). There appears to be a relationship between having an older sibling that has assisted in the child's development and the level of the child's adaptive functioning.

Future Care Plans. Six of the 12 families have discussed, explored and made preliminary plans for their respective child's future care, while the other six have either not made plans or deferred planning to a later date. Figure 13 lists whether or not the families have made preliminary future care plans for their children. Figure 13 also displays the relationship of the families having made

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Involved Older Sibling	X		X		X	X		X		X	X	X	8
No Involved Older Sibling		X		X			X		X				4

A. Has the Child Had an Involved Older Sibling?

Adaptive Functioning	Involved Older Sibling	No Involved Older Sibling
Ranks 1-6	6	0
Ranks 7-12	2	4
TOTAL	8	4

B. Frequency of the Child Having an Involved Older Sibling by Overall Adaptive Functioning Rank

Figure 12. Distribution of DS Children by Whether They Have Had an Involved Older Sibling

DS Child	A	B	C	D	E	F	G	H	I	J	K	L	
Rank	6	8	7	10	3	1	9	2	12	11	4	5	TOTAL
Preliminary Plans	X				X	X		X			X	X	6
No Preliminary Plans		X	X	X			X		X	X			6

A. Have Preliminary Plans Been Made for the Child's Future Care?

Preliminary Plans for Child's Future Care

Adaptive Functioning	Preliminary Plans	No Preliminary Plans
Ranks 1-6	6	0
Ranks 7-12	0	6
TOTAL	6	6

B. Frequency of Preliminary Plans Made for Child's Future Care by Overall Adaptive Functioning Rank

Figure 13. Distribution of DS Children by Whether Their Families Have Made Future Care Plans

preliminary care plans and the children's overall adaptive functioning rank. All of the children with ranks indicating higher adaptive functioning are from families that have made preliminary future care plans, while those with ranks indicating lower adaptive functioning are from families that have made no such plans. This frequency distribution is statistically significant at the $\rho<.001$ level ($\chi^2 = 12.00$ df = 1). There appears to be a relationship between the family's having made future care plans and the child's level of adaptive functioning.

In sum the level of adaptive functioning of DS children appears to vary with certain events and experiences of their respective families. The area that the family lives in, the age at which the family first involved their child in a training program, who initiated the training placement, how involved the family has been in actively lobbying for improvements to training programs, interaction, the family's participation in family oriented activities, the family's community involvement, the extent the child is involved in trips into the community, having an older sibling that devotes time and attention to the child, and the extent to which the family has made future plans for the child all appear to vary with the level of the DS child's adaptive functioning.

Visual inspection of Figures 2-13 suggest that the individual families are family consistent in the presence/extent of the discussed events and experiences variables. A family that has involved their child in home-based training programs is likely to have involved their child in structured social programs also. To assess

the consistency of these variables within the individual families, each variable was correlated with the other eleven variables. The twelve family variables were also correlated with the child's intellectual level. Table 17 is a correlation matrix for the twelve family events and experiences variables and the child's intellectual levels. Almost all of the correlation coefficients between the family variables were positive, strong, and significant suggesting a high degree of consistency of the presence/extent of these variables within families. Only one of the family variables--Involved in Home-Based Programs--was significantly correlated with the child's intellectual level. In short, families of DS children appear to be family consistent in engaging in, having and providing for events, exercises, and experiences that are related to the level of the children's adaptive functioning. Intellectual level of the child does not appear to be related to the family variables.

STEPWISE MAXR: Having posited a relationship between adaptive functioning performance and existence of particular family variables, the data were submitted to the MAXR technique of the STEPWISE procedure (Hocking, 1976) for further analysis. The STEPWISE MAXR is a stepwise regression procedure that explores the best fit of a collection of independent variables to be included in a regression model. This technique compares each variable with all others in all possible combinations to produce the best multivariable model, as indicated by the highest R^2 value, without losing significance with the F statistic.

TABLE 17

Matrix of Correlation Coefficients for Family Variables

	Geographic Location	Age Started First Program	Who Initiated Program	Parents Lobbied for Programs	Involved in Home-Based Programs	Involved Structured Social Programs	Opportunities for Peer Interaction	Family Oriented Activities	Family's Community Involvement	Trips into the Community	Involved Older Sibling	Future Care Plans	Intelligence
Geographic Location	1.00 .00	0.66 .05	0.84 .001	0.84 .001	0.68 .05	0.37	0.71 .01	0.66 .05	0.51	0.66 .05	0.84 .001	0.51 NS	0.17 NS
Age Started First Program		1.00 .00	0.84 .001	0.84 .001	0.68 .05	0.71 .01	0.71 .01	0.66 .05	0.85 .001	0.66 .05	0.84 .001	0.85 .001	0.17 NS
Who Initiated Program			1.00 .00	1.00 .00	0.82 .01	0.60 .05	0.60 .05	0.84 .001	0.71 .05	0.84 .001	1.00 .00	0.71 .05	0.35 NS
Parents Lobbied for Programs				1.00 .00	0.82 .01	0.60 .05	0.60 .05	0.84 .001	0.71 .05	0.84 .001	1.00 .00	0.71 .05	0.35 NS
Involved in Home-Based Programs					1.00 .00	0.49	0.49	0.68 .05	0.58 .05	0.68 .05	0.82 .01	0.58 .05	0.58 .05
Involved Structured Social Programs						1.00 .00	0.66 .05	0.71 .01	0.85 .001	0.71 .01	0.60 .05	0.85 .001	0.17 NS
Opportunities for Peer Interaction							1.00 .00	0.71 .01	0.85 .001	0.71 .01	0.60 .05	0.85 .001	0.17 NS
Family Oriented Activities								1.00 .00	0.85 .001	1.00 .001	0.84 .001	0.85 .001	0.51 NS
Family's Community Involvement									1.00 .00	0.85 .001	0.71 .05	1.00 .001	0.33 NS
Trips into the Community										1.00 .00	0.84 .001	0.85 .001	0.51 NS
Involved Older Sibling											1.00 .00	0.71 .05	0.35 NS
Future Care Plans												1.00 .00	0.33 NS
Child's Intellectual Level													1.00 .00

Top number represents the correlation coefficient.
Bottom number represents the level of significance (p is nonsignificant or less than .05, .01 or .001).

The collection of independent variables from which the regression models were extracted were the twelve family events, exercises, and experiences variables identified earlier, and intellectual level. Figure 14 lists these variables. The dependent variables were the nine adaptive functioning areas, as indicated by the ABS percentile scores. The best regression model was determined for each of the nine dependent variables. The model, the corresponding R^2 value, the F statistic and the level of significance for each dependent variable is presented below.

Independent Functioning. The best regression model for independent functioning was a seven variable model. The independent variables included in this model were as follows:

1. Geographic Location
2. Age Started First Program
3. Who Initiated First Program
4. Involved in Home-Based Programs
5. Involved in Structured Social Programs
6. Family's Community Involvement
7. Child's Intellectual Level

The R^2 value for this model was .94 ($F = 8.99$ df =7) with a significance level of $\rho<.025$. This suggests that, using the current data, the seven listed variables taken together account for 99% of the variance of independent functioning, and that level of independent functioning could be accurately predicted from this model. Thus a DS child who lives in a suburban area, started

1. Geographic Location of Families of DS Children. (Suburban or Rural)
2. Age DS Child Started First Program. (Before Age 6 vs. Age 6 or Older)
3. Who Initiated DS Child's First Program. (Parent(s) or Other(s))
4. Did Parent(s) Lobby for Program Improvements? (Parent(s) Lobbied or Parent(s) Did Not Lobby)
5. Has the Child Been Involved in a Home-Based Training Program? (Involved or Not Involved)
6. Has the Child Been Involved in a Structured Social Program? (Involved or Not Involved)
7. Has the Child Had Opportunities for Peer Interaction? (Opportunities or No Opportunities)
8. Occurrence of Family Oriented Activities. (Frequent or Rare)
9. Extent of Family's Community Involvement. (2 or More Activities vs. No Activities)
10. Occurrence of Child's Trips Into the Community. (Frequent Trips or Infrequent Trips)
11. Has the Child Had an Involved Older Sibling? (Involved Older Sibling or No Involved Older Sibling)
12. Have Preliminary Plans Been Made for the Child's Future Care? (Preliminary Plans or No Preliminary Plans)
13. DS Child's Intellectual Level. (Moderate M.R. or Severe M.R.)

Figure 14. Compilation of Independent Variables

his/her first training program--that the parents initiated--before the age of six, who has been involved in home-based training programs and structured social programs, whose family is actively involved in the community, and whose intellectual level is in the moderately retarded range will function higher in the area of independent functioning.

Physical Development. The best regression model for physical development was a five variable model. The independent variables included in this model were as follows:

1. Involved in Structured Social Programs
2. Opportunities for Peer Interaction
3. Family Oriented Activities
4. Family's Community Involvement
5. Child's Intellectual Level

The R^2 value for this model was .79 ($F = 4.58$ df = 5) with a significance level of $\rho<.046$. This suggests that, using the current data, the five listed variables taken together account for 79% of the variance of physical development and that level of physical development could be accurately predicted from this model. Thus, a DS child who has been involved in structured social programs, who has had opportunities for peer interaction, whose family has engaged in frequent family-oriented activities and has been actively involved in the community, and whose intellectual level is in the moderately retarded range will function higher in the area of physical development.

Economic Activity. The best regression model for economic activity was a four variable model. The independent variables included in this model were as follows:

1. Age Started First Program
2. Who Initiated First Program
3. Involved in Home-Based Programs
4. Family Oriented Activities

The R^2 value for this model was .73 ($F = 4.84$ $df = 4$) with a significance level of $\rho<.035$. This suggests that, using the current data, the four listed variables taken together account for 73% of the variance of economic activity and that level of economic activity could be accurately predicted from this model. Thus, a DS child who started his/her first training program--that his/her parents initiated--before the age of six, who has been involved in home-based training programs, and whose family has engaged in frequent family-oriented activities will function higher in the area of economic activity.

Language Development. The best regression model for language development was a six variable model. The independent variables included in this model were as follows:

1. Geographic Location
2. Who Initiated First Program
3. Involved in Home-Based Programs
4. Involved in Structured Social Programs
5. Family Oriented Activities

6. Child's Intellectual Level

The R^2 value for this model was .86 (F = 5.17 df = 6) with a significance level of $\rho<.046$. This suggests that, using the current data, the six listed variables taken together account for 86% of the variance of language development and that level of language development could be accurately predicted from this model. Thus, a DS child who lives in a suburban area, whose parents initiated his/her first training program, who has been involved in home-based training programs and structured social programs, whose family has engaged in frequent family-oriented activities, and whose intellectual level is in the moderately retarded range will function higher in the area of language development.

Numbers and Time. The best regression model for numbers and time was a seven variable model. The independent variables included in this model were as follows:

1. Geographic Location
2. Age Started First Program
3. Involved in Home-Based Programs
4. Involved in Structured Social Programs
5. Family Oriented Activities
6. Family's Community Involvement
7. Child's Intellectual Level

The R^2 value for this model was .92 (F = 6.93 df = 7) with a significance level of $\rho<.04$. This suggests that, using the current data, the seven listed variables taken together account for 92% of the

variance of numbers and time and that level of numbers and time could be accurately predicted from this model. Thus, a DS child who lives in a suburban area, whose parents initiated his/her first training program before the age of six, who has been involved in home-based training programs and structured social programs, whose family has engaged in frequent family-oriented activities, and whose intellectual level is in the moderately retarded range will function higher in the area of numbers and time.

Domestic Activity. The best regression model for domestic activity was a five variable model. The independent variables included in the model were as follows:

1. Geographic Location
2. Age Started First Program
3. Who Initiated First Program
4. Involved in Home-Based Programs
5. Family's Community Involvement

The R^2 value for this model was .81 ($F = 5.24$ $df = 5$) with a significance level of $\rho<.034$. This suggests that, using the current data, the five listed variables taken together account for 81% of the variance of domestic activity and that level of domestic activity could be accurately predicted from this model. Thus, a DS child who lives in a suburban area, who started his/her first training program--that his/her parents initiated--before the age of six, who has been involved in home-based training programs and structured

social programs, whose family has been actively involved in the community will function higher in the area of domestic activity.

Self Direction. The best regression model for self direction was a seven variable model. The independent variables included in this model were as follows:

1. Geographic Location
2. Involved in Home-Based Programs
3. Involved in Structured Social Programs
4. Opportunities for Peer Interaction
5. Family Oriented Activities
6. Family's Community Involvement
7. Child's Intellectual Level

The R^2 value for this model was .96 ($F = 18.09$ $df = 7$) with a significance level of $\rho<.007$. This suggests that, using the current data, the seven listed variables taken together account for 96% of the variance of self direction and that level of self direction could be accurately predicted from this model. Thus, a DS child who lives in a suburban area, who has been involved in home-based training programs and structured social programs, who has had opportunities for peer interaction, whose family have engaged in frequent family-oriented activities and have been actively involved in the community, and whose intellectual level is in the moderately retarded range will function higher in the area of self direction.

Responsibility. The best regression model for responsibility

was a seven variable model. The independent variables included in this model were as follows:

1. Geographic Location
2. Who Initated First Program
3. Involved in Home-Based Programs
4. Involved in Structured Social Programs
5. Opportunities for Peer Interaction
6. Family Oriented Activities
7. Child's Intellectual Level

The R^2 value for this model was .98 ($F = 45.82$ $df = 7$) with a significance level of $\rho<.001$. This suggests that, using the current data, the seven listed variables taken together account for 98% of the variance of responsibility and that level of responsibility could be accurately predicted from this model. Thus, a DS child who lives in a suburban area, whose parents initiated his/her first training program, who has been involved in home-based training programs and structured social programs, who has had opportunities for peer interaction, whose family have engaged in frequent family-oriented activities and have been actively involved in the community, and whose intellectual level is in the moderately retarded range will function higher in the area of responsibility.

Socialization. The best regression model for socialization was a six variable model. The independent variables included in this model were as follows:

1. Geographic Location

2. Who Initated First Program
3. Involved in Home-Based Programs
4. Involved in Structured Social Programs
5. Family Oriented Activities
6. Child's Intellectual Level

The R^2 value for this model was .91 ($F = 8.12$ $df = 6$) with a significance level of $\rho<.018$. This suggests that, using the current data, the six listed variables taken together account for 91% of the variance of socialization and that level of socialization could be accurately predicted from this model. Thus, a DS child who lives in a suburban area, whose parents initiated his/her first training program, who has been involved in home-based training programs and structured social programs, whose family has engaged in frequent family-oriented activities, and whose intellectual level is in the moderately retarded range will function higher in the area of socialization.

CHAPTER V

DISCUSSION

A. IMPLICATIONS OF THE STUDY

The purpose of this study was to gain information on home-reared adolescent DS children and their families, a population that has been addressed all too infrequently in the scientific literature. The main intent of the study was to descriptively report on the functioning of this defined group by noting the differences, commonalities, and trends of their abilities and experiences.

Adaptive Functioning. The nine areas (domains) of adaptive functioning were fairly consistent for the DS children. The ABS profiles for each child displayed little scatter among scores and, for the most part, the different areas of adaptive functioning appeared consistently developed; overall higher functioning children tended to have higher scores in all nine domains, and overall lower functioning children tended to have lower scores in all nine domains. When compared as a homogeneous sub-group to the larger more general population of profoundly to mildly mentally retarded individuals, the DS children displayed no relative deficits in their adaptive functioning. As a group, the DS children's adaptive functioning, as measured by ABS performance, was consistently at the mean level or above for each of the nine adaptive functioning domains when compared to normative data for the larger population

of retarded individuals. Further, as a sub-group, the DS children displayed significantly higher adaptive functioning in the areas of Domestic Activity, Self Direction and Responsibility.

All of this suggests that DS children may display different overall levels of adaptive functioning when compared to their DS peers, but as a group DS children display consistency in the different areas of adaptive functioning. When compared as a group to mentally retarded individuals in general, DS children display no obvious relative deficits or weaknesses in the various areas of adaptive functioning and in fact display relative strength in the area of domestic activity, self direction, and responsibility. Being able to perform household chores, initiate one's own activities, and assume responsibility are useful and necessary abilities for independent living and it may be--given their overall consistency of adaptive functioning, too--that DS individuals may have some advantage of potential for independent living over their non-DS mentally retarded counterparts.

Although adaptive functioning was assessed in terms of nine areas or domains, each DS child's nine ABS scores were fairly consistent and it was easy to postulate the level of overall adaptive functioning for each child. Each adaptive behavior domain correlated highly and significantly with all of the others, despite the very different behavior tasks keyed to each domain, and the level of functioning in a domain could be predicted from the level of functioning in a seemingly unrelated other domain. It appears, then, that whatever affects adaptive functioning--genetically

determined physiological limitation, environmental factors, or some combination thereof--affects the different aspects of adaptive functioning in a fairly uniform way for DS children. The behavioral manifestations of adaptive functioning probably will be internally consistent for each individual DS child; it is unlikely that a child will present outstanding relative strength in one area and/or glaring relative weakness in another area of adaptive functioning.

Intelligence and Adaptive Functioning. There was a suggestion from the current data that some relationship, albeit not significant, exists between intellectual level and level of adaptive functioning for DS children. While intelligence and adaptive functioning may covary, the implications for this finding are subject to wide interpretation and speculation.

The field of psychology has long debated the existence, characteristics, determination, and purpose of the concept called intelligence, and the scientific and otherwise literature of the field is replete with theories, explanations, truths, and descriptions of this elusive concept; the field is not united on either the philosophy or utility of intelligence. For this discussion, intelligence is merely that which is measured by intelligence tests (while acknowledging criticisms of intelligence testing).

That intellectual level and level of adaptive functioning may covary suggests some possible interaction between the two concepts. Perhaps the genetically determined physiological limitation, environmental factors, or whatever combination thereof that determines

intellectual and adaptive functioning in DS children, affects intelligence and adaptive behaviors in similar ways. Perhaps the distinction, and the separate behaviors that each respective type of test purports to measure may be more related than our imposed conceptualizations suggest. The behavioral tasks keyed to the adaptive functioning domains of Language Development and Numbers and Time are very similar to tasks assessed by intelligence tests, and yet Language Development and Numbers and Time were shown to be highly correlated with the dissimilar domains of Domestic Activity and Self Direction. The separate concepts of intelligence and adaptive behavior may well be similar aspects of some variable of overall behavioral functioning determined by genetically determined physiological limitations and environmental factors. Neither intelligence nor adaptive behavior necessarily predispose and/or predetermine one to the other.

Family Experiences. The individual descriptive family narratives and the synopsis of the 12 families' experiences suggested that it has not been easy for the families to raise a DS child in their homes. It is interesting, though, that none of the families complained of this responsibility and, instead, several commented that having had the experience of raising a DS child has been beneficial for their families. Almost all of the families stressed the importance of treating the DS child as much like a normal child as possible. However, society at large appears to have been less than supportive in this regard.

A major complaint common to most of the families was the availability of few appropriate and beneficial training and social programs and the lack of information, advice, and support from the professional community. This complaint has social, political, and economic ramifications and will need to be addressed by the larger societal system. A DS child will not be treated like a normal child as long as he/she is relegated to the status of second class citizen with inferior programs and general neglect by the ostensibly altruistic professional community. There appears to be a need for greater education of the general public on DS, mental retardation, and other handicaps so that these populations can receive the financial, social, and moral support they need and deserve. The families' experiences indicated that the difficulties of raising a DS child go beyond the internal family system and implicate the larger societal system.

In spite of the seeming lack of support from society and their communities, many families have been very active and tenacious in their respective child's training and development. With these families, the involvement appears to have extended to the family and community as well. The families appeared to be fairly consistent in the absence or presence of the different identified family events and experiences variables. Simply put, some families have been consistently actively involved in their child's development and training, involved within their families, and active in their communities while other families consistently have not. The different vairables were highly correlated with each other and it appears that

families were fairly consistently high or low across these variables. What causes some families to be more active than others can not be ascertained from the current data but it is clear that some families consistently take greater initiative, make greater effort, and are generally more involved than others.

Relationship of Adaptive Functioning to Family Experience Variables. Having noted that adaptive functioning is fairly consistent across domains and that families are either consistently high or low on the different family experience variables, it was suggested that level of adaptive functioning was related to the family experience variables. The series of frequency distributions of overall adaptive functioning ranks by the family experience variables and the regression models for each of the adaptive functioning domains indicated that DS children who display higher adaptive functioning come from families that are generally more active and have been more involved in their child's training and development.

While a definite cause and effect relationship can not be asserted from the current data, it is clear from the non-manipulative observation and description of the 12 DS children and families that the families that have been family oriented, active with their community, active in securing and participating in their child's programs and generally involved with their child have children that display higher adaptive functioning. The consistency of the family activity/involvement across different variables suggests that there may be some type of underlying attitude, orientation, motivation,

and/or characteristic common to these families. This hypothesized activity/involvement orientation appears to be fairly entrenched in the families' characteristic style of behavior and also appears to be present across time. It is reasonable and likely that this family activity/involvement orientation allows for an environment that is conducive to the development and maintenance of appropriate and useful adaptive behaviors. Thus, a DS child that benefits from an environment that is enriched by a family orientation toward activity/involvement may display higher adaptive functioning than a child that does not. Recognizing that a cause and effect relationship has not been established and that it is possible that unidentified intervening variables may account for the relationship between family activity/involvement and adaptive functioning, it still appears prudent to suggest that the greater the family's orientation towards activity/involvement can be, the higher the child's adaptive functioning will be.

B. APPLICATIONS OF THE STUDY

While the main purpose of this study was merely to report descriptively on the functioning of home-reared adolescent DS children and their families--the "necessary first steps"--the study has value for applied use.

Normative Data. The results of the DS children's performance on the ABS, as presented in synopsis form, can serve as normative information for the adaptive functioning of home-reared adolescent

DS children. Professionals working with DS children and their families have had need of accurate normative data on DS children's adaptive skills and behaviors to best plan and implement training programs and to counsel parents on relative expectations.

The synopsis presents the specific behaviors that this particular sub-group of DS children were able to perform for each adaptive behavior domain and, thus, offers a descriptive reference for the adaptive functioning for this population. In addition to the descriptive synopsis, the compilation of ABS percentile scores for each domain allows numerical data on adaptive functioning for home-reared adolescent DS children. The ABS percentile tables in the ABS manual are normative data for mental retardation in general, the table in this study is specific to DS and, thus, can be used by professionals dealing with the adaptive functioning of this particular defined population.

Information for Parents of DS Children. The descriptive family narratives can be used by parents of newborn DS children to gain information on the experiences that other families have had with DS children. A complaint of families starting out with a DS child is that they don't know what to do, what to expect or how to proceed with their child. Having other families' experiences available in narrative descriptive form may provide information and insight on what life with a DS child in the family can be like. Often, parents need to be reassured that they are not the only ones to have faced the task and responsibility of raising a child

with special needs and demands. The descriptive family narratives present in a realistic fashion the experiences, issues, and difficulties of families that have raised DS children in the home and this information can be useful for parents just starting to raise their newborn DS children at home.

Program Development to Improve Adaptive Functioning. Given the discussed relationship between family activity/involvement orientation and adaptive functioning, it is logical to assume that programs that increase this orientation variable may see long-term improvement in the level of adaptive functioning. In addition to the need for research that this indicates, it also suggests the possible applied value of professionals developing programs that can improve this family activity/involvement orientation. Programs of an educational nature for families with DS children can be developed that address the variables from the regression models for each of the nine adaptive functioning domains. Families can be instructed that particular family events, experiences and/or activities can result in improvement in their child's adaptive functioning. In short, professionals counseling families with DS children can use the information from this study on the relationships of family activity/involvement variables and adaptive functioning to develop programs to improve the DS child's level of adaptive functioning.

C. LIMITATIONS OF THE STUDY

This study was concerned with adolescent home-reared DS

children and their families and, as such, makes no claims to generalizability to other age ranges, institutionalized populations, or other geographical areas. A distinction was made between home-reared and institutionalized DS children and it is unlikely that the normative information on adaptive functioning is applicable to institutionalized children.

Generalization to other age ranges may also be inaccurate. The population studied was adolescent DS children between the ages of 12 and 16. These children were born in the mid to late 1960's and grew up in a social and political climate somewhat different than 1980. Mandatory public education for the handicapped, directives and rulings have only recently been implemented and current school and training programs have vastly improved. Thus, the issues that these families of adolescent DS children have faced may be different than and not apply to issues and problems of families of other age ranges of DS children.

Generalization to other geographical areas also may be inaccurate. While DS is a specific genetic disorder and the children with this disorder are fairly homogeneous, cultural and other factors affecting a family in East Tennessee may be quite different from those of a family from an industrialized northern city. Social, cultural, political, and economic factors may preclude generalization of results of families of DS children in East Tennessee to families of DS children in other geographical areas.

Another limitation of the study is the nature of the data. Most of the information obtained on the families was self report data

and, as such, can be of questionable reliability and validity. However, the main purpose of the study was to gain information on the experiences of DS children and their families, and as such, the most appropriate way of obtaining this initial data was by talking with DS children and their families.

D. DIRECTIONS FOR FUTURE RESEARCH

There is a need for more research in the field of mental retardation, in general, and in DS specifically. The medical literature on DS is fairly complete, but the psycho-social-educational literature is dismally lacking. The areas of family and adaptive functioning need more attention.

A next step in the study of DS children and their families is to obtain basic descriptive information on other age ranges. Only when this basic descriptive material--the "necessary first step"--has been obtained and catalogued on all age ranges can the researcher adequately and completely plan a useful investigative research program.

An area that needs further research is the investigation of the relationships of family and community activity and involvement to the level of the DS child's adaptive functioning. There are clear indications from the current study that DS children with relatively higher adaptive functioning seem to have families who are more active and involved in their families and communities. This relationship needs to be further investigated and the issue of cause and effect needs to be addressed.

The hypothesized concept of some type of family activity/involvement orientation needs to be further explored and specified. There is good preliminary evidence that some families are higher than others on this dimension and the parameters of this family dimension need to be investigated. Perhaps a next step would be an involved research project that would investigate family and community interaction patterns using unobtrusive direct observation and objective report of pre-specified behaviors that are subject to reliability checks. Families with non-DS retarded children and with normal children also would have to be included with this study to determine whether this hypothesized family dimension is specific to DS.

Following specification of this family dimension, an experimental study that manipulates or controls the hypothesized variables to determine the effect on adaptive functioning would be appropriate and necessary. A program that attempts to instruct or train families that on their own have not displayed evidence of this family activity/involvement orientation dimension can ascertain whether the dimension can be taught and, if so, whether the same effects on adaptive functioning hold true. The value for applied use, as addressed earlier, is promising.

Finally, there is a continuing need for more descriptive information on DS in general to assist parents of DS children who do not know what to expect from their child or how to proceed in his/her training and development. Professionals also have need of this

descriptive information so that they can move beyond their badly outdated speculative folklore on DS children and their families.

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APPENDICES

APPENDIX A

Down's Syndrome Children and Their Families - Consent Form

The purpose of this project is to learn more about Down's Syndrome children and their families. You will be asked questions about your child for an adaptive behavior scale. This will give an idea of the different things your child is able to do. You will also be asked to talk about your child and your family and what you do at home and in your community. This discussion will be tape recorded to make it easier to study later. This tape will be kept confidential and will be erased after it is studied. At any point in the discussion you may request that the tape be stopped and/or erased.

If at any time you have any questions, please feel free to call me; I will be glad to answer any questions about this project. I am also available to discuss any services that may be helpful to your child or family through the Birth Defects Evaluation Center or other agencies.

John L. Hawley, Jr., M.A.
Project Director
Home Phone: 615-637-2548
Office Phone: 615-971-3911

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I agree to have my child and family participate in the Down's Syndrome Children and Their Families Project. I understand that my identity will remain confidential and agree that the project director is free to publish the results of this project. I understand that I am free to withdraw my consent and participation with the project at any time.

Name_____

Signed_____

Date_____

APPENDIX B

1. Describe the geographical area of the family's home.
2. What is the proximity of the family's home to the nearest town?
3. What is the size of the nearest town?
4. What is the type of density of the neighborhood of the family's home?
5. What type of dwelling does the family live in?
6. Describe the family's home in terms of size, age, and appointments.

APPENDIX C

1. Describe your current and past family composition and living arrangements.

2. Describe the formal training programs outside of the home that the child has been involved in (examples: schools, speech therapy).

   a. How did your child become involved in these programs?

   b. How beneficial have these programs been?

3. Describe any activities or programs that you have done at home for your child's training (example: early stimulation programs).

   a. How did your child become involved in these programs?

   b. How beneficial have these programs been?

4. Describe any social activities or programs in the community that your child has been involved in (examples: scouts, recreation programs).

   a. How did your child become involved in these programs?

   b. How beneficial have these programs been?

5. Describe your child's informal interaction with his/her peers.

   a. What opportunities for peer interaction does your child have?

6. Describe any regular daily family schedules (examples: meal-time, bedtime, times parents are in the house).

7. Describe the activities that your family does together.

   a. How has your child been incorporated in these activities?

   b. Are there any associated problems?

8. Describe the family's routine trips into the community (example: grocery shopping).

   a. Does your child usually go along?

   b. Are there any associated problems?

9. Describe the family's special trips into the community (example: entertainment).

    a. Does your child usually go along?

    b. Are there any associated problems?

10. Describe the family's involvement with church and civic activities and organizations.

    a. How is your child incorporated in these activities?

    b. Are there any associated problems?

11. Describe the family's contacts with friends and extended family.

    a. How is your child incorporated in these contacts?

    b. Are there any associated problems?

12. Describe the interaction between your DS child and his/her brothers and sisters.

13. Describe the differences between raising your DS child and raising your other children.

14. What special problems have you faced raising a DS child in your family?

15. What has been most helpful in raising your child?

16. How has having a DS child changed your family?

17. Where do you see your child ten years from now?

    a. What thoughts or plans do you have for his/her future?

18. What advice do you have for other families of DS children or for professionals working with DS children and their families?

VITA

John L. Hawley, Jr. was born in Okinawa on April 2, 1953. He attended elementary, junior high, and high school in Fairfax County, Virginia and graduated from George C. Marshall High School in June 1971. The following September he entered George Mason University in Fairfax, Virginia and he received a Bachelor of Arts degree with a major in Psychology in May 1975. He stayed at the George Mason University to begin his graduate studies and he received a Master of Arts degree with a major in Psychology in May 1977.

Mr. Hawley entered the Graduate School of The University of Tennessee, Knoxville in September 1977. He received the Doctor of Philosophy degree with a major in Psychology in March 1982, after completing an internship in clinical psychology at the Alexandria Community Mental Health Center in Alexandria, Virginia.

Mr. Hawley is currently employed as a clinical psychologist with the Northwest Center for Community Mental Health in Reston, Virginia. He is married to the former Cynthia Lea Hibbs of Vienna, Virginia.