

**A REPORT TO
THE SOUTH CAROLINA DEPARTMENT
OF HEALTH AND HUMAN SERVICES**

**THE COMPONENTS OF
EMPLOYMENT SUCCESS AND FAILURE
AMONG PERSONS WITH DISABILITIES
IN THE STATE OF SOUTH CAROLINA**

**PART I: ELIGIBILITY DETERMINATION
FOR MEDICAID**

**PRODUCED BY
SYSTEM WIDE SOLUTIONS, INC.
FOR
THE COLLEGE OF SOCIAL WORK
UNIVERSITY OF SOUTH CAROLINA**

**George W. Appenzeller, MSW
Sarah Meadows, MSW
Malia Nelson
Andrea Evans-Wolfe**

MARCH 31, 2005

EXECUTIVE SUMMARY

In March of 2004, the South Carolina Department of Health and Human Services (SC DHHS) received a \$500,000 Medicaid Infrastructure Grant (MIG) authorized by the *Ticket to Work and Work Incentives Improvement Act of 1999*. The goal of this MIG is to provide resources to break down the barriers that stand between people with disabilities and employment in the community. The MIG is governed by a Work Plan that includes 25 activities. Among these activities are three that are designed to create a base of information about the barriers that exist to persons with disabilities working and what factors account for success of persons with disabilities working. This report will ultimately consist of five parts. This first part will cover issues associated with the Medicaid eligibility process.

According to the U.S. Census Bureau, there are 514,963 working age persons with disabilities residing in the state of South Carolina. They make up 23% of the state's working age citizens. Almost half of these people (45%) are not currently employed. Many of these individuals who are not employed have job skills and want to work. These unemployed persons with disabilities are a resource that is not tapped by the State at this time. Each of these persons who enter the workforce becomes a tax payer who can provide greater support for him or herself and his or her family. These individuals can make South Carolina more competitive in the world economy.

A total of 70 persons with disabilities and eight persons who are responsible parties for persons with disabilities were interviewed individually or in groups. As far as practical, persons with all types of disabilities were included. In addition, the chiefs of the Bureau of Eligibility Processing and the Bureau of Beneficiary and System Support at the Department of Health and Human Services and two eligibility workers in the field were interviewed. All interviews were recorded, other than those with the bureau chiefs. Demographic and service information was gathered on the persons with disabilities and caregivers.

The recordings and notes of the interviewers were used to write process recordings of the interviews. The process recordings were read by three staff members. The staff members identified what they believed to be the issues raised and described in the interviews. The staff members then met and discussed the issues they identified until consensus was reached. Findings were then written. Upon the completion of the findings being written, the staff members developed their individual findings and recommendations. The staff members met and discussed the findings and recommendations until they reached consensus. The report was then finalized.

Several themes were identified from the interviews with persons with disabilities and the responsible parties. These are:

- Having health insurance is seen as a life or death issue by many persons with disabilities and the Medicaid eligibility decisions are therefore seen as decisions about whether they live or die.
- Recipients who qualify through the Working Disabled program recognize its worth.
- The application process is confusing and difficult to understand.

- Earnings and asset limits are counterproductive to providing incentives for working.
- There is great resentment about the intrusive nature of the eligibility process.
- The consumers have suggestions for improvements.

Several themes were also identified by the professionals interviewed. These are:

- Having health insurance is seen as a life or death issue by many persons with disabilities and the Medicaid eligibility decisions are therefore seen as decisions about whether they live or die.
- There are numerous barriers in the eligibility criteria to persons working.
- There are numerous barriers to eligibility workers doing their jobs well.
- The professionals have suggestions for improvements.

It is clear from the interviews with persons with disabilities, responsible parties and professionals that the Medicaid eligibility process and the rules that govern it do not support persons with disabilities seeking and keeping employment. The overwhelming thought in the mind of the person with disabilities who is trying to become eligible is that Medicaid may be the difference between living and dying. The overwhelming thought in the mind of the eligibility worker is that he or she must follow a complex and sometimes contradictory set of criteria. These two thoughts take precedence over everything else, including work for the person with disabilities.

Nine short term and three long term recommendations are made in the report. These are:

Short Term

1. The complexity of the present system that serves persons with disabilities requires a great deal of knowledge and skills on the part of professionals to help persons with disabilities return to work. Many states have put a great deal of effort into hiring and training benefits coordinators who help persons with disabilities wend their way through the system. South Carolina has used federal funds to provide a few benefits coordinators at Vocational Rehabilitation. The services that benefits coordinators provide appear to be an essential part of helping persons with disabilities obtain and keep jobs. It is recommended that at least one worker in each SC DHHS area office be trained to be a benefits coordinator and given the authority to carry out those functions.
2. It is recommended that the on-line policy manual be programmed to allow for on-line search capability.
3. It is recommended that a wall-sized chart be designed that answers common questions and explains the various eligibility categories.
4. It is recommended that training on different disabilities be provided to eligibility workers along with training on being sensitive to the needs of persons with specific disabilities.

5. In order to provide more accurate information, it is recommended that eligibility workers be provided with knowledge about what is covered under Medicare, the TEFRA program, and other similar programs.
6. It is recommended that eligibility workers be trained on the work of other agencies such as Vocational Rehabilitation, the Department of Veterans Affairs, DDSN, and others that serve persons with disabilities.
7. It is recommended that eligibility workers be informed about the work of private community services such as free health clinics.
8. It is recommended that collaborative meetings at the local level among providers, agency staff and eligibility workers be held to exchange information in order to understand what each does and how they can cooperate to be more efficient and effective.
9. It is recommended that the automated system be modified after consultation with eligibility workers to determine the more common problems. Once upgrading is completed, the parallel paper system can be largely abolished.

Long Term

1. It is recommended that a method be developed to allow persons with disabilities who work to pay a share of the costs of Medicaid coverage, the share to increase as their income increases.
2. It is recommended that a group of professionals and persons with disabilities, who are provided health care by Medicaid, be formed to develop recommended levels of income and assets for Medicaid eligibility. This group would have as its first priority balancing the costs and benefits of modifying these criteria so that persons with disabilities find it financially possible to work.
3. It is recommended that the policy manual be revised to make it more “user friendly” in determining eligibility.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	I
TABLE OF CONTENTS	IV
TABLE OF FIGURES.....	V
INTRODUCTION.....	1
The Medicaid Infrastructure Grant Project.....	1
The Report	1
Conducting the Research and Report Production	1
Importance of Persons with Disabilities Working in South Carolina.....	2
METHODOLOGY FOR PART ONE: ISSUES RELATED TO THE ELIGIBILITY	
PROCESS	3
Research Questions.....	3
Instruments and Protocols.....	3
Sample.....	3
Interview Methods	4
Analysis of Interviews	5
Analysis of Demographic Data.....	5
Limitations of the Study.....	6
FINDINGS FOR PART ONE: ISSUES RELATED TO THE ELIGIBILITY PROCESS ..	7
Description of the Interviewees	7
Description of Interviewees with a Disability	7
Description of Responsible Parties Interviewed.....	20
Summary of Themes Identified by the People Interviewed.....	22
Medicaid Is Seen as a Life or Death Issue.....	22
Recipients Acknowledge Value of Medicaid Working Disabled Program	23
The Application Process is Confusing.....	23
Earnings and Asset Limits are Counterproductive	24
Resentment of Intrusive Process.....	25
Interviewees Suggestions for Improvements	26
Summary of Themes Identified by Eligibility Workers	27
Health Insurance is Seen as a Life and Death Issue.....	27
Barriers to Working in Eligibility Criteria.....	27
Barriers to Eligibility Workers Doing Their Jobs Well	28
Suggestions for Improvements	29
DISCUSSION AND CONCLUSIONS FOR PART ONE.....	30
RECOMMENDATIONS FOR PART ONE.....	31
Short Term	31
Long Term	32
APPENDIX ONE: INTERVIEW SCHEDULES FOR INDIVIDUAL AND GROUP	
INTERVIEWS WITH PEOPLE WITH DISABILITIES.....	33
APPENDIX TWO: QUESTIONS FOR ELIGIBILITY WORKERS.....	56

TABLE OF FIGURES

Table 1: Category of Disability for Persons Interviewed	7
Table 2: Types of PEB Disabilities of Interviewees	7
Table 3: When PEB Disability was Acquired.....	8
Table 4: Types of BDD Disabilities of Interviewees.....	8
Table 5: When BDDD was Acquired	8
Table 6: Types of TA Disabilities of Interviewees	9
Table 7: When TA Disability was Acquired.....	10
Table 8: Ethnicity, Gender, and Age of All Interviewees.....	10
Table 9: Education Level of All Interviewees	11
Table 10: All Interviewees Who Receive SSDI/SSI.....	11
Table 11: Health Insurance Coverage for All Interviewees.....	11
Table 12: Types of Assistance Received by All Interviewees.....	12
Table 13: Work Experience of Interviewees	13
Table 14: Ethnicity, Gender, and Age of Interviewees Who are Working.....	13
Table 15: Education Level of Interviewees Who are Working	14
Table 16: Interviewees Who are Working Who Receive SSDI/SSI.....	14
Table 17: Health Insurance Coverage for Interviewees Who are Working.....	15
Table 18: Types of Assistance Received by Interviewees Who are Working.....	15
Table 19: Work Experience of Interviewees Who are Working.....	16
Table 20: Monthly Wages from Working of All Interviewees.....	16
Table 21: Category of Disability for Interviewees Who are Working.....	17
Table 22: Ethnicity, Gender, and Age of Interviewees Who are Not Working.....	17
Table 23: Education Level of Interviewees Who are Not Working	18
Table 24: Interviewees Who are Not Working Who Receive SSDI/SSI.....	18
Table 25: Health Insurance Coverage for Interviewees Who are Not Working.....	19
Table 26: Types of Assistance Received by Interviewees Who are Not Working.....	19
Table 27: Work Experience of Interviewees Who are Not Working.....	20
Table 28: Category of Disability for Interviewees Who are Not Working.....	20
Table 29: Ethnicity, Gender, and Age of Responsible Parties Interviewed.....	21
Table 30: Education Level of Responsible Parties Interviewed	21
Table 31: Health Insurance Coverage for Responsible Parties Interviewed.....	22

INTRODUCTION

The Medicaid Infrastructure Grant Project

In March of 2004, the South Carolina Department of Health and Human Services (SC DHHS) received a \$500,000 Medicaid Infrastructure Grant (MIG) authorized by the *Ticket to Work and Work Incentives Improvement Act of 1999*. The goal of this MIG is to provide resources to break down the barriers that stand between people with disabilities and employment in the community. The grant was written by an interagency group composed of representatives from the Department of Disabilities and Special Needs (DDSN), the Department of Vocational Rehabilitation (VR), the Department of Mental Health (DMH), the SC Department of Health and Human Services (DHHS), the Employment Security Commission (SCES), Commission for the Blind (COB), Department of Social Services (DSS), Department of Education (DOE), Department of Health and Environmental Control (DHEC), and Protection and Advocacy for People with Disabilities (P&A).

The MIG is governed by a Work Plan that includes 25 activities. Among these activities are three that are designed to create a base of information about the barriers that exist to persons with disabilities working and what factors account for success of persons with disabilities working. This report provides that base of information.

The Report

This report consists of five Parts. The first Part, to be delivered on March 31, 2005, will cover issues associated with the Medicaid eligibility process. The Second and Third Parts, to be delivered on May 31, 2005, will cover the barriers to working and the factors accounting for success at working as reported by persons with disabilities who are working and ones who are not. The Fourth Part, to be delivered on June 30, 2005, will report the barriers and success factors as reported by professionals in the field. The Fifth Part, to be delivered on October 15, 2005, will report on the findings of a survey of employers. A final summary of findings, conclusions, and recommendations will accompany the final report in October.

Conducting the Research and Report Production

The research was conducted and reports produced by System Wide Solutions, Inc. under subcontract to the University of South Carolina. The College of Social Work of the University of South Carolina provided expert advice from faculty as well as master's and doctoral level students to support the research. System Wide Solutions (SWS) has been working with the College of Social Work and the SC DHHS since July of 1997 on research, policy, and evaluation issues regarding individuals with disabilities who are receiving Medicaid support.

Importance of Persons with Disabilities Working in South Carolina

According to the U.S. Census Bureau, there are 514,963 working age persons with disabilities residing in the state of South Carolina. They make up 23% of the state's working age citizens. Almost half of these people (45%) are not currently employed. Many of these individuals who are not employed have job skills and want to work. These unemployed persons with disabilities are a resource that is not tapped by the State at this time. Each of these persons who enter the workforce becomes a tax payer who can provide greater support for him or herself and his or her family. These individuals can make South Carolina more competitive in the world economy.

METHODOLOGY FOR PART ONE: ISSUES RELATED TO THE ELIGIBILITY PROCESS

Research Questions

The primary research questions for Part One are:

- What are the barriers to persons with disabilities working that are created by the eligibility system?
- In what ways does the eligibility system help persons with disabilities become and stay employed?

Instruments and Protocols

An interview schedule for persons with disabilities and their primary caregivers was developed that would cover the research questions for Parts One, Two, and Three. This instrument may be found in Appendix One. A full protocol for the use of this instrument in both an individual and group setting was developed. This protocol may also be found in Appendix One.

An additional interview schedule was developed for interviewing eligibility workers. This instrument may be found in Appendix Two.

Sample

There were four criteria that guided the selection of the sample. These are:

- The sample would include as many different types of disability as possible.
- The sample would include both working and non-working persons with disabilities.
- The sample would include a predominance of persons with disabilities, but also some persons who are the family members of persons with disabilities.
- The sample would be geographically representative.

Initial efforts were made to recruit persons enrolled in Medicaid under the Working Disabled category. This proved to be difficult for two reasons. First, not many persons take advantage of this category, therefore the pool of potential participants is small. Secondly, the SC DHHS interpretation of HIPPA requires that individuals be asked in writing if they can be contacted by researchers. The individuals must then respond in writing that they may be contacted. SC

DHHS sent letters to individuals in the Working Disabled category asking them to participate in the project. 30%, or eleven people, responded. Of these, eight agreed to be interviewed.

In order to identify additional participants, the researchers used two approaches: the first was a “snowball” approach to identify potential interviewees. The second was contacting disabilities organizations to help organize group interviews. These methods both proved to be effective.

The “snowball” method identifies one person with the appropriate characteristics who in turn identifies another person who can in turn identify another person and so on. The key to the snowball method is making sure that no two people are completely alike. They must have differences in their demographic profiles. About 50% of the persons interviewed were identified in this fashion. The remaining 50% were identified by organizations of persons with disabilities. No two organizations used in the sample methodology are composed of persons with the same disability.

Interview Methods

The primary consideration in the interview methods was to gather as much information as possible related to the research questions. There were three ways in which this was assured.

- Interviews occurred at a place chosen by the person or persons being interviewed. For individuals, this was in their home, with the exception of one person. For groups of individuals, it was the place where an organization they belong to regularly works or meets.
- The interview schedule and protocol (see Appendix One) was designed to allow the interviewees to speak in their own style. The interviewers held a conversation with the interviewees ensuring that all questions were answered, but not forcing the conversation to follow the order of the questions.
- As much as possible, the invitation to take part in an interview was made by someone familiar with the interviewee, rather than the researchers.

As far as practical, persons with all types of disabilities were included. Disabilities were broken into three major areas. These are:

- Psychological, Emotional, Behavioral (PEB)
- Traumatic or Acquired (TA)
- Birth Defect and Developmental Disability (BDDD)

Specifically, the sample matrix is as follows:

Type of Disability	Number Sought Working	Number Interviewed	Number Sought Not Working	Number Interviewed
Sight Impairment	3		3	
Deaf/Hard of Hearing	3		3	
Mobility Impairment - Wheelchair	3		3	
Mobility Impairment - Other	3		3	
Chemical Dependency	3		3	
Attention Deficit Disorder	3		3	
Developmental Disability	3		3	
Traumatic or Acquired Brain Injury	3		3	
Coordination Impairment	3		3	
Speech/Language Impairment	3		3	
Learning Disabled	3		3	
Psychological Disability/Emotional Behavioral Disorder	3		3	
Mental Retardation	3		3	
Autism	3		3	
TOTAL	42		42	

In addition, the directors of the two divisions of the Eligibility Bureau at the Department of Health and Human Services and two eligibility workers in the field were interviewed. All interviews were recorded, other than those with the directors. Demographic and service information was gathered on the persons with disabilities.

Analysis of Interviews

The recordings and notes of the interviewers were used to write process recordings of the interviews. The process recordings were read by three staff members. The staff members identified what they believed to be the issues raised and described in the interviews. The staff members then met and discussed the issues they identified until consensus was reached. Findings were then written. Upon the completion of the findings being written, the staff members developed their individual findings and recommendations. The staff members met and discussed the findings and recommendations until they reached consensus. The report was then completed.

Analysis of Demographic Data

The demographic data was entered into an Access database. This database was imported in the Statistical Package for the Social Sciences and tables and charts describing the sample developed.

Limitations of the Study

Many of the people interviewed for this study have been receiving Medicaid and other benefits for several years. Therefore many of the experiences of the interviewees occurred in the past, although they have also had more recent experiences with the application and eligibility process during annual reviews of their status.

FINDINGS FOR PART ONE: ISSUES RELATED TO THE ELIGIBILITY PROCESS

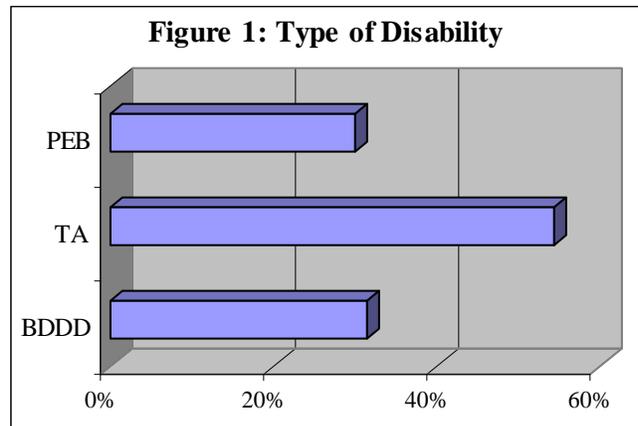
Description of the Interviewees

Description of Interviewees with a Disability

Types of Disabilities

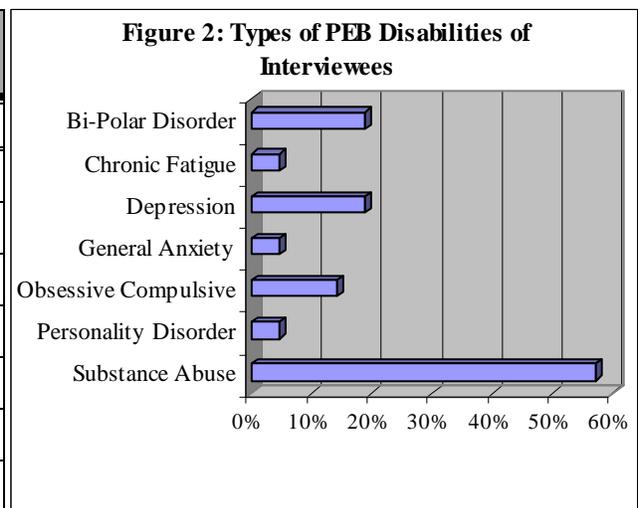
A total of 70 people with disabilities were interviewed. Several of these people had multiple types of disabilities. Of these, 30% have a psychological, emotional, or behavioral (PEB) disability; 54.3% have a traumatic or acquired (TA) disability; and 31.4% have a birth defect or developmental disability (BDDD). (See Table 1 and Figure 1.)

Table 1: Category of Disability for Persons Interviewed		
N=70	#	%
Psychological, Emotional, Behavioral (PEB)	21	30.0%
Traumatic or Acquired (TA)	38	54.3%
Birth Defect and Developmental Disability (BDDD)	22	31.4%



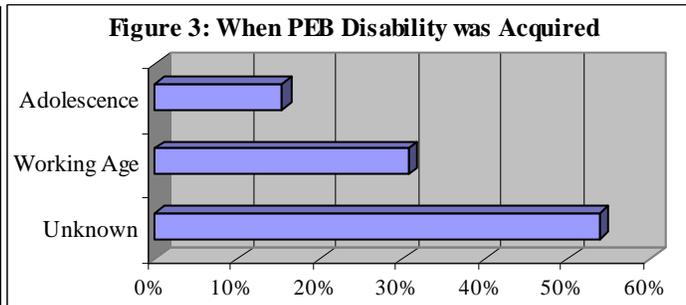
Of the 21 people who stated they have a PEB disability, 57.1% have substance abuse problems, 19% have bi-polar disorder or manic depression, 19% have depression, and 14.3% have obsessive compulsive disorder. One person (4.8%) each has chronic fatigue, general anxiety, and a personality disorder. (See Table 2 and Figure 2.)

Table 2: Types of PEB Disabilities of Interviewees		
N=21	#	%
Bi-Polar Disorder	4	19.0%
Chronic Fatigue	1	4.8%
Depression	4	19.0%
General Anxiety	1	4.8%
Obsessive Compulsive	3	14.3%
Personality Disorder	1	4.8%
Substance Abuse	12	57.1%



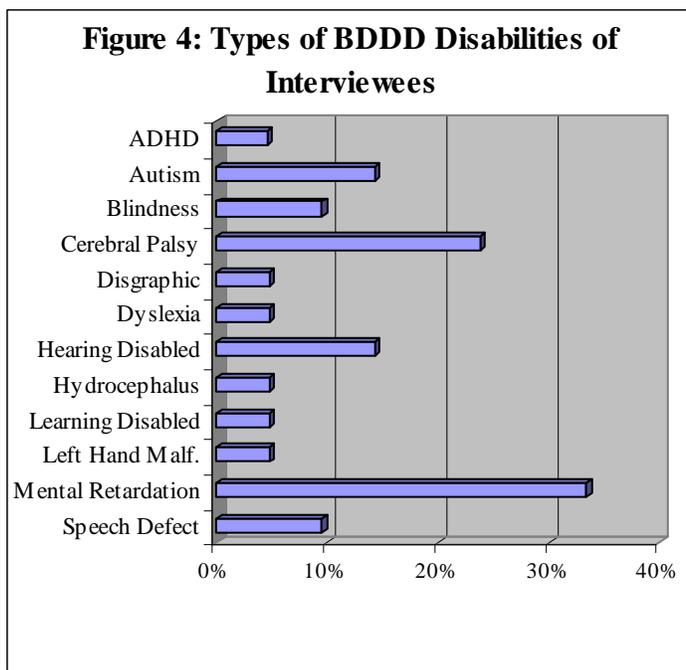
Of the 26 PEB disabilities identified, 15.4% were acquired during adolescence and 30.8% were acquired while the person was of working age. The date of onset was unreported for 53.8% of disabilities. The majority of these were substance abuse problems. (See Table 3 and Figure 3.)

Table 3: When PEB Disability was Acquired		
N=26	#	%
Adolescence (ages 13-18)	4	15.4%
Working Age (ages 19-64)	8	30.8%
Unknown	14	53.8%



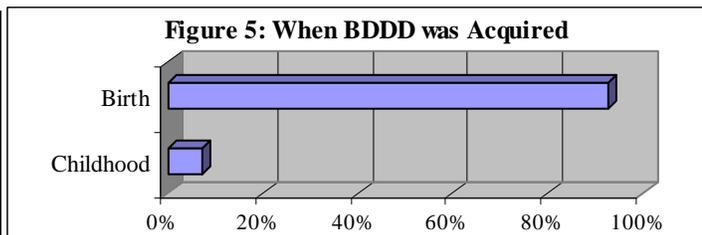
Of the 22 people who stated they have a birth defect or developmental disability; 33.3% stated they have mental retardation, 23.8% stated they have cerebral palsy, 14.3% stated they have autism, 14.3% stated they are hearing disabled, 9.5% stated they are blind, and 9.5% stated they have a speech defect. One person each stated they have ADHD, disgraphic disability, Dyslexia, Hydrocephalus, a learning disability, and left hand malformation. (See Table 4 and Figure 4.)

Table 4: Types of BDDD Disabilities of Interviewees		
N=22	#	%
ADHD	1	4.5%
Autism	3	14.3%
Blindness	2	9.5%
Cerebral Palsy	5	23.8%
Disgraphhic	1	4.8%
Dyslexia	1	4.8%
Hearing Disabled	3	14.3%
Hydrocephalus	1	4.8%
Learning Disabled	1	4.8%
Left Hand Malformation	1	4.8%
Mental Retardation	7	33.3%
Speech Defect	2	9.5%



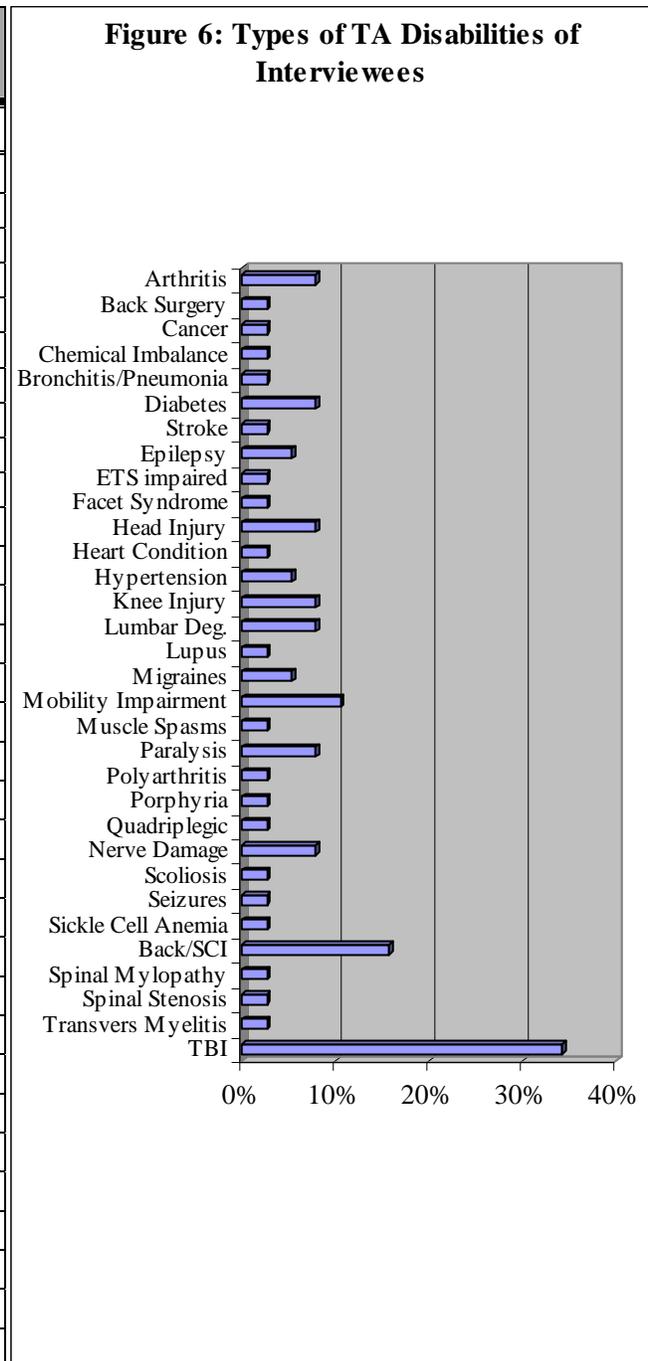
Of the 28 BDDD identified, 92.9% were acquired at birth and 7.1% were acquired during childhood. (See Table 5 and Figure 5.)

Table 5: When BDDD was Acquired		
N=28	#	%
Birth	26	92.9%
Childhood (ages 1-12)	2	7.1%



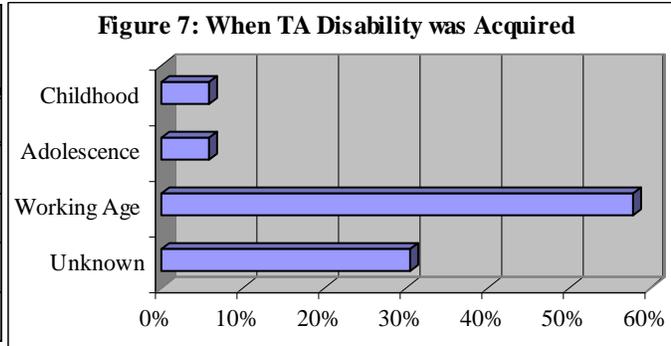
Of the 38 people who reported they have a traumatic or acquired disability; 34.2% stated they have a traumatic brain injury, 15.8% stated they have a back or spinal cord injury, and 10.5% stated they have a mobility impairment. Several other disabilities were listed by these persons, which can be found in the table below. (See Table 6 and Figure 6.)

Table 6: Types of TA Disabilities of Interviewees		
N=38	#	%
Arthritis	3	7.9%
Back Surgery	1	2.6%
Cancer	1	2.6%
Chemical Imbalance	1	2.6%
Chronic Bronchitis/Pneumonia	1	2.6%
Diabetes	3	7.9%
Stroke	1	2.6%
Epilepsy	2	5.3%
Executive thinking skills impaired	1	2.6%
Facet Syndrome	1	2.6%
Head Injury	3	7.9%
Heart Condition	1	2.6%
Hypertension	2	5.3%
Knee Injury	3	7.9%
Lumbar Degeneration	3	7.9%
Lupus	1	2.6%
Migraines	2	5.3%
Mobility Impairment	4	10.5%
Muscle Spasms	1	2.6%
Paralysis	3	7.9%
Polyarthritis	1	2.6%
Porphyria	1	2.6%
Quadriplegic	1	2.6%
Nerve Damage	3	7.9%
Scoliosis	1	2.6%
Seizures	1	2.6%
Sickle Cell Anemia	1	2.6%
Back/Spinal Cord Injury	6	15.8%
Spinal Mylopathy	1	2.6%
Spinal Stenosis	1	2.6%
Transverse Myelitis	1	2.6%
Traumatic Brain Injury	13	34.2%



Of the 69 TA disabilities identified, 5.8% were acquired during childhood, 5.8% were acquired during adolescence, and 58% were acquired when the person was of working age. The date of onset was unreported for 30.4% of disabilities. (See Table 7 and Figure 7.)

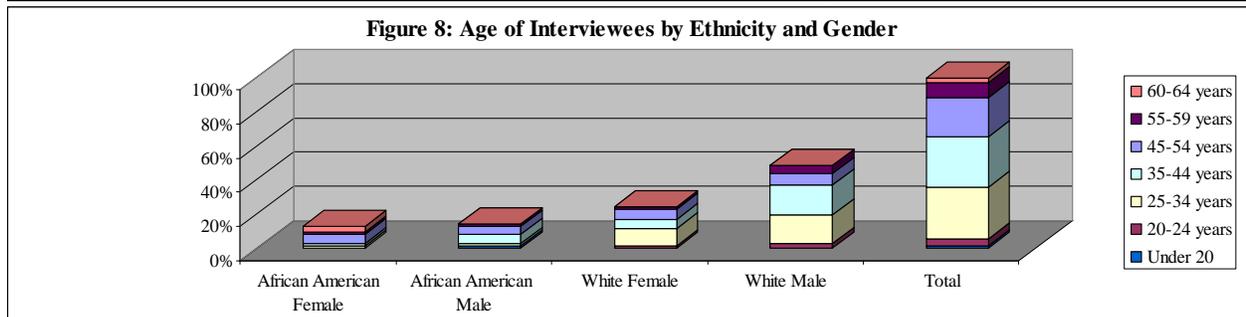
	#	%
N=69		
Childhood (ages 1-12)	4	5.8%
Adolescence (ages 13-18)	4	5.8%
Working Age (ages 19-64)	40	58.0%
Unknown	21	30.4%



Description of All Persons with Disabilities Interviewed

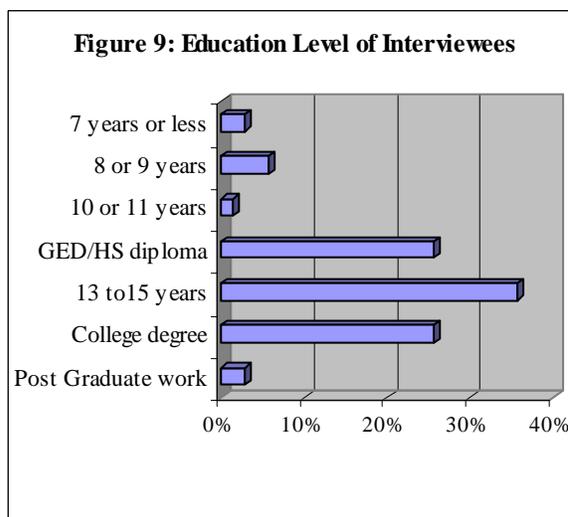
Of the 70 persons with disabilities who were interviewed; 12.9% are African American females, 14.3% are African American males, 24.3% are white females, and 48.6% are white males. The majority of these interviewees are between the ages of 25 and 34 (30%), 35 and 44 (30%), or 45 to 54 (22.9%). (See Table 8 and Figure 8 for breakdowns of ethnicity and gender by age.)

	African American Female		African American Male		White Female		White Male		Total	
	#	%	#	%	#	%	#	%	#	%
Under 20	0	0.0%	1	1.4%	0	0.0%	0	0.0%	1	1.4%
20-24 years	0	0.0%	0	0.0%	1	1.4%	2	2.9%	3	4.3%
25-34 years	1	1.4%	1	1.4%	7	10.0%	12	17.1%	21	30.0%
35-44 years	1	1.4%	4	5.7%	4	5.7%	12	17.1%	21	30.0%
45-54 years	4	5.7%	3	4.3%	4	5.7%	5	7.1%	16	22.9%
55-59 years	1	1.4%	1	1.4%	1	1.4%	3	4.3%	6	8.6%
60-64 years	2	2.9%	0	0.0%	0	0.0%	0	0.0%	2	2.9%
Total	9	12.9%	10	14.3%	17	24.3%	34	48.6%	70	100.0%



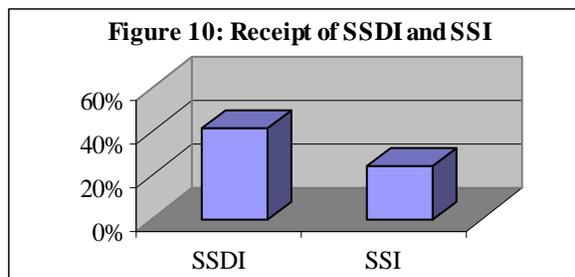
Of the 70 interviewees with a disability; 2.9% have seven years of education or less, 5.7% have eight or nine years of education, one person (1.4%) has ten or eleven years of education, 25.7% have twelve years of education or their GED or HS diploma, 35.7% have more than 12 years but less than 16 years of education, 25.7% have a college degree, and 2.9% have done some post graduate work. (See Table 9 and Figure 9.)

Table 9: Education Level of All Interviewees		
	#	%
Seven years or less	2	2.9%
Eight or nine years	4	5.7%
Ten or eleven years	1	1.4%
Twelve years or GED or HS diploma	18	25.7%
More than 12 but less than 16 years	25	35.7%
College degree (16 years)	18	25.7%
Post Graduate Work	2	2.9%
Total	70	100.0%



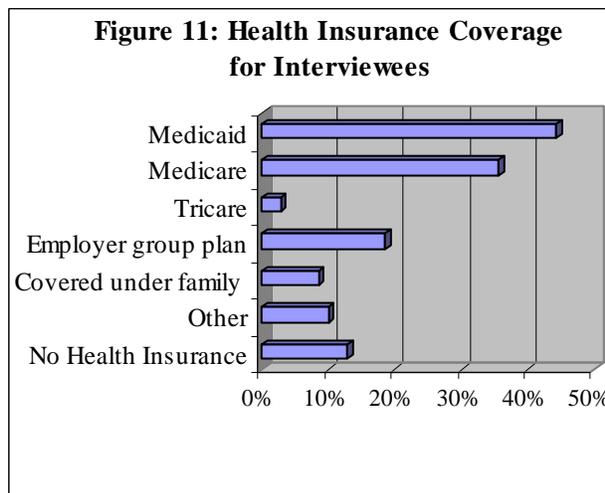
Of the 70 interviewees with a disability, 41.4% are currently receiving Social Security Disability Income (SSDI) and 24.3% are currently receiving Supplemental Security Income (SSI). (See Table 10 and Figure 10.)

Table 10: All Interviewees Who Receive SSDI/SSI		
N=70	#	%
Social Security Disability Income	29	41.4%
Supplemental Security Income	17	24.3%



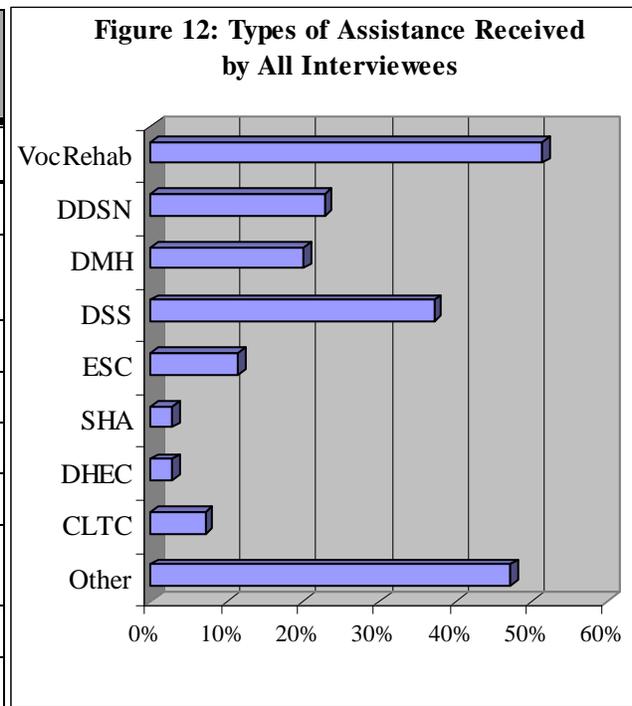
Of the 70 interviewees; 44.3% have Medicaid coverage, 35.7% have Medicare coverage, 2.9% have Tricare coverage, 18.6% are covered under an employer group plan, 8.6% are covered under another family member, 10% have other types of health insurance, and 12.9% do not have any health insurance. Of the seven interviewees with other types of health insurance; two have Blue Cross Blue Shield, one makes a COBRA payment, one is covered under the HASCI waiver, one has VA medical and dental coverage, and one did not specify. (See Table 11 and Figure 11.)

Table 11: Health Insurance Coverage for All Interviewees		
n=70	#	%
Medicaid	31	44.3%
Medicare	25	35.7%
Tricare	2	2.9%
Employer group plan	13	18.6%
Covered under family member	6	8.6%
Other	7	10.0%
No Health Insurance Coverage	9	12.9%



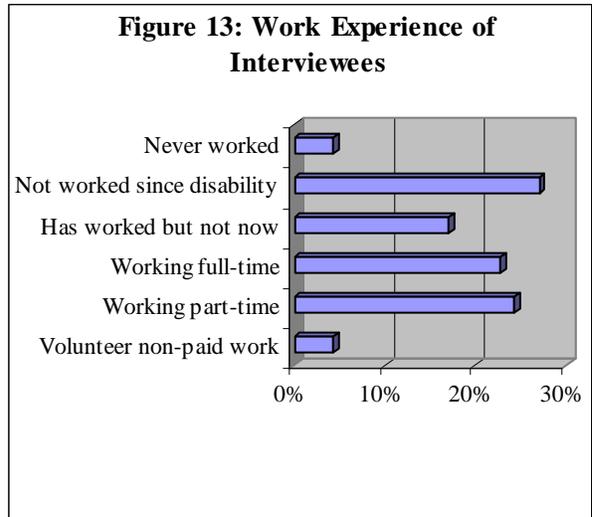
Of the 70 interviewees; 51.4% have received Vocational Rehabilitation assistance, 22.9% have received assistance from the Department of Disabilities and Special Needs, 20% have received assistance from the Department of Mental Health, 37.1% have received assistance from the Department of Social Services, 11.4% have received assistance from the Employment Security Commission, 2.9% have received assistance from the State Housing Authority, 2.9% have received assistance from the Department of Health and Environmental Control, 7.1% have received assistance from the Division of Community Long Term Care, and 47.1% have received assistance from other places. Of the other places; 14 people (20%) received assistance from the Alcohol and Drug Abuse Commission, three people (4.3%) have received assistance from the Commission for the Blind, four people (5.8%) have received assistance from the SC Department of Health and Human Services – Medicaid Eligibility, and three people (4.3%) have received assistance from the VA hospital. (See Table 12 and Figure 12.)

Table 12: Types of Assistance Received by All Interviewees		
n=70	#	%
Vocational Rehabilitation	36	51.4%
Department of Disabilities and Special Needs	16	22.9%
Department of Mental Health	14	20.0%
Department of Social Services	26	37.1%
Employment Security Commission	8	11.4%
State Housing Authority	2	2.9%
Department of Health and Environmental Control	2	2.9%
Community Long Term Care	5	7.1%
Other	33	47.1%



Of the 70 interviewees; 4.3% have never worked, 27.1% have not worked since acquiring their disability, 17.1% have worked since acquiring their disability, but are not currently working, 22.9% are currently working full-time, 24.3% are currently working part-time by choice, and 4.3% are currently doing volunteer non-paid work. (See Table 13 and Figure 13.)

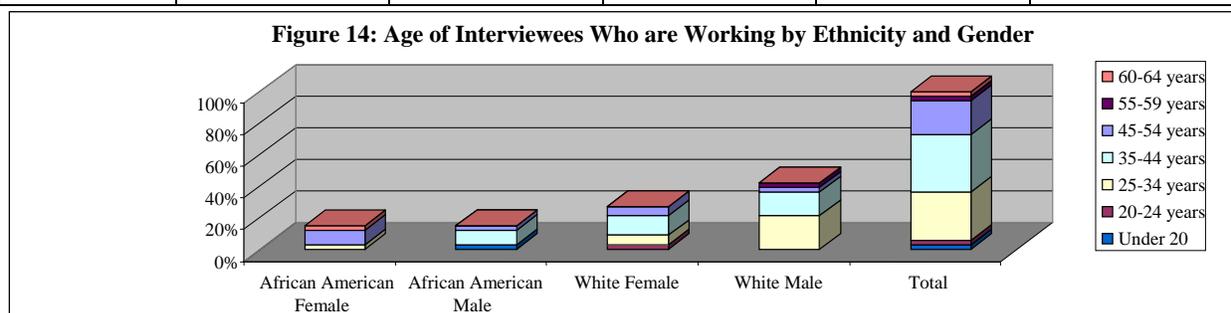
Table 13: Work Experience of Interviewees		
	#	%
Has never worked	3	4.3%
Has not worked since acquiring disability	19	27.1%
Has worked since acquiring disability but is not currently working	12	17.1%
Currently working full-time (at least 30 hours/wk)	16	22.9%
Currently working part-time (less than 30 hours/wk)	17	24.3%
Currently doing volunteer non-paid work	3	4.3%
Total	70	100.0%



Description of Interviewees with a Disability Who Are Working

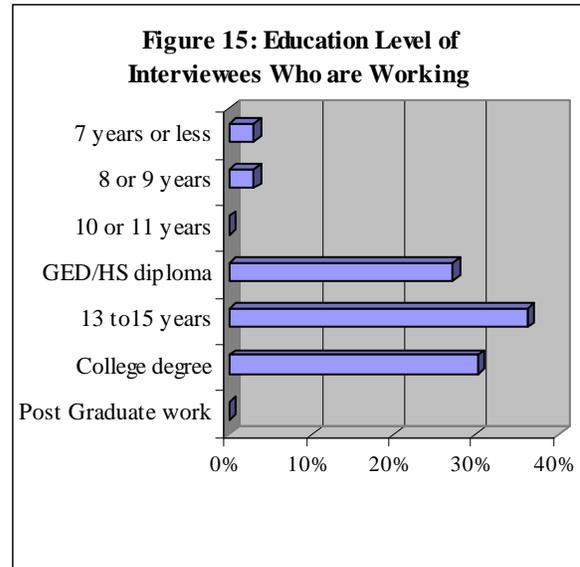
Of the 33 interviewees with disabilities who are currently working; 15.2% are African American females, 15.2% are African American males, 27.3% are white females, and 42.4% are white males. The majority of these interviewees are between the ages of 25 and 34 (30.3%), 35 and 44 (36.4%), or 45 to 54 (21.2%). (See Table 14 and Figure 14 for breakdowns of ethnicity and gender by age.)

Table 14: Ethnicity, Gender, and Age of Interviewees Who are Working										
	African American Female		African American Male		White Female		White Male		Total	
	#	%	#	%	#	%	#	%	#	%
Under 20	0	0.0%	1	3.0%	0	0.0%	0	0.0%	1	3.0%
20-24 years	0	0.0%	0	0.0%	1	3.0%	0	0.0%	1	3.0%
25-34 years	1	3.0%	0	0.0%	2	6.1%	7	21.2%	10	30.3%
35-44 years	0	0.0%	3	9.1%	4	12.1%	5	15.2%	12	36.4%
45-54 years	3	9.1%	1	3.0%	2	6.1%	1	3.0%	7	21.2%
55-59 years	0	0.0%	0	0.0%	0	0.0%	1	3.0%	1	3.0%
60-64 years	1	3.0%	0	0.0%	0	0.0%	0	0.0%	1	3.0%
Total	5	15.2%	5	15.2%	9	27.3%	14	42.4%	33	100.0%



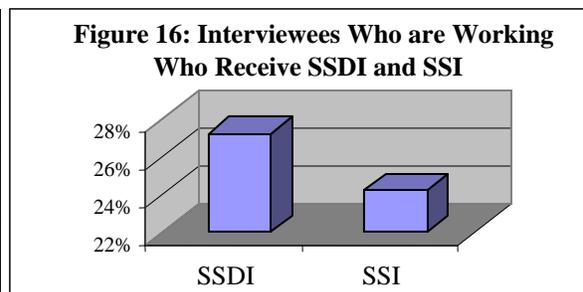
Of the 33 interviewees with disabilities who are currently working; 3% have seven years of education or less, 3% have eight or nine years of education, 27.3% have twelve years of education or their GED or HS diploma, 36.4% have more then 12 years but less than 16 years of education, and 30.3% have a college degree. (See Table 15 and Figure 15.)

Table 15: Education Level of Interviewees Who are Working		
	#	%
Seven years or less	1	3.0%
Eight or nine years	1	3.0%
Ten or eleven years	0	0.0%
Twelve years or GED or HS diploma	9	27.3%
More than 12 but less than 16 years	12	36.4%
College degree (16 years)	10	30.3%
Post Graduate Work	0	0.0%
Total	33	100.0%



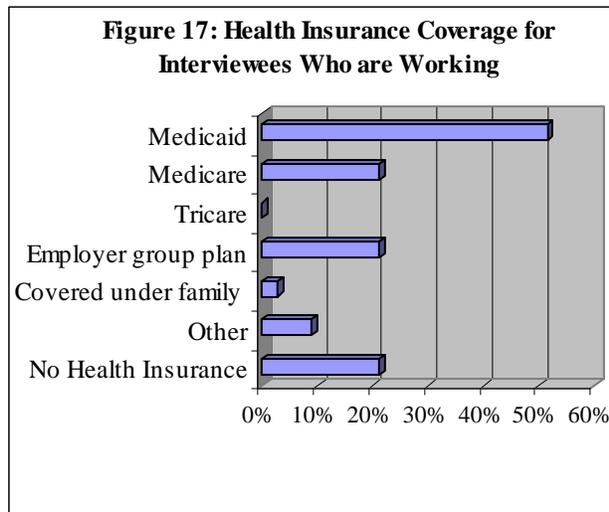
Of the 33 interviewees with disabilities who are currently working; 27.3% are currently receiving Social Security Disability Income (SSDI) and 24.2% are currently receiving Supplemental Security Income (SSI). (See Table 16 and Figure 16.)

Table 16: Interviewees Who are Working Who Receive SSDI/SSI		
N=33	#	%
Social Security Disability Income	9	27.3%
Supplemental Security Income	8	24.2%



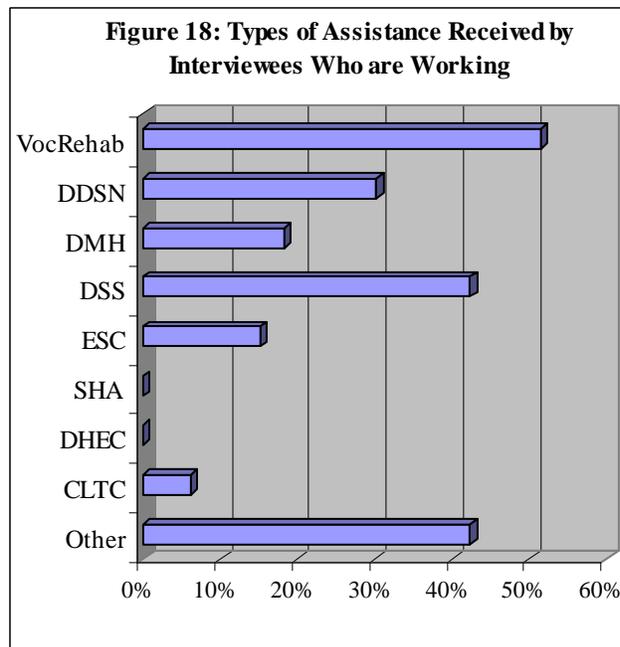
Of the 33 interviewees with disabilities who are currently working; 51.5% have Medicaid coverage, 21.2% have Medicare coverage, 21.2% are covered under an employer group plan, one person (3%) is covered under another family member, 9.1% have other types of health insurance, and 21.2% do not have any health insurance. All seven of the interviewees who reported having no health insurance coverage are currently working full-time. (See Table 17 and Figure 17.)

Table 17: Health Insurance Coverage for Interviewees Who are Working		
n=33	#	%
Medicaid	17	51.5%
Medicare	7	21.2%
Tricare	0	0.0%
Employer group plan	7	21.2%
Covered under family member	1	3.0%
Other	3	9.1%
No Health Insurance Coverage	7	21.2%



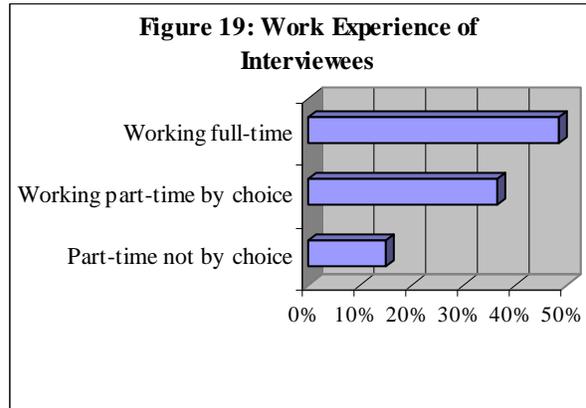
Of the 33 interviewees with disabilities who are currently working; 51.5% have received Vocational Rehabilitation assistance, 30.3% have received assistance from the Department of Disabilities and Special Needs, 18.2% have received assistance from the Department of Mental Health, 42.4% have received assistance from the Department of Social Services, 15.2% have received assistance from the Employment Security Commission, 6.1% have received assistance from the Division of Community Long Term Care, and 42.4% have received assistance from other places. Of these other places, seven people (21.2%) received assistance from the Alcohol and Drug Abuse Commission, two people (6.1%) have received assistance from the Commission for the Blind, and two people (6.1%) have received assistance from the SC DHHS. (See Table 18 and Figure 18.)

Table 18: Types of Assistance Received by Interviewees Who are Working		
n=33	#	%
Vocational Rehabilitation	17	51.5%
Department of Disabilities and Special Needs	10	30.3%
Department of Mental Health	6	18.2%
Department of Social Services	14	42.4%
Employment Security Commission	5	15.2%
State Housing Authority	0	0.0%
Department of Health and Environmental Control	0	0.0%
Community Long Term Care	2	6.1%
Other	14	42.4%



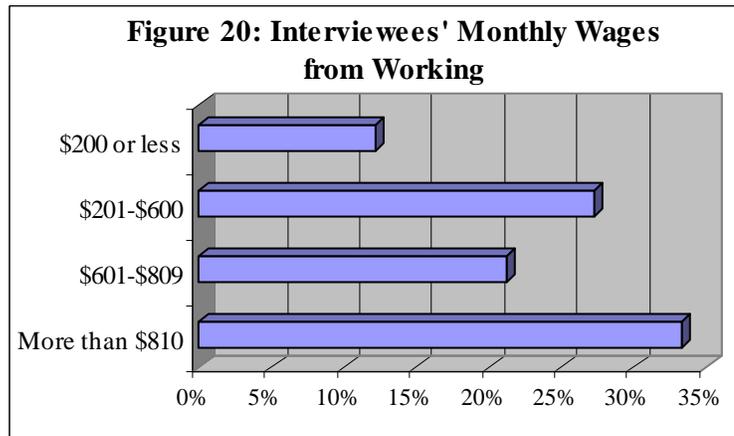
Of the 33 interviewees with disabilities who are currently working; 48.5% are currently working full-time, 36.4% are currently working part-time by choice, and 15.2% are currently working part-time not by choice. (See Table 19 and Figure 19.) Of those who stated they are working part-time not by choice, one person stated it is because that is the limit of their contract, one person stated it is because they cannot find anything accessible, and one person stated it is because they do not want to lose their Medicaid.

Table 19: Work Experience of Interviewees Who are Working		
	#	%
Currently working full-time (at least 30 hours/wk)	16	48.5%
Currently working part-time (less than 30 hours/wk) by choice	12	36.4%
Currently working part-time (less than 30 hours/wk) not by choice	5	15.2%
Total	33	100.0%



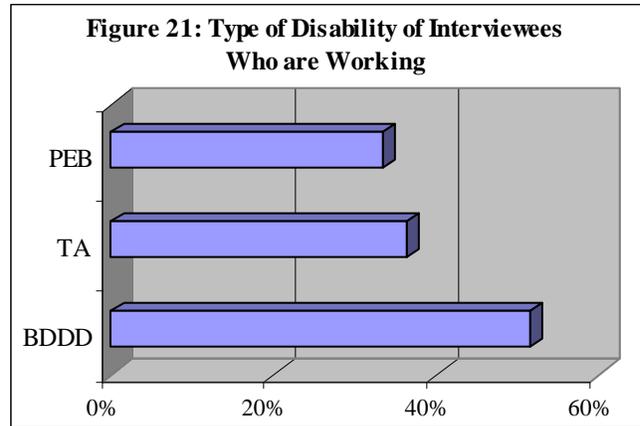
Of the 33 people who stated that they are currently working either full-time or part-time; 12.1% are making \$200 or less per month, 27.3% are making between \$201 and \$600 per month, 21.2% are making between \$601 and \$809 per month, and 33.3% are making more than \$810 per month. The remaining 6.1% did not report their monthly wages. (See Table 20 and Figure 20.)

Table 20: Interviewees' Monthly Wages from Working		
	#	%
\$200 or less	4	12.1%
\$201-\$600	9	27.3%
\$601-\$809	7	21.2%
More than \$810	11	33.3%
Unknown	2	6.1%
Total	33	100.0%



Of the 33 interviewees with disabilities who are working; 33.3% have a psychological, emotional, or behavioral (PEB) disability, 36.4% have a traumatic or acquired (TA) disability, and 51.5% have a birth defect or developmental disability (BDDD). (See Table 21 and Figure 21.)

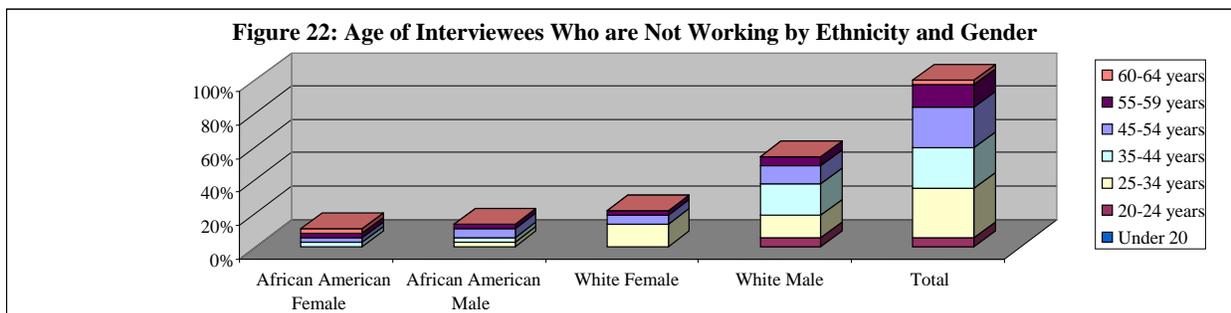
Table 21: Category of Disability for Interviewees Who are Working		
N=70	#	%
Psychological, Emotional, Behavioral (PEB)	11	33.3%
Traumatic or Acquired (TA)	12	36.4%
Birth Defect and Developmental Disability (BDDD)	17	51.5%



Description of Persons with Disabilities Who Are Not Working

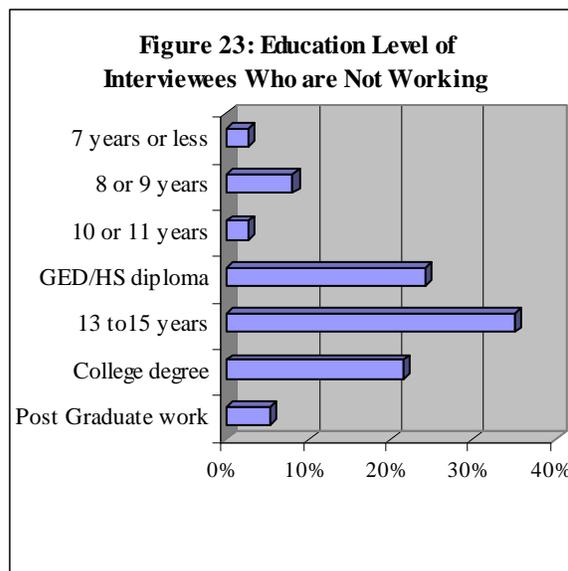
Of the 37 persons with disabilities who are not working; 10.8% are African American females, 13.5% are African American males, 21.6% are white females, and 54.1% are white males. The majority of these interviewees are between the ages of 25 and 34 (29.7%), 35 and 44 (24.3%), or 45 to 54 (24.3%). (See Table 22 and Figure 22 for breakdowns of ethnicity and gender by age.)

Table 22: Ethnicity, Gender, and Age of Interviewees Who are Not Working										
	African American Female		African American Male		White Female		White Male		Total	
	#	%	#	%	#	%	#	%	#	%
Under 20	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
20-24 years	0	0.0%	0	0.0%	0	0.0%	2	5.4%	2	5.4%
25-34 years	0	0.0%	1	2.7%	5	13.5%	5	13.5%	11	29.7%
35-44 years	1	2.7%	1	2.7%	0	0.0%	7	18.9%	9	24.3%
45-54 years	1	2.7%	2	5.4%	2	5.4%	4	10.8%	9	24.3%
55-59 years	1	2.7%	1	2.7%	1	2.7%	2	5.4%	5	13.5%
60-64 years	1	2.7%	0	0.0%	0	0.0%	0	0.0%	1	2.7%
Total	4	10.8%	5	13.5%	8	21.6%	20	54.1%	37	100.0%



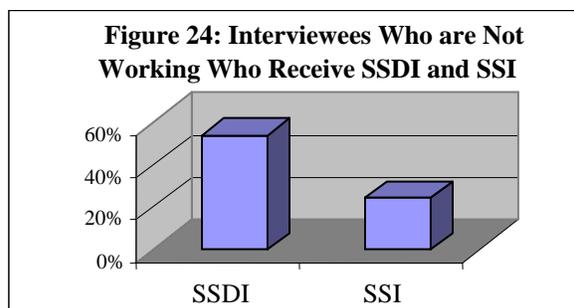
Of the 37 interviewees with disabilities who are not working; one person (2.7%) has seven years of education or less, 8.1% have eight or nine years of education, one person (1.4%) has ten or eleven years of education, 24.3% have twelve years of education or their GED or HS diploma, 35.1% have more than 12 years but less than 16 years of education, 21.6% have a college degree, and 5.4% have done some post graduate work. (See Table 23 and Figure 23.)

Table 23: Education Level of Interviewees Who are Not Working		
	#	%
Seven years or less	1	2.7%
Eight or nine years	3	8.1%
Ten or eleven years	1	2.7%
Twelve years or GED or HS diploma	9	24.3%
More than 12 but less than 16 years	13	35.1%
College degree (16 years)	8	21.6%
Post Graduate Work	2	5.4%
Total	37	100.0%



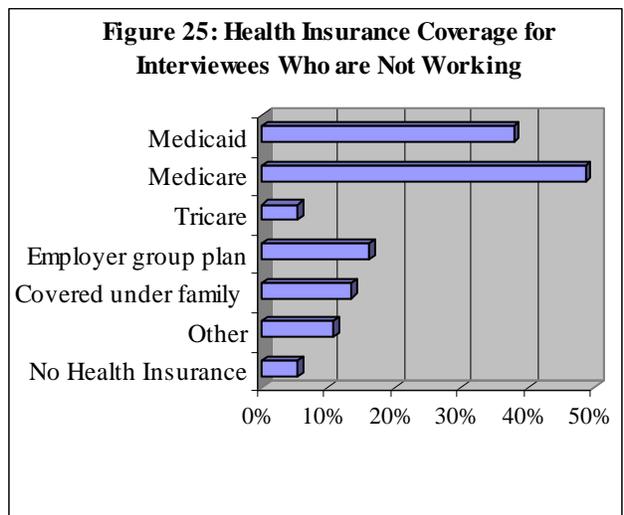
Of the 37 interviewees with disabilities who are not working, 54.1% are currently receiving Social Security Disability Income (SSDI) and 24.3% are currently receiving Supplemental Security Income (SSI). (See Table 24 and Figure 24.)

Table 24: Interviewees Who are Not Working Who Receive SSDI/SSI		
N=37	#	%
Social Security Disability Income	20	54.1%
Supplemental Security Income	9	24.3%



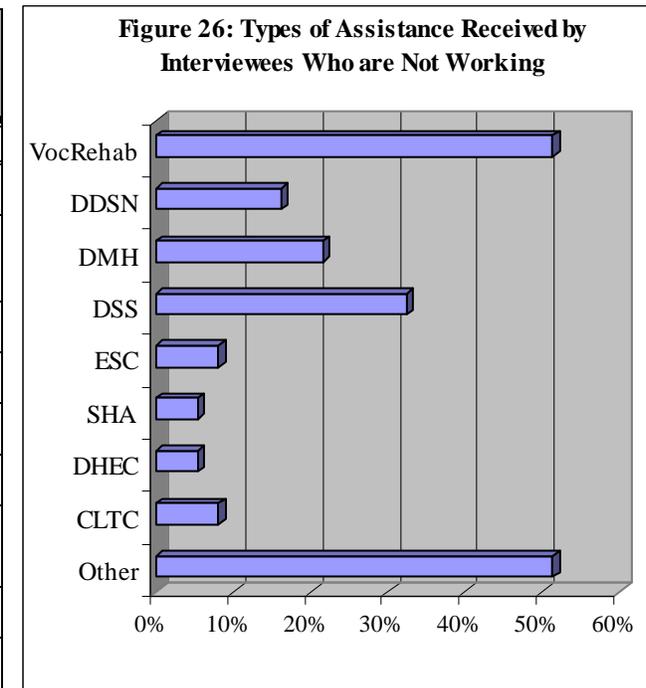
Of the 37 interviewees with disabilities who are not working; 37.8% have Medicaid coverage, 48.6% have Medicare coverage, 5.4% have Tricare coverage, 16.2% are covered under an employer group plan, 13.5% are covered under another family member, 10.8% have other types of health insurance, and 5.4% do not have any health insurance. Of the four interviewees with other types of health insurance, two have Blue Cross Blue Shield, one has VA medical and dental coverage, and one did not specify. (See Table 25 and Figure 25.)

Table 25: Health Insurance Coverage for Interviewees Who are Not Working		
n=37	#	%
Medicaid	14	37.8%
Medicare	18	48.6%
Tricare	2	5.4%
Employer group plan	6	16.2%
Covered under family member	5	13.5%
Other	4	10.8%
No Health Insurance Coverage	2	5.4%



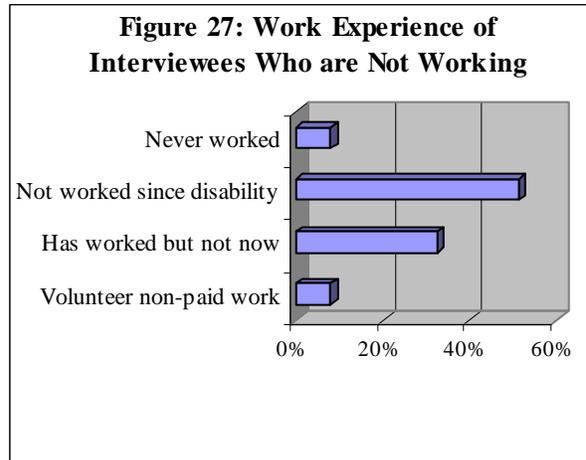
Of the 37 interviewees with disabilities who are not working; 51.4% have received Vocational Rehabilitation assistance, 16.2% have received assistance from the Department of Disabilities and Special Needs, 21.6% have received assistance from the Department of Mental Health, 32.4% have received assistance from the Department of Social Services, 8.1% have received assistance from the Employment Security Commission, 5.4% have received assistance from the State Housing Authority, 5.4% have received assistance from the Department of Health and Environmental Control, 8.1% have received assistance from the Division of Community Long Term Care, and 51.4% have received assistance from other places. Of these other places, seven people (18.9%) received assistance from the Alcohol and Drug Abuse Commission, two people (5.4%) have received assistance from the PEP, and two people (5.4%) have received assistance from the SC Department of Health and Human Services. (See Table 26 and Figure 26.)

Table 26: Types of Assistance Received by Interviewees Who are Not Working		
n=37	#	%
Vocational Rehabilitation	19	51.4%
Department of Disabilities and Special Needs	6	16.2%
Department of Mental Health	8	21.6%
Department of Social Services	12	32.4%
Employment Security Commission	3	8.1%
State Housing Authority	2	5.4%
Department of Health and Environmental Control	2	5.4%
Community Long Term Care	3	8.1%
Other	19	51.4%



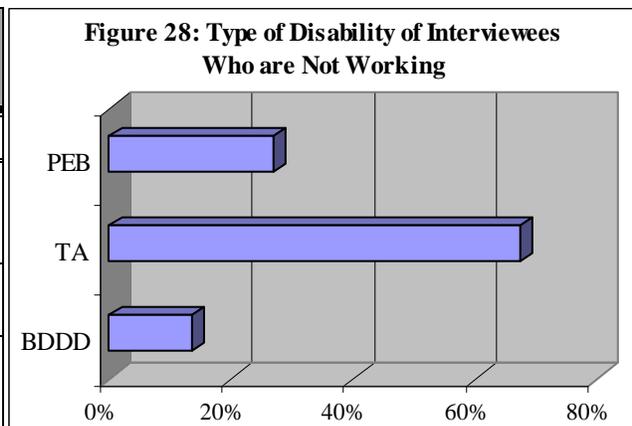
Of the 37 interviewees with disabilities who are not working; 8.1% have never worked, 51.4% have not worked since acquiring their disability, 32.4% have worked since acquiring their disability, but are not currently working, and 8.1% are currently doing volunteer non-paid work. (See Table 27 and Figure 27.)

Table 27: Work Experience of Interviewees Who are Not Working		
	#	%
Has never worked	3	8.1%
Has not worked since acquiring disability	19	51.4%
Has worked since acquiring disability but is not currently working	12	32.4%
Currently doing volunteer non-paid work	3	8.1%
Total	37	100.0%



Of the 37 interviewees with disabilities who are not working; 27% have a psychological, emotional, or behavioral (PEB) disability, 67.6% have a traumatic or acquired (TA) disability, and 13.5% have a birth defect or developmental disability (BDDD). (See Table 28 and Figure 28.)

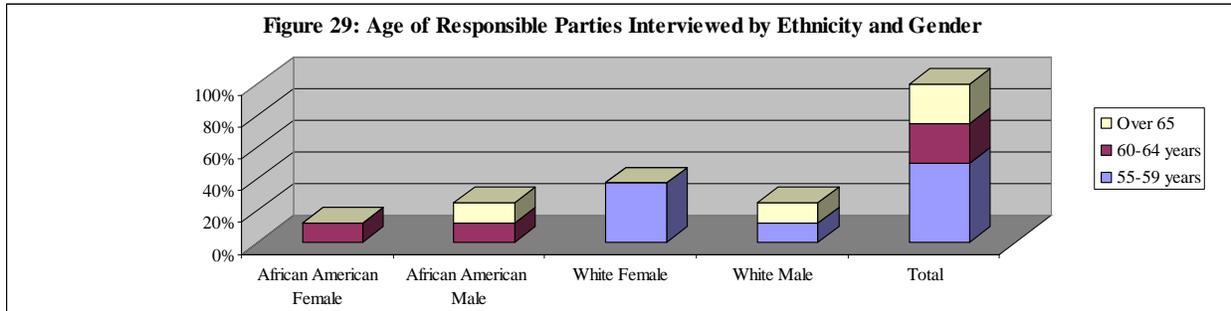
Table 28: Category of Disability for Interviewees Who are Not Working		
N=37	#	%
Psychological, Emotional, Behavioral (PEB)	10	27.0%
Traumatic or Acquired (TA)	25	67.6%
Birth Defect and Developmental Disability (BDDD)	5	13.5%



Description of Responsible Parties Interviewed

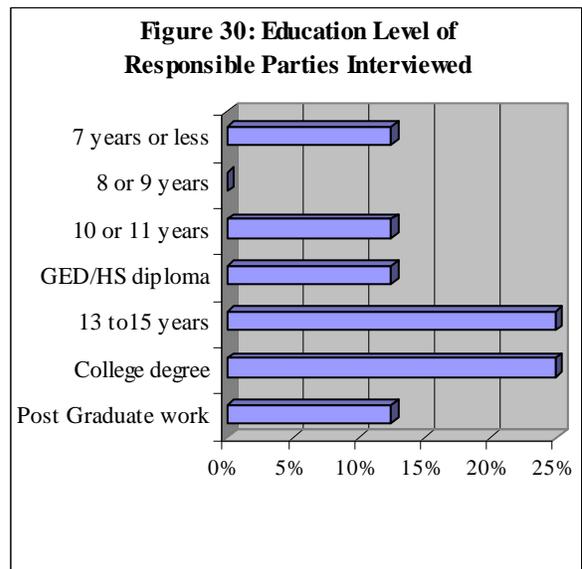
Of the eight responsible parties interviewed; 12.5% are African American females, 25% are African American males, 37.5% are white females, and 25% are white males. The majority of these interviewees are between the ages of 55 and 59 (50%). Another 25% of interviewees are between the ages of 60 and 64, and 25% are over 65 years old. (See Table 29 and Figure 29 for breakdowns of ethnicity and gender by age.)

