# A STATEWIDE SURVEY OF PUBLIC VOCATIONAL REHABILITATION COUNSELORS' PERCEPTIONS OF CONSUMERS WITH AUTISM

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# A STATEWIDE SURVEY OF PUBLIC VOCATIONAL REHABILITATION COUNSELORS' PERCEPTIONS OF CONSUMERS WITH AUTISM

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A Thesis

Submitted to

the Graduate Faculty of

Auburn University

in Partial Fulfillment of the

Requirements for the

Degree of

Master of Science

Auburn, Alabama May 11, 2006

# A STATEWIDE SURVEY OF PUBLIC VOCATIONAL REHABILITATION COUNSELORS' PERCEPTIONS OF CONSUMERS WITH AUTISM

# Margie Cannon

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## **VITA**

The author is the daughter of Alberta Cannon of Opelika, Alabama and the late Charlie Davis "C. D." Cannon, Sr. The author graduated from Beauregard High School in May 1982. In June 1996, she received an Associate degree in Applied Science–Office Administration with emphasis on Medical Office Administration from Southern Union State Community College. She graduated from Southern Union Community College with highest honors. In May 2002, she received a Bachelors of Science degree in Rehabilitation Services Education from Auburn University, graduating cum laude. The author began her graduate program in May 2002, majoring in Vocational Rehabilitation Counseling.

#### THESIS ABSTRACT

# A STATEWIDE SURVEY OF PUBLIC VOCATIONAL REHABILITATION COUNSELORS' PERCEPTIONS OF CONSUMERS WITH AUTISM

## Margie Cannon

Master of Science, May 11, 2006 (B. S., Auburn University 2002)

122 Typed Pages

Directed by Dr. Clarence Brown

Autism is a lifelong neurological developmental disability that results (to varying degrees) in social, communication, and behavior impairments. Autism is primarily diagnosed in childhood, therefore, a preponderance of the literature and research findings focus on children with autism. Literature and research findings about adults with autism, particularly in regards to the vocational rehabilitation needs of this population, are minimal at best. It can be inferred that the vocational rehabilitation needs of adults with autism have been virtually ignored.

The eligibility criteria for vocational rehabilitation services program: (a) the individual has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; (b) the individual can benefit in terms of an employment outcome from vocational rehabilitation services; and (c) the individual

requires vocational rehabilitation services to prepare for, secure, retain, or regain employment. Historically, persons with autism have been excluded from vocational rehabilitation services on the pretext that these persons could not benefit in terms of an employment outcome because it was assumed that they were unfit to work. Rehabilitation legislation mandates that individuals with significant disabilities (autism is identified in rehabilitation legislation as a significant disability) be given priority in receipt of vocational rehabilitation services.

Although it cannot be determined that persons with autism are underserved in the receipt of vocational rehabilitation services because the size of the pool of potential applicants with autism is unknown, however, in relation to this study, persons with autism have been underserved in the receipt of vocational rehabilitation services in terms of vocational rehabilitation services vocational rehabilitation counselors believed were appropriate for persons with autism and the vocational rehabilitation services they actually provided to consumers with autism. More than half of the participants reported that 85% of the vocational rehabilitation services provided through the Alabama Department of Rehabilitation Services were appropriate for consumers with autism. Yet, less than half of the participants provided 85% of the vocational rehabilitation services to consumers with autism. In addition, nearly half of the participants of this study (47%) reported that they do not consider themselves knowledgeable about autism. The results of this study indicate that vocational rehabilitation counselors could benefit from professional development in the area of autism in order to be effective in providing the appropriate and necessary vocational rehabilitation services for this ever increasing group of individuals with autism.

#### **ACKNOWLEDGEMENTS**

The author would like to thank Dr. Clarence Brown (thesis chairperson), Dr. Vivian Larkin, and Dr. Robert Simpson (thesis committee members) for their guidance and belief in the feasibility of this study. Additionally, the author would like to thank Dr. E. Davis Martin, Jr., Dr. Marie Kraska, Dr. AmySue Reilly, and Dr. Margaret "Peggy" Shippen for their assistance during the writing of this study.

The author extends her gratitude to Mr. James "Jim" Harris, III, Assistant Commissioner of Alabama Department of Rehabilitation Services, Adult Vocational Rehabilitation Services, for granting his permission to do the study. Also, the author appreciates the vocational rehabilitation counselors of the Alabama Department of Rehabilitation Services, who participated in this study. Finally, the author would like to thank those individuals who assisted, encouraged, supported, and motivated her during the writing of this study.

The author's inspiration for this study is her beloved son, Antonio Codell "Tony" Cannon, to whom she dedicates this study and to all persons with autism.

| Style manual or journal used: <u>Publication Manual of the American Psychological</u> |
|---|
| Association (5th ed.), Washington, DC: Author.  |
| Computer software used: Microsoft Office Word 2000 and SPSS 12.0 for                  |
| Windows   |

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## I. INTRODUCTION

The Autism Society of America (n.d.), the National Institute of Child Health and Human Development ([NICHD], 2001), and the National Institute of Neurological Disorders and Stroke (2004) regard autism as a complex disability. Autism is a lifelong neurological developmental disability in which the definitive cause of the disorder is unknown (Locke, Banken & Mahone, 1994; Schopler, 2001; Smith, 1990). Autism is primarily diagnosed in children around age three, the beginning stage of the developmental period (Autism Society of Alabama, n.d.; Edwards, 2001; Giddan & Giddan, 1991; Osterling, Dawson, & McPartland, 2001).

Professionals agree that once a child is diagnosed with autism, early intervention that address the child's individual needs are critical for the child's well being (Edwards, 2001; Freeman, 1997; Marcus, Garfinkle, & Wolery, 2001). Yet, since autism is a lifelong disability, individual needs change across the lifespan. As adults, individuals with autism are faced with challenges in their lives such as the world-of-work, community living, and social activities (Strock, 2004). Regarding the world-of-work, this may prove to be demanding for many persons with autism, depending on the severity and extent of the deficits of autism they exhibit (Van Bourgondien & Woods, 1992).

Historically, vocational opportunities for persons with autism have been either severely limited or nonexistent (Belfiore & Mace, 1994; Giddan & Giddan, 1991; Smith,

Belcher, & Juhrs, 1995). Vocational service providers such as vocational rehabilitation (VR) counselors find that persons with autism present unique challenges (Olney, 2000). Because of the nature of autism, the working age population of persons with autism has been traditionally excluded from rehabilitation funding for VR services on the assumption that these individuals were not employable (Smith et al.).

According to the Rehabilitation Act Amendments of 1998 (Title IV of the Workforce Investment Act of 1998), the purpose of state-federal VR programs is to assist persons whose disabilities result in a "substantial impediment to employment." For those individuals whose disabilities present a "substantial impediment to employment", it must be *presumed* that those individuals seeking assistance through VR programs will benefit by gaining and maintaining competitive employment in an integrated setting. According to Title IV-Rehabilitation Act Amendments of 1998 (herein referred to as Title IV), for an individual to be presumed eligible for VR services, the individual must meet the eligibility criteria which include: (a) the individual has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; (b) the individual can benefit in terms of an employment outcome from VR services; and (c) the individual requires VR services to prepare for, secure, retain, or regain employment. Once a VR counselor determines a consumer eligible for VR services, the VR counselor and the VR consumer will jointly develop an Individualized Plan for Employment (IPE). Title IV stipulates that the IPE should consist of the description of the specific employment outcome that is chosen by the eligible individual, consistent with the unique strengths, resources, priorities, concerns, abilities, capabilities,

interests, and informed choice of the eligible individual, and, to the maximum extent appropriate, results in employment in an integrated setting.

Because of the nature of autism, VR counselors are reluctant to work with individuals who may exhibit social, communication, and behavioral challenges (Olney, 2000). Nonetheless, VR programs are legally mandated to give priority to "individuals with significant disabilities" and, in Title IV, autism is noted as one of several significant disabilities listed under the statute "individuals with a significant disability." Yet, even though VR programs are mandated to give priority to "individuals with significant disabilities" over individuals with less significant disabilities who are seeking VR services, access to those services can be limited if VR counselors presume that consumers with autism will not be successful at obtaining employment.

## Statement of the Research Problem

Historically, residential placement of persons with autism was the norm (Smith, 1990; Van Bourgondien & Reichle, 2001). Vocational rehabilitation programs have not been receptive to providing employment support services for persons with autism because of low expectations that persons with autism could work (Smith et al., 1995). The focus of this study was to determine whether persons with autism are underserved in the receipt of VR services.

# Need for the Study

Persons with autism have been historically excluded from the receipt of VR services (Smith et al., 1995). However, as cited in Title IV, the following principles state that: (a) individuals with disabilities, including individuals with the most significant disabilities, are generally presumed to be capable of engaging in gainful employment and the provision of individualized VR services can improve their ability to become gainfully employed; (b) individuals with disabilities must be provided the opportunities to obtain gainful employment in integrated settings; (c) individuals who are applicants for such programs or eligible to participate in such programs must be active and full partners in the VR process, making meaningful and informed choices during assessments for determining eligibility and VR needs; and (d) in the selection of employment outcomes for the individuals, services needed to achieve the outcomes, entities providing such services, and the methods used to secure such services.

#### Purpose of the Study

To be determined eligible for VR services, federal guidelines stipulate that an individual: (a) has a physical or mental impairment which constitutes or results in a substantial impediment to employment; (b) be able to benefit from services in terms of becoming employed; and (c) require VR services to prepare for, secure, retain, or regain employment (Title IV, 1998).

The American Psychiatric Association (APA) regards autism as a mental disorder of a medical nature. Published by the APA, the fourth and text-revision edition of the

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000) notes that the essential features of autism are impairments in social interaction, communication, and behavior development. Those impairments can result in a "substantial impediment to employment." Due to significant developmental delays, individuals with autism meet the stipulations of the federal guidelines of having a mental impairment that result in a substantial impediment to employment and would require VR services to prepare for, secure, retain, or regain employment. However, VR counselors must determine whether individuals with autism can benefit from receiving VR services in terms of achieving an employment outcome. The purpose of this study, therefore, is to investigate whether VR counselors perceive individuals with autism as being able to benefit from receiving VR services.

## **Research Questions**

For this study, the following research questions were developed:

- 1. Are vocational rehabilitation counselors knowledgeable about autism?
- 2. What vocational rehabilitation services do vocational rehabilitation counselors believe are appropriate for persons with autism?
- 3. Are vocational rehabilitation counselors actually providing vocational rehabilitation services to persons with autism?

#### **Definition of Terms**

In order to avoid any ambiguity, confusion, or misunderstanding in the usage of terms, a definition section has been added to this study:

Competitive Employment: Work in the competitive labor market that is performed on a full-time or part-time basis in an integrated setting, and for which an individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals who are not disabled (Federal Register for Department of Education, 2001).

Designated State Unit: The State vocational rehabilitation bureau, division, or other organizational unit that is primarily concerned with vocational rehabilitation or vocational and other rehabilitation of individuals with disabilities and that is responsible for the administration of the vocational rehabilitation program of the State agency (Federal Register for Department of Education, 2001).

Developmental Disability: The term "developmental disability" means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually

planned and coordinated (Developmental Disabilities Assistance and Bill of Rights Act of 2000).

Employment Outcome: With respect to an individual: (a) entering or retaining full-time or, if appropriate, part-time competitive employment in the integrated labor market to the greatest extent practicable; (b) satisfying the vocational outcome of supported employment; or (c) satisfying any other vocational outcome determined to be appropriate including self-employment, telecommuting, or business ownership, that is consistent with an individual's strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice (Federal Register for Department of Education, 2001; Title IV, 1998).

Individual with a Significant Disability: An individual with a disability who has a severe physical or mental impairment with seriously limits one or more functional capacities (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) in terms of an employment outcome; whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time; and who has one or more physical or mental disabilities resulting from amputation, arthritis, autism, etc. (Title IV, 1998).

Individualized Educational Program (IEP): A written statement for each child with a disability that is developed, reviewed, and revised (Individuals with Disabilities Education Improvement Act [IDEIA], 2004).

Individualized Plan for Employment (IPE): A written document prepared on forms provided by the designated State unit. The IPE consists of a description of the

specific employment outcome that is chosen by the eligible individual, consistent with the unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the eligible individual, and, to the maximum extent appropriate, results in employment in an integrated setting. The IPE shall be agreed to, and signed by, such eligible individual or, as appropriate, the individual's representative, and approved and signed by a qualified VR counselor employed by the State unit (Title IV, 1998).

Integrated Setting: With respect to the provision of services, means a setting typically found in the community in which applicants or eligible individuals interact with non-disabled individuals other than non-disabled individuals who are providing services to those applicants or eligible individuals; with respect to an employment outcome, means a setting typically found in the community in which applicants or eligible individuals interact with non-disabled individuals, other than non-disabled individuals who are providing services to those applicants or eligible individuals, to the same extent that non-disabled individuals in comparable positions interact with other persons (Federal Register for Department of Education, 2001).

*Job Coach*: A person who is hired by the placement agency to provide specialized training to assist the employee with a disability in learning and performing the job and adjusting to the work environment (Office of Disability Employment Policy, 1993).

*Major Life Activities*: As defined in the Americans with Disabilities Act of 1990, includes walking, sitting, seeing, hearing, standing, breathing, reaching, learning, speaking, concentrating, sleeping, performing manual tasks, working, lifting, caring for oneself, and interacting with others.

Ongoing Support Services: Services provided to individuals with the most significant disabilities; provided at a minimum, twice monthly to make an assessment regarding the employment situation at the worksite of each such individual in supported employment, or, under special circumstances, especially at the request of the client, off site; based on the assessment, to provide for the coordination or provision of specific intensive services, at or away from the worksite, that are needed to maintain employment stability; consisting of a particularized assessment supplementary to the comprehensive assessment; the provision of skilled job trainers who accompany the individual for intensive job skill training at the worksite; job development, job retention, and placement services; social skills training; regular observation or supervision of the individual; follow-up services such as regular contact with the employers, the individual, the individual's representatives, and other appropriate individuals, in order to reinforce and stabilize the job placement; facilitation of natural supports at the worksite; and any other service or a service similar to another service (Title IV, 1998).

Social Security Disability Insurance (SSDI): As defined in the Social Security Administration's Redbook (2005), the SSDI program provides benefits to persons with disabilities or individuals who are blind who are "insured" by workers' contributions to the Social Security trust fund. These contributions are required by the Federal Insurance Contributions Act (FICA) which created Social Security taxes, which are paid, based on one's earnings or those of one's spouse or one's parents. Title II of the Social Security Act authorizes SSDI benefits.

Substantially Limits: As defined in the Americans with Disabilities Act of 1990, an inability to perform the major life activity or a significant restriction as to the condition, manner, or duration under which an individual can perform a particular major life activity as compared to the condition, manner, or duration under which the average person in the general population can perform the same major life activity.

Administration's Redbook (2005), the SSI program makes cash assistance payments to the aged, blind, and individuals with disabilities (including children under age 18) who have limited income and resources. The Federal Government funds the SSI program from general tax revenues. Most states pay a supplemental benefit to individuals in addition to their Federal benefits. Some of these states have arranged with the Social Security Administration to combine their supplementary payment with Social Security's Federal payment into one monthly check to SSI recipients. Other states manage their own programs and make their payments separately. Title XVI of the Social Security Act authorizes SSI benefits.

Supported Employment: Competitive work in integrated work settings, or employment in integrated work settings in which individuals are working toward competitive work, consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individuals; for individuals with the most significant disabilities for whom competitive employment has not traditionally occurred; or for whom competitive employment has been interrupted or intermittent as a result of a significant disability; and any extension provided by the designated State unit

for a period of time not to extend beyond 18 months, unless under special circumstances the eligible individual and the rehabilitation counselor or coordinator involved jointly agree to extend the time in order to achieve the rehabilitation objectives identified in the IPE; and extended services after the transition provided by a State agency, a nonprofit private organization, employer or any other appropriate resource, after an individual has made the transition from support provided by the designated State unit in order to perform such work (Title IV, 1998).

Substantial Gainful Activity (SGA): As defined in the Social Security

Administration's Redbook (2005), the Social Security Administration (SSA) evaluates
the work activity of individuals claiming or receiving disability benefits under SSDI,
and/or claiming benefits because of a disability (other than blindness) under SSI. Under
SSDI and SSI, SSA uses earnings guidelines to evaluate the beneficiary's work activity to
decide the work activity is SGA and whether SSA may consider one has a disability
under the law. While this is only one of the tests used to decide if a person has a
disability, it is a critical first step in the disability evaluation.

Transition Services: A coordinated set of activities for a child with a disability that is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; is based on the individual child's needs taking into account the child's

strengths, preferences, and interests; and includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation (IDEIA, 2004).

Trial Work Period/Experience for Individuals with Significant Disabilities: Prior to any determination that an individual with a disability is incapable of benefiting from vocational rehabilitation services in terms of an employment outcome because of the severity of that individual's disability, the designated State unit must conduct an exploration of the individual's abilities, capabilities, and capacity to perform in realistic work situations to determine whether or not there is clear and convincing evidence to support such a determination (Federal Register for Department of Education, 2001).

*Undue Hardship*: As defined in the Americans with Disabilities Act of 1990, any action that creates "significant difficulty or expense" for an employer given the "size of the employer, the resources available, and the nature of the operation."

VR Counselor: A professional who assists people in dealing with the personal, social, and vocational effects of disabilities; counsels people with disabilities resulting from birth defects, illness or disease, accidents, or the stress of daily life; evaluates the strengths and limitations of individuals, provide personal and vocational counseling, and arrange for medical care, vocational training, and job placement; interviews both individuals with disabilities and their families; evaluates school and medical reports; confers and plans with physicians, psychologists, occupational therapists, and employers to determine the capabilities and skills of the individual; confers with the client; assists

the client to develop a rehabilitation program that often includes training to help the client develop job skills; works toward increasing the client's capacity to live independently (Occupational Outlook Handbook, 2004).

VR Services: Any services described in an individualized plan for employment necessary to assist an individual with a disability in preparing for, securing, retaining, or regaining an employment outcome that is consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individual, etc. (Title IV, 1998).

# Limitations of the Study

This study surveyed VR counselors working for the Alabama Department of Rehabilitation Services. The VR counselors surveyed were employed in the public sector and work only with young adults and adults with disabilities. No data were collected from VR counselors employed in proprietary or private, non-profit rehabilitation agencies in Alabama or any other state, therefore data gathered from this study cannot be generalized to VR counselors beyond the Alabama Department of Rehabilitation Services. Also, data collected for this survey depends on the self-reporting and the self-assessment of the public VR counselors who participated in this study.

Based on the numbers of surveys distributed and the number of surveys returned, not all VR counselors employed by the Alabama Department of Rehabilitation Services chose to respond although the return rate was higher than average rate (58%). In addition, upon the compilation of the returned surveys, all male VR counselors who responded

were Caucasian/Euro-American males. Additionally, female VR counselors' participation outnumbered male VR counselors' participation by 3 to 1. While the return rate was higher than average, the lack of response by all VR counselors employed by the Alabama Department of Rehabilitation Services, the non-response of male VR counselors from minority racial/ethnic groups, and the overwhelmingly female VR counselors' participation in this study suggests a lack of full representation and diversity among the VR participants of this study.

# Summary

The reader has been introduced to the dilemma of persons with autism being limited in attempting to access VR services. Historically, VR has been reluctant or unwilling to assist persons with autism on the assumption that attributes of autism can impede opportunities to gain employment. Unless the designated State unit can provide "clear and convincing evidence" that proves otherwise, rehabilitation legislation makes the presumption that an individual, regardless of the severity of the disability, can work.

This study is to explore public vocational rehabilitation counselors' perceptions of consumers with autism. Chapter 1 introduces the reader to a brief overview of autism and how the disability has impacted the participation of persons with autism in the vocational rehabilitation system. Chapter 2 is the literature review in which the reader is given the historical background of autism, diagnostic criteria for autism, and widely accepted treatment/intervention programs for persons with autism. In addition, federal rehabilitation legislation and other federal employment-related disability legislation and

supports are discussed. Chapter 3 addresses the methodology of the research, significant findings as a result of the research, a discussion of the findings, and the implication of the findings. Chapter 4 concludes by summarizing the dilemma of persons with autism accessing vocational rehabilitation services and recommendations for vocational rehabilitation counselors to work with persons with autism.

#### II. LITERATURE REVIEW

Autism has been established as a lifelong neurological developmental disability, usually diagnosed in childhood, with an unknown etiology (Autism Society of America, n.d.; Edwards, 2001; Osterling et al., 2001). This chapter discusses the identification, definition, and diagnostic criteria of autism, and treatment/intervention programs for persons with autism. In addition, the following federal employment-related disability legislation are discussed: Rehabilitation Act of 1973 and its subsequent amendments; Americans with Disabilities Act of 1990; School-to-Work Opportunities Act of 1994; and the Ticket to Work and Work Incentives Act of 1999. Employment-incentive supports for persons receiving SSDI and/or SSI are also discussed.

## History of Autism Identification

Arguably, it was the late Dr. Leo Kanner, child psychiatrist and founder of the Children's Psychiatric Service unit of the Johns Hopkins Hospital, who gave notoriety to the term autism with his paper, "Autistic Disturbance of Affective Contact" (1943) that was published in the now defunct journal, *The Nervous Child*. The paper is an account of Dr. Kanner's initial observations of eleven (11) cases of infantile psychoses, including eight boys and three girls, from ages two through eight. According to Kanner (1973), the features exhibited by the children in his seminal research:

consist of a profound withdrawal from contact with people, an obsessive desire for the preservation of sameness, a skillful and even affectionate relation to objects, the retention of an intelligent and pensive physiognomy, and either mutism or the kind of language which does not seem intended to serve the purpose of interpersonal communication. An analysis of this language has revealed a peculiar reversal of pronouns, neologisms, metaphors, and apparently irrelevant utterances which become meaningful to the extent to which they can be traced to the patient's experiences and their emotional implications. (pp. 51–52)

In 1944, Kanner, after much deliberation, decided to classify the cases of infantile psychoses that he observed as "early infantile autism." He believed that features of autism were formed during infancy and because he observed that the 11 children demonstrated unusual preoccupation and self-involvement with their own environment that warranted an identification of a new disorder (Kanner, 1973).

## Definition of Autism

The prefix of the term autism (*aut*) is a derivative of the Greek term *autos* meaning self (Physician's Desk Reference Medical Dictionary, 2000). The suffix of the term autism, *ism*, refers to a "state, condition, or property" (Merriam-Webster's Medical Desk Dictionary [Merriam-Webster's], 2002). Autism, according to Merriam-Webster's, is defined as:

a developmental disorder that appears by age three and that is variable in expression but is recognized and diagnosed by impairment of the ability to communicate with others, and by stereotyped behavior patterns especially as exhibited by a preoccupation with repetitive activities of restricted focus rather than with flexible and imaginative ones. (p. 66)

## Diagnosis of Autism

It has been more than 60 years since Kanner coined the term *early infantile autism* (Strock, 2004). However, in the DSM-IV-TR (2000), the American Psychiatric Association uses the term Autistic Disorder in reference to autism. Before an individual is diagnosed as having Autistic Disorder, the individual must meet the criteria set forth by the American Psychiatric Association. The diagnostic criteria for Autistic Disorder are listed below:

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
  - (1) qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
    - (b) failure to develop peer relationships appropriate to developmental level
    - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects or interests)

- (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least the following:
  - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
  - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - (c) stereotyped and repetitive use of language or idiosyncratic language
  - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals

- (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- (d) persistent preoccupation with parts or objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (DSM-IV-TR, 2000, p. 75).

There are other disorders that closely resemble Autistic Disorder. These include Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism) (DSM-IV-TR, 2000, pp. 69–84). These disorders as well as Autistic Disorder are collectively known as Pervasive Developmental Disorders (PDDs), characterized by severe and pervasive impairments in several areas of development, which include social interaction and communication, and the presence of stereotypical behavior, interests, and activities (DSM-IV-TR, 2000). However, there are those professionals who use the term *autism spectrum disorders* (ASD) in reference to the PDDs (Autism Society of America, n.d.; NICHD, 2005; Strock, 2004; Osterling et al., 2001). Due to the common reference of PDD and ASD as interchangeable terms, more information is warranted about the disorders categorized as PDD/ASD. Rett's Disorder is found only in females. Female infants usually have a normal prenatal and perinatal period with normal psychomotor

development up through the first five months of life. The onset of the symptoms of Rett's Disorder are: (a) deceleration of head growth between ages 5 and 48 months; (b) loss of previously acquired hand skills between the ages of five months and 30 months with subsequent development of stereotypical hand movements (e.g., hand wringing); (c) loss of early social engagement (although social interaction develops later); (d) appearance of poorly coordinated gait or trunk movements; and (e) severely impaired expressive and receptive language development with severe psychomotor retardation (DSM-IV-TR).

Childhood Disintegrative Disorder is marked by: (a) marked regression in multiple areas of functioning following two years of a typical development period; (b) significant loss of previously acquired skills before age 10 in at least two of the following areas: receptive or expressive language; social skills or adaptive behavior; bowel or bladder control; play; and motor skills; (c) qualitative impairments in at least two of the following areas: social interaction; communication; and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities; and (d) the disturbance is not better accounted for by another PDD or by Schizophrenia (DSM-IV-TR, 2000).

Individuals diagnosed with Asperger's Disorder have no clinically significant cognitive or language delays; however, they have severe and sustained impairments in social interaction and restricted repetitive and stereotyped patterns of behavior, interests, and activities. These delays cause clinically significant impairments in social, occupational, or other important areas of functioning. In addition, the criteria for Asperger's Disorder are not met for another specific PDD or Schizophrenia. Individuals who have the diagnosis of Pervasive Developmental Disorder Not Otherwise Specified

(including Atypical Autism) exhibit severe and pervasive developmental delays in reciprocal social interaction associated with either impairments in verbal or nonverbal communication skills or with the presence of stereotypical behavior, interests, and activities. This disorder does not meet the criteria for a specific PDD, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder (DSM-IV-TR, 2000).

# **Treatment/Intervention Programs**

In most instances, persons with autism have problems with (a) communication (both verbal and nonverbal); (b) social interactions (e.g. engaging in a conversation); and (c) routines or repetitive behaviors (e.g., repeating words, phrases, or actions over and over again) (NICHD, 2001; NICHD, 2005). Not only do communication, social interaction, and behavior delays affect persons with autism, but individuals with autism can also exhibit, to varying degrees, some or all of these associated features: (1) insistence on sameness/resistance to change; (2) difficulty with or unable to express wants and needs; (3) laughing and/or crying for no apparent reason; showing distress for reasons not apparent to others; (4) preference to be alone/aloof manner; (5) tantrums; (6) not wanting to cuddle and/or be cuddled; (7) unresponsive to typical teaching methods; (8) sustained odd play; (9) obsessive attachment to objects; (10) apparent over-sensitivity or under-sensitivity to pain; (11) no apparent fear of danger; (12) noticeable physical over-activity or extreme under-activity; (13) uneven gross/fine motor skills; (14) acts as if deaf; (15) slower or unable to interpret with others think/unable to interpret gestures and

facial expressions; and (16) poor eye contact (Autism Society of America, n. d.; Strock, 2004).

For persons with autism and other ASDs, most professionals agree that once diagnosed with an ASD, implementation of early intervention programs is crucial in reducing symptoms of ASD and improving developmental outcomes for persons with ASD (Autism Society of American, n.d.; Freeman, 1997; Goin & Myers, 2004, para. 3; Strock, 2004). To treat the impediments that autism can impose on those diagnosed with the disability, there are several treatment/intervention programs designed for persons with autism. Yet, addressing each and every treatment/intervention program designed for persons with autism is beyond the scope of this study. However, the treatment/intervention programs discussed in this study are widely accepted in the treatment of persons with autism.

## **Educational Setting**

By law, students with disabilities from ages 3–21 are entitled to special education services from their local educational agencies (IDEIA, 2004). IDEIA mandates — that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.

In addition, IDEIA mandates that each child with a disability in the local education agency has an Individualized Education Program (IEP), a document that includes the following: (a) the child's present level of performance, including how the

child's disability affects the child's involvement and progress in the general curriculum; or for preschool children, as appropriate, how the disability affects the child's participation in appropriate activities; (b) a statement of measurable annual goals, including benchmarks or short-term objectives related to meeting the child's needs that result from the child's disability to enable the child to be involved in and progress in the general curriculum; and meeting each of the child's other educational needs that result from the child's disability; (c) a statement of the special education and related services and supplementary aids and services to be provided to the child, or on behalf of the child, and a statement of the program modifications or supports from school personnel what will be provided for the child to advance appropriately toward attaining the annual goals; (d) to be involved and progress in the general curriculum and to participate in extracurricular and other nonacademic activities; and to be educated and participate with other children with disabilities and nondisabled children in the activities; (e) an explanation of the extent, if any, to which the child will not participate with nondisabled children in the regular class and activities; (f) a statement of any individual modifications in the administration of State or districtwide assessments of student achievement that are needed in order for the child to participate in such assessment; if the IEP Team determines that the child will not participate in a particular State or districtwide assessment of student achievement (or part of such an assessment), a statement of why that assessment is not appropriate for the child; and how the child will be assessed; (g) the projected date for the beginning of the services and modifications; and the anticipated frequency, location, and duration of those services and modifications; (h) beginning at

age 14, and updated annually, a statement of the transition service needs of the child under the applicable components of the child's IEP that focuses on the child's courses of study (such as participation in advanced-placement courses or a vocational education program); (i) by age 16 (or younger, if determined by the IEP Team), a statement of needed transition services for the child, including, when appropriate, a statement of the interagency responsibilities or any needed linkages; and beginning at least one year before the child reaches the age of majority under State law, a statement that the child has been informed of his or her rights under this title, if any, that will transfer to the child on reaching the age of majority; and (j) a statement of how the child's parents will be regularly informed (by such means as periodic report cards), at least as often as parents are informed of their nondisabled children's progress, of their child's progress toward the annual goals; and the extent to which that progress is sufficient to enable the child to achieve the goals by the end of the year.

For the child with autism, proponents advocate that a highly structured individualized educational program is best to address the specific needs of the child (Autism Society of American, n.d; Freeman, 1997; Strock, 2004). It is critical that educational professionals are properly informed about autism in order to avoid developing an educational curriculum that is inappropriate for the child. An inappropriate educational curriculum program could impair the child's ability to develop to his or her fullest potential (Autism Society of America).

## Applied Behavior Analysis

Applied Behavior Analysis (ABA) is an intervention technique that is regarded as an effective treatment for persons with autism and other ASDs (Strock, 2004; Osterling et al., 2001; Schoen, 2003; Simpson, 2001, Taylor, 1989). The purpose of ABA is to engage individuals with autism in socially valid responses by targeting undesirable behaviors and bringing those behaviors under control (Osterling et al.; Simpson). ABA relies on accurate interpretation of the interaction between antecedents (events in the environment immediately preceding the undesirable behavior) and consequences (events that follow the undesirable behavior) and uses that information to systematically plan desired learning and behavior change programs (Coucouvanis, 1997; Simpson, 2001). Recognizing antecedent variables such as environmental analysis, manipulation of curricula, and classroom conditions coupled with the application of scientifically valid principles of behavior such as reinforcement are the catalysts to produce desirable behaviors from persons with autism (Simpson). The ABA method is also used to address challenging behaviors exhibited by persons with autism before and between episodes of the behaviors, and during and after the episode in which the challenging behaviors had occurred (NICHD, 2001).

The ABA method has been credited for the foundation of numerous effective intervention programs for persons with ASD (Osterling et al., 2001; Simpson, 2001). Simpson mentioned that there are those who assert that the ABA method is the *only* effective instructional method for persons with autism. This assertion is reinforced by evidence that ABA has a foundation of well-established scientific principles, and

laboratory and field studies. Additionally, Simpson noted the applicability and utility of ABA in teaching persons with autism skills and desirable behaviors needed for independent functioning in typical settings has been shown to be beneficial, which is supported by numerous scientifically valid demonstrations of ABA.

Critics of ABA oppose the notion that this method should be used *exclusively* in teaching individuals with autism (Schoen, 2003; Simpson, 2001). Some argue that practitioners of ABA are unyielding in their insistence on using a single approach that does not instruct students with ASD in independent use of functional skills in natural settings. In addition, critics also complain that the ABA method can be (a) stressful on the person with ASD; (b) intense; (c) rigid; (d) dogmatic; and (e) likely to produce prompt-dependent children (Schoen; Simpson).

Disagreement as to who should be responsible for implementing instruction is another controversy surrounding ABA. Undoubtedly, professionals who teach children, youth, and adults with ASD should possess the knowledge and skills for the design, application, and evaluation of ABA programs (Simpson, 2001). Yet, who should assume the role of coordinating the ABA program for students with ASD, teachers or professionals specializing in ABA, remain in question. Also, the ABA technique relies on having a teaching assistant paired with only one student with ASD (i.e., one-on-one). There are those who question, in general, the practicality of having one teaching assistant per student. Also, Simpson noted that the teaching assistant may lack professional teacher preparation for ABA, and/or the one-on-one relationship could result in the student becoming dependent on the teaching assistant.

Treatment and Education of Autistic and Related Communications Handicapped
Children

In 1972, the state legislature of North Carolina mandated that the Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH) treatment/intervention program be the permanent, statewide program to serve children who have autism (Van Bourgondien & Schopler, 1996). In 1979, North Carolina legislators mandated that TEACCH extend it services to adolescents and adults who have autism based on the realization that autism lasts a lifetime (Van Bourgondien & Schopler). Intervention based on the nature of autism is the primary focus of the TEACCH program.

Schopler and colleagues developed the TEACCH program (Osterling et al., 2001). A primary focus of TEACCH emphasizes the importance of parent-professional collaboration, working together to maximize the outcome of persons with autism (Campbell, Schopler, Cueva, & Hallin, 1996, para. 5; Van Bourgondien & Schopler, 1996, para. 3). TEACCH recognizes that family members can provide valuable information about their loved one with autism. In addition, family members in the role of advocates often have the best perspective on the long-term needs of the loved one with autism (Van Bourgondien & Schopler).

Prior to the initiation of treatment, diagnosis and assessment are the first steps necessary to develop an appropriate treatment program for the individual with autism (Van Bourgondien & Schopler, 1996, para. 10, & para. 11). For diagnostic purposes, it is important to identify symptoms that the individual with autism exhibits. Regarding

assessment, TEACCH considers assessment the foundation of the treatment plan (Van Bourgondien & Schopler, 1996, para. 11). TEACCH considers the assessment as the means of gaining information about unique aspects of the person with autism in order to develop an *individualized* treatment plan (Van Bourgondien & Schopler, para. 11). For adolescents and adults with autism, the primary formal assessment tool utilized by TEACCH is the Adolescent and Adult Psychoeducational Profile (AAPEP) (Van Bourgondien & Schopler, para, 12). The AAPEP is a criterion-referenced test utilized to assess the skills of the person with autism functioning successfully in such environments as vocational settings and community residential settings.

The primary components of the TEACCH program are (a) structured teaching; (b) communication training; (c) utilization of leisure and social skills; and (d) stress reduction (Van Bourgondien & Schopler, 1996). Each component is described below.

Structured teaching. Consists of both an educational strategy and a reduction of challenging behaviors. The educational strategy relies on building upon special education instruction. Reduction of challenging behaviors relies on analyzing antecedent events leading to the cause of undesirable behaviors then restructuring the environment with the hope of decreasing or eliminating the undesirable behaviors. TEACCH professionals employ visual approaches and visual cues such as schedules, work lists, physical and/or material instruction to persons with autism to decrease frustration, reduce or eliminate undesirable behaviors, and to foster independent functioning.

Communication training. TEACCH utilizes communication methods (e.g., verbal, pictures, gestures, etc.,) based on the individual's communication abilities. TEACCH

promotes communication training in living, work, and recreational environments.

Alternative communication systems for those adults with autism who are nonverbal are recommended; however, for those who are verbal, instruction in learning the social aspects of communication (e.g., initiating a conversation, choosing topics of conversation) is emphasized rather than adopting an alternative communication system.

Leisure and social skills. Knowing how to occupy one's free time is an indication that an individual with autism can successfully adapt to different settings. To instruct adults with autism how to use their leisure time, TEACCH employs such devices referred to as "free time lists" and "choice boards" that depict photographs, objects, written labels, etc., of leisure activities. To foster social skills, an adult with autism is paired with another individual or becomes involved with group interactions for the purpose of learning and understanding appropriate social rules.

Stress reduction. Persons with autism experience stress and frustration just as other people do. There are those who proclaim that, at times, when persons with autism exhibit undesirable behaviors, it is there way of expressing their frustration or to alleviate stress. To help alleviate stress, a recommendation is to provide interesting activities for persons with autism to do instead of repetitive tasks.

Critics of the TEACCH program says that TEACCH: (1) "gives in" to autism rather than fights it; (2) its exclusionary approach segregates children with autism; (3) it does not place enough emphasis on communication and social development; (4) independent work centers may isolate when there is a need to be with other children to develop social skills (Autism Society of America, n.d.).

#### Social Stories

Social Stories (also known as Social Scripts) was developed in 1991 by Gray (Autism Society of America, n.d.). Social Stories is an intervention approach used to enhance the social interaction abilities of persons with autism (Edelson, 1995). Social Stories are written for the person with autism, in the form of a story, addressing a particular social setting and suitable social behaviors for that particular social setting. For the story, the author utilizes four types of defined sentence styles — descriptive, directive, perspective, and control (Edelson). The descriptive sentences describe what people do in particular social situations; directive sentences direct the person with autism to an appropriate response; perspective sentences provide insight to other people's reactions to a situation so that the individual with autism can understand how other people perceive certain events; and control sentences are ways in which the person with autism can facilitate his or her memory in a manner that would aid him or her in social settings. Not only does the writer utilizes descriptive, directive, perspective, and control sentences in the story, but also the writer should anticipate and include answers to questions (e.g., who, what, when, where, and why) to clarify to the person with autism what he or she may need in preparation for a particular social environment. Once a story is written, it can be put into practice. If the person with autism can read, he or she can read the story how many times necessary until he or she feels comfortable with how he or she will respond in a particular social situation in which the story was based upon. If the person with autism is not able to read, the story can be read to him or her until, likewise, until he or she becomes cognizant of social norms in a particular social situation in which the story was based. Ultimately, the use of a story can be faded out once the person with autism has demonstrated his or her understanding of behavior that is considered suitable for a particular social situation (Edelson).

Advantages of the Social Stories method include: (1) developed specifically to address characteristics of autism; (2) tailored to the specific needs of the individual with autism; (3) time and cost efficient and flexible; (4) stabilization of behavior specific to the situation is addressed; (5) reduction in frustration and anxiety of the person with autism; and (6) improved behavior of the person with autism when Social Stories interventions are consistently implemented (Autism Society of America, n.d.).

Disadvantages to use of the Social Stories method are: (1) there is no empirical data to support the Social Stories approach; and (2) it depends on the writing skill of the author and the author's understanding of autism (Autism Society of America).

Picture Exchange Communication System

Bondy and Frost developed the Picture Exchange Communication System (PECS) (Ganz, 2002). An alternative form of communication, PECS is a system where persons are taught to request and to comment by looking at picture cards shown to them by a communication partner (Hourcade, Pilotte, West, & Parette, 2004). Individuals who are being instructed in the PECS program are not required to possess such prerequisite skills such as recognition of picture symbols on the cards or the ability to communicate by means of gesturing or sign language (Hourcade, et al.). PECS has been applied successfully with persons with developmental disabilities such as autism (Hourcade et al.). A concern regarding the use of PECS is that it may suppress the need for the

individual with autism to talk; however, there is no evidence that supports that contention (Autism Society of America, n.d.).

Psychopharmacological Intervention

Psychopharmacological intervention (i.e., medications) is often prescribed for persons with autism primarily to reduce challenging and disruptive behaviors such as self-aggression, temper tantrums and outbursts, and stereotypical body movements (Edwards, 2001; Oswald, Ellis, Singh, & Singh, 1994; Sikich, 2001). Medications such as antipsychotics (e.g., Thioridazine), opiod antagonists (e.g., Naltrexone), and antihypertensives (i.e., beta-blockers), to name a few, have been reported not only as reducing undesirable behaviors, but also improving social relatedness abilities for children, adolescents, and adults with autism (McDougle, 1998; Oswald et al).

Some researchers believe that prescribing medications should be avoided (Johnson, 2005). If prescribing medications is unavoidable, Johnson advises that prior to beginning psychopharmacological intervention for the individual with ASD, the following guidelines should be taken into consideration: (1) there are no known medications that consistently treat the core symptoms of ASD; (2) start with the lowest dosage possible; (3) medications serve as an adjunct to individualized behavior management and educational plans; (4) medications can enhance the effects of educational and/or therapeutic interventions and foster inclusion opportunities when challenging behaviors jeopardize progress in educational and/or therapeutic programs; (5) monitor for side effects and co-morbid psychiatric disorders; (6) rule out a new medical condition (i.e., by having the individual with autism undergo a physical exam) that might

be causing undesirable behaviors; and (7) medication should target the most challenging of behaviors.

### Treatment/Intervention Recommendations

There is a general consensus among those involved in the lives of persons with autism that treatment/intervention should begin as early as possible so that appropriate services can be obtained, resulting in a better prognosis for the outcome for persons with autism (Freeman, 1997; Goin & Myers, 2004). In order to help ensure that the treatment/intervention program is the best program for the individual with autism, Freeman recommends approaching any new treatment with hopeful skepticism. The goal of any treatment should be to help the person with autism become a fully functioning member of society. Freeman also recommends: (1) be wary of any program or techniques that is said to be appropriate for *every* person with autism; (2) be wary of any program that thwarts individualization and potentially results in harmful program decisions; (3) be cognizant that any treatment represents one of several available options for the individual with autism; (4) be aware that no new treatment/intervention should be implemented until its components can specify assessment procedures necessary to determine whether it will be appropriate for the individual with autism; and (5) be aware that new treatments often have not been validated scientifically.

Federal Employment-Related Disability Legislation and Supports

Society has a dismal history regarding its treatment of persons with disabilities. To elaborate, during the Middle Ages, disability was often seen as either "God's punishment" or "being possessed by the devil", resulting in people with disabilities being "feared, hated, and often persecuted and tortured as collaborators of the Evil One and bringers of all kinds of misfortune to their towns and their fellow men" (Rubin & Roessler, 2001, p. 3). In the latter half of the 19<sup>th</sup> century, Sir Francis Galton introduced the term "eugenics," defined as 'the science which deals with all influences that improve the inborn qualities of a race' (Rubin & Roessler, 2001, p. 15). Ultimately, eugenics movements became prevalent in America, with the goal of colonizing and sterilizing all undesirable subgroups (e.g., people with disabilities) (Rubin & Roessler). Years ago, people with mental and/or physical disabilities were routinely called "imbeciles", "cretins", "morons" and "idiots" (Edwards, 2001; Etheredge, 2005). These examples are just a few of the negative attitudes perpetrated against persons with disabilities. Decades of mistreatment against persons with disabilities have resulted in vocational, social, environmental, and educational barriers (Bates, 1989; Granello & Wheaton, 2001). To rectify society's history of exclusionary and discriminatory practices against persons with disabilities, a number of federal laws have been enacted to promote the integration and inclusion of persons with disabilities into society. In addition, these laws are enacted to safeguard the civil rights of persons with disabilities. However, as it relates to this study, federal employment-related disability legislation and supports are discussed.

## The Rehabilitation Act of 1973

The following five mandates were implemented into the Rehabilitation Act of 1973:

- Serving individuals with severe disabilities. With the goal of obtaining
  gainful employment, states were required to provide VR services for
  persons with more severe disabilities before providing services for those
  with less severe disabilities.
- 2. Promoting consumer involvement. Joint collaboration between the consumer and the VR counselor throughout the VR process. If a consumer is determined eligible for VR services, the consumer and the VR counselor jointly completes an Individualized Written Rehabilitation Program (IWRP). All the VR objectives for the consumer must be clearly stated in the IWRP.
- 3. Stressing program evaluation. State rehabilitation agencies would be held accountable for providing information on: (a) the percentage of the existing target population being served; (b) the timeliness and adequacy of their services; (c) the suitability of the employment in which clients are placed and the sustention of that employment; and (d) client satisfaction with VR.
- 4. Supporting research. Provisions for innovation and expansion grants and for the continuation of research and training centers, rehabilitation engineering research centers, and other related projects and

demonstrations. Also special programs that emphasizes research with severe disability groups.

5. Advancing the civil rights of persons with disabilities. Due to society's adverse treatment of persons with disabilities the following civil rights provisions were included in the Rehabilitation Act of 1973:

Section 501: Affirmative Action in Federal Hiring – Mandates "nondiscrimination by the federal government in its own hiring practices" and calls for each federal department, agency, and instrumentality to submit an "affirmative action program plan for the hiring, placement, and advancement" of individuals with disabilities to the U. S. Civil Service.

Section 502: Accessibility – Required that federal agencies make their respective buildings accessible for those with physical disabilities.

Section 503: Affirmative Action by Federal Contract Recipients – Prohibits discrimination in employment on the basis of physical or mental disabilities and requires affirmative action on the part of all federal contract recipients and their subcontractors who receive annual federal contracts exceeding the amount of \$10,000.

Section 504: Equal Opportunities – Prohibits the exclusion of a qualified person with a disability from participation in any federal program or activity, or from "any program or activity receiving federal financial assistance." Under Section 504, a person with a disability cannot

"be found unqualified without considering whether a reasonable accommodation would render the individual qualified."

Rehabilitation Act Amendments of 1986

Supported employment was initially defined in the Developmental Disabilities

Act Amendments of 1984. At that time, supported employment was defined as: (a) paid
employment for persons with developmental disabilities for whom competitive
employment is unlikely and who, because of their disabilities, need on-going support to
perform in a work setting; (b) is conducted in a variety of settings, particularly work sites
in which persons without disabilities are employed; and (c) is supported by any activity
needed to sustain paid work by persons with disabilities including supervision, training,
and transportation (Browning, 1997). The definition for supported employment was
expanded in the Rehabilitation Act Amendments of 1986, public law 99-506 (Browning,
1997). (The expanded definition for supported employment can be found in Chapter 1,
under the section, Definition of Terms).

The need for supported employment arose due to dissatisfaction with the traditional sheltered workshop environment and the need for community inclusion, by having persons with severe disabilities working competitively in the community (Brooke, Inge, Armstrong, & Wehman, eds., 1997). The philosophical values behind supported employment are:

*Presumption of Employment*: A conviction that everyone, regardless of the level or the type of disability, has the capability and right to a job.

Competitive Employment: A conviction that employment occurs within the local labor market in regular community businesses.

*Control*: A conviction that when people with disabilities choose and regulate their own employment supports and services, career satisfaction will result.

Commensurate Wages and Benefits: A conviction that people with disabilities should earn wages and benefits equal to that of coworkers performing the same or similar jobs.

Focus on Capacity and Capabilities: A conviction that people with disabilities should be viewed in terms of their abilities, strengths, and interests rather than their disabilities.

*Importance of Relationships*: A conviction that community relationships both at, and away from work, leads to mutual respect and acceptance.

*Power of Supports*: A conviction that people with disabilities need to determine their personal goals and receive assistance in assembling the supports necessary to achieve their ambitions.

Systems Change: A conviction that traditional systems must be changed to ensure customer control, which is vital to the integrity of supported employment.

Importance of Community: A conviction that people need to be connected to the

formal and informal networks of a community for acceptance, growth, and development (Brooke, Inge, Armstrong, & Wehman, eds., 1997, p. 4).

The Rehabilitation Act Amendments of 1986 also include: (a) provisions for exclusive funds for supported employment, and authorization of case service dollars for

individuals traditionally served by the VR program (Brooke, Inge, Armstrong, & Wehman, eds., 1997, p. 3); (b) expansion of rehabilitation engineering services for persons with disabilities; (c) and a gradual reduction of federal funding to state-federal VR programs to 75% by fiscal year 1993 (Gandy, Martin, & Hardy, 1999; Rubin & Roessler, 2001).

Rehabilitation Act Amendments of 1992

The following statutes were amended to the Rehabilitation Act in 1992:

- State rehabilitation agencies were mandated to establish Rehabilitation
   Advisory Councils to provide guidance in regards to agency policies and procedures. The majority of the council members must be people with disabilities who are members of the community or members of disability service or advocacy organizations.
- 2. State VR agencies were required to "describe the manner in which individuals with disabilities will be given choice and increased control in determining their VR goals and objectives." Persons with disabilities could select their own career goals and develop their own IWRP; the consumer and/or his or her representative could participate in the annual review of the consumer's IWRP. The IWRP could be modified at any time during the VR process, however, the IWRP would not be binding until the consumer or the consumer's representative signed the revised IWRP.

- 3. Emphasized VR services to persons with the "most severe disability"; order of selection was established which meant that VR consumers with the severest disabilities were entitled to first access to VR services.
- 4. VR counselors have 60 days to determine whether a consumer is eligible for VR services. If the VR counselor needed more than 60 days to determine eligibility, the VR counselor, with the consumer's permission, could schedule an extended evaluation period up to 18 months. During the extended evaluation period, the VR counselor is required to follow up on the consumer's progress every 90 days.
- 5. Interagency collaboration (i.e., written interagency agreements) between state-federal VR agencies and other agencies that persons with disabilities come in contact with or receive services.
- 6. Client Assistance Projects (CAP): Client/advocacy programs for VR consumers. CAP informs individuals of their rights and benefits under the Rehabilitation Act and can also serve in the advocacy capacity regarding the consumer's relationship with agencies in which consumers are receiving or seeking VR services.

## Rehabilitation Act Amendments of 1998

The Rehabilitation Act Amendments of 1998 is also known as Title IV of the Workforce Investment Act of 1998. The Workforce Investment Act (WIA), P.L.105-220), signed into law on August 7, 1998 by former President William Jefferson Clinton, encompasses a number of workforce employment and job training programs such as the

Employment Services and VR. Under Title IV (1998), federal workforce agencies are required to help job seekers get access to various employment opportunities and/or training (Rubin & Roessler, 2001). The following amendments of Title IV are listed below:

- The IWRP had been changed to Individualized Plan for Employment
   (IPE), thus increasing clients' control of the vocational planning process
   by giving clients the right to develop some or all their vocational plans
   with or without input from the VR counselor.
- 2. Persons with severe disabilities are now referred to as "individuals with significant disabilities."
- 3. For eligibility purposes, the trial work period replaced the extended evaluation period for assessing those with the most significant disabilities.
- 4. Expanded access to services with the establishment of cooperative agreements between VR and other agencies covered by and linked to the Workforce Investment Act; the establishment of formal linkages and roles with the "one-stop" service delivery setting; and the establishment of expanding services through its own (VR) internal procedures.
- Outreach to traditionally underserved populations that is serving minorities with disabilities and hiring qualified professional minorities reflecting the racial and ethnic makeup in American society.

6. Service provision by qualified personnel, which is a "qualified VR counselor" with a master's degree in rehabilitation counseling and certified as a rehabilitation counselor.

Americans with Disabilities Act of 1990

The Americans with Disabilities Act (ADA) became law in 1990 (Gandy, Martin, & Hardy, 1999; Rubin & Roessler, 2001). Signed into law by former President George Herbert Walker Bush, the ADA of 1990 is civil rights legislation enacted to give protection and, if necessary, legal recourse for persons with disabilities due to discriminatory practices from representatives of public and private entities. The United States Equal Employment Opportunity Commission is the federal agency responsible for the enforcement of the ADA. Before an individual can qualify for protection under the ADA, the individual must meet the definition of disability under ADA. According to the ADA, disability is defined as: (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such an impairment; or (c) being regarded as having an impairment."

The ADA of 1990 addresses five specific areas: Title I – Employment; Title II – Public Services; Title III – Public Accommodations and Services Operated by Private Entities; Title IV – Telecommunications; and Title V – Miscellaneous Provisions.

Title I – Employment, prohibits discrimination on the basis of disability with regard to job application procedures, hiring, advancement, discharge, compensation, training, and other privileges of employment (Gandy et al., 1999). Title I of the ADA is to ensure that qualified persons with a disability are able to get equal access to employment as those

qualified persons without a disability (Rubin & Roessler, 2001). In order for a person with a disability to be qualified for a job, he or she must be able to perform the essential functions of the job with or without reasonable accommodations (Rubin & Roessler). If a qualified job applicant or employee with a disability requires accommodations, the employer must make reasonable accommodations if making reasonable accommodations do not impose undue hardship on the employer (Rubin & Roessler).

School-to-Work Opportunities Act of 1994

The purpose of the School-to-Work Opportunities Act of 1994 (P. L. 103-239) is to assist *all* secondary students transition successfully into the world of work (Benz, Yovanoff, & Doren, 1997; Lewis, Stone, Shipley, & Madzar, 1998). Under the School-to-Work Opportunities Act, school-to-work transition programs should provide students with: (a) school-based and work-based learning; (b) career awareness, career exploration, and career counseling; (c) academic and occupational instruction that is integrated and focused on high standards of achievement; (d) work experiences and job training that could lead toward the awarding of work skill certificates; (e) workplace mentoring; (f) strong experience in and understanding of all aspects of the industry students are preparing to enter; and (g) connecting activities such as post-program planning and post-program evaluations that will help students bridge school and work-based learning opportunities while they are in school, and secondary and postsecondary learning opportunities once they leave high school (Benz, et al., para. 3 & para. 4; North Central Regional Educational Laboratory, n.d.).

Ticket to Work and Work Incentives Act of 1999

The Ticket to Work and Work Incentives Act of 1999 is for the benefit of working age individuals with disabilities who receive Social Security Disability

Insurance (SSDI) and/or Supplemental Security Income (SSI) payments. SSDI and SSI recipients receive a "ticket" in the mail. Recipients can choose to use their ticket to obtain VR services or other support services from approved providers of their choice to help them go to work. The approved providers are called "Employment Networks" which are private organizations or government agencies that have agreed to work with the Social Security Administration in providing employment services to SSDI and SSI beneficiaries. Participation in the Ticket to Work program is strictly voluntary, and services will be provided to no cost to those who chose to participate (Social Security Administration Red Book, 2005)

The ticket allows recipients to: (a) increase their choice in obtaining rehabilitation and vocational services to help them go to work and attain their employment goals; (b) removes barriers that require people with disabilities to choose between health care coverage and work; and (c) assures that individuals with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits (Social Security Online, The Work Site, n.d.). For those SSDI and SSI recipients who seek VR services and intend to achieve an employment outcome, they are presumed eligible for VR services (Federal Register for Department of Education, 2001).

## **Employment-Incentive Supports**

There are many individuals with disabilities who receive SSDI and/or SSI cash benefits who desire to work. Many, however, are afraid to work for fear of losing their cash benefits or healthcare coverage (i.e., Medicaid and Medicare). Yet, SSA has a number of employment-related incentives for SSDI and SSI recipients who desire to work without the immediate loss of their cash benefits or healthcare coverage. Below is a listing of employment SSDI and SSI employment supports. (*Note: Some of the employment supports are only applicable to SSDI recipients and some are only applicable to SSI recipients and the rest are applicable to both SSDI and SSI recipients*). SSDI employment supports are:

Impairment-Related Work Expenses: SSA deducts the cost of items and services that a person with a disability needs to work because of the person's impairment (e.g., attendant care services) if SSA decides that the person is engaging in SGA. It does not matter if the person also needs the items for normal daily activities. SSA can usually deduct the cost of those same items from earned income to figure the person's SSI payment.

Subsidy and Special Conditions: "Subsidy" and "special conditions" are SSA's names for support the individual with a disability receives on the job that may result with the individual receiving more pay than the actual value of the services the individual performs. "Subsidy" is support provided by one's employer. "Special conditions" are generally provided by someone other than the individual's employer (e.g., VR).

SSA considers the existence of subsidy and special conditions when SSA makes an SGA decision. SSA use only earnings that represent the real value of the work the individual performs to decide if the individual's work is at the SGA level. Subsidy or special conditions may exist if: (a) the individual receives more supervision than other workers doing the same or a similar job for the same pay; (b) the individual has fewer or simpler tasks to complete than other workers doing the same job for the same pay; or (c) the individual has a job coach or mentor who helps the individual perform some of the individual's work. If the individual's employer and/or other involved parties cannot or will not set the real value of the individual's work, SSA will decide the value of the individual's work.

Unincurred Business Expenses (Self-Employed Only): Support contributed to the individual's self-employment effort by someone else. If one is self-employed, SSA deducts unincurred business expenses from earnings when SSA make an SGA decision.

Unsuccessful Work Attempt: An effort to do substantial work (in employment or self-employment) which the individual has stopped or reduced to below the SGA level after a short time (6 months or less). This change must have resulted because of the individual's impairment, or removal of special conditions related to the individual's impairment that was essential to the further performance of the individual's work. When SSA makes an SGA decision for initial eligibility for SSDI benefits, SSA does not count earnings during an unsuccessful work attempt that occurred prior to an individual having been awarded benefits.

When SSA makes an SGA decision to determine if the individual's disability benefits continues or ceases because of the individual's work, SSA does not count earnings during an unsuccessful work attempt. During the extended period of eligibility, SSA considers unsuccessful work attempt(s) as part of the SGA decision(s) for months up to and including the month (if any) in which SSA ceases the individual's disability benefits. During the trial work period, or after the month (if any) in which SSA ceases the individual's disability benefits, SSA does not consider unsuccessful work attempts because they only have effect when an SGA decision is made.

Trial Work Period: The trial work period is an incentive for the personal rehabilitation efforts of SSDI beneficiaries who work. The trial work period lets the person test his or her ability to work or run a business for at least 9 months and receive full SSDI benefits if the person's impairment does not improve.

Extended Period of Eligibility: During the 36 consecutive months following the trial work period, if the person qualifies, SSA may restart one's SSDI benefits without a new application, disability determination, or waiting period.

Continuation of Medicare Coverage: An individual can receive at least 93 consecutive months of hospital and supplemental medical insurance after the trial work period. This provision allows health insurance to continue when the individual goes to work and is engaging in SGA.

Medicare for Individuals with Disabilities Who Work: Some individuals with disabilities who have returned to work can buy continued Medicare coverage

when their premium-free Medicare ends due to work activity. States are required to help pay the hospital insurance premiums for some working individuals with disabilities.

Continued Payment Under a VR Program (also known as Section 301): If the SSA finds a beneficiary no longer has a disabling impairment due to medical improvement, the beneficiary's payments usually stop. However, if the beneficiary participates in an appropriate program of VR services, employment services or other support services, the beneficiary's payments may continue until the beneficiary's participation in the program ends.

To qualify, the beneficiary must be participating in an appropriate program of VR services, employment services or other support services before the beneficiary's disability ends under SSA rules; and SSA must review the situation and decide that the beneficiary's continued participation in the program would increase the likelihood of the beneficiary's permanent removal from the disability benefit rolls. The individual's benefits may continue until the individual completes the program, the individual's participation in the program stops, or SSA decides that the individual's continued participation in the program will not increase the likelihood of the individual's permanent removal from the disability benefit rolls (Social Security Administration, Red Book, 2005).

The SSI employment supports are:

*Impairment-Related Work Expenses*: (see SSDI employment supports).

Subsidy and Special Conditions (for initial eligibility only): (see SSDI employment supports). Note: SSA does not take into account subsidy or special conditions when SSA figures an individual's SSI payment amount.

Unsuccessful Work Attempt for (initial eligibility only): (see SSDI employment supports). Note: SSA only considers an unsuccessful work attempt at the time a person with a disability files an initial claim. Unsuccessful work attempts are not considered after that time.

Earned Income Exclusion: SSA does not count most on the individual's earned income when SSA figures the individual's SSI payment amount. SSA does not count the first \$65 of the individual earnings in a month plus one-half of the remainder. This means that SSA count less than one-half of the individual's earnings when SSA figures the individual's SSI payment amount. SSA applies this exclusion in addition to the \$20 general income exclusion (an exclusion that is first applied to any unearned income that the individual may receive).

Student Earned Income Exclusion: If a beneficiary is under age 22 and regularly attending school, SSA do not count up to \$1,380 of earned income per month when SSA figures the SSI payment amount. The maximum yearly exclusion is \$5670. These amounts are for the year 2005; they are adjusted each year based on the cost-of-living. NOTE: Prior to April 1, 2005, the individual must have been unmarried and not head of a household in order to use the student earned income exclusion.

Blind Work Expenses: If the individual is blind, SSA do not count any earned income that the individual uses to meet expenses in earning that income when SSA decides the individual's SSI eligibility and payment amount.

Plan to Achieve Self-Support (PASS): Under an approved PASS, the individual with a disability may set aside income and/or resources over a reasonable time period that will enable the individual to reach a work goal to become financially self-supporting. The individual can then use the income and resources that he or she has set aside to obtain occupational training or education, purchase occupational equipment, establish a business, etc. SSA does not count the income and resources that the individual has aside under a PASS when SSA decides eligibility and payment amount.

Property Essential to Self-Support: SSA does not count some or all of certain property necessary for self-support when the SSI resources test is applied. 
Special SSI Payments for Individuals Who Work – section 1619(a): The beneficiary can receive SSI cash payments even when the beneficiary's earned income (gross wages and/or net earnings from self-employment) is at the SGA level. This provision eliminates the need for the trial work period or extended period of eligibility under SSI.

NOTE: If the beneficiary is blind, this does not apply to the beneficiary because current law does not apply the SGA requirement to individuals who are blind.

Medicaid While Working – section 1619(b): An individual with a disability can receive continued Medicaid coverage even if the individual's earnings alone or in

combination with his or her other income become too high for SSI cash payments. To qualify, the person must: (a) have been eligible for an SSI cash payment for at least one month; (b) still have a disability; (c) still meet all other eligibility rules, including the resources test; (d) need Medicaid in order to work; and (e) have gross earned income that is insufficient to replace SSI, Medicaid, and any publicly funded attendant care.

Special Benefits for Individuals Eligible Under Section 1619 (a) or (b) Who Enter a Medical Treatment Facility: If the individual is eligible under section 1619, the individual can receive SSI cash benefits for up to two (2) months while in a Medicaid facility or a public medical or psychiatric facility.

Reinstating Eligibility Without a New Application: If an individual has been ineligible for SSI and/or Medicaid for 12 months or less for any reason other than medical recovery, the individual may be able to restart his or her SSI cash payments and/or Medicaid coverage without a new application.

Continued Payment Under a VR Program (also known as Section 301): (See SSDI employment supports) (Social Security Administration, 2005, Red Book).

## Summary

This chapter gives the reader the fundamental background about autism and what constitutes a diagnosis of autism. Several treatment/intervention programs were discussed that are widely reported to be beneficial in assisting persons with autism. The purpose of any reputable treatment/intervention program for individuals with autism is to maximize

their daily functional living skills and to promote their independence and participation in society.

In relation to this study, major federal employment-related disability legislation and supports were also discussed. Because people with disabilities have historically encountered discrimination in regards to employment (e.g., hiring, wages, firing, etc.), laws have been enacted to promote the integration, inclusion, and equality of persons with disabilities in the workplace. If necessary, persons with disabilities can seek legal recourse in the event of workplace discrimination.

The federal rehabilitation laws and other federal employment-related disability legislation and supports were discussed for the purpose of informing the reader that assistance is available for persons with disabilities to gain employment. However, according to rehabilitation legislation, VR is legally mandated to assist persons with significant disabilities enter into the workforce and autism is identified in rehabilitation legislation as a significant disability. Yet, literature addressing the provision of VR services for persons with autism is minimal. The literature that does exist argues that VR has limited or excluded persons with autism from the receipt of VR services, assuming that they are unable to work. This indicates that persons with autism have been underserved in the receipt of VR services.

# III. A STATEWIDE SURVEY OF PUBLIC VOCATIONAL REHABILITATION COUNSELORS' PERCEPTIONS OF CONSUMERS WITH AUTISM

The Autism Society of America (n.d.), the National Institute of Child Health and Human Development ([NICHD], 2001), and the National Institute of Neurological Disorders and Stroke (2004) regard autism as a complex disability. Autism is a lifelong neurological developmental disability in which the definitive cause of the disorder is unknown (Locke, Banken, & Mahone, 1994; Schopler, 2001; Smith, 1990). Autism is primarily diagnosed in children, around age three, the beginning stage of the developmental period (Autism Society of Alabama, n.d.; Edwards, 2001; Giddan & Giddan, 1991; Osterling, Dawson, & McPartland, 2001).

Professionals agree that once a child is diagnosed with autism, early intervention that address the child's individual needs are critical for the child's well being (Edwards, 2001; Freeman, 1997; Marcus, Garfinkle, & Wolery, 2001). Yet, since autism is a lifelong disability, individual needs change across the lifespan. As adults, individuals with autism are faced with challenges in their lives such as the world-of-work, community living, and social activities (Strock, 2004). Regarding the world-of-work, this may prove to be demanding for many persons with autism, depending on the severity and extent of the deficits of autism they exhibit (Van Bourgondien & Woods, 1992).

Historically, vocational opportunities for persons with autism have been either severely limited or nonexistent (Belfiore, & Mace, 1994; Giddan & Giddan, 1991; Smith, Belcher, & Juhrs, 1995). Vocational service providers such as vocational rehabilitation (VR) counselors find that persons with autism present unique challenges (Olney, 2000). Because of the nature of autism, the working age population of persons with autism has been traditionally excluded from rehabilitation funding for VR services on the assumption that these individuals were not employable (Smith et al.).

According to the Rehabilitation Act Amendments of 1998 (Title IV of the Workforce Investment Act of 1998), the purpose of state-federal VR programs is to assist persons whose disabilities result in a "substantial impediment to employment." For those individuals whose disabilities present as a "substantial impediment to employment", it must be presumed that those individuals seeking assistance through VR programs will benefit by gaining and maintaining competitive employment in an integrated setting. According to Title IV-Rehabilitation Act Amendments of 1998 (herein will be referred to as Title IV), for an individual to be presumed eligible for VR services, the individual must meet the eligibility criteria which include: (a) the individual has a physical or mental impairment which constitutes or results in a substantial impediment to employment; (b) the individual can benefit in terms of an employment outcome from VR services; and (c) the individual requires VR services to prepare for, secure, retain, or regain employment. Once a VR counselor determines a consumer eligible for VR services, the VR counselor and the VR consumer will jointly develop an Individualized Plan for Employment (IPE). Title IV stipulates that the IPE should consist of the

description of the specific employment outcome that is chosen by the eligible individual, consistent with the unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the eligible individual, and, to the maximum extent appropriate, results in employment in an integrated setting.

Because of the nature of autism, VR counselors are reluctant to work with individuals who may exhibit social, communication, and behavioral challenges (Olney, 2000). Nonetheless, VR programs are legally mandated to give priority to "individuals with significant disabilities" and, in Title IV, autism is noted as one of several significant disabilities listed under the statute "individuals with a significant disability." Yet, even though VR programs are mandated to give priority to "individuals with significant disabilities" over individuals with less significant disabilities who are seeking VR services, access to those services can be limited if VR counselors presume that consumers with autism will not be successful at obtaining employment.

# Statement of the Research Problem

Historically, residential placement of persons with autism was the norm (Smith, 1990; Van Bourgondien, & Reichle, 2001). Vocational rehabilitation programs have not been receptive to providing employment support services for persons with autism because of low expectations that persons with autism could work (Smith, Belcher, & Juhrs, 1995). The focus of this study was to determine whether persons with autism are underserved in the receipt of VR services.

## Purpose of the Study

To be determined eligible for VR services through the VR program, federal guidelines stipulate that an individual: (a) has a physical or mental impairment which constitutes or results in a substantial impediment to employment; (b) be able to benefit from services in terms of becoming employed; and (c) require VR services to prepare for, secure, retain, or regain employment (Title IV, 1998).

The American Psychiatric Association (APA) regards autism as a mental disorder of a medical nature. Published by the APA, the fourth and text-revision edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000) notes that the essential features of autism are impairments in social interaction, communication, and behavior development. Those impairments can result in a "substantial impediment to employment." Due to significant developmental delays, individuals with autism meet the stipulations of the federal guidelines of having a mental impairment that result in a substantial impediment to employment and would require VR services to prepare for, secure, retain, or regain employment. However, VR counselors must determine whether individuals with autism can benefit from receiving VR services in terms of achieving an employment outcome. The purpose of this study, therefore, is to investigate whether VR counselors perceive individuals with autism as being able to benefit from receiving VR services.

### **Research Questions**

For this study, the following research questions were developed:

- 1. Are vocational rehabilitation counselors knowledgeable about autism?
- 2. What vocational rehabilitation services do vocational rehabilitation counselors believe are appropriate for persons with autism?
- 3. Are vocational rehabilitation counselors actually providing vocational rehabilitation services to persons with autism?

## Methodology

Subjects

The target population for this study was VR counselors employed by the Alabama Department of Rehabilitation Services. The majority of the VR counselors who participated in study were primarily female (77%) and primarily Caucasian females (56%). All male VR counselors who responded (n=21) were Caucasian.

Thirty percent of the VR counselors reported having obtained certification as a rehabilitation counselor (Certified Rehabilitation Counselor, [CRC]). Thirty percent of the VR counselors were in the 40-49 age group, followed closely by the 30–39 age group (29%) and the 50–59 age group (25%). Thirty percent of the respondents had more than one year, but less than or equivalent to five years of experience as a VR counselor. Twenty five percent of the respondents had more than 10 years, but less than or equivalent to 15 years of experience as a VR counselor. Overall, half of the respondents (47%) have experience as a VR counselor greater than five years, but less than or equivalent to 15 years of service as shown on Table 1.

Table 1

Counselors' Demographic Information (Based on Age Group, Race/Ethnicity,

Certification/Licensure, and Length of Service as a Vocational Rehabilitation Counselor)

|                                    | Male <sup>3</sup> | Female **   | Total *** |
|------------------------------------|-------------------|-------------|-----------|
|                                    | (n = 21)          | (n = 72)    | (n = 93)  |
| Age Group                          |                   |             |           |
| 20–29                              | 1 (5%             | 6) 12 (17%) | 13 (14%)  |
| 30–39                              | 2 (9.5%           | 6) 25 (35%) | 27 (29%)  |
| 40–49                              | 8 (38%            | 6) 20 (28%) | 28 (30%)  |
| 50–59                              | 10 (48%           | 6) 13 (18%) | 23 (25%)  |
| 60+                                | 0 (0%             | (3%)        | 2 (2%)    |
| Race/Ethnicity                     |                   |             |           |
| African-American                   | 0 (09             | 6) 17 (24%) | 17 (18%)  |
| Caucasian                          | 21 (100%          | 6) 52 (72%) | 73 (78%)  |
| Other                              | 0 (09             | (4%)        | 3 (3%)    |
| Certification/Licensure            |                   |             |           |
| Certified Rehabilitation Counselor | 7 (33%            | 6) 21 (29%) | 28 (30%)  |
| Certified Case Manager             | 1 (5%             | (0%) 0 (0%) | 1 (1%)    |
| Licensed Professional Counselor    | 1 (5%             | (0%) 0 (0%) | 1 (1%)    |
| Other                              | 0 (09             | (7%) 5 (7%) | 5 (5%)    |

(table continues)

Table 1 (continued)

|                                 | Male *   | Female ** | Total *** |
|---------------------------------|----------|-----------|-----------|
|                                 | (n = 21) | (n = 72)  | (n = 93)  |
| Length of Service****           |          |           |           |
| < One (1) year                  | 0 (0%)   | 5 (7%)    | 5 (5%)    |
| $> 1$ yr., but $\leq 5$ yrs.    | 4 (19%)  | 24 (33%)  | 28 (30%)  |
| $>$ 5 yrs., but $\leq$ 10 yrs.  | 4 (19%)  | 17 (24%)  | 21 (23%)  |
| $>$ 10 yrs., but $\leq$ 15 yrs. | 4 (19%)  | 19 (26%)  | 23 (25%)  |
| >15 yrs.                        | 9 (43%)  | 7 (10%)   | 16 (17%)  |
|                                 |          |           |           |

<sup>\*</sup> In Column 1, the numbers on the left side of the percentages (in parentheses) are the number of male VR counselors who responded for each category. The percentages represent the number of male VR counselors who responded in each of the categories, divided by the total number of male VR counselors who participated in the study.

### Instrument

The researcher developed a survey instrument titled *Vocational Rehabilitation*Services for Consumers with Autism (see Appendix A). The construction of the survey instrument was derived from various sources: other survey instruments and

<sup>\*\*</sup>In Column 2, the numbers on the left side of the percentages (in parentheses) are the number of female VR counselors who responded for each category. The percentages represent the number of female VR counselors who responded in each of the categories, divided by the total number of female VR counselors who participated in the study.

<sup>\*\*\*</sup> In Column 3, the numbers on the left side of the percentages (in parentheses) are the number of male and female VR counselors combined who responded in each of the categories, divided by the total number of VR counselors who participated in the study.

<sup>\*\*\*\*</sup> Length of Service: > Is "greater than; < Is "less than"; ≤ Is "less than/equal to"

questionnaires, textbooks on research, journal articles, books and the Internet. The section on the survey that lists the VR services provided through Alabama Department of Rehabilitation Services was obtained from a brochure (2002) distributed by the Alabama Department of Rehabilitation Services. The instrument consisted of close-ended and narrative/open-ended questions and was divided into four (4) sections: Section I. Counselor's Demographic Information; Section II. Counselor's Knowledge of Autism; Section III. Referral and Eligibility; and Section IV. Services.

A preponderance of the questions on the survey consisted of nominal/categorical variables (i.e., close-ended questions). Data collected for the close-ended questions was entered into SPSS 12.0 for Windows. All narrative responses were recorded on index cards. Narrative responses pertaining to: (a) ineligibility determination of consumers with autism for vocational rehabilitation services (Section III); (b) advantages and disadvantages of Milestones (Section IV); (c) job-related weaknesses of consumers with autism (Section IV); (d) job-related strengths of consumers with autism (Section IV); and (e) additional comments regarding serving consumers with autism (Section IV) were each compiled and grouped based on the survey question. Narrative responses will be discussed throughout this study.

## Procedures

Initial approval to conduct the study was sought from the Assistant Commissioner for Adult Vocational Rehabilitation Services of the Alabama Department of Rehabilitation Services (see Appendix B). After receiving approval from the Assistant

Commissioner, approval for the study was sought from and granted by Auburn University's Institutional Review Board for Research Involving Human Subjects.

When this study was conducted, the Assistant Commissioner's office reported that the Alabama Department of Rehabilitation Services had 161 VR counselors; therefore, the researcher prepared 161 survey packets for distribution. Enclosed in each survey packet was: (a) the survey instrument; (b) an information sheet inviting the VR counselors to participate in the study, informing them the purpose of the study, informing them that participation in the study was anonymous and voluntary, and that deciding not to participate in the study would not jeopardize relations with the Alabama Department of Rehabilitation Services nor the Rehabilitation and Special Education Department at Auburn University (see Appendix C); and (c) a stamped, letter-size envelope, addressed to the researcher, to whom the participants would return their survey instruments via U. S. postal service.

The researcher traveled to Montgomery, AL, location of the headquarters of the Alabama Department of Rehabilitation Services, and delivered the 161 survey packets to the Assistant Commissioner of Adult Vocational Rehabilitation Services. On the day of delivery, the Assistant Commissioner distributed the appropriate number of survey packets to the VR unit supervisors. The VR unit supervisors subsequently distributed the survey packets to the VR counselors under their supervision. The return of the survey instruments occurred during a two-month period. Approximately 93 survey instruments were returned to the researcher yielding a 58% return rate.

#### Results

Vocational rehabilitation counselors were asked whether or not they consider themselves knowledgeable about autism. Fifty-percent of the VR counselors responded that they consider themselves knowledgeable, 47% did not consider themselves knowledgeable, and 3% percent did not respond. They were also asked how they acquired knowledge about autism (see Table 2).

Table 2

Resources of Acquired Knowledge of Autism (Between FY 2000 – FY 2002)

| Resources             | Frequency* | Percentage** |
|-----------------------|------------|--------------|
| Counseling Session(s) | 15         | 16%          |
| Friend/Acquaintance   | 13         | 14%          |
| Journal Articles      | 28         | 30%          |
| Relative              | 4          | 4%           |
| Training Workshops    | 43         | 46%          |
| Other***              | 31         | 33%          |
|                       |            |              |

<sup>\*</sup>Frequency: Represents the number of VR counselors, per each resource, who responded where they had acquired knowledge of autism.

<sup>\*\*</sup>Percentage: The frequency rate converted to percentage rate; represents the number of VR counselors, per each resource, who responded where they had acquired knowledge of autism.

<sup>\*\*\*</sup>Other: Resources in which some of the respondents had acquired knowledge of autism include: job coaching a person with autism; educational and academic setting; previous employment; co-worker collaboration; a rehabilitation center; and the Internet.

The majority of VR counselors receive referrals of prospective consumers from several sources. The researcher presented a list of referral sources on the survey and requested that the VR counselors respond to those referral sources from which they have received referrals of persons with autism (see Table 3). The study revealed that school systems were VR counselors' major source of referrals of persons with autism. Should future researchers want to replicate this study, the VR counselors they may want to specifically target are transitional rehabilitation counselors because the majority of the VR counselors responded that a majority of their referrals of persons with autism were from the school systems.

Vocational rehabilitation counselors were asked to approximate the number of persons with autism that had been referred to them for vocational rehabilitation services. The researcher also asked the VR counselors to approximate the number of persons with autism they determined *eligible* for VR services. To view a comparison of the VR counselors' responses of the approximation of the number of referrals received and the approximation of persons with autism determined eligible for vocational rehabilitation services see Table 4.

Table 3

Vocational Rehabilitation Counselors' Sources of Referrals of Persons with Autism

(Between FY 2000 – FY 2002)

| Sources           | Frequency* | Percentage** |
|-------------------|------------|--------------|
| Self-referral     | 4          | 4%           |
| Parent/Guardian   | 17         | 18%          |
| School system     | 36         | 39%          |
| Community agency  | 5          | 5%           |
| Healthcare agency | 2          | 2%           |
| Other***          | 3          | 3%           |
| Other             | 3          | 370          |

<sup>\*</sup>Frequency: Represents the number of vocational rehabilitation counselors, per each source, who responded receiving referrals of persons with autism.

<sup>\*\*</sup>Percentage: The frequency rate converted to percentage rate; represents the number of vocational rehabilitation counselors, per each source, who responded receiving referrals of persons with autism.

<sup>\*\*\*</sup>Other: Resources in which some of the respondents received referrals of persons with autism include one-stop centers and a group home for persons with autism.

Table 4

Approximations of the Number of Persons with Autism Referred and Determined Eligible for VR Services (Between FY 2000 – FY 2002)

| Approximations | Referred * | Determined Eligible ** |
|----------------|------------|------------------------|
| 0              | 40 (43%)   | 37 (93%)               |
| 1–5            | 41 (44%)   | 40 (98%)               |
| 6–10           | 9 (10%)    | 5 (56%)                |
| 11–15          | 1 (1%)     | 1 (100%)               |

<sup>\*</sup> This column reflects the number and percentage of VR counselors, per each approximation, who indicated receiving referrals of persons with autism.

Interestingly, 43% of the VR counselors reported that they did not receive any referrals of persons with autism, therefore, it was expected that 43% of the VR counselors could not determine any persons with autism eligible for VR services. However, there is a discrepancy among the 40 VR counselors who reported receiving zero (0) referrals of persons with autism and 37 VR counselors who reported determining 0 persons with autism eligible for VR services. Overall, the majority of the VR counselors reported that

<sup>\*\*</sup> This column reflects the number of VR counselors, per each approximation, who determined persons with autism eligible for VR services (in the case of 0, the number of VR counselors who did not determine any persons with autism eligible due to reporting not receiving any referrals on persons with autism). The percentages were derived by dividing the number of VR counselors, per each approximation, who determined persons with autism eligible for VR services (and in the case of 0, the number of VR counselors that did not determine persons with autism eligible for VR services), by the number of VR counselors who received referrals of persons with autism (in the case of 0, did not receive referrals of persons with autism) per each approximation, respectively.

five or fewer individuals with autism across a three- year span (FY 2000 – FY 2002) were referred for VR services. In addition, the majority of the VR counselors reported that five or fewer individuals with autism across a three- year span (FY 2000 – FY 2002) were determined eligible for VR services.

Regarding gender and eligibility determination for VR services for consumers with autism, the percentage rates of male consumers with autism determined eligible for VR were greater than the percentage rates of female consumers with autism determined eligible for VR. The rate in which VR counselors found more males than females with autism eligible for services may relate to the fact that autism is found in males more than females. According to the DSM-IV-TR (2000), autism affects males four to five times more frequently than it affect females.

The VR counselors were requested to approximate, by race/ethnicity, the percentage of consumers with autism determined eligible for VR services. Consumers with autism who are Caucasian were represented more than any other racial/ethnic group. The American Indian/Native American group was the only racial/ethnic group identified as *not* having been determined eligible for VR services.

Each survey instrument included a comprehensive list of VR services provided through the Alabama Department of Rehabilitation Services (2003) for adult consumers with disabilities. The VR services are grouped under headings that are descriptive of their general functions. The researcher requested that the VR counselors identify which VR service(s) they believe are *appropriate* for consumers with autism and which VR services(s) they *actually provided* for their consumers with autism (see Table 5).

Table 5

Percentages of and the Differences Between Appropriate and Actually Provided

Vocational Rehabilitation (VR) Services for Consumers with Autism (Between FY 2000 – FY 2002)

| VR Services                         | Appropriate | Actually Provided | Difference |
|-------------------------------------|-------------|-------------------|------------|
| Domain 1: Evaluation and Assessment |             |                   |            |
| General Medical Examinations        | 51%         | 3%                | 48%        |
| Specialty Examinations              | 52%         | 12%               | 40%        |
| Aptitude and Interest Testing       | 65%         | 26%               | 39%        |
| Vocational Evaluations              | 74%         | 45%               | 29%        |
| Psychological Examinations          | 70%         | 27%               | 43%        |
| Employability Assessments           | 67%         | 28%               | 39%        |
| On-the-Job Evaluations              | 62%         | 22%               | 40%        |
| Domain 2: Counseling and Guidance   |             |                   |            |
| Disability-related Issues           | 69%         | 28%               | 41%        |
| Vocational Planning                 | 72%         | 45%               | 27%        |
| Job-Readiness Preparation           | 76%         | 46%               | 30%        |

(table continues)

Table 5 (continued)

| VR Services                                 | Appropriate    | Actually Provided | Difference |
|---|----------------|-------------------|------------|
|   | 11 1           |                   |            |
| Domain                                      | 3: Physical Re | estoration        |            |
| Medical Treatment                           | 32%            | 2%                | 30%        |
| Surgery/Hospital Care                       | 27%            | 0%                | 27%        |
| Purchase of Assistive Devices               | 55%            | 5%                | 50%        |
| Domain 4: Training and Related Services     |                |                   |            |
| Specific Skills Training in School          | 67%            | 12%               | 55%        |
| Facility Training                           | 71%            | 29%               | 42%        |
| On-the-Job Training                         | 76%            | 24%               | 52%        |
| Domain 5: Equipment and Transportation      |                |                   |            |
| As Needed for Training or Employm           | ent 72%        | 19%               | 53%        |
| Domain 6: Job Development and Job Placement |                |                   |            |
| Labor Market Data                           | 42%            | 7%                | 35%        |
| Job Leads                                   | 60%            | 27%               | 33%        |
| Job Analysis and Job Matching               | 70%            | 22%               | 48%        |
| Job Site Coaching                           | 77%            | 30%               | 47%        |
| Job Clubs                                   | 36%            | 3%                | 33%        |
| Rehabilitation Engineering                  | 55%            | 9%                | 46%        |
| Technology                                  | 55%            | 4%                | 51%        |

(table continues)

Table 5 (continued)

| VR Services                         | Appropriate | Actually Provided | Difference |
|-------------------------------------|-------------|-------------------|------------|
| Domain 7: Post-Placement Assistance |             |                   |            |
| Follow-up After Employment          | 73%         | 26%               | 47%        |
| Job Modification or Restructuring   | 63%         | 5%                | 58%        |
| Job Accommodations                  | 71%         | 18%               | 53%        |

The majority of the VR counselors (77%) reported that Job Site Coaching is appropriate for consumers with autism. The VR service that represents the widest gap between what VR counselors believed to be appropriate for consumers with autism and what is actually provided to consumers with autism is Job Modification or Restructuring.

Sixty-three percent of VR counselors reported that Job Modification or Restructuring was appropriate for consumers with autism yet *only* 5% percent of the VR counselors actually provided Job Modification or Restructuring, a *58%* difference.

Twenty-seven percent of the VR counselors responded that Surgery/Hospital Care is appropriate for consumers with autism, yet Surgery/ Hospital Care was the *only* VR service in which VR counselors did *not* actually provide to consumers with autism.

Vocational rehabilitation counselors were requested to approximate the percentage of their consumers with autism placed in sheltered workshops (SW) for FY 2000 – FY 2002. Ten percent of the VR participants reported placing consumers with autism in SW. Vocational rehabilitation programs have traditionally used SW programs

for those consumers with disabilities who needed additional job training before entering the workforce (Association for Persons in Supported Employment [APSE], 2001; Baydur, 1995; Smith et al., 1995). Vocational rehabilitation counselors have often closed consumers as "rehabilitated" or as "successful employment outcome" during their placement in sheltered workshops (APSE, 2001). However, VR counselors can no longer close consumers in sheltered workshops as "rehabilitated" or as a "successful employment outcome" (APSE). Vocational rehabilitation funds can be used for shortterm training programs in sheltered workshops, but the final employment placement must be in integrated employment setting (APSE). Sheltered workshops have been criticized for: (a) supplying work that requires minimal learning on part of the consumers; (b) segregating consumers, thus not placing them in competitive integrated employment; (c) retaining the best workers for the more demanding work; (d) making incorrect assumptions that consumers prefer or are more competent at tasks that involve sitting or standing at tables and using mostly their fine motor and coordination skills; and (e) tasks are not situated for the consumers' needs (Falvey, Bishop, & Gage, 1995; Smith et al.; Rubin & Roessler, 2001).

Fourteen percent of the VR counselors responded when asked to approximate the percentage of their consumers with autism placed into competitive employment *without* job site coaching. Competitive employment without job site coaching is the ideal job placement for VR consumers. Job placement of this nature is considered the least intrusive (i.e., no outside ongoing supports) in the workplace. Persons with autism who

are regarded as minimally affected by their disability are capable of holding employment without job site coaching (Smith et al., 1995).

Twenty-five percent of the VR counselors approximated the percentage of consumers with autism they placed into supported employment (SE) for FY 2000 – FY 2002. The study revealed that the VR participants in this study utilized SE more for consumers with autism than SW and CE combined.

There are five SE placement models available to assist consumers who need ongoing supports: (1) Individual Placement Model of Competitive Employment (the only individual option); (2) Enclave; (3) Mobile Work Crew; (4) Dispersed Group or Cluster Option; and (5) Entrepreneurial/Small Business Model (Brooke, Inge, Armstrong, & Wehman, 1997). The Individual Placement Model of Competitive Employment was utilized the most for consumers with autism with 25% of the VR participants reported utilizing the individual option. None of the VR counselors reported having had a consumer with autism utilize the entrepreneurial/small business model.

The Alabama Department of Rehabilitation Services pays supported employment vendors to provide ongoing supports to consumers through *Milestones*, an outcome-based incremental payment program. Twenty-five percent of the VR counselors reported that *Milestones* was utilized on behalf of their consumers with autism. For those VR counselors who utilized *Milestones*, it was requested they state its advantages and disadvantages. The majority of the VR counselors reported that the greatest advantages of *Milestones* are: (a) it tailors to the individual needs of the consumer; and (b) it provides

on-going support and follow-up. The greatest disadvantage stated about *Milestones* is that it can be a long process in placing consumers into employment.

### Discussion

Three research questions were developed as a result of this study:

1. Are vocational rehabilitation counselors knowledgeable about autism?

There is little surprise that nearly half (47%) of the subjects reported a lack of knowledge about autism. Institutionalization of persons with autism was common throughout the majority of the 20<sup>th</sup> century with little hope offered or expected of persons with autism (Giddan & Obee, 1996). Historically, the needs of individuals with autism have been ignored once persons with autism grew into adolescence and adulthood (Giddan & Obee). Another contributing factor to VR counselors' lack of knowledge about autism is that graduate programs in Rehabilitation Counseling typically do not address the specifics associated with developmental disabilities (Olney, 2001). As a consequence, VR counselors may be ill prepared to serve individuals diagnosed with a developmental disability such as autism (Olney).

2. What vocational rehabilitation services do vocational rehabilitation counselors believe are appropriate for persons with autism?

From the 27 vocational rehabilitation services listed on the survey, more than half of the vocational rehabilitation counselors reported that 23 of the vocational rehabilitation services (85%) were appropriate for consumers with autism.

3. Are vocational rehabilitation counselors actually providing vocational rehabilitation services to persons with autism?

With the exception of Surgery/Hospital care, vocational rehabilitation counselors are providing vocational rehabilitation services to consumers with autism. However, as shown in Table 5, the study revealed significant differences between VR services that VR counselors reported they believe as appropriate for consumers with autism and VR services that VR counselors reported they actually provided for consumers with autism. Less than half of the VR counselors reported they did *not* actually provide those services they reported as appropriate for consumers with autism. The only VR services that slightly more than half of the participants reported they actually provided to consumers with autism were: (a) Vocational Planning (72% of the VR respondents reported this service was appropriate for consumers with autism but only 45% of the respondents actually provided this service for consumers with autism); (b) Job Readiness (76% of the VR respondents reported this service was appropriate for consumers with autism but only 46% of the respondents actually provided this service for consumers with autism); and (c) Vocational Evaluation (74% of the VR respondents reported this service was appropriate for consumers with autism but only 45% of the respondents actually provided this service for consumers with autism). Although the purpose of a vocational evaluation is to assess a consumer's vocational aptitudes, interests, and behavior in order to determine the services need to obtain employment goals (Roessler & Baker, 1998) it has been found that vocational evaluations have been used to exclude persons with autism from receiving VR services (Smith et al., 1995).

The researcher inquired about the number of persons with autism receiving VR services for FY 2000 –FY 2002 by speaking with the Assistant Commissioner for Adult Vocational Rehabilitation Services of the Alabama Department of Rehabilitation Services (J. H., personal communications, October14, 2005 & October 17, 2005). The Assistant Commissioