MYELOMENINGOCELE, MENINGOCELE AND THE EFFECTS OF EARLY INFANT EDUCATION

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF EDUCATION IN THE GRADUATE SCHOOL OF THE TEXAS WOMAN'S UNIVERSITY

COLLEGE OF EDUCATION

ΒY

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DENTON, TEXAS AUGUST, 1982

DEDICATION

. . . to Jon Paul, who made this study so necessary.

ACKNOWLEDGMENTS

No research project is ever accomplished by only one person, and this study is no exception. Sincere appreciation goes to many individuals for their constant assistance and encouragement.

To Mr. Loyd Martin and the many wonderful therapists at Dallas Society for Crippled Children, I extend my sincere appreciation for answering my innumerable questions and for providing such a stimulating location for the study.

I am also indebted to Joanne Cafiero of the Dallas Spina Bifida Association for her assistance in locating a population, and to all the parents who viewed this as a worthy project and allowed their children to participate.

Thank you is not enough to say for the constant source of encouragement, and never ending sense of humor I found in my committee chairman, Dr. Michael Wiebe. This project would never have been completed without his direction. To my other committee members, including Dr. Chester Gorton, Dr. Wallace Edge, Dr. Marjorie Keele and Dr. Claudine Sherrill, I thank you

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for your many suggestions and recommendations.

I am particularly indebted to Dr. Ernest Watkins for his guidance throughout my studies, and in his providing the opportunity for me to teach at the university level. I am extremely grateful.

A very special thank you goes to my talented cousin, Allen Dixon, for the excellent illustrations. To my many friends, but especially to my wonderful mother, I will be forever indebted for their understanding and forgiving all the things left undone, all the occasions unattended, for all the things left unsaid and the many instances when I seemed so preoccupied.

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CHAPTER I

Introduction

"Myelomeningocele, meningocele and spina bifida are open defects in the spinal canal due to abnormal fetal development and comprise the most serious and handicapping disorder in children" (Bleck, 1975, p. 181). The term spina bifida is often used to represent all three forms when in actuality the conditions are very different. In myelomeningocele, there is an outpouching of the spinal cord through the incompletely formed vertebral column (Bleck, 1975; Brunt, 1980). Meningocele is similar except that the outpouching contains only the covering of the spinal cord and not the cord itself (Bleck, 1975). Matthews and Miller (1972) emphasized the seriousness of meningo-myelocele forms. Both types are immediately diagnosable at birth because of the obvious swelling over the lower spine (rarely in the cervical area). Without immediate medical intervention ulceration and infection of the enlarging sac is almost inevitable.

When an infant is diagnosed as meningocele, the nerve pathways to the lower part of his body usually

function normally and paralysis is not usual. Apgar and Beck (1972) noted that the prognosis for the myelomeningocele infant is neither simple or optimistic. Because the abnormality occurs early during fetal life, many major nerves will not have developed in a normal manner. Flaccid paralysis of the lower limbs and trunk is a common symptom. Control of the sphincters used in bladder and bowel control may never be achieved.

The third type of incomplete closure of the neural tube or of its coverings is spina bifida occulta (Matthews and Miller, 1972). This is generally a harmless condition caused by the incomplete formation of the posterior arches of one or several vertebrae. In such cases, the individual and/or physician may be completely unaware the condition exists until some injury to the area results in radiological studies being made.

Symptoms of overt hydrocephalus developed in 70% of cases following closure of the spinal defect (Matthews and Miller, 1972; Woods, 1975). Bleck (1975) found hydrocephalus to be an associated deformity in 90 to 95% of children with myelomeningocele. When hydrocephalus occurs, the cerebrospinal fluid builds up in the ventricles of the brain or in the spaces at the base

of the brain. Matthews and Miller (1972) reported that if hydrocephalus is allowed to advance unchecked, mental retardation, optic atrophy, ocular palsies and spastic weaknesses of the limbs are almost inevitable. Fortunately, permanent drainage systems (shunts) can frequently be used to relieve the pressure caused by excessive fluid, reducing secondary mental retardation and other clinical problems.

Statement of Problem

Apgar and Beck (1972) reported that until recent years few children survived with spina bifida for more than a few months. Those who survived were usually mentally retarded and severely handicapped. Because of the low survival rate, educational planning was considered unnecessary.

Ayrault (1964) and Conway (1977) believed that programs of stimulation for neurologically impaired infants should be provided in addition to routine health care. Denenberg (1970) and Nash (1970) reinforced Ayrault and Conway by proposing that the majority of spina bifida children could profit from an organized nursery education by the age of two years. However,

current literature reflects no educational programs for spina bifida children.

<u>Purpose</u>

This research project demonstrated the effects of an infant stimulation or early education program with children diagnosed as having myelomeningocele or meningocele type spina bifida. The stimulation program was conducted by professional therapists in a private facility for handicapped children. The specific behavioral changes of children involved in the stimulation program were compared to those of children who had not participated in such a program.

The Developmental Activities Screening Inventory (DASI) (DuBose and Langley, 1977) was used to assess the differences between the proposed research groups.

<u>Hypotheses</u>

Ho₁: There will be no significant differences in scores obtained by the DASI between children diagnosed myelomeningocele and who are involved in a stimulation program versus those who have not been involved in such a program.

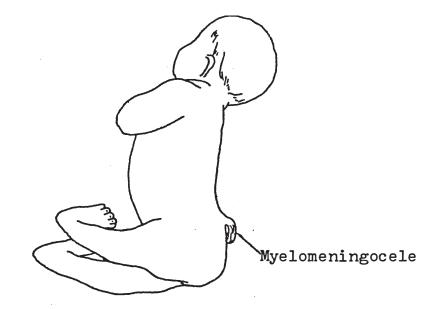
- Ho₂: There will be no significant differences in scores obtained by the DASI between children diagnosed meningocele and who are involved in a stimulation program versus those who have not been involved in such a program.
- Ho3: There will be no significant differences in scores obtained by the DASI between children diagnosed myelomeningocele and meningocele.

CHAPTER II

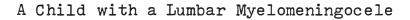
Review of the Literature

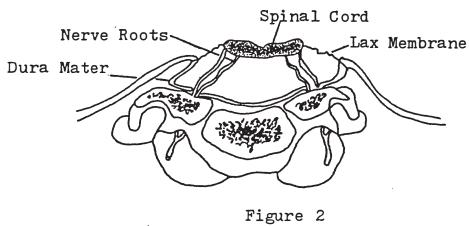
Every expectant parent has planned and counted upon producing a perfectly normal infant. Very few parents have considered the possibility that their child will be born with a serious handicapping condition and consequently find themselves filled with guilt, anger and despair when the attending physician informs them that their eagerly awaited infant has a life-threatening condition.

Approximately one out of 1000 live births will result in one form or another of spina bifida (Bleck, 1975). "Myelomeningocele, meningocele and spina bifida are open defects in the spinal canal due to abnormal fetal development and comprise the most serious and handicapping disorder in children" (Bleck, 1975, p. 181). The term spina bifida is often used to represent all three forms when in actuality the conditions are very different. As illustrated in Figures 1 and 2, in myelomeningocele, there is an outpouching of the spinal cord through the incompletely formed vertebral column (Bleck, 1975; Brunt, 1980). Meningocele, Figures 3 and









Cross Section of the Spinal Cord

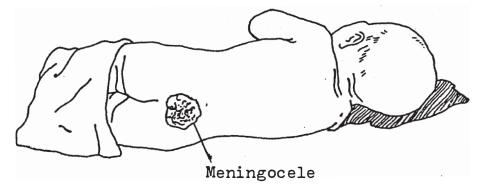
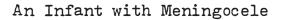


Figure 3



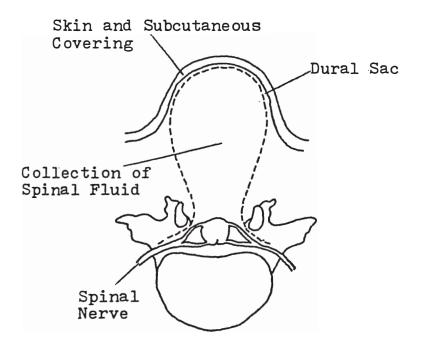


Figure 4

Cross Section of Spinal Cord and Vertebra

4, is similar except that the outpouching contains only the covering of the spinal cord and not the cord itself (Bleck, 1975). Some authorities refer to myelomeningocele and meningocele jointly as spina bifida cystica (Molnar and Taft, 1977). Matthews and Miller (1972) emphasized the seriousness of meningo-myelocele forms. Both types are immediately diagnosable at birth because of the obvious swelling over the lower spine (rarely in the cervical area). Without immediate medical intervention, ulceration and infection of the enlarging sac is almost inevitable. Lorber (1971) found the "overwhelming majority of untreated infants with myelomeningocele die early in life" (p. 280).

When an infant is diagnosed as meningocele, the nerve pathways to the lower part of his body usually function normally and paralysis is not usually present. Apgar and Beck (1972) noted that the prognosis for the myelomeningocele infant is neither simple or optimistic. Because the abnormality occurs early during fetal life, many major nerves will not have developed in a normal manner. Flaccid paralysis of the lower limbs and trunk is a common symptom. Control of the sphincters used in bladder and bowel control may never be achieved. Ventriculitis is the most serious threat to the life and

subsequent development of a myelomeningocele infant (Lorber, 1971). Ventriculitis can occur during the newborn period because of infection of the myelomeningocele site or later in children with a shunt system for the treatment of hydrocephalus.

The third type of incomplete closure of the neural tube or of its coverings is spina bifida occulta (Matthews and Miller, 1972; Molnar and Taft, 1977). This is generally a harmless condition caused by the incomplete formation of the posterior arches of one or several vertebrae. In such cases, the individual and/or physician may be completely unaware the condition exists until some injury to the area results in radiological studies being made. In a few instances there may be some malformation of the spinal cord and nerve roots at the point of the defect giving rise to some lower extremity weakness. This weakness may become obvious when the child begins to walk but rarely causes significant limitations (Molnar and Taft, 1977).

Symptoms of overt hydrocephalus developed in 70% of cases following closure of the spinal defect (Matthews and Miller, 1972; Woods, 1975). Bleck (1975) found hydrocephalus to be an associated deformity in 90 to 95% of children with myelomeningocele. When hydrocephalus

occurs, the cerebro-spinal fluid builds up in the ventricles of the brain or in the spaces at the base of the brain. Lorber (1971), Matthews and Miller (1972) reported that if hydrocephalus is allowed to advance unchecked, mental retardation, optic atrophy, ocular palsies and spastic weaknesses of the limbs are almost inevitable. Fortunately permanent drainage systems (shunts) can frequently be used to relieve the pressure caused by excessive fluid, reducing secondary mental retardation and other clinical problems.

Bleck (1975) found some form of spina bifida occurs in children between 0.1 and 4.13 times in 1000 live births with no definite racial or genetic patterns. Other authorities disagree. Molnar and Taft (1977) note the incidence of neural tube defects in Ireland and among Irish descendants living elsewhere is rather high. Woods (1975) found the causes to be multifactorial with a higher incidence of first born children and children of birth orders five or over. J. M. Elwood (1976) found the prevalence of spina bifida to vary with impersonal factors such as geography, year and season, and with personal factors such as race, age, parity and socioeconomic status of the mother. In reporting a study done by Renwick, Woods (1975) suggested a teratological

cause, i.e., blight in potatoes. A high incidence of spina bifida and hydrocephalus occurring in winter was reported by British general practitioners in Canada. This trend has been seen in the United States as well, but without further study is inconclusive (J. M. Elwood, 1976).

Spina bifida is more common in the United States among the white population than in blacks. The incidence in Jewish births has been found to be low and almost nonexistent in Indian births (J. M. Elwood, 1976). There is a higher level of spina bifida in Britain in areas with soft water; infant death rates from spina bifida are also greater in those areas of the United States with soft water supplies. J. M. Elwood (1976) and Woods (1975) are in agreement that there is an increased incidence of spina bifida in the lower social classes.

J. M. Elwood (1976) and Laurence (1976) found an excess of girls are born with spina bifida, but the proportion of boys increases with gestational age and is greater in live infants rather than stillborn infants. By the age of nine or ten, more boys have survived. Surviving females are usually more handicapped.

Currently, research is in progress in the United Kingdom into secondary prevention of "open" spina bifida cases by identifying elevated levels of alphafetoprotein in the amniotic fluid and in the maternal blood prior to 20 weeks gestation. The results to date suggest that elevated levels of alpha-fetoprotein may be associated with fetal malformations of both the Central Nervous System and of other body systems (J. H. Elwood, 1976). British researchers suggest that this screening may eventually become a routine procedure in geographic areas known to have a high incidence of myelomeningocele (Molnar and Taft, 1977).

Apgar and Beck (1972) noted that until recent years very few children survived with spina bifida for more than a few months, and those who did were usually mentally retarded and severely handicapped. Because of the low survival rate, little educational planning was developed. Ayrault (1964) and Conway (1977) believed that in addition to providing routine health care, programs of stimulation should be provided for neurologically impaired infants. Denenberg (1970) and Nash (1970) reinforced Ayrault and Conway by proposing that the majority of spina bifida children could profit by an organized nursery education by the age of two years.

Tizard (1968) saw the social and educational problems of children having spina bifida as extraordinarily complex.

Nationwide interest in infant education programs in the United States is of fairly recent origin. "It is significant that most current national interest in infant care is not for the express purpose of improved quality of experience for the infant, but to provide custodial day care for children of working parents" (Lambie, Bond and Weikart, 1975, p. 263). Most early education programs have focused on low income and/or minority group children in an effort to help them cope more effectively in the mainstream of society (Lambie, Bond and Weikart, 1974).

Austin (1976) and Bronfenbrenner (1975) suggested that without family involvement, intervention is likely to be unsuccessful. Nielson, Collins, Meisel, Lowry, Engh and Johnson (1975) assumed in their program that the earlier the identification and intervention the better. They agreed with Austin and Bronfenbrenner that the parents are the "primary programmers" of their infants and should therefore be a central focus in any intervention program. In a study conducted by Gordon (1969) it was found that para-professionals can be used to teach mothers how to stimulate their children, and

that a parent education program should be part of a comprehensive system. In further study Gordon and Jester (1972) concluded that professionals generally worked more effectively with girls and their mothers while para-professionals were equally effective with both sexes.

According to Sluckin (1971), "What the infant learns depends both on his learning capacity and on the opportunity for learning provided by the environment" (p. 11). Hebb (1971) theorized "that all learning tends to utilize and build on any earlier learning, instead of replacing it so that much earlier learning tends to be permanent" (p. 103). While most research has focused upon normal infants, several studies have found that handicapped infants can benefit from early teaching (Kaiser and Hayden, 1977; White, 1979). Every handicapped infant is an individual with unique needs. Special programs must be designed to meet their special needs.

CHAPTER III

Method

This study assessed the differences between groups on scores as obtained on the Developmental Activities Screening Inventory (DASI) (DuBose and Langley, 1977). All children selected for this study had been medically diagnosed as having myelomeningocele or meningocele type spina bifida.

Procedure

<u>Subjects</u>

Group I was to consist of 15 children diagnosed as myelomeningocele and who had been seen at Dallas Society for Crippled Children in their infant or early childhood program.

Group II was to consist of 15 children diagnosed as meningocele and who had been seen at Dallas Society for Crippled Children in their infant or early childhood program, but no children who met this condition were available for the study.

Group III was to consist of 15 children who had been diagnosed as either myelomeningocele or meningocele but

had not been seen in any infant or early childhood program.

Criteria for matching included medical diagnosis, intellectual functioning, age, sex, race and socioeconomic level where feasible. The preciseness of each match depended upon the availability of the subjects given the rareness of the disorder and the limited number of treatment facilities.

Dallas Society for Crippled Children provides an Infant Development Program for any high risk infant between the ages of zero and two years. Although the program includes infants with a diagnosed neurological problem, no diagnosis beyound "high risk" is mandatory. The Infant Development Program is based on a team approach using professionally certified occupational therapists, physical therapists, speech language pathologists and social workers who provide the special skills necessary to promote physical, pre-speech and language, mental, social and emotional growth in the infant. All therapists have received special training in infant education.

One of the primary goals of the Infant Development Program is to utilize the parents as an important member of the "team" so that easier and more effective management of the infant will occur in the home situation. The

social services provided by Dallas Society for Crippled Children assist the parents through individual or group counselling in understanding and accepting their child's problems while concurrently learning the mechanics of daily living.

Infants from zero to 18 months are seen one day a week for 45 to 90 minute sessions, the time being dependant upon the parents inclusion in the parent training group. During the weekly therapy session the infant is seen by all members of his team.

The physical and occupational therapists at Dallas Society for Crippled Children follow the neurodevelopmental approach to treatment (previously known as the "Bobath approach"). The treatment consists of inhibiting abnormal reflex activity while advancing the child's motor behavior from its lowest level, filling in the gaps, and advancing him on a broad front (Pearson and Williams, 1972). "The problem of treatment is not one of strengthening or relaxing individual muscle groups, but one of improving the coordination in posture and movement and of obtaining a more normal postural tone" (Pearson and Williams, 1972, p. 114).

All treatment provided by this method involves "handling" the child in order that postural tone can be

reduced, increased and steadied. Normal responses to handling can be facilitated while abnormal patterns can be inhibited.

A great deal of handling continues for the first three years or longer. During this period the child will acquire all the basic patterns of many higher skills by first helping and cooperating with the therapist before doing them alone. "The learning of movements, like any other process of learning, takes place with the help and guidance of sensory messages. A child does not learn a movement but rather, the 'sensations of movements'" (Pearson and Williams, 1972, p. 115).

As it is necessary to treat the whole child, no division can be made between those responsible for the treatment and management. Pearson and Williams (1972) found that a united team must have the same fundamental approach and the same concept of treatment in order to plan and execute an integrated and well coordinated treatment program. The Infant Development Program at Dallas Society for Crippled Children follows such a plan.

The occupational therapist works toward the development of normal body movements and positions for the future development of hand skills including reach, grasp and release, as well as eye-hand coordination, handedness,

perception, and self-help skills. When the child is physically and mentally ready, constructive play, prewriting, feeding and early dressing activities are introduced. In addition to the neurodevelopmental approach to treatment, the occupational therapist will use special techniques of sensory and perceptory training such as that provided by the Frostig materials and Jean Ayers.

The overall goal of the physical therapist is to make handling of the child easier and to allow the child to reach his full physical potential. This goal is achieved by assessing the infant's motoric development and teaching the parents specific skills in handling their child. Techniques used may consist of progressive developmental training (head control, sitting balance), generalized or specific strengthening activities, maintenance of range of motion, positioning for prevention of deformity, relaxation techniques, and utilization of special adaptive equipment. The primary treatment method is the neurodevelopmental approach.

The speech language pathologists assist the team in evaluating and encouraging the infant's pre-speech, language and cognitive development. Here again, the speech language pathologist works closely with the

infant's parents by making them aware of ways in which they can provide experiences and opportunities in language which will benefit their child's overall intellectual, emotional and social growth. Of primary importance to the speech language pathologist is the sequence of development of oral patterns and any delay or abnormal deviation in the child. The speech language pathologist may also demonstrate feeding techniques to assist the speech mechanism, coordinate breathing and facilitate health and nutrition.

High risk infants are evaluated every six months by the team members unless the attending physician finds it necessary to evaluate more frequently. From these evaluations new goals are set with measurable objectives listed.

From the age of 18 months, the child's weekly sessions increase in number from one time a week to two or four days depending upon his individual needs. At this time the child's team of specialists may also be adjusted as he enters the Early Childhood Developmental Education Program.

Instrument

The Developmental Activities Screening Inventory

(DASI) was used to evaluate each of the children (DuBose and Langley, 1977).

The DASI has been designed as an informal screening measure for children functioning between the ages of six and 60 months. Because the DASI is a non-verbal test, it does not penalize children with auditory impairments or language disorders (DuBose and Langley, 1977).

The 55 DASI test items are arranged in nine developmental levels and generate a developmental age score based upon a variety of skills including:

- 1) fine-motor coordination;
- 2) cause-effect and means-end relationships;
- 3) association;
- 4) number concepts;
- 5) size discrimination and
- 6) seriation.

The authors of the DASI reported four validity studies. One study compared the DASI to either the Infant Intelligence Scale or the Merrill-Palmer Scale of Mental Tests. Pearson product moment correlations were obtained to determine the relationship between the two sets of data. A significant correlation of .90 was obtained, indicating that the two sets of data are closely related (DuBose and Langley, 1977). When the same group of language delayed children's DASI scores were compared to receptive language scores obtained from the Receptive-Expressive-Emergent Language Scale of the Preschool Language Scale a correlation coefficient of .19 was obtained indicating that there is no significant relationship between DASI and receptive language (DuBose and Langley, 1977).

Another study of 42 delayed and nondelayed children between the ages of seven and 74 months compared the DASI, the Denver Developmental Screening Test (DDST) and the Preschool Attainment Record (PAR). A correlation coefficient of .95 was found when DASI and DDST scores were compared. A correlation coefficient of .97 was obtained between the DASI and PAR (DuBose and Langley, 1977).

When the DASI, PAR and DDST tests were compared on 14 day-care children with no known developmental delays ranging between the ages of 15 and 56 months, a correlation coefficient of .92 was obtained when DASI was compared with PAR and a coefficient of .87 was obtained when compared with DDST. Both coefficients were significantly beyond the .001 level (DuBose and Langley, 1977).

The DASI was designed to be administered by classroom teachers with a basic knowledge of child development.

Analysis of the Data

Following collection of the data, each subject's developmental age score obtained with the DASI was coded for computer analysis. The data were organized into the three groups defined for the study.

Group I was to consist of 15 children diagnosed as myelomeningocele and who had been seen at Dallas Society for Crippled Children in their infant or early childhood program.

Group II was to consist of 15 children diagnosed as meningocele and who had been seen at Dallas Society for Crippled Children in their infant or early childhood program, but no children who met this condition were available for the study.

Group III was to consist of 15 children who had been diagnosed as either myelomeningocele or meningocele but had not been seen at any infant or early childhood program.

Using SPSS Subprogram Oneway each of this study's null hypotheses were tested (Nie, Hull, Jenkins, Steinbrenner and Bent, 1975). Each analysis compared DASI scores according to the Following:

Ho₁: Group I versus Group III
Ho₂: Group II versus Group III
Ho₃: Group I versus Group II.

CHAPTER IV Results

Early educational intervention with preschool aged children has been an interest of educators for some time, but has rarely been considered for young children with spina bifida. Because of the historically low survival rate, educational planning was not considered necessary.

This study was proposed to determine the differences in scores obtained by the Developmental Activities Screening Inventory (DASI) between young children diagnosed myelomeningocele or meningocele and who were involved in a stimulation program as opposed to those who had not taken part in such a program. Due to the low incidence of the disorder the subjects for this study could not be randomly selected from a large population but were selfselected from a small group of available children. No children diagnosed as meningocele were found within the available population.

The demographic information about the subjects included in this study may be found in Appendix A. The subjects ranged in age from eight months to 41 months.

There were two subjects under the age of one year, four subjects between one and two years, three subjects between two and three years and five subjects between three and four years. Five subjects (34%) were male and nine (64%) were female. All 14 subjects were diagnosed myelomeningocele and 12 subjects had been shunted for hydrocephalus.

The differences between the subjects seen at Dallas Society for Crippled Children (DSCC) and the subjects not participating in such a program can be determined by reviewing the measures of central tendency in Table 1. With a mean chronological age (CA) of 36.14 months, the seven subjects seen at Dallas Society for Crippled Children had a mean developmental quotient (DQ) of 95.71 with a standard deviation (S) of 15.60. The seven control subjects (mean CA of 17.14 months) had a mean developmental quotient of 96.57 with a standard deviation of 23.54. As reported in Table 2, these scores were found to be non-significant with an <u>F</u> Ratio of .006. The critical value of <u>F</u> equaled 4.75.

Measures of Central Tendency

| for DSCC | and | Control | Subjects |
|----------|-----|---------|----------|
|----------|-----|---------|----------|

| Variable | DSCC Sur X | jects <u>S</u> | Control X | Subjects <u>S</u> |
|-------------------------------|---------------|-------------------|--------------|----------------------|
| Chronological Age (months) | 36.14 | 5.28 | 17.14 | 6.51 |
| DASI DQ | 95.71 | 15.60 | 96.57 | 23.54 |

| Tabl | е | 2 |
|------|---|---|
|------|---|---|

ANOVA Summary Table

| Source | <u>df</u> | <u>SS</u> | <u>MS</u> | <u>F</u> Ratio | |
|-----------|-----------|-----------|-----------|----------------|--|
| Treatment | 1 | 2.57 | 2.57 | .006 | |
| Error | 12 | 5583.14 | 465.26 | | |
| Total | 13 | 5585.71 | | | |
| | | _ | 1 | | |

Critical Value of F(.95, 1, 12) = 4.75

Because of the rejection of the null hypothesis, several post hoc analyses were performed to determine if any differences existed within groups.

The differences between the male subjects seen at Dallas Society for Crippled Children and the male subjects in the control group are reported in Table 3. With a mean chronological age of 35 months, the three subjects seen at Dallas Society for Crippled Children had a mean developmental quotient of 83 with a standard deviation of 5.72. The two subjects in the control group (mean chronological age of 17.5 months) had a mean developmental quotient of 101.5 with a standard deviation of 9.5. As reported in Table 4, these scores were found to be non-significant with an <u>F</u> Ratio of .058. The critical value of <u>F</u> equaled 10.13.

Table 3

Measures of Central Tendency

| between Male Subjects | | | | | | | |
|----------------------------|--------------|---------------------|--------------|---------------|--|--|--|
| Variable | DSCC Su X | ibjects <u>S</u> | Control X | Subjects S | | | |
| Chronological Age (months) | 35 | 5.72 | 17.5 | 8.5 | | | |
| DASI DQ | 83 | 7.79 | 101.5 | 9.5 | | | |

| Table 4 | Ta | bl | e | 4 |
|---------|----|----|---|---|
|---------|----|----|---|---|

| | A | 10VA Summary 1 | Table | |
|-------------|-----------|--------------------------------|-------------|----------------|
| Source | <u>df</u> | <u>SS</u> | <u>MS</u> . | <u>F</u> Ratio |
| Treatment | 1 | 410.7 | 410.7 | .058 |
| Error | 3 | 21147.5 | 7049.17 | |
| Total | 4 | 21558.2 | | |
| Critical Va | lue of | $\underline{F}(.95, 1, 3)^{=}$ | = 10.13 | |

The differences between the female subjects seen at Dallas Society for Crippled Children and the female subjects in the control group are reported in Table 5. The four subjects seen at Dallas Society for Crippled Children (mean chronological age of 37 months) had a mean developmental quotient of 105.25 with a standard deviation of 4.74. The five control subjects (mean chronological age of 17 months) had a mean developmental quotient of 94.6 with a standard deviation of 26.95. As reported in Table 6, these scores were found to be non-significant with an <u>F</u> Ratio of .410. The critical value of <u>F</u> equaled 5.59.

Table 5

Measures of Central Tendency

| between | Female | Sub: | jec ts |
|---------|--------|------|--------|
|---------|--------|------|--------|

| Variable | $\frac{DSCC}{\underline{X}}$ Sub | jects <u>S</u> | Control X | Subjects <u>S</u> |
|-------------------------------|----------------------------------|-------------------|--------------|----------------------|
| Chronological Age (months) | 37 | 4.74 | 17 | 5.51 |
| DASI DQ | 105.25 | 12.97 | 94.6 | 26.95 |

| Ta | bl | е | 6 |
|----|----|---|---|
| | | | |

ANOVA Summary Table

| Source | <u>df</u> | <u>SS</u> | <u>MS</u> . | <u>F</u> Ratio | |
|-----------|-----------|-----------|-------------|----------------|--|
| Treatment | 1 | 252.05 | 252.05 | .410 | |
| Error | 7 | 4303.95 | 614.85 | | |
| Total | 8 | 4556 | | | |

Critical Value of $F(.95, 1, 7)^{=} 5.59$

The differences between the male and female subjects seen at Dallas Society for Crippled Children are reported in Table 7. With a mean chronological age of 35 months, the three male subjects had a mean developmental quotient of 83 with a standard deviation of 7.79. The four female subjects (mean chronological age of 37 months) had a mean developmental quotient of 105.25 with a standard deviation of 12.97. As reported in Table 8, these scores were non-significant with an <u>F</u> Ratio of 4.96. The critical value of <u>F</u> equaled 6.61.

Table 7

Measures of Central Tendency

| among | DSCC | Subj | ects |
|-------|------|------|------|
|-------|------|------|------|

| Variable | Mal <u>e</u> Su X | ıbjects <u>S</u> | $\frac{\text{Female}}{\underline{X}}$ | Subjects <u>S</u> |
|-------------------------------|----------------------|---------------------|---------------------------------------|----------------------|
| Chronological Age (months) | 35 | 5.72 | 37 | 4.74 |
| DASI DQ | 83 | 7.79 | 105.25 | 12.97 |

| Tab | le | 8 |
|-----|----|---|
|-----|----|---|

| | AN | OVA Summary Ta | able | |
|-------------|--------|---------------------------------------|--------|----------------|
| Source | df | <u>SS</u> | MS | <u>F</u> Ratio |
| Treatment | 1 | 848.68 | 848.68 | 4.96 |
| Error | 5 | 854.75 | 170.95 | |
| Total | 6 | 1703.43 | | |
| Critical Va | lue of | ^F (.95, 1, 5) ⁼ | 6.61 | |

The differences between the male and female subjects in the control group are reported in Table 9. With a mean chronological age of 17.5 months, the two male subjects had a mean developmental quotient of 101.5 with a standard deviation of 9.5. The five female subjects (mean chronological age 17 months) had a mean developmental quotient of 94.6 with a standard deviation of 26.95. As reported in Table 10, these scores were non-significant with an <u>F</u> Ratio of .089. The critical value of <u>F</u> equaled 6.61.

Table 9

| Measures | of | Central | Tendency |
|----------|----|---------|----------|
| | | | |

among Control Subjects

| Variable | $\frac{Male Sub}{\underline{X}}$ | jects <u>S</u> | Female X | Subjects <u>S</u> | |
|-------------------------------|----------------------------------|-------------------|-------------|----------------------|---|
| Chronological Age (months) | 17.5 | 8.5 | 17 | 5.51 | - |
| DASI DQ | 101.5 | 9.5 | 94.6 | 26.95 | |

| | | Table 10 | | |
|-------------|--------|-----------------------------|--------|----------------|
| | AN | OVA Summary Ta | able | |
| Source | df | <u>SS</u> | MS | <u>F</u> Ratio |
| Treatment | 1 | 68.01 | 68.01 | .089 |
| Error | 5 | 3811.7 | 762.34 | |
| Total | 6 | 3879.71 | | |
| Critical Va | lue of | $\frac{F}{(.95, 1, 5)}^{=}$ | 6.61 | |

The differences between the total sample of males and the total sample of females are reported in Table 11. With a mean chronological age of 28 months, the five male subjects in the study had a mean developmental quotient of 90.4 with a standard deviation of 12.44. The nine female subjects (mean chronological age of 25.89 months) had a mean developmental quotient of 99.33 with a standard deviation of 22.50. As reported in Table 12, these scores were found to be non-significant with an <u>F</u> Ratio of .578. The critical value of <u>F</u> equaled 4.75.

Table 11

Measures of Central Tendency

Between all Male and Female Subjects

| Variable | Male Su X | bjects <u>S</u> | Female $\frac{\overline{X}}{\overline{X}}$ | Subjects S |
|-------------------------------|--------------|--------------------|--|---------------|
| Chronological Age (months) | 28 | 11.05 | 25.89 | 11.20 |
| DASI DQ | 90.4 | 12.44 | 99.33 | 22.50 |

Table 12

ANOVA Summary Table

| Source | <u>df</u> | <u>SS</u> | <u>MS</u> | <u>F</u> Ratio | |
|-------------|-----------|------------------------------------|-----------|----------------|--|
| Treatment | 1 | 256.51 | 256.51 | . 578 | |
| Error | 12 | 5329.2 | 444.1 | | |
| Total | 13 | 5585.71 | | | |
| Critical Va | lue of | <u>F</u> (.95, 1, 12) ⁼ | = 4.75 | | |

This study, utilizing measures of central tendency and analysis of variance indicates there were no significant global differences between groups. There were no overall significant differences between children within an early stimulation program and those not in such a program.

CHAPTER V

Conclusions and Recommendations

The purpose of this study was to demonstrate the effects of an infant stimulation or early education program with children diagnosed as having myelomeningocele or meningocele type spina bifida. The stimulation program was conducted by professional therapists at Dallas Society for Crippled Children. The specific behavioral changes of children involved in the stimulation program were compared to those of children who had not participated in such a program. According to the statistical results of this study there were no global significant differences between groups. There were no overall significant differences between children within an early stimulation program and those not in such a program.

Although there were no significant differences between groups based on the measures of central tendency and analysis of variance, one group approached significance on scores earned on the Developmental Activities Screening Inventory (DASI). This comparison measured the differences between DASI scores achieved by the

male and female subjects seen at Dallas Society for Crippled Children. The female subjects scored a mean developmental quotient (DQ) that was 22.25 points higher than the mean developmental quotient of the male subjects. No such tendency was recorded for any other grouping. This tendency may suggest that young female subjects benefit more readily from an early stimulation program than do young male subjects.

In comparing the demographic information about the subjects, there were several factors to consider. There were more female than male subjects in both groups, but the difference was pronounced within the control group where there were approximately 71% female subjects to 29% male subjects. There was also a wide difference between mean chronological ages for the two groups with the Dallas Society for Crippled Children subjects being older.

Several questions arose as a result of this study which indicate the need for further investigation. One question that needs consideration is what is the motivating factor that make some parents seek out an early stimulation program as opposed to those parents that do not see such a need? Is the motivating factor based upon medical recommendation, the family's views on

education, financial background or some combination of all of these?

If the decision is based upon medical recommendation, why is there such wide disagreement among the medical profession as to the value of such programs, or even the value of saving these infants' lives? Is there a need to educate physicians as to the increased capabilities of surviving spina bifida children?

A very important question, but one that cannot be answered immediately, is will there be differences between spina bifida children seen in early stimulation programs and those children not in such programs when they enter kindergarten or first grade? Subtle differences were observed during this study. The children seen at Dallas Society for Crippled Children appeared more independent, had more advanced language skills and were consistently more cooperative in the testing situation.

The findings of this study suggested a need for continued research to investigate the effectiveness of early stimulation programs designed for the very young spina bifida child. To ensure quality interventions, research must continue to investigate the many questions that continue to surround the spina bifida child.

APPENDICES

Appendix A

Demographic Information on Subjects

in Research Groups

| Varia | ble | DSCC Subjects | Control Subjects |
|--------|---|-----------------------|----------------------------|
| CA: | 6 to 11 months 12 to 17 months 18 to 23 months 24 to 29 months 30 to 35 months 36 to 41 months | 0 0 2 0 5 | 2 1 3 1 0 0 |
| Sex: | Male Female | 3 4 | 2 5 |
| Hydroc | cephalus (Shunted) | 7 | 5 |
| Brain | Stem Damage | 1 | 0 |

Appendix B

| Variable | Sex | CA | DA | DQ |
|------------------|--------|----------------------|----------------------|------------|
| DSCC Subjects | | | | |
| 01 | Μ | 27 | 22 | 82 |
| 02 | F | 29 | 32 | 110 |
| 03A 04 | M F | 29 38 38 40 | 32 28 43 46 | 74 113 |
| 04 05 06 | F | 40 | 46 | 115 |
| 06 | M | 40 | 37 | 93 |
| 07 | F | 41 | 37 34 | 93 83 |
| Control Subjects | | | | |
| 01B | F | 8 | 11 | 138 |
| 02 | M | 9 14 | 10 | 111 |
| 030 | F | 14 | 8 | 57 |
| 04 0 FB | ד ת | 18 | 14 22 | 78 |
| 05B 06 | F F | 22 23 | 23 | 100 100 |
| 07 | M | 26 | 23 24 | 92 |

Raw Data for All Subjects

A Brain Stem Damage B No Hydrocephalus C Spinal defect not surgically closed for four weeks; shunted at five weeks

Appendix C

General Permission Forms

CONSENT TO PARTICIPATE IN PRE-SCHOOL RESEARCH PROJECT

Dallas Society for Crippled Children is participating in a research project which will study the effectiveness of an infant stimulation or early education program with children diagnosed as having myelomeningocele or meningocele type spina bifida. The specific behavioral changes of children involved in the stimulation program will be compared to those of children who have not participated in such a program. Susan Blanchard, the primary researcher, will evaluate each child using the Developmental Activities Screening Inventory (DASI).

It is asked that parents of children involved in this program permit Miss Blanchard to use the statistics obtained from the test as part of a dissertation paper at Texas Woman's University. No identifying information regarding the child will be used in writing the research. You may withdraw your permission at any time.

If you would like additional information contact Susan Blanchard, 337-8776. Please complete the form below and return to Dallas Society for Crippled Children as soon as possible.

I give permission for my child:

Name

_ to participate in the Pre-School

Date of Birth

research project at the Dallas Society for Crippled Children. I understand that scores obtained will be used in a research dissertation, but that all identifying information will remain confidential.

Signature

Relationship

Date

Witness

No medical service or compensation is provided by Texas Woman's University as a result of injury from participation in research.

CONSENT TO PARTICIPATE IN PRE-SCHOOL RESEARCH PROJECT

The Dallas Spina Bifida Association is participating in a research project which will study the effectiveness of an infant stimulation or early education program with children diagnosed as having myelomeningocele or meningocele type spina bifida. The specific behavioral changes of children involved in the stimulation program at Dallas Society for Crippled Children will be compared to those of children who have not participated in such a program. Susan Blanchard, the primary researcher, will evaluate each child using the Developmental Activities Screening Inventory (DASI).

It is asked that parents of children involved in this organization permit Miss Blanchard to use the statistics obtained from the test as part of a dissertation paper at Texas Woman's University. No identifying information regarding the child will be used in writing the research. You may withdraw your permission at any time.

If you would like additional information contact Susan Blanchard, 337-8776. Please complete the form below and return to her at 2646 Texas Drive, Dallas, Texas 75211 as soon as possible.

I give permission for my child:

Name

_ to participate in the Pre-School

Date of Birth

research project at the Dallas Society for Crippled Children. I understand that scores obtained will be used in a research dissertation, but that all identifying information will remain confidential.

Signature

Relationship

Date

Witness

No medical service or compensation is provided by Texas Woman's University as a result of injury from participation in research.



June 14, 1982

Re: Susan Blanchard Spina Bifda Study

TO WHOM IT MAY CONCERN:

The Dallas Society for Crippled Children supports the study that Susan Blanchard is doing with spina bifida children. We have assisted Mrs. Blanchard in locating children and parents to be in the study. We have worked with Mrs. Blanchard in securing the parents' permission. The Dallas Society for Crippled Children is providing space for Mrs. Blanchard to perform her study.

Sincerely,

Loyd F. Martin Program Director

LFM:gw

REFERENCES

- Apgar, V., & Beck, J. <u>Is my baby all right?</u> New York: Trident Press, 1972.
- Austin, G. R. <u>Early childhood education: An inter-</u> <u>national perspective.</u> New York: Academic Press, 1976.
- Ayrault, E. W. <u>You can raise your handicapped child.</u> New York: G. P. Putnam's Sons, 1964.
- Bleck, E. E. Myelomeningocele, meningocele, spina bifida. In E. E. Bleck & A. A. Nagel (Eds.), <u>Physically handicapped children: A medical atlas</u> for teachers. New York: Grune & Stratton, 1975.
- Bronfenbrenner, U. Is early intervention effective? In B. Z. Friedlander, G. M. Sterritt & G. E. Kirk (Eds.), <u>Exceptional infant</u> (Vol. 3). New York: Brunner/Mazel, 1975.
- Brunt, D. Characteristics of upper limb movements in a sample of meningomyelocele children. <u>Perceptual</u> and Motor Skills, 1980, <u>51</u>, 431-437.
- Conway, B. L. <u>Pediatric neurologic nursing.</u> St. Louis: C. V. Mosby Co., 1977.
- Denenberg, V. H. (Ed.). <u>Education of the infant and</u> young child. New York: Academic Press, 1970.
- DuBose, R., & Langley, M. B. <u>D.A.S.I. Developmental</u> <u>activities screening inventory</u>. New York: Teaching Resources, 1977.
- Elwood, J. H. Anencephaly and spina bifida in the British Isles. In S. Kelly, E. B. Hook, D. T. Janerich & I. H. Porter (Eds.), <u>Birth defects</u>, <u>risks and consequences</u>. New York: Academic Press, 1976.

- Elwood, J. M. Anencephalus and spina bifida in North America. In S. Kelly, E. B. Hook, D. T. Janerich & I. H. Porter (Eds.), <u>Birth defects, risks and</u> <u>consequences.</u> New York: Academic Press, 1976.
- Gordon, I. J. <u>Early child stimulation through parent</u> <u>education</u>. Washington, D. C.: U. S. Department of Health, Education & Welfare, National Institute of Education, 1969. (ERIC Document Reproduction Service).
- Gordon, I. J., & Jester, R. E. <u>Instructional strategies</u> <u>in infant stimulation</u>. Gainesville, Florida: Institute for Development of Human Resources, 1972. (Journal Supplement Abstract Service Document, American Psychological Assoc.), 1972, <u>2</u>, 122.
- Hebb, D. O. The relation of early to later learning. In W. Sluckin (Ed.), <u>Early learning and early</u> <u>experience, selected readings.</u> Baltimore: Penguin Books, 1971.
- Kaiser, C. E., & Hayden, A. H. The education of the very very young or but what can you teach an infant. <u>Educational Horizons</u>, 1977, <u>56</u>(1), 4-15.
- Lambie, D. Z., Bond, J. T., & Weikart, D. P. <u>Home</u> <u>teaching with mothers & infants</u>. Ypsilanti, Michigan: High/Scope Educational Research Foundation, 1974.
- Lambie, D. Z., Bond, J. T., & Weikart, D. P. Framework for infant education. In B. Z. Friedlander, G. M. Sterritt & G. Kirk (Eds.), <u>Exceptional infant</u> (Vol. 3). New York: Brunner/Mazel, 1975.
- Laurence, K. M. Discussion. In S. Kelly, E. B. Hook, D. T. Janerich & I. H. Porter (Eds.), <u>Birth defects</u>, <u>risks and consequences</u>. New York: Academic Press 1976.
- Lorber, J. Results of treatment of myelomeningocele. <u>Developmental Medicine and Child Neurology</u>, 1971, <u>13</u>(3), 279-303.

- Matthews, W. B., & Miller, H. <u>Diseases of the nervous</u> <u>system.</u> Oxford: Blackwell Scientific Publications, 1972.
- Molnar, G. E., & Taft, L. T. Pediatric rehabilitation part II: spina bifida and limb deficiencies. <u>Current Problems in Pediatrics</u>, 1977, <u>7</u>(4), 2-55.
- Nash, D. F. E. The impact of total care with special reference to myelodysplasia. <u>Studies in Hydro-</u> <u>cephalus and Spina Bifida</u>, 1970, <u>12</u>(6), 9-12.
- Nie, N. H., Hull, C. H., Jenkins, J. G., Steinbrenner, K., & Bent, D. <u>Statistical package for the social</u> <u>sciences, second edition</u>. New York: McGraw-Hill Book Co., 1975.
- Nielson, G., Collins, S., Meisel, J., Lowry, M., Engh, H., & Johnson, D. An intervention program for atypical infants. In B. Z. Friedlander, G. M. Sterritt & G. E. Kirk (Eds.), <u>Exceptional infant</u> (Vol. 3). New York: Brunner/Mazel, 1975.
- Pearson, P. H., & Williams, C. E. (Eds.). <u>Physical</u> <u>therapy services in the developmental disabilities</u>. Springfield, Illinois: Charles C. Thomas, 1972.
- Sluckin, W. (Ed.). <u>Early learning and early experience</u>, <u>selected readings</u>. Baltimore: Penguin Books, 1971.
- Tizard, J. Children with myelomeningocele; social and educational problems. <u>Studies in Hydrocephalus</u> and Spina Bifida, 1968, Supplement 15, 1-9.
- White, B. L., Kaban, B. T., & Attanucci, J. S. <u>The</u> <u>origins of human competence</u>. Lexington, Massachusetts: Lexington Books, 1979.
- Woods, G. E. <u>The handicapped child: assessment and</u> <u>management.</u> Oxford: Blackwell Scientific Publications, 1975.