Table 29: Ethnicity, Gender, and Age of Responsible Parties Interviewed										
	African American Female		African American Male		White Female		White Male		Total	
	#	%	#	%	#	%	#	%	#	%
55-59 years	0	0.0%	0	0.0%	3	37.5%	1	12.5%	4	50.0%
60-64 years	1	12.5%	1	12.5%	0	0.0%	0	0.0%	2	25.0%
Over 65	0	0.0%	1	12.5%	0	0.0%	1	12.5%	2	25.0%
Total	1	12.5%	2	25.0%	3	37.5%	2	25.0%	8	100.0%



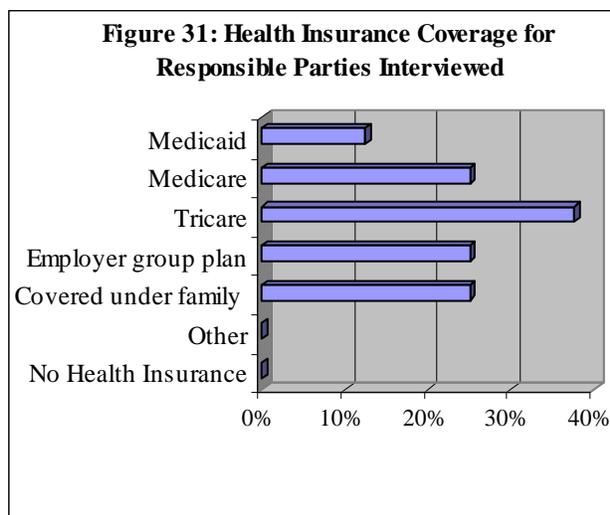
Of the eight responsible parties interviewed; one person (12.5%) has seven years of education or less, one person (12.5%) has ten or eleven years of education, one person (12.5%) has twelve years of education or their GED or HS diploma, 25% have more than 12 years but less than 16 years of education, 25% have a college degree, and one person (12.5%) has done some post graduate work. (See Table 30 and Figure 30.)

Table 30: Education Level of Responsible Parties Interviewed		
	#	%
Seven years or less	1	12.5%
Eight or nine years	0	0.0%
Ten or eleven years	1	12.5%
Twelve years or GED or HS diploma	1	12.5%
More than 12 but less than 16 years	2	25.0%
College degree (16 years)	2	25.0%
Post Graduate Work	1	12.5%
Total	8	100.0%



Of the eight responsible parties interviewed, one person (12.5%) has Medicaid coverage, 25% have Medicare coverage, 37.5% have Tricare coverage, 25% are covered under an employer group plan, and 25% are covered under another family member. (See Table 31 and Figure 31.)

Table 31: Health Insurance Coverage for Responsible Parties Interviewed		
n=37	#	%
Medicaid	1	12.5%
Medicare	2	25.0%
Tricare	3	37.5%
Employer group plan	2	25.0%
Covered under family member	2	25.0%
Other	0	0.0%
No Health Insurance Coverage	0	0.0%



Summary of Themes Identified by the People Interviewed

Several major themes regarding the eligibility process emerged from a content analysis of the interviews. These themes are:

- Having health insurance is seen as a life or death issue by many persons with disabilities and the Medicaid eligibility decisions are therefore seen as decisions about whether they live or die.
- Recipients who qualify through the Working Disabled program recognize its worth.
- The application process is confusing and difficult to understand.
- Earnings and asset limits are counterproductive to providing the incentives for working.
- There is great resentment about the intrusive nature of the eligibility process.
- The consumers have suggestions for improvements.

Medicaid Is Seen as a Life or Death Issue

Interviewees mentioned repeatedly that they could not obtain life-sustaining medical care or medications without Medicaid benefits. For most persons with disabilities, there are no health care alternatives. Even persons receiving Medicare need Medicaid to provide what Medicare will not provide. Persons with disabilities attempting to become eligible for Medicaid are therefore very anxious and may appear to be irrational to some workers.

- Medicaid benefits are essential to persons with disabilities who require expensive medications. Subjects who mentioned this had various disabilities that require ongoing prescriptions and medical care including lupus, arthritis, head and spinal cord injuries, and mental health disorders.
- A common view held by persons interviewed was “A check is replaceable, medical benefits are not”. Private health insurance companies are reluctant to cover persons with disabilities. To persons with disabilities, guarding the health benefits of Medicaid and Medicare is all important.

- Even for persons with disabilities who are working, qualifying for health care insurance through an employer is difficult for several reasons. First, the time between getting a job and getting the insurance can be as much as a year (due to waiting periods and pre-existing conditions). Because these people are working full time, they have lost coverage from Medicaid. So there is a period of no health care coverage. Many employer policies do not cover pre-existing conditions or they require long waiting periods. Also in the low wage jobs that are often available, it is hard to make co-pays and deductibles.
- Medicaid benefits provide durable medical equipment that individuals could not otherwise afford, such as home handrails and a handicapped toilet. Such equipment is essential to minimal functioning.

Recipients Acknowledge Value of Medicaid Working Disabled Program

Medicaid recipients who have taken advantage of the Medicaid Working Disabled program acknowledge its value. Although this category represented the minority of the study participants, those who worked and maintained their Medicaid benefits recognized that these benefits were critical to their being able to work at all. Several people believed that they could not be able to work without having Medicaid provide their health care.

- One woman stated that she could not afford her medical expenses without Medicaid. The Medicaid Drug Card is essential to her. She takes a number of medications and simply couldn't get along without the card.
- Parents of a man who is deaf said that they are grateful for benefits he has received in the past, SSI and Medicaid. They could not have managed without those benefits. Now he is an adult working full time and his eligibility will end soon. They worry about how to obtain health coverage for him.

The Application Process is Confusing

The application process is seen as lengthy and overwhelming. Many consumers feel that it is unduly complicated.

- People interviewed for this project usually do not distinguish between the various programs that provide State and Federal assistance. They do not differentiate between applying for Medicaid and applying for SSI or SSDI benefits. They also do not make distinctions between different state offices. They just report that they "had to go to the DSS office" or other government office to fill out paperwork. When asked specifically about the Medicaid application experience, they describe it as long and confusing.
- A woman with terminal cancer qualified for Medicaid but was turned down for SSI, even though she met the criteria. She had no other income. After multiple surgeries, she weighs 76 pounds and is on infusion therapy. While she is waiting to be reconsidered for SSI, her only sources of income are Food Stamps and the generosity of a former employer.
- When one consumer applied for disability benefits, it took 18 months before she was approved. She said, "This lady kept calling me". The subject seemed very frustrated that it had taken so long to get approval. "I needed the help."

- The application process can be lengthy and frustrating. One woman had trouble applying for Medicaid benefits and finally was qualified through the assistance of Senator Strom Thurmond's office. Medicaid pays for her pain medication pump.
- The Medicaid system is terribly complicated and nearly impossible to understand. Consumers believe that it takes a lot of time and often the help of a lawyer to get the right benefits. The mistakes made by the system can result in individuals having to pay large sums of money back to Medicaid.
- A family that had moved here found that the eligibility system in South Carolina was puzzling and not as accessible as they experienced when living in other states (Ohio and Michigan).
- Participants thought that DHHS has a complicated formula to figure out how much money individuals can earn and retain Medicaid. They asserted that eligibility workers would not explain the formula. One subject declared, "DSS (sic) failed me."
- They viewed the workers who process their benefits applications as generally ill-informed about the regulations for various benefit programs.
- A few subjects stated that the eligibility workers treated them well and were helpful.
- Mentioned frequently was the large amount of paperwork to get initial approval and to maintain eligibility for Medicaid. Some applicants for benefits had to submit hard copies of documents, such as bank account statements and pay stubs, even though eligibility workers can access this information on-line from the SC Department of Revenue, with the consumer's permission. They believed that requiring them to get hard copies was an unnecessary and expensive step.
- Some persons with disabilities state that they were treated with respect during the application process, but many others felt that they were demeaned or that their needs related to their disability were not considered. Consumers think that eligibility workers generally do not know about the various disabilities. For example, persons who have to use a wheelchair for mobility were required to sit for hours at a DSS office, which was physically very difficult for them.
- "They (the government) don't care. They don't give us (people with disabilities) supportive funds and don't realize it is hard to find a job if you have a disability."
- Interviewees believe that the Medicaid Working Disabled category does not work for most people. People think they are not able to qualify because the eligibility workers do not understand the rules on reducing earned income by the necessary out of pocket expenses for a person with disabilities to go to work. They assert that the appropriate (income) deductions are not being allowed.

Earnings and Asset Limits are Counterproductive

Many of the interviewees who have been receiving benefits for some time believe that the income and asset limits have not changed in at least ten years. People seem to regard the asset limitations as particularly troubling. Interviewees do not see any rationale for having rules that discourage savings and planning for emergencies.

- Some people state that the rules are very confusing about how much they can earn. They believe eligibility workers give contradictory or ambiguous advice about earnings limits.
- Interviewees think that eligibility workers do not always subtract the allowable items when determining qualifying income.
- Many individuals have had their SSI or SSDI benefit checks reduced because they earned too much from a full time or part time job. This occurred even when they asked for guidance on how much they could earn and still maintain benefits. Interviewees frequently referred to this reduction in their SSI or SSDI check as a “penalty”.
- A number of interviewees report that they have had to pay back thousands of dollars to Social Security or Medicaid because of overpayment. They report this as “a painful experience” they would not want to repeat.
- One individual with autism said that he liked the salary at his previous full time job, but he was earning too much money. The government then cut his SSI check back by \$25 a month. It took him three years to pay back what he owed for earning too much. He said that he definitely prefers to work more than he is doing now, but he does not want to have to pay back money that he worked to earn. He now works one day per week as a custodian.
- There is a widespread view that the Medicaid restrictions regarding income and assets make it even more difficult for persons with disabilities to work. One subject, who is deaf, has worked all her adult life. She noted that she can only earn 250% of poverty level and have \$2,000 in cash assets. Although Vocational Rehabilitation paid for her first set of hearing aids, she has to replace them from time to time, and that costs \$5,000. Because of the asset limits, she cannot save for the purchase in advance, so she is always in debt.
- Asset limits are regarded as unduly restrictive. These limits mean that persons receiving benefits cannot save in advance for expected replacement of durable medical equipment or for emergencies. One subject with a mental health disorder supported this view by stating that even though he has two children, he cannot have more than \$2,000 in financial assets or his benefits will be taken away. He asked, "How can you climb out of poverty with these restrictions?" Participants seemed to resent the fact that saving for an emergency was not supported.

Resentment of Intrusive Process

A theme that emerged with some interviewees was the intrusiveness of the government on the lives of persons with disabilities. There was some expressed resentment of the invasion of privacy, particularly from the younger persons interviewed.

- One man in his 20's with head and spinal cord injury working full time stated, “The government is always over my shoulder”. He explained that he cannot earn more than \$35,000 per year or he risks losing his benefits. He also reported that he cannot have any assets in his name because the government will seize his property when he dies. The interviewee feels that the government infringes on his privacy and independence because he is required to give them a record of his check stubs. He sometimes regrets the decision that his mother made to sign him up for Medicaid. He was not aware of the decision because he

- One blind man working 30 hours per week sees some government action exerting too much control over individuals who receive Medicaid or SSI as not helpful. He described this as government being “Big Brother”.

Interviewees Suggestions for Improvements

Interviewees offered a range of suggestions on how to improve the current Medicaid and Social Security eligibility process for persons with disabilities. These suggestions usually emerged during discussions about what they believed was the attitude of government about their working or not working. Some suggestions were based on consumer’s misunderstanding of the process, while others were based on an accurate understanding of the situation.

- A number of participants said that they would like to see a Medicaid buy-in program in South Carolina. This would not only allow people to work, but also to advance in their work. If they are working and do not have medical benefits, if something happens to them, someone has to pay for their care anyway. Interviewees believe that it is illogical to cut off Medicaid in the event of their working.
- A paraplegic man sees the Ticket to Work program as beneficial, otherwise he would not be able to work and keep his benefits. If he gets one more promotion at work, he would make too much to be able to keep getting personal care aide and housekeeping assistance. He would be willing to pay directly for that service if it were a reasonable amount or pay for "personal care insurance" at rates like an able-bodied person pays for health care.
- Making the State Insurance Plan available to persons with disabilities in lieu of Medicaid would be one way of dealing with assuring medical coverage. Many persons with disabilities work at non-profits because these organizations are generally more understanding of their needs. Perhaps non-profit organizations could be allowed to participate in the State Insurance Plan.
- A consumer on the Head and Spinal Cord waiver wishes he could continue to be eligible for the services agencies provide without being forced to use all of them at this time. He has been told that if he does not use the services available, he will lose them. This person explained to the interviewer that he does not want to use all the services if he does not need them right now, but wants to “save his spot” in case he needs them in the future.
- Once benefits are lost, re-applying for Medicaid and other benefits is like starting all over again and many consumers do not want to take that chance. In the case of a young woman who had had a stroke, once she left a rehab program, there was nothing for her to do. While she was training for work, she maintained benefits. However, if she goes to work, she will lose benefits. What happens later if she loses the job? She wonders how long it would take to get benefits again.
- Many consumers said that the income level is set too low for qualification for Medicaid. Participants believe that a change would pay for itself through increased payroll taxes of working persons with disabilities.

- Having a reimbursement system would also be more cost effective for purchasing medical supplies. The cost to Medicaid for supplies is often higher than it is to buy the same things off the shelf.
- More money spent on health care prevention would also save money in the long run. It appears that there is no foresight in the Medicaid program, investing now to save more later.
- Having one number to call and one place to go to apply for benefits or questions would really be helpful. Interviewees believe that workers need to be better informed about regulations and benefits. State and Federal both need to co-locate. A single payer system would settle a lot of this.
- A blind woman asserted that, “the government should be happy that I am working because they don’t have to take care of me”. She is working as an entrepreneur to take care of herself financially. She also says that she is hardly ever sick, so she rarely uses the medical benefits. She uses her Medicare benefits once a year to get her annual check-up, and she has only used Medicaid once in the last ten years or so to get some dental work done. The interviewee believes that not all people with disabilities should be grouped into the same category. She believes that persons with severe disabilities should get more money to pay for medicine.

Summary of Themes Identified by Eligibility Workers

Two eligibility workers and the directors of the two divisions in the Bureau of Eligibility Services at the SC DHHS were interviewed. One worker works with DDSN clients and the other with clients with disabilities. The workers were assured that their comments would not be attributed to them individually, but that they could not be assured anonymity given the circumstances. An interview schedule was followed. In many respects, the themes identified by the professionals were similar to those identified by the persons with disabilities. These are:

- Having health insurance is seen as a life or death issue by many persons with disabilities and the Medicaid eligibility decisions are therefore seen as decisions about whether they live or die.
- There are numerous barriers in the eligibility criteria to persons working.
- There are numerous barriers to eligibility workers doing their jobs well.
- The professionals have suggestions for improvements.

Health Insurance is Seen as a Life and Death Issue

Persons with disabilities are very frightened about losing their Medicaid coverage. It is, quite literally in many cases, a matter of life and death. When they want to go to work, or are working, they often call in asking if they are making too much to keep their Medicaid. A big part of the eligibility worker’s job is checking on this for the recipients, especially around the annual review time.

Barriers to Working in Eligibility Criteria

The income and asset level limits make it difficult for people to work. There are expenses to working for everyone, but especially for persons with disabilities. That is taken partially into

account in determining eligibility. But asset limits are especially a problem, in that some of the assistive technology is expensive and must be bought by persons with disabilities, and they can't save enough money to do so. It is difficult to save money to do the socially responsible thing, like paying off bills caused by the disability or purchase a burial site.

The income and asset policies in general are very strict. Being \$5 over in income means losing benefits. Policies could be more lenient. Persons who are willing to work and willing to contribute should be the first ones to get Medicaid, but are instead discriminated against by the system. The system discourages what the society encourages - savings, working, building assets, home ownership, and so on. Those who want to pay their bills are penalized.

Small amounts of money are of great significance to persons with disabilities. The \$3.00 co-pay on prescriptions, for example, means some people simply don't get the medications, which potentially shortens their lives. Because a hard copy of the social security determination must be provided rather than using the on-line system to confirm the determination, this costs the individual \$16.

Many policies should be reviewed. For example, the rule that requires the financial information of a spouse be filed if the couple has been separated for less than five years is very problematic. The separated spouse is certainly not going to provide any help, and they often cannot be found. As another example, the differences in income limits among different categories, like those for the working disabled under 65 and those over 65, are irrational.

People do not use the Working Disabled category because of the income and asset limits. They simply don't qualify, and would be penalizing themselves to take advantage of it.

People who have worked and paid taxes all their lives are disturbed when something happens to them that they have no control over and they find that it is too difficult to get the minimal help provided by the system. Workers question whether the system is serving those whom it should be serving in the way it should be serving them.

Barriers to Eligibility Workers Doing Their Jobs Well

The first barrier that the eligibility workers addressed was the lack of a responsible party to provide information for those with disabilities who cannot provide it for themselves. Many clients do not have any family or any family members who are interested in what they are going through. This makes it very difficult for workers to get the information they need.

The intrusive nature of the questions asked during eligibility determination leads to difficulties. People do not want to give some of the information. Other agencies question the need for the information. It is hard to explain the need for things like bank statements. Employers are not always cooperative, in that they are reluctant to give private information about employees.

The automated data system is not being used appropriately. It is being used to parallel the existing paper system, rather than to replace it. For example, Social Security and income information could be verified on the system, but procedures only allow the automated system to be used as a lead. The paper confirmation is still required. The system is not user friendly. The

programming, for example, does not allow for switching eligibility categories. Switching categories requires a manual method that must go through higher authority and takes two to three weeks. Workers could do the same thing in a few minutes if the programming issue was addressed.

Suggestions for Improvements

The policy manual being on-line is helpful. But it would be more helpful if the programming allowed for quick reference, like a keyword search. People sometimes hang up because it takes too long to find an answer to a question. It would even be of more assistance to workers if the entire manual were revised and modernized.

A wall chart that answers common questions and explains the eligibility categories would enable workers to quickly answer questions on the phone and aid with clients in the office.

Training on different disabilities would help workers understand the causes and effects. Workers could then speak with more understanding with recipients and the parents of DDSN clients. More understanding of conditions would allow them to know how to help potential recipients gather information and be more comfortable in the office. This could defuse situations when recipients may get angry and upset.

It would also be helpful to have more information about what is covered under Medicare, the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) program, and other similar programs. Eligibility workers understand the basics but need to know more detail. Workers also need to know more about how other agencies work; such as Vocational Rehabilitation, the Department of Veterans Affairs, DDSN, and others that serve persons with disabilities. This also holds true for private community services such as free health clinics. They would then be in a position to refer applicants to other services.

The workers suggested collaborative meetings with providers, agency staff, and eligibility workers to exchange information in order to understand what each do, and how they can cooperate to be more efficient and effective.

The parallel nature of the automated and hand systems should be reconciled. The automated system should be modified to rectify some of the common problems that occur when it is used.

DISCUSSION AND CONCLUSIONS FOR PART ONE

It is clear from the interviews with persons with disabilities, responsible parties, and professionals that the Medicaid eligibility process and the rules that govern it do not support persons with disabilities seeking and keeping employment. The overwhelming thought in the mind of the person with disabilities who is trying to become eligible is that Medicaid may be the difference between their living and dying. The overwhelming thought in the mind of the eligibility worker is that he or she must follow a complex and sometimes contradictory set of criteria. These two thoughts take precedence over everything else, including work for the person with disabilities.

The premises upon which the eligibility criteria were originally based no longer apply. People now live and can work, who would not have lived or worked forty years ago when Medicaid began. Assistive technology and medical science have far outstripped the beliefs that undergird the Medicaid program. Rather than adapt the program rules to the real world changes, the program has attempted to adapt the real world changes to an outmoded system. The result is a patchwork of rules, regulations, policies, and procedures that simply do not fit the facts with which persons with disabilities and eligibility workers must live. (In fairness, this is true of most of the services for persons with disabilities.) The eligibility system is like an old tire that keeps getting patches put on it, but that still loses air.

A number of modifications to the South Carolina Medicaid eligibility process will help the present system be more helpful to both recipients and workers. But more substantive changes will be necessary to create the support that is important to tapping the potential work force of persons with disabilities who are not now working, or who are working a limited amount.

In general then, there are both short term and medium term modifications that can be made to the eligibility system that will help persons with disabilities find and keep jobs. Recommendations for moving towards these changes are provided in the next section.

RECOMMENDATIONS FOR PART ONE

Short Term

1. The complexity of the present system that serves persons with disabilities requires a great deal of knowledge and skills on the part of professionals to help persons with disabilities return to work. Many states have put a great deal of effort into hiring and training benefits coordinators who help persons with disabilities wend their way through the system. South Carolina has used federal funds to provide a few benefits coordinators at Vocational Rehabilitation. The benefits coordinators provided appear to be an essential part of helping persons with disabilities get and keep jobs. It is recommended that at least one worker in each SC DHHS area office be trained to be a benefits coordinator and given the authority to carry out those functions.
2. It is recommended that the on-line policy manual be programmed to allow for on-line search capability.
3. It is recommended that a wall-sized chart be designed that answers common questions and explains the various eligibility categories.
4. It is recommended that training on different disabilities be provided to eligibility workers along with training on being sensitive to the needs of persons with specific disabilities.
5. In order to provide more accurate information, it is recommended that eligibility workers be provided with knowledge about what is covered under Medicare, the TEFRA program, and other similar programs.
6. It is recommended that disability workers be trained on the work of other agencies such as Vocational Rehabilitation, the Department of Veterans Affairs, DDSN, and others that serve the disabled population.
7. It is recommended that disability workers be informed about the work of private community services such as free health clinics.
8. It is recommended that collaborative meetings at the local level among providers, agency staff, and eligibility workers be held to exchange information in order to understand what each does and how they can cooperate to be more efficient and effective.
9. It is recommended that the automated system be modified after consultation with eligibility workers to determine the more common problems. The parallel paper system can be largely abolished once upgrading is completed.

Long Term

1. It is recommended that a method be developed to allow persons with disabilities who work to pay a share of the costs of Medicaid coverage, the share to increase as their income increases.
2. It is recommended that a group of professionals and persons with disabilities, who are provided health care by Medicaid, be formed to develop recommended levels of income and assets for Medicaid eligibility. This group would have as its first priority, balancing the costs and benefits of modifying these criteria so that persons with disabilities find it financially possible to work.
3. It is recommended that a complete revision be made of the policy manual to make it more “user friendly” in making eligibility determinations.

**APPENDIX ONE: INTERVIEW SCHEDULES FOR
INDIVIDUAL AND GROUP INTERVIEWS WITH
PEOPLE WITH DISABILITIES**

Medicaid Infrastructure Grant Individual Interview Protocol Persons with Disabilities Who Are Not Working

Goal: What is the experience of persons with disabilities who have worked in the past but no longer are or have never worked.

Supplies needed: Directions or map and contact phone number for meeting place, copy of protocol questions for staff members, SWS business cards, recorder, mike, , legal pad and pen for note-taking.

Participant Number: The participant number begins with the initials of the interviewee, the date of the interview expressed as MM/DD/YYYY and a W (if working) or an N (if not working).

Roles: Interviewer explains the project, keeps interview on track with questions and prompts. Scribe takes notes and monitors recorder. Interviewer should pose major questions and only use specific probes if the desired content is not forthcoming.

1. **Introduction** – Thank participant. Briefly state your name and introduce scribe. Go through demographic form and fill out with participant.
2. **State purpose of project** - to determine what needs to be done to make it easier for persons with disabilities who want to work to be successful at getting and keeping a job. That we are doing similar interviews around the state.
Interviewer will be asking a few questions and the participant will have a chance to say a much or as little as he or she wishes about that
Time frame will be approximately one hour.
Assure confidentiality.
We want to record the session (and will ask permission), but will remove any identifiers when we do our write ups. (If participant objects, scribe takes detail notes.)
Ask if any questions about the reason you are here and what we will be doing.
Tell who/how to contact someone if you have questions - Distribute business cards.
3. **Warm-up questions**
Ask what people's living arrangements are.

Get more specificity about disabilities if needed using demographic form as guide
4. **Key question** – You are people with disabilities who are not presently working. Tell us about your desires to work, what barriers and problems there may be about getting and keeping a job, and what your experience with working has been.
(Allow people to answer as they feel comfortable doing. Use follow up questions when necessary to make sure all of the issues we are interested in get covered.)

5. Follow-Up Questions

- A. Have you ever been employed? If so, how long, type of work, reasons for losing your job, was employment prior to becoming a person with a disability?
 - B. Would you like to go to work?
 - C. What has kept you from doing going to work?
 - D. What do you see as the government's attitude about their working?
 - 1. What is government doing to help?
 - 2. What is government doing that hinders you?
 - E. What do you think employers' attitudes would be about your working?
 - F. What could employers do to help?
 - G. What could employers do that would not be helpful?
 - H. On your demographic form you said you had received services from agencies.
Can you tell us how satisfied you are with the support from those agencies?
6. **Wrap-up** - Summarize major themes, thank respondent for his or her input.
Adjourn no later than 90 minutes after start time.
Label notes with name of participant, location participant number and date.

Completion: All notes and transcripts are to be kept in locked Medicaid Infrastructure file. Scribe prepares process recording and puts into file labeled "Working Persons with Disabilities Transcripts -2003/04." Advise Andrea when each process recording is finished. E-mail process recording to George and Sarah.

Location _____ Date _____ Participant Number _____

Format For Note Taking for Non-Working Individual Interviews

Use this format to take brief notes during Interview

3. Warm-up questions

Ask what people's living arrangements are.

- 4. Key question** – You are people with disabilities who are not presently working. Tell us about your desires to work, what barriers and problems there may be about getting and keeping a job, and what your experience with working has been.

5. Follow Up Questions

A. Have you ever been employed? If so, how long, type of work, reasons for losing your job, was employment prior to becoming a person with a disability?

B. Would you like to go to work?

C. What has kept you from doing going to work?

D. What do you see as the government's attitude about their working?

1. What is government doing to help?

2. What is government doing that hinders you?

E. What do you think employers' attitudes would be about your working?

F. What could employers do to help?

G. What could employers do that would not be helpful?

H. On your demographic form you said you had received services from agencies. Can you tell us how satisfied you are with the support from those agencies?

Overall observations:

Location _____ Date _____ Group Number _____

Medicaid Infrastructure Grant Group Interview Protocol Persons with Disabilities Who Are Working

Goal: What is the experience of persons with disabilities who have chosen to go back to work and are succeeded at doing so.

Supplies needed: Directions or map and contact phone number for meeting place, copy of interview questions for staff members, SWS business cards, recorder, mike, , legal pad and pen for note-taking, drinks and snacks sufficient for six people.

30 minutes prior to time - Arrive at site to meet site contact person and introduce selves. Ask where to conduct group. Set up room in horseshoe shape or around a table, if possible. Put out snacks in basket or on a side table.

Group Number: The Group Number will occur in sequence, ie, the first group will be 001. Subsequent to the group, the individual numbers will be assigned to the demographic information sheet.

Roles: Moderator explains the project, keeps group on track with questions and prompts. Scribe documents group numbers and demographics, takes notes and monitors recorder. Moderator should pose major questions and only use specific probes if the desired content is not forthcoming.

- 1. Introduction** - Welcome participants. Offer snacks and drinks. Ask to fill out demographic form. Assist as necessary.
Briefly state your name as moderator.
- 2. State purpose of group** - to determine what needs to be done to make it easier for persons with disabilities who want to work to be successful at getting and keeping a job. That we are doing similar groups around the state.
Moderator will be asking a few questions and each person will have a chance to say a much or as little as they wish about that - a general discussion.
Time frame will be approximately one hour.
Assure confidentiality.
We want to tape record the session (and will ask their permission), but will remove any identifiers when we do our write ups. (If anyone objects, scribe takes detail notes.)
Ask if any questions about the reason you are here and what we will be doing.
Tell who/how to contact someone if you have questions - Distribute business cards.
Introduce SWS staff - role is outside evaluators, based in Columbia through USC. We often work with DHHS. I will be moderator and (name) ____ will be assisting by taking notes. Scribe starts tape recorder.

3. Warm-up questions

Ask for kind of work people are doing and what their living arrangements are.

- 4. Key question** – You are people with disabilities who have chosen to work. Tell us about your experience getting and keeping a job.
(Allow people to answer as they feel comfortable doing. Use follow up questions when necessary to make sure all of the issues we are interested in get covered.)

5. Follow-Up Questions

1. How have you been successful? What did you do and what did others do to make it work?
2. What were the barriers that got in your way?
3. What are your fears about working and continuing to work?
4. What do you see down the road for you in relation to working?
5. What is the government's attitude about your working?
 - a. What is government doing to help?
 - b. What is government doing that hinders you?
6. What is your employer's attitude about your working?
 - a. What is your employer doing to help?
 - b. What is your employer doing that hinders you?
7. Why do you want to work?
8. Do you ever feel like quitting? Why?
9. How satisfied are you with the work you are doing? Is there work you would rather do?
10. How are things working out in regards to personal assistance?
 - a. Are there barriers to getting what you need?
 - b. What can government do to make their getting the right personal assistance easier.
11. How is your transportation situation working out?
 - a. What can government do to help with that?
12. How did you find out about your job?
13. Did you initially need a job coach and/or specialized training? If so, for how long and how intensive?
14. What type of accommodations is needed on your job - wheelchair ramps, accessible bathrooms, special keyboards, etc.?
15. Are you working full-time or part-time? Is this by choice?

16. Many of you said on your demographic forms that you have used services from different agencies. Can you tell us how satisfied you are with the support from those agencies?

6. **Wrap-up** - Summarize major themes, thank them for their input.

Adjourn no later than 90 minutes after start time.

Clean up room. Pack supplies. Scribe label tape with group, location and date. Label notes with group, location and date.

Completion: All tapes, notes and transcripts are to be kept in locked Medicaid Infrastructure file. Scribe transcribes tape and puts into file labeled "Working Persons with Disabilities Transcripts - 2003/04." Advise Andrea when each transcript is completed.

After completion of each group, set up blank tapes, supplies and "treats" to be ready for next session.

Location _____ Date _____ Group Number _____

Format for note-taking

Use this format to take brief notes during focus groups

After moderator asks each question, note response of each participant as C1, C2, etc. Write key phrase or word, rather than complete sentence. Take detailed notes only if someone objects to tape recording. If a particular participant does not respond, you do not need to write anything.

Example:

Q: What were the barriers that got in your way?

C1 Transportation. Had to arrange for pickup by relatives.

C2 Finding the right person for attendant care.

C3 Not getting the right kind of job leads at first.

3. Warm-up questions

Ask for kind of work people are doing and what their living arrangements are.

- 4. Key question** – You are people with disabilities who have chosen to work. Tell us about your experience getting and keeping a job.

5. Follow-Up Questions

A. How have you been successful? What did you do and what did others do to make it work?

B. What were the barriers that got in your way?

C. What are your fears about working and continuing to work?

D. What do you see down the road for you in relation to working?

E. What is the government's attitude about your working?

1. What is government doing to help?

2. What is government doing that hinders you?

F. What is your employer's attitude about your working?

1. What is your employer doing to help?

2. What is your employer doing that hinders you?

G. Why do you want to work?

H. Do you ever feel like quitting? Why?

I. How satisfied are you with the work you are doing? Is there work you would rather do?

J. How are things working out in regards to personal assistance?

1. Are there barriers to getting what you need?

2. What can government do to make their getting the right personal assistance easier.

K. How is your transportation situation working out?

1. What can government do to help with that?

L. How did you find out about your job?

M. Did you initially need a job coach and/or specialized training? If so, for how long and how intensive?

N. What type of accommodations is needed on your job - wheelchair ramps, accessible bathrooms, special keyboards, etc.?

O. Are you working full-time or part-time? Is this by choice?

P. Many of you said on your demographic forms that you have used services from different agencies. Can you tell us how satisfied you are with the support from those agencies?

Overall observations of group or process:

Medicaid Infrastructure Grant Interview Protocol Persons with Disabilities Who Are Working

Goal: What is the experience of persons with disabilities who have chosen to go back to work and are succeeded at doing so.

Supplies needed: Directions or map and contact phone number for meeting place, copy of protocol questions for staff members, SWS business cards, recorder, mike, , legal pad and pen for note-taking.

Participant Number: The participant number begins with the initials of the interviewee, the date of the interview expressed as MM/DD/YYYY and a W (if working) or an N (if not working).

Roles: Interviewer explains the project, keeps interview on track with questions and prompts. Scribe takes notes and monitors recorder. Interviewer should pose major questions and only use specific probes if the desired content is not forthcoming.

1. **Introduction** – Thank participant. Briefly state your name and introduce scribe. Go through demographic form and fill out with participant.
2. **State purpose of project** - to determine what needs to be done to make it easier for persons with disabilities who want to work to be successful at getting and keeping a job. That we are doing similar interviews around the state.
Interviewer will be asking a few questions and the participant will have a chance to say a much or as little as he or she wishes about that
Time frame will be approximately one hour.
Assure confidentiality.
We want to record the session (and will ask permission), but will remove any identifiers when we do our write ups. (If participant objects, scribe takes detail notes.)
Ask if any questions about the reason you are here and what we will be doing.
Tell who/how to contact someone if you have questions - Distribute business cards.
3. **Warm-up questions**
Ask for kind of work participant is doing and what their living arrangements are.
Get more specificity about disabilities if needed using demographic form as guide
Ask what kind of work did before disability (if disability happened after coming of work age)
4. **Key question** – You are a person with disabilities who has chosen to work. Tell us about your experience getting and keeping a job.
(Allow people to answer as they feel comfortable doing. Use follow up questions when necessary to make sure all of the issues we are interested in get covered.)
5. **Follow-Up Questions**
 1. How have you been successful? What did you do and what did others do to make it work?

2. What were the barriers that got in your way?
 3. What are your fears about working and continuing to work?
 4. What do you see down the road for you in relation to working?
 5. What is the government's attitude about your working?
 - a. What is government doing to help?
 - b. What is government doing that hinders you?
 6. What is your employer's attitude about your working?
 - a. What is your employer doing to help?
 - b. What is your employer doing that hinders you?
 7. Why do you want to work?
 8. Do you ever feel like quitting? Why?
 9. How satisfied are you with the work you are doing? Is there work you would rather do?
 10. How are things working out in regards to personal assistance?
 - a. Are there barriers to getting what you need?
 - b. What can government do to make their getting the right personal assistance easier.
 11. How is your transportation situation working out?
 - a. What can government do to help with that?
 12. How did you find out about your job?
 13. Did you initially need a job coach and/or specialized training? If so, for how long and how intensive?
 14. What type of accommodations is needed on your job - wheelchair ramps, accessible bathrooms, special keyboards, etc.?
 15. Are you working full-time or part-time? Is this by choice?
 16. You said on your demographic forms that you have used services from different agencies. Can you tell us how satisfied you are with the support from those agencies? (Be sure that people have put down all of the agencies that are helping them, or have helped them.)
- 6. Wrap-up** - Summarize major themes, thank for his or her input. Adjourn no later than 90 minutes after start time. Pack supplies. Scribe label tape with location, interview number and date. Label notes with participant name, number, location and date.

Completion: All tapes, notes and transcripts are to be kept in locked Medicaid Infrastructure file. Scribe writes up process recording and puts into file labeled "Working Persons with Disabilities Transcripts -2003/04." Advise Andrea when each process recording is completed.

Location _____ Date _____ Participant Number _____

Format for note-taking

Use this format to take brief notes during interviews

3. Warm-up questions

Ask for kind of work people are doing and what their living arrangements are.

Get more specificity about disabilities if needed using demographic form as guide

Ask what kind of work did before disability (if disability happened after coming of work age)

4. Key question – You are people with disabilities who have chosen to work. Tell us about your experience getting and keeping a job.

5. Follow-Up Questions

A. How have you been successful? What did you do and what did others do to make it work?

B. What were the barriers that got in your way?

C. What are your fears about working and continuing to work?

D. What do you see down the road for you in relation to working?

E. What is the government's attitude about your working?

1. What is government doing to help?

2. What is government doing that hinders you?

F. What is your employer's attitude about your working?

1. What is your employer doing to help?

2. What is your employer doing that hinders you?

G. Why do you want to work?

H. Do you ever feel like quitting? Why?

I. How satisfied are you with the work you are doing? Is there work you would rather do?

J. How are things working out in regards to personal assistance?

1. Are there barriers to getting what you need?

2. What can government do to make their getting the right personal assistance easier.

K. How is your transportation situation working out?

1. What can government do to help with that?

L. How did you find out about your job?

M. Did you initially need a job coach and/or specialized training? If so, for how long and how intensive?

N. What type of accommodations is needed on your job - wheelchair ramps, accessible bathrooms, special keyboards, etc.?

O. Are you working full-time or part-time? Is this by choice?

P. Many of you said on your demographic forms that you have used services from different agencies. Can you tell us how satisfied you are with the support from those agencies?

Overall observations:

Location _____ Date _____ Group Number _____

Medicaid Infrastructure Grant Group Interview Protocol Persons with Disabilities Who Are Not Working

Goal: What is the experience of persons with disabilities who have worked in the past but no longer are.

Supplies needed: Directions or map and contact phone number for meeting place, copy of protocol questions for staff members, SWS business cards, tape recorder, mike, blank tapes, legal pad and pen for note-taking, drinks and snacks sufficient for six people.

Group Number: The Group Number will occur in sequence, i.e., the first group will be 001. Subsequent to the group, the individual numbers will be assigned to the demographic information sheet.

30 minutes prior to time - Arrive at site to meet site contact person and introduce selves. Ask where to conduct group. Set up room in horseshoe shape or around a table, if possible. Put out snacks in basket or on a side table.

Roles: Moderator explains the project, keeps group on track with questions and prompts. Scribe documents group numbers and demographics, takes notes and monitors tape recorder. Moderator should pose major questions and only use specific probes if the desired content is not forthcoming.

- 1. Introduction** - Welcome participants. Offer snacks and drinks. Ask to fill out demographic form. Assist as necessary.
Briefly state your name as moderator.
- 2. State purpose of group** - to determine what needs to be done to make it easier for persons with disabilities who want to work to be successful at getting and keeping a job. That we are doing similar groups around the state.
Moderator will be asking a few questions and each person will have a chance to say a much or as little as they wish about that - a general discussion.
Time frame will be approximately one hour.
Assure confidentiality.
We want to record the session (and will ask their permission), but will remove any identifiers when we do our write ups. (If anyone objects, scribe takes detail notes.)
Ask if any questions about the reason you are here and what we will be doing.
Tell who/how to contact someone if you have questions - Distribute business cards.
Introduce SWS staff - role is outside evaluators, based in Columbia through USC. We often work with DHHS. I will be moderator and (name) _____ will be assisting by taking notes. Scribe starts tape recorder.

- 3. Warm-up questions**
Ask what people's living arrangements are.

- 4. Key question** – You are people with disabilities who are not presently working. Tell us about your desires to work, what barriers and problems there may be about getting and keeping a job, and what your experience with working has been.
(Allow people to answer as they feel comfortable doing. Use follow up questions when necessary to make sure all of the issues we are interested in get covered.)

5. Follow-Up Questions

- A. Have you ever been employed? If so, how long, type of work, reasons for losing your job, was employment prior to becoming a person with a disability?
 - B. Would you like to go to work?
 - C. What has kept you from doing going to work?
 - D. What do you see as the government's attitude about their working?
 - 1. What is government doing to help?
 - 2. What is government doing that hinders you?
 - E. What do you think employers' attitudes would be about your working?
 - F. What could employers do to help?
 - G. What could employers do that would not be helpful?
 - H. Many of you said on your demographic forms that you have used services from different agencies. Can you tell us how satisfied you are with the support from those agencies?
- 6. Wrap-up** - Summarize major themes, thank them for their input.
Adjourn no later than 90 minutes after start time.
Clean up room. Pack supplies. Scribe label tape with group, location and date. Label notes with group, location and date.

Completion: All tapes, notes and transcripts are to be kept in locked Medicaid Infrastructure file. Scribe transcribes tape and puts into file labeled "Working Persons with Disabilities Transcripts - 2003/04." Advise Andrea when each transcript is completed.

After completion of each group, set up blank tapes, supplies and "treats" to be ready for next session.

Location _____ Date _____ Group Number _____

Format for note-taking

Use this format to take brief notes during focus groups

After moderator asks each question, note response of each participant as C1, C2, etc. Write key phrase or word, rather than complete sentence. Take detailed notes only if someone objects to tape recording. If a particular participant does not respond, you do not need to write anything. Example:

Q: What were the barriers that got in your way?

C1 Transportation. Had to arrange for pickup by relatives.

C2 Finding the right person for attendant care.

C3 Not getting the right kind of job leads at first.

1. **Warm-up questions**

Ask what people's living arrangements are.

2. **Key question** – You are people with disabilities who are not presently working. Tell us about your desires to work, what barriers and problems there may be about getting and keeping a job, and what your experience with working has been.

3. **Follow-Up Questions**

A. Have you ever been employed? If so, how long, type of work, reasons for losing your job, was employment prior to becoming a person with a disability?

B. Would you like to go to work?

C. What has kept you from doing going to work?

D. What do you see as the government's attitude about their working?

1. What is government doing to help?

2. What is government doing that hinders you?

E. What do you think employers' attitudes would be about your working?

F. What could employers do to help?

G. What could employers do that would not be helpful?

H. Many of you said on your demographic forms that you have used services from different agencies. Can you tell us how satisfied you are with the support from those agencies?

Overall observations of group or process:

DEMOGRAPHIC INFORMATION SHEET

1. My age is:

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> Less than 20 | <input type="checkbox"/> 45-54 years |
| <input type="checkbox"/> 20-24 years | <input type="checkbox"/> 55-59 years |
| <input type="checkbox"/> 25-34 years | <input type="checkbox"/> 60 to 64 years |
| <input type="checkbox"/> 35-44 years | <input type="checkbox"/> Over 64 years |

2. I am

- | | |
|--------------------------------|----------------------------------|
| <input type="checkbox"/> A man | <input type="checkbox"/> A woman |
|--------------------------------|----------------------------------|

3. I am

- White
- African - American
- Hispanic
- Asian
- Other

4. I went to school for:

- Seven years or less
- Eight or nine years
- Ten or eleven years
- Twelve years or a GED or a high school diploma
- More than 12 but less than 16 years
- College degree (16 years)
- Post graduate work (more than 16 years)

5. I receive Social Security Disability payments.

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

6. I receive Supplemental Security Income (SSI).

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

7. What health insurance do you have (check all that apply)?

- | | |
|--|--|
| <input type="checkbox"/> Medicaid | <input type="checkbox"/> Covered under another family member |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Other (Please explain) |
| <input type="checkbox"/> Tricare | _____ |
| <input type="checkbox"/> Employer group plan | _____ |

8. I am receiving or have received assistance from (check all that apply)

- Vocational Rehabilitation
- Department of Disabilities and Special Needs
- Department of Mental Health
- Department of Social Services
- Employment Security Commission
- State Housing Authority
- Department of Health and Environmental Control
- Community Long Term Care
- Other (please explain) _____

9. I have had the following work experience:

- I have never worked.
- I have not worked since I acquired my disability.
- I have worked since I acquired my disability, but I am not currently working.
- I am currently working full-time (At least 30 hours/week)
- I am currently working part-time (Less than 30 hours/week)
Is this by choice? ____Yes ____No
If not, why not? _____
- I am currently doing volunteer non-paid work.

10. My wages from working each month are:

- None (Don't work)
- \$200 or less
- \$201- \$600
- \$601 - \$809
- More than \$810

11. My disabilities are:

	DISABILITY	WHEN STARTED
1		
2		
3		
4		

APPENDIX TWO: QUESTIONS FOR ELIGIBILITY WORKERS

QUESTIONS FOR ELIGIBILITY WORKERS

1. What do you think are the barriers to persons with disabilities working?
2. What are the barriers to your doing your job as well as you would like to?
3. What are the supports provided by the system that are most helpful to you?
4. What training and job aids, like written materials, would you like to have to help you