A COMPARISON OF THE PERCEPTIONS OF FUTURE ADULT FUNCTIONING OF ADOLESCENTS WITH SPINA BIFIDA, THEIR PARENTS, AND ADOLESCENTS WITHOUT AN IDENTIFIED DISABILITY

THESIS

Presented to the Graduate Council of the University of North Texas in Partial Fulfillment of the Requirements For the Degree of

MASTER OF SCIENCE

By

Hal M. Cain, B.A.
Denton, Texas
December, 1990
Cain, Hal M., A Comparison of the Perceptions of Future Adult Functioning of Adolescents With Spina Bifida, Their Parents, and Adolescents Without an Identified Disability. Master of Science (Rehabilitation Counseling), December, 1990, 51 pp., 3 tables, 2 figures, references, 16 titles.

A study was conducted to investigate factors associated with the perceived future self-efficacy in adolescents with spina bifida. Thirteen adolescents with spina bifida and their parents were surveyed. Seventeen adolescents without an identified disability and their parents were also surveyed. The Questionnaire of Future Adult Activities (QFAA) and the Health Attribution Test (HAT) were administered. Parent responses were compared to those of adolescents and adolescent responses were compared between groups. There was no overall correlation between parent and adolescent responses. Differences were found between responses of adolescents with spina bifida and adolescents without an identified disability. Limited correlations were found between the QFAA and the HAT.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>LIST OF TABLES</th>
<th>vi</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF FIGURES</td>
<td>vii</td>
</tr>
</tbody>
</table>

## Chapter

I. INTRODUCTION ................................................. 1

II. THE PROBLEM AND ITS SETTING ............................. 3

- Statement of Problem
- Statement of Purpose
- Research Questions
- The Hypotheses
- Limitations
- Assumptions
- Significance of Study

III. REVIEW OF RELATED LITERATURE ............................. 8

IV. METHOD ....................................................... 14

- Subjects
- Instrumentation
- Procedure
- Analysis of Data

V. RESULTS ....................................................... 20

VI. DISCUSSION .................................................. 26

VII. SUMMARY .................................................... 35
TABLE OF CONTENTS (CONT.)

APPENDIX A -- QUESTIONNAIRE OF FUTURE ADULT ACTIVITIES:
   FORM A .................................................. 37
APPENDIX B -- QUESTIONNAIRE OF FUTURE ADULT ACTIVITIES:
   FORM P .................................................. 40
APPENDIX C -- GROUPING OF HEALTH ATTRIBUTION TEST ITEMS 43
APPENDIX D -- DEMOGRAPHIC INFORMATION SHEET ................. 46
APPENDIX E -- COVER/INSTRUCTION LETTER ......................... 48
REFERENCES .................................................. 50
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Subject Demographic Information</td>
<td>15</td>
</tr>
<tr>
<td>2. Parent/Adolescent Correlations (r) on QFAA</td>
<td>22</td>
</tr>
<tr>
<td>3. Mean Responses of Adolescents on QFAA</td>
<td>24</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Total scores on QFAA for Group I ..........</td>
<td>28</td>
</tr>
<tr>
<td>2. Total scores on QFAA for Group II ..........</td>
<td>30</td>
</tr>
</tbody>
</table>
Spina bifida is a condition which occurs in the first trimester of gestation that manifests as a malformation or incomplete formation of the central nervous system (CNS) at the spinal cord level at birth. Severity of the condition ranges from minimum, nonlimiting, to severe total dependence on others for life support. Paraplegia, neurogenic bowel and bladder disorder, hydrocephalus, and seizure disorder are among the conditions associated with spina bifida. Occurrence of spina bifida has been estimated as high as 2 out of every 1000 births (Spina Bifida Association of America, 1984).

Increased survival rate due to advances in postnatal medical care of infants with spina bifida (Blum, 1983) and the passage of The Education of all Handicapped Children Act of 1975 (Public Law 94-142) mandating the right to a public education have heightened the public's awareness of spina bifida, as well as other disabilities. Health care professionals are now challenged to help integrate a population into society which has not previously been adequately served.
Very little information exists about the special needs, attitudes, and expectations of these young persons and their families regarding their transition into their community. It follows that if persons with spina bifida are being transitioned into the community, more needs to be known about how adolescents in this group, as well as their families, envision their futures. Moreover, there may be certain extrinsic factors, such as parental expectations and the adolescent's perceived locus of control, that affect a successful transition into society. Therefore, the following study was conducted.
CHAPTER II

THE PROBLEM AND ITS SETTING

Statement of Problem

Previously, there has been no research that specifically addresses the perceptions of adolescents with spina bifida or the perceptions of their parents regarding the level of future community integration and independence expected to be obtained by these adolescents. Furthermore, there is a lack of information about how adolescents with spina bifida view their futures and personal health issues compared to how adolescents without an identified disability view their futures and personal health issues.

Statement of Purpose

The purpose of this study was to identify and compare differences between the self-ratings of adolescents with spina bifida and their parents' ratings of the adolescents' future independent functioning. In addition, the self-ratings of adolescents with spina bifida were compared to the self-ratings of adolescents without an identified disability on scales predicting future adult independent functioning. The study also investigated the relationship between perceived health locus of control and self-ratings of future independent functioning of adolescents.
Research Questions

I. How do the self-ratings of estimated future functioning of adolescents with spina bifida compare to their parents' ratings of their estimated future functioning?

II. What are the differences in the self-ratings of estimated future independent functioning of adolescents with spina bifida and adolescents without an identified disability?

III. Is there a relationship between health locus of control and subjects' ratings of their estimated future functioning?

The Hypotheses

I. It was hypothesized that there will be a significant correlation between the adolescents' self-ratings on projected independent functioning scales and their parents' ratings of their adolescent's projected functioning.

II. It was hypothesized that there will be a significant difference between the mean rating of adolescents with spina bifida and the mean rating of adolescents without an identified disability on projected independent functioning scales.

III. It was hypothesized that there will be a significant correlation between the adolescents' ratings on projected independent functioning scales and measures of their perceived health locus of control.
Limitations

The present study looked only at the ratings of adolescents and parents who chose to participate by completing the Questionnaire of Future Adult Activities, the Health Attribution Test, and forms of demographic information. Results from data gathered on this limited, volunteer sample may not generalize to persons in the research sample population who did not choose to respond. Also, since participants in this study were sought through spina bifida organizations such as the Spina Bifida Association and other agencies/facilities that serve persons with spina bifida, subjects sampled are likely to be persons who are actively involved in acquiring services for themselves and others. Therefore, results of this study may not generalize to persons and families who are not as active in a service delivery system. Finally, the sample of subjects were limited to Texas residents only and may not be representative of persons who live outside of that state.

Assumptions

It was assumed that the persons sampled, adolescents with spina bifida, adolescents without an identified disability, and the parents of these adolescents, will have some concept of the adolescents' future strengths and weaknesses in relation to independent functioning.

Significance of Study

By identifying the differences between how adolescents with spina bifida, those without an identified disability,
and their respective parents view the future, information gained in this study may be helpful in guiding counseling and transitional services for adolescents with spina bifida and their families. Information about the relationship between health locus of control and perceived future functioning may assist service providers in the development of improved strategies for involving the adolescent with spina bifida and his or her family in planning for the adolescent's transition and integration into the community. Because the habilitation process of a young person with spina bifida involves his or her parents' cooperation and intervention, an understanding of how closely parents' views of their child's future functioning match those of the child should aid in aligning goals and objectives that are mutually agreed upon.

There are several other potential applications of knowledge derived from this study. Results may be used to alert caregivers to the effects of parental attitudes on the self-confidence, self-esteem, and self-efficacy of adolescents with spina bifida. Parent education classes sponsored by facilities and private practitioners may incorporate such information into their presentations. Further, the development of a questionnaire to assess a young person's idealizations of himself or herself as an adult is another by-product of this study. Such an assessment instrument can aid in measuring the degree of
perceived self-efficacy obtained by adolescents (i.e., pretest-posttest). The results of this instrument could be used in developing and evaluating individual and family programs and counseling.
CHAPTER III

REVIEW OF RELATED LITERATURE

There are several terms used to describe how one views him or herself. Terms such as "self-efficacy," "self-esteem," "self-image," and "self-perception" are among those commonly used to label this concept of "looking" at one's self. Coopersmith and his team of researchers, in the late 1950s through the mid 1960s, were some of the first to investigate how we develop our self-esteem (Coopersmith, 1967). They viewed self-esteem as positive and negative attitudes toward oneself. In studying the antecedents to developing self-esteem in school age children, Coopersmith and his colleagues concluded that the way persons see themselves is determined by their interaction with others in their environments. Paradoxically, how one deals with his or her environment is based on one's view of self. Parental influence was found to have an impact on the development of the self-esteem. Persons with high self-esteem were found to have parents that were supportive and accepting of independence and creativity in the child. In general, these children had lower levels of anxiety and were more socially skilled. On the other hand, children with low self-esteem
lived in conditions of rejection and uncertainty of their parents' expectations. These children were more anxious and socially withdrawn.

Bandura (1977) proposes that cognitive processes and social learning are major components in developing a strong sense of self-efficacy. The modeling that takes place in one's home environment through childhood accounts for most of this social learning. He also contends that how one perceives his or her ability to function in a given situation, self-efficacy, plays a crucial role in adjusting behavior to deal appropriately with that situation. In his research, Bandura found that self-efficacy is a better predictor of behavior when one is presented with unfamiliar tasks than is one's past behavior.

In studies that have been conducted to investigate the families who have a child born with spina bifida, various factors have been found to affect the quality of life for all the family members, including the fact that one member has a handicapping condition (Walker, Thomas, & Russell, 1971; Dorner, 1975; McCormick, Charney, & Stemmler, 1986). The number of persons with spina bifida living to early adulthood and beyond are increasing (Dorner, 1975). Blum (1983) points out that advances in medical technology have increased the survival rate of persons born with myelomeningocele (spina bifida) and thereby expanded our
consideration of the effects of this disability on psychosocial, educational/vocational, and family relationships through "developmental" years.

Persons with spina bifida, especially girls, tend to physically mature earlier than persons without spina bifida, but are slower to mature emotionally and socially than their nondisabled peers (Hayden, Davenport, & Campbell, 1979; Blum, 1983). The neurological dysfunctions associated with spina bifida can affect areas such as sexual functioning, impacting adolescents not only physically, but also psychosocially (Dorner, 1977; Hayden, et al., 1979). Self-esteem, self-concept, and social contact have been found to be inversely related to level of independent functioning (Dorner, 1975; Hayden, et al., 1979; Blum, 1983; Sherman, Berling & Oppenheimer, 1985). However, one study that used siblings as a nondisabled control group did not find this inverse relationship to be true (MacBriar, 1983). Hayden, et al. (1979) found in their study that adolescents with spina bifida had poorer adjustment and lower self-esteem than a comparison group of adolescents without spina bifida. Twenty percent of the parents in their group of adolescents with spina bifida were unaware of these negative attitudes. However, in a comparison of the adolescents' and their parents' responses, both groups of parents did not recognize how often their children were depressed. The study also found that adolescents with
spina bifida participated in fewer team sports, had fewer extracurricular activities, and fewer close friends than did the control group. Feldman and Varni (1985) found that children with spina bifida had knowledge relating to health and illness that was more advanced than their overall cognitive development.

Parental expectations for independence and a separate family life for the adolescent with spina bifida was also explored in previous studies. Parents tended to be less confident that their children with spina bifida would marry or even have an intimate relationship than were the children themselves (Dorner, 1977; Hayden, et al., 1979). In Dorner's study (1977), 28 of 63 parents surveyed expected their children with spina bifida to marry and have children and another 9 of that group speculated that their child would get married but not have children. This compares to a previous report (Dorner, 1976) that approximately two-thirds of adolescents with spina bifida interviewed wanted to and thought they would be able to get married and half of those adolescents thought they would want and could have children.

Studies of parental influence in populations with other disabilities have been conducted. Long and Moore (1979) found that parents of children with epilepsy were more restrictive and less optimistic of the future for these children than for their nondisabled children. These expectations were correlated with lower self-esteem and academic achievement of the children with epilepsy.
More recently, maternal trait anxiety and overprotection have been associated with lower self-esteem in children with cystic fibrosis (Cappelli, McGrath, MacDonald, Boland, et al., 1988). Parents' support was found to be a significant predictor of self-esteem in children with congenital/acquired limb deficiencies (Varni, Rubenfeld, Talbot, & Setoguchi, 1989).

Although previous research has addressed the issues of self-confidence and self-esteem of children and adolescents with spina bifida, until now the prospect of independence as an adult has been addressed only in terms of marriage and psychosexual issues. Most of what has been done in the way of previous research appears to center around the physical limitations of the person with spina bifida. While limitations are important to consider, positive aspects and expectations need to be explored. It is not clear if the parents of children with spina bifida and the children themselves have the same outlook for the futures of the children and if parents' perceptions affect the perception of their adolescent. The impact of perceived health locus of control in adolescents with spina bifida also needs further study.
CHAPTER IV

METHOD

Subjects

The research group for this study consisted of 13 adolescents (male n = 6, female n = 7) with spina bifida and their parents (fathers n = 7, mothers n = 12) (Group I). A comparison group (Group II) was comprised of 17 adolescents (male n = 3, female n = 14) without an identified disability and their parents (fathers n = 10, mothers n = 16). The adolescents in Group I ranged in age from 10.92 years to 19.08 years (\( \bar{x} = 14.94 \)). Mothers in this group ranged in age from 32.83 years to 54.67 years (\( \bar{x} = 41.15 \)). Fathers ranged in age from 33.75 years to 55.83 years (\( \bar{x} = 43.87 \)). Group II adolescents were between the ages of 12.83 years and 17.67 years (\( \bar{x} = 15.36 \)). Mothers in Group II ranged in age from 33.25 years to 49.75 years (\( \bar{x} = 41.78 \)) while fathers' ages ranged from 36.5 years to 54.83 years (\( \bar{x} = 42.88 \)).

Completed level of education for the adolescents ranged from 1 to 11 years for Group I (\( \bar{x} = 7.00 \)) and 5 to 10 years in Group II (\( \bar{x} = 8.06 \)). Three of the adolescents in Group I were enrolled in Special Education classes at the time of
this study. The range of educational levels for the parents was from Grade 12 to 20 (doctoral level) for Group I ($\bar{X} = 15.20$) and Grade 11 to 20 for Group II ($\bar{X} = 15.91$). Table 1 illustrates these demographics.

Distribution of questionnaire packets to potential subjects took place over a period of six months. Subjects for Group I were sought through the Spina Bifida Association of Texas and their local chapters and from the Scottish Rite Hospital for Crippled Children, Dallas, Texas. Subjects for Group II were obtained through school districts in Denton and Lubbock counties. Completed questionnaires were collected by either being mailed directly to the researcher or were forwarded by the clinic nurse coordinator at Scottish Rite Hospital. All subjects resided in the State of Texas at the time of this study.

Subjects were excluded if their returned forms or questionnaires were incomplete, responding adolescents were reported to have an identified disability other than spina bifida, responding child was not within the adolescent age range, and/or there was no corresponding parent or adolescent form returned.

**Instrumentation**

A 20 item Questionnaire of Future Adult Activities (QFAA) was developed by the researcher. Form "A" of the QFAA is a self-rating tool for the adolescent; Form "P" is for the parents' ratings of their adolescent (see Appendices
Table 1
Subject Demographic Information

<table>
<thead>
<tr>
<th></th>
<th>Group I</th>
<th>Group II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Male adolescents</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Number of Female adolescents</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Number of Fathers</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Number of Mothers</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>Mean age of Adolescents (years)</td>
<td>14.94</td>
<td>15.61</td>
</tr>
<tr>
<td>Mean age of Mothers (years)</td>
<td>41.15</td>
<td>41.78</td>
</tr>
<tr>
<td>Mean age of Fathers (years)</td>
<td>43.87</td>
<td>42.86</td>
</tr>
<tr>
<td>Mean education of Adolescents (years)</td>
<td>7.00</td>
<td>8.06</td>
</tr>
<tr>
<td>Mean education of Parents (years)</td>
<td>15.20</td>
<td>15.91</td>
</tr>
<tr>
<td>Number of Adolescents Enrolled in Special Ed.</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>
A & B). The instrument was designed to measure adolescents’ and parents’ expectations regarding the adolescents’ future social and vocational functioning. The QFAA (form A) was reviewed by a panel of professionals. This panel was comprised of three professors of rehabilitation, two psychologists in private practice, and the dean of research at a major university. These persons were selected because of their familiarity with research forms and/or knowledge of the subject population. Also, feedback on Form A was given by the 12 year old female. Comments from the panel and the adolescent were used to make revisions on the QFAA that were needed for clarity of reading and general style.

Both forms of the QFAA ask respondents to rate each item based on a 5-point scale, with "5" being the most in agreement and "1" being the least in agreement with the statement. A total score is derived by summing the ratings of the 20 questions. The interitem consistency of the QFAA was tested using all subject responses. Consistency was found to be high with a significant Cronbach Coefficient Alpha ($r = .89$).

The Health Attribution Test (HAT) developed by Achterberg and Lawlis (1990) as a measurement of perceived locus of control for one’s own health was given to adolescents in both groups. The HAT is a self-administered 22 item questionnaire in which one rates his or her agreement with statements about the causations of illnesses
and responsibility for one's health. These 22 statements are factored into three categories; "Internal," "Powerful Others," and "Chance" (see Appendix C). There are six possible responses for each statement ranging from "Strongly disagree" to "Strongly agree." For the purposes of this study, the six responses were weighted from "0" (Strongly disagree) to "5" (Strongly agree). A raw score was then tabulated for each of the three locus of control categories by adding the weighted responses of the items that fell within each category. At the time of this study, no reliability or validity information data for the HAT was available.

Finally, an information sheet for obtaining demographic data was used (see Appendix D). This data sheet was completed by the parents.

Procedure

Subjects were asked to respond to the questionnaires by mail. A cover letter to both the adolescent and parent explaining the general nature of the study, stating the consent and confidentiality policy, and overall directions (see Appendix E) was included. Enclosed with the cover letter were 1) one copy of the QFAA-A, 2) two copies of the QFAA-P, 3) one copy of the HAT, 4) two copies of the demographic information sheet, and 5) a self-addressed, postage-paid return envelope. Each form in the individual packets was number coded in order to account for family
sets. These items were distributed to persons who were identified as belonging to either Group I or Group II adolescent/parent sets.

Packets were distributed during weekly spina bifida clinics by the clinic nurse coordinator and via mail to spina bifida association contacts who agreed to help with the distribution. A few of the packets were mailed directly to the participants following their telephone approval. Other packets were distributed in classrooms and at local P.T.A. meetings associated with local school systems. A total of 200 packets were distributed. Of these, 37 were returned. The majority of the responses were received by mail. Several completed responses were collected by the spina bifida clinic coordinator.

Instructions were identical for both groups and stated that parents and adolescents were to complete their respective forms independently from one another (see Appendix E). The instructions specified that name or other traceable identification was not to be marked on any of the forms in order to maintain confidentiality.

Analysis of Data

Paired t-tests were conducted between parents' average scores and the adolescent's score for Group I and Group II on the total scores and items 1-20 of the QFAA. Where there was only one parent responding, that parent's score was used. Independent t-tests were conducted on the
adolescents' total QFAA scores and items 1-20 of the QFAA form A between Group I and Group II. Finally, Pearson correlations with probabilities were conducted comparing QFAA form A responses to the three factors of the HAT (internal v. powerful others v. chance locus of control) by group.
CHAPTER V

RESULTS

Data generated from the responses of participants in this study were subjected to statistical analysis and were considered in relation to each of the three hypotheses.

**Hypothesis I:** There will be a significant correlation between the adolescents' self-ratings on projected independent functioning scales and their parents' ratings of their projected functioning.

Pearson's Correlation of relatedness between parents' average scores (PQ) and their adolescents' scores (AQ) were calculated using the total QFAA scores within each of the respective groups. In addition, correlations for each of the 20 questions were computed. In Group I (families where spina bifida is a factor) no overall correlation was found \( r = .382 \). There were six questions which showed significant correlations. These were questions 1 \( r = .633 \), 2 \( r = .807 \), 4 \( r = .673 \), 7 \( r = .689 \), 8 \( r = .631 \), and 11 \( r = .648 \).

In Group II (families without spina bifida being a factor) overall correlation was not found to be significant \( r = .542 \). Correlations between PQ(1-20) and AQ(1-20) in
this group were significant for three questions: 7 (r = .795), 8 (r = .696), and 13 (r = .644). Table 2 contains the correlations for total scores and correlations per question for both groups.

Paired T-tests were also conducted using the total QFAA scores of parents and adolescents as well as on PQ (1-20) and AQ (1-20) for both groups. In Group I there were no significant differences found between parents' and adolescents' total ratings and in 18 out of the 20 questions answered (p < .05). Significant differences in the ratings were found in questions 12 (t = -2.416; p = .033) and 16 (t = 2.910; p = .013).

In Group II, no significant difference was found between parents' and adolescents' total QFAA scores. Sixteen out of the 20 questions answered by this group were found to have no significant differences between the parents' and adolescents' answers (p < .05). The four questions where significant differences existed were questions 7 (t = -2.135; p = .049), 8 (t = -2.791; p = .013), 11 (t = -2.545; p = .022), and 17 (t = -3.359; p = .004).

Even though few differences were found in parent and adolescent responses, no significant overall correlations and a limited number of significant item correlations were found. Based on these analyses, Hypothesis I was rejected.
<table>
<thead>
<tr>
<th>QFAA question #</th>
<th>Group I (n = 13)</th>
<th>Group II (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.633</td>
<td>-.512</td>
</tr>
<tr>
<td>2</td>
<td>.807</td>
<td>.205</td>
</tr>
<tr>
<td>3</td>
<td>.061</td>
<td>.414</td>
</tr>
<tr>
<td>4</td>
<td>.673</td>
<td>.160</td>
</tr>
<tr>
<td>5</td>
<td>-.243</td>
<td>.446</td>
</tr>
<tr>
<td>6</td>
<td>.095</td>
<td>.295</td>
</tr>
<tr>
<td>7</td>
<td>.689</td>
<td>.795</td>
</tr>
<tr>
<td>8</td>
<td>.631</td>
<td>.696</td>
</tr>
<tr>
<td>9</td>
<td>.200</td>
<td>.317</td>
</tr>
<tr>
<td>10</td>
<td>.031</td>
<td>.308</td>
</tr>
<tr>
<td>11</td>
<td>.648</td>
<td>.372</td>
</tr>
<tr>
<td>12</td>
<td>.113</td>
<td>.498</td>
</tr>
<tr>
<td>13</td>
<td>.087</td>
<td>.644</td>
</tr>
<tr>
<td>14</td>
<td>-.123</td>
<td>.025</td>
</tr>
<tr>
<td>15</td>
<td>.455</td>
<td>.559</td>
</tr>
<tr>
<td>16</td>
<td>-.456</td>
<td>-.016</td>
</tr>
<tr>
<td>17</td>
<td>.264</td>
<td>.432</td>
</tr>
<tr>
<td>18</td>
<td>.067</td>
<td>-.111</td>
</tr>
<tr>
<td>19</td>
<td>.428</td>
<td>---- *</td>
</tr>
<tr>
<td>20</td>
<td>-.146</td>
<td>-.060</td>
</tr>
<tr>
<td>Total Score</td>
<td>.382</td>
<td>.542</td>
</tr>
</tbody>
</table>

* no variance in responses, correlations not generated
Hypothesis II: There will be a significant difference between the mean rating of adolescents with spina bifida and the mean rating of adolescents without an identified disability on projected independent functioning scales.

Independent T-tests of total scores on the QFAA and on each of the 20 questions were conducted between both groups of adolescents. Results showed a significant difference between groups on their total scores ($t = -2.131; p = .042; \bar{x}_d = -6.95$). Three of the 20 questions were significantly different ($p < .05$). These questions were: 2 ($t = -2.391; p = .024; \bar{x}_d = -0.824$), 7 ($t = -2.457; p = .020; \bar{x}_d = -0.710$), and 17 ($t = -2.182; p = .038; \bar{x}_d = -0.923$). Table 3 shows the mean ratings for both groups and the differences of these means for total scores and for each question.

Hypothesis II is supported based on the observed difference in the total scores between groups.

Hypothesis III: There will be a significant correlation between the adolescents' ratings of projected independent functioning scales and measures of their perceived health locus of control.

For both Groups I and II, results of a Pearson's Correlation analysis showed no correlations between total QFAA scores and each of the three HAT factors: internal control, powerful other, and chance. One question was significantly correlated with the independent control
Table 3

Mean Responses of Adolescents on QFAA

<table>
<thead>
<tr>
<th>QFAA question #</th>
<th>Group I (n = 13)</th>
<th>Group II (n = 17)</th>
<th>Difference of Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.000</td>
<td>4.235</td>
<td>-0.235</td>
</tr>
<tr>
<td>2</td>
<td>4.000</td>
<td>4.824</td>
<td>-0.824</td>
</tr>
<tr>
<td>3</td>
<td>4.231</td>
<td>4.647</td>
<td>-0.416</td>
</tr>
<tr>
<td>4</td>
<td>3.846</td>
<td>4.294</td>
<td>-0.448</td>
</tr>
<tr>
<td>5</td>
<td>3.000</td>
<td>2.941</td>
<td>0.059</td>
</tr>
<tr>
<td>6</td>
<td>2.308</td>
<td>2.588</td>
<td>-0.280</td>
</tr>
<tr>
<td>7</td>
<td>4.231</td>
<td>4.941</td>
<td>-0.710</td>
</tr>
<tr>
<td>8</td>
<td>3.769</td>
<td>4.353</td>
<td>-0.584</td>
</tr>
<tr>
<td>9</td>
<td>3.923</td>
<td>4.000</td>
<td>-0.077</td>
</tr>
<tr>
<td>10</td>
<td>3.692</td>
<td>4.000</td>
<td>-0.308</td>
</tr>
<tr>
<td>11</td>
<td>4.231</td>
<td>4.765</td>
<td>-0.534</td>
</tr>
<tr>
<td>12</td>
<td>3.769</td>
<td>4.118</td>
<td>-0.349</td>
</tr>
<tr>
<td>13</td>
<td>3.769</td>
<td>3.176</td>
<td>0.593</td>
</tr>
<tr>
<td>14</td>
<td>4.154</td>
<td>3.882</td>
<td>0.272</td>
</tr>
<tr>
<td>15</td>
<td>3.231</td>
<td>3.824</td>
<td>-0.593</td>
</tr>
<tr>
<td>16</td>
<td>2.462</td>
<td>3.059</td>
<td>-0.597</td>
</tr>
<tr>
<td>17</td>
<td>3.077</td>
<td>4.000</td>
<td>-0.923</td>
</tr>
<tr>
<td>18</td>
<td>2.923</td>
<td>3.353</td>
<td>-0.430</td>
</tr>
<tr>
<td>19</td>
<td>4.592</td>
<td>5.000</td>
<td>-0.308</td>
</tr>
<tr>
<td>20</td>
<td>4.154</td>
<td>4.412</td>
<td>-0.258</td>
</tr>
</tbody>
</table>

Total Score 73.462  80.412  -6.95
factor for Group I (question 18; \( r = .761, p = .003 \)) and one
question was significantly correlated with the chance factor
for Group II (question 13; \( r = .670, p = .003 \)). No other
significant correlations were found.

In consideration of these data, and the limited number
of significant correlations found, Hypothesis III was
rejected.
CHAPTER VI

DISCUSSION

The results of this study indicate that, in general, parents' expectations of their adolescent's future independent functioning and the adolescent's expectations of their own future independent functioning are not related. However, consideration of the mean differences showed that some agreement exists between parents and adolescents with regard to their expectations of the adolescents' futures.

For families in which the adolescent had spina bifida (Group I), no overall correlation between the parents' and adolescents' total scores on the Questionnaire of Future Adult Activities (QFAA) was found. Parent and adolescent answers appeared to be related to each other on less than one third (6 out of 20) of the questions. A significant positive relationship was found on questions that asked about future living situations (1 & 4), future educational issues (2, 7, & 11), and the adolescent's future community involvement (8). For these six questions, as parent ratings increased so did the adolescent self-ratings. Although there were only six questions that showed such a relationship, there were only two out of the 20 questions...
in which the adolescent's and parents' answers showed significant statistical differences. All other ratings by the adolescents and their parents were close, with either the parent or the adolescent having the same or slightly higher rating.

A visual inspection of the scatter plot for the total of the 20 QFAA parent and adolescent scores (see Figure 1) revealed a tendency for relatedness of the parents and adolescent answers but with a low correlation coefficient ($r = .382$). It could be that more questions were not shown to be statistically related because of the small sample size, especially when one considers how many similar parent and adolescent responses were obtained.

In comparison, in the families where the adolescents did not have an identified disability (Group II), only three of the 20 questions showed a significant relationship between the parents' ratings and adolescent's self-ratings. Questions which showed a positive relationship for this group dealt with the topics of education (7), community involvement (9), and vocation (13). As with Group I, when the parents' ratings increased so did the adolescents' self-ratings. In Group II there were four of the 20 questions that showed a significant difference between the parents' ratings and the adolescent's self-ratings as compared to only two questions that showed discrepancies in parent and adolescent ratings for Group I. This lesser
Figure 1 - Total Scores on QFAA for Group I

*ADOLESCENT TOTAL*

*PARENT TOTAL*
degree of discrepancy in Group I as compared to Group II may be attributed to the extra amount of time parents of adolescents with spina bifida spend with their children, assuming a greater level of dependency on the part of the child. The information exchanged during these frequent interactions could result in more similar responses.

Sample size may be a factor in the results for Group II as well. Visual inspection of the parents' and adolescents' total QFAA ratings on a scatter plot for this group also showed some tendency for relatedness (see Figure 2). In fact, as a group, Group II, with more respondents, had a higher overall correlation ($r = .542$) than Group I, although still not statistically significant. This further supports the idea that group size may be a factor in the low number of correlations observed.

One of the questions in which parent and adolescent answers differed for Group I explored the prospect of the adolescent having children of his or her own (question 12). Parents in this group were less optimistic about their adolescents having children than were the adolescents themselves. Physical anomalies associated with spina bifida can make conceiving and/or carrying a fetus to term for a female or fathering a child for the male with spina bifida impossible. The parents of these adolescents may have more knowledge of these physical limitations and therefore may have a more "realistic" view of the prospects of their
Figure 2 - Total Scores on QFAA for Group II
adolescents becoming biological parents than the adolescents themselves. Another explanation may be that parents of persons with disabilities may avoid issues of their children's sexuality and deny the prospects of their children becoming pregnant or fathering a child. In contrast, no discrepancy between parents' and adolescents' answers were found for question 12 in Group II.

The other question which yielded a significant difference in ratings for Group I was question 16. In this question the adolescents were less certain about themselves living with one or more persons who are not related to them than were their parents. One reason for this may relate to differences in the interpretation of the question. Adolescents and parents could construe this question as referring to a "live-in" attendant, group or community living facilities, or even an institutional setting. For the parent concerned about his or her adolescent with spina bifida being able to function independently on a daily basis, the possibility of live-in attendant care may be a prevalent concern. Another explanation may be that the adolescents, for various reasons, do not perceive living in a roommate situation as an attractive option and be less inclined to imagine themselves in that type of a living arrangement. In Group II no differences were found in the parent and adolescent ratings of this question.
Another finding of this study is that there is a difference in the way that adolescents with spina bifida and adolescents without an identified disability view their futures with respect to post-secondary education. Although the differences in the self-ratings on the QFAA of adolescents in these groups were significant overall, there were only three of the 20 questions where adolescents' average responses in Group I differed significantly from the average responses of adolescents in Group II. All three of these questions dealt with post-secondary education. One question asked whether the adolescent envisions himself or herself continuing his or her education after high school (question 2). Group II adolescents were more assured that they would continue their education after high school ($\bar{x} = 4.824$) than Group I adolescents ($\bar{x} = 4.000$). Another question where the two groups differed asked about attending college for at least one year (question 7). Again Group II answered more affirmatively ($\bar{x} = 4.941$) than Group I ($\bar{x} = 4.231$). The last question asked about obtaining a graduate degree (question 17). As with the other two questions, Group II members rated themselves in a more optimistic manner ($\bar{x} = 4.000$) than did Group I ($\bar{x} = 3.077$).

Differences in this area may be attributable to a couple of factors. Three of the adolescents in Group I were enrolled in special education classes at the time of this study and others in this group may have had special
education experiences in the past. Perhaps the exposure to special education classes diminishes the perceived prospect of post-secondary education for these adolescents. In addition, despite the adoption of Section 504 of the Rehabilitation Act of 1973 which cleared the way for more students to attend public colleges and universities by reducing discrimination based on disability, few academically successful role models for these adolescents exist. This lack of role models may lower the expectations of self-efficacy in an academic world.

The last finding this study generated was that there is little relation between perceived locus of health control, as measured by the Health Attribution Test (HAT), and perception of future adult activities in either group. No correlation was found between the adolescents' total QFAA scores and their HAT scores. In Group I there was one question on the QFAA in which significant correlation was found. This question asking if the adolescent saw himself or herself as a future community leader (question 18) and was positively correlated with an "internal" locus of control relating to health issues. It can be argued that one of the characteristics commonly found in persons viewed as leaders is an internal motivation or locus of control.

In Group II there was also only one question where a relationship between perceived health locus of control and future adult activities was found to be significant.
Question 13, which asked if the adolescent would be working under the direct supervision of another person, was positively correlated with a high rating of "chance" with respect to health issues.

The reasons for the lack of correlation between HAT ratings and ratings on the QFAA for these adolescents are not clear. Some possible reasons may be that 1) the validity of the QFAA for measuring perceived future independent functioning is as yet unproven and therefore may yield insufficient results, 2) the HAT was not developed to be used with adolescents and therefore its use in this study may not be valid, 3) there truly may be no relation between perceived health locus of control and perceived future adult activities, 4) adolescents' perceptions of control over their health may not necessarily generalize to perceptions of control over other aspects of their lives, and 5) the sample size may have been too small.
CHAPTER VII

SUMMARY

Analysis of data adequately supported only one of the three stated hypotheses. The one hypothesis that was supported compared the responses of adolescents with spina bifida to the responses of adolescents without an identified disability. Failure to find significant results on the other two hypotheses may be attributable to the small sample size. In spite of the lack of support for one of the rejected hypotheses, there appears to be some evidence of correlation between parent and adolescent responses on how the adolescent's future is viewed.

There were more similar responses between adolescents and parents in families in which the adolescent had spina bifida than between adolescents and parents in families in which the adolescent did not have an identified disability.

When asked about their future adult activities, adolescents with spina bifida rated themselves slightly less favorably than their non handicapped peers. The area of post-secondary education showed the most discrepancy between groups. Adolescents with spina bifida were less optimistic about continuing their education after high school than adolescents without an identified disability.
No overall correlation was found between adolescents’ responses regarding future activities and responses regarding health locus of control.

The tendencies for relatedness of parent and adolescent responses found in this study were not conclusive. Issues of independent living, post-secondary education, and community involvement were shown to be areas where parents and their adolescents with spina bifida had concurrent responses. However, specifics as to the magnitude and influential factors of these associations will need to be investigated on a larger scale. In addition, this expansion should include adolescents with other types of disabilities.

Counseling and guidance for post-secondary education preparation with adolescents who have spina bifida should be investigated in the interest of adequately meeting the needs of this population. More needs to be known about why adolescents with spina bifida are not as assured about their education after high school.

The value of an instrument such as the QFAA is still unproven. Continued development of such a tool would be an asset in researching these questions that are yet unanswered.
APPENDIX A

QUESTIONNAIRE OF FUTURE ADULT ACTIVITIES
FORM A
Questionnaire of Future Adult Activities
Form A

For each of the statements listed below, try to imagine how you will be or what you will have done by the time you are an adult, about age 30. Circle the number beside each statement that best fits how you agree with the statement about you at age 30. Think about each statement separately. Circle only one number. There are no right or wrong answers.

EXAMPLE: "I will move after high school." 5-4-3-2-1

By circling the "4" this person is pretty sure they will move after high school but not certain. If they would have circled the "5" they would be convinced that they would move after high school. Please circle only one number for each statement.

5 = DEFINITELY WILL, 4 = PROBABLY WILL, 3 = NOT SURE
2 = PROBABLY NOT, 1 = DEFINITELY NOT

1. I will be living independently on my own. 5-4-3-2-1

2. I will have continued my education after I have graduated from high school. 5-4-3-2-1

3. I will have friends who live in other cities. 5-4-3-2-1

4. I will not be living with my parents or other family members such as a brother or sister. 5-4-3-2-1

5. I will have my own business. 5-4-3-2-1

6. I will be an executive in a large company. 5-4-3-2-1

7. I will have attended college for at least one year. 5-4-3-2-1

8. I will be involved in activities in the community where I live. 5-4-3-2-1

9. I will be married and live with my husband or wife. 5-4-3-2-1

10. I will be active and participate in recreational sports. 5-4-3-2-1

(please continue on next page)
QFAA (form A)

5 = DEFINITELY WILL  4 = PROBABLY WILL  3 = NOT SURE
2 = PROBABLY NOT  1 = DEFINITELY NOT

11. I will have graduated from college.  5-4-3-2-1

12. I will have children of my own.  5-4-3-2-1

13. I will have a job where I am working under the
direct supervision of another person.  5-4-3-2-1

14. I will be asked to give my opinion or advice
on topics I know a lot about.  5-4-3-2-1

15. I will have attended graduate school for
at least one year.  5-4-3-2-1

16. I will be living with one or more persons
who are not members of my family.  5-4-3-2-1

17. I will have obtained a graduate degree
(master's or doctorate).  5-4-3-2-1

18. I will be the leader of an organization
or group in my community.  5-4-3-2-1

19. I will have graduated from high school.  5-4-3-2-1

20. I will be living on money I have earned for
myself, not money that people have given me.  5-4-3-2-1

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
APPENDIX B

QUESTIONNAIRE OF FUTURE ADULT ACTIVITIES
FORM P
Questionnaire of Future Adult Activities
Form P

For each of the statements listed below, try to imagine how your child will be or what he or she will have done by age 30. Circle the number beside each statement that best fits how you agree with the statement. Think about each statement separately. Circle only one number. There are no right or wrong answers to these statements.

EXAMPLE: "My child will move after high school." 5-4-3-2-1

By circling the "4" this person is pretty sure their child will move after high school but not certain. If they would have circled the "5" they would be convinced that their child would move. Please circle only one number for each statement.

5 = DEFINITELY WILL, 4 = PROBABLY WILL, 3 = NOT SURE
2 = PROBABLY NOT, 1 = DEFINITELY NOT

1. My child will be living independently on their own. 5-4-3-2-1

2. My child will have continued his or her education after graduating from high school. 5-4-3-2-1

3. My child will have friends who live in other cities. 5-4-3-2-1

4. My child will not be living with me or other family members such as a brother or sister. 5-4-3-2-1

5. My child will have his or her own business. 5-4-3-2-1

6. My child will be an executive in a large company. 5-4-3-2-1

7. My child will have attended college for at least one year. 5-4-3-2-1

8. My child will be involved in activities in the community where he or she is living. 5-4-3-2-1

9. My child will be married and live with his wife or her husband. 5-4-3-2-1

(please continue on next page)
QFAA (form P)

page 2.

5 = DEFINITELY WILL  4 = PROBABLY WILL  3 = NOT SURE  
2 = PROBABLY NOT  1 = DEFINITELY NOT

10. My child will be active and participate in recreational sports.  5-4-3-2-1

11. My child will have graduated from college.  5-4-3-2-1

12. My child will have children of his or her own.  5-4-3-2-1

13. My child will have a job where he or she is working under the direct supervision of another person.  5-4-3-2-1

14. My child will be asked his or her opinion or advice on topics he or she knows well.  5-4-3-2-1

15. My child will have attended graduate school for at least one year.  5-4-3-2-1

16. My child will be living with one or more persons who are not members of our family.  5-4-3-2-1

17. My child will have obtained a graduate degree. (master's or doctorate).  5-4-3-2-1

18. My child will be the leader of an organization or group in his or her community.  5-4-3-2-1

19. My child will have graduated from high school.  5-4-3-2-1

20. My child will be living on money he or she has earned for himself or herself, not money that has been given to him or her by other people.  5-4-3-2-1

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
APPENDIX C

GROUPING OF HEALTH ATTRIBUTION TEST ITEMS
HAT questions grouped according to locus of control category.

Internal Control:

1. "I can usually keep myself healthy by paying close attention to what I eat."
6. "Thinking positive thoughts can help me get well and stay well."
7. "If I keep my body in shape through exercise, I can ward off much sickness."
9. "If I could just understand how my body functioned, I could figure out how to get well and stay healthy."
11. "Everyone should be responsible for their own health and not push the responsibility off on a doctor."
12. "Sickness or accidents are a lesson in life and carry a message."
13. "I believe little children can learn to be healthy if they are exposed to proper teachings."
21. "I can usually tell when I am about to get sick, and with some care on my part I can avoid it."

Powerful Other:

2. "When I get sick or hurt it is usually God's way of punishing me for my sins."
4. "If I were extremely sick, I might go to a faith healer."
8. "If I breath in cold germs, I’ll almost always catch a cold."
14. "Other countries who are our enemies are probably responsible for the high rate of disease here."
15. "No matter what I do I will get sick or hurt sooner or later."
17. "Only medical doctors know how to treat illnesses."
18. "Diet and nutrition have very little to do with health, people will get sick no matter what they do."
22. "My life is chiefly controlled by powerful others."
HAT questions by category (cont.)

Chance:

3. "If I don't catch a cold or flu or have an accident once a year it is because I am very lucky."

4. "If I were extremely sick, I might go to a faith healer."

5. "Most diseases or accidents can happen to anybody at any time."

10. "I will still get sick or hurt if that is what is supposed to happen even if I set my mind to stay healthy."

11. "Everyone should be responsible for their own health and not push the responsibility off on a doctor."

16. "It always amazes me that people think they can control whether they'll get sick or hurt or not."

19. "All the talk about nutrition and exercise is foolish; some people are just basically healthy and others aren't."

20. "Some people just seem to be accident prone."
APPENDIX D

DEMOGRAPHIC INFORMATION SHEET
INFORMATION SHEET

Parent or guardian, please provide the following information. Your name or your child's name is not needed and should be left off this sheet. Please return this attached to your questionnaire when complete. Thanks.

1. What is your adolescent's date of birth? mo.__/dy.__/yr.__

2. What is your adolescent's gender? male / female (please circle)

3a. What grade in school is he or she in now? ______

3b. Most of his or her classes are: regular ed / special ed. (please circle)

4. Does your child have a disability and, if so, what is the nature of the disability? no yes

5. Please list the age and gender of any other children living with you at this time.
   age ______ gender _____ | age ______ gender _____
   age ______ gender _____ | age ______ gender _____
   age ______ gender _____ | age ______ gender _____
   age ______ gender _____ | age ______ gender _____

6. Your date of birth is mo.__/dy.__/yr.__.

7. Please circle your relation to the adolescent: mother / father / stepfather / stepmother / grandmother / grandfather / guardian. ______

8. Are you a single parent? yes / no (please circle)

9. Please circle your highest level of education completed: less than high school / high school / college / master's / doctorate.

10. What is your usual occupation? ______________________

THANK YOU
APPENDIX E

COVER/INSTRUCTION LETTER
December 1, 1989

Dear Adolescent & Parent(s):

The University of North Texas, Center for Rehabilitation Studies, is sponsoring a study looking at how young people view their future and what role, if any, their parents play in this view.

Your help is needed in this important research project. If you are between the ages of 11 and 18, or the parent of someone between these ages, we invite you to participate in this study. It will involve only a few minutes of your time (10 - 15 minutes) to fill out the questionnaires enclosed. Participation is strictly voluntary and you have the right to "pull out" any time you wish. Your replies will be kept completely confidential. Should you decide to participate, please do not write your name, address, or any other identifying information on any form.

Your responses will be analyzed with the responses of others who participate in this study. Information gained by looking at these responses will be of benefit to persons receiving services from vocational specialists, counselors, and other professionals who work with parents and adolescents.

The Questionnaire of Future Adult Activities, Form A, and Health Attribution Test are to be filled out by the adolescent. The Questionnaire of Future Adult Activities, Form P, and the Information Sheet is to be filled out by parent(s). The adolescent and parent(s) should fill out their questionnaires independently without talking to each other. Once the questionnaires have been completed, please use the post-paid return envelope to mail questionnaires back to researchers. Should you have any questions regarding this study, please feel free to call:

Hal Cain (806) 745-6311  
Genie Bodenhamer (817) 565-3467

or write:

Center for Rehab Studies  
Genie Bodenhamer, Ph.D.  
P.O. Box 13438, NTS  
Denton, TX 76203-3438

Thank you in advance for your interest and participation.

Sincerely,

Hal M. Cain, B.A.  
Master's Candidate

Sincerely,

Eugenia M. Bodenhamer, Ph.D.  
Associate Professor, CRS

Enclosures
REFERENCES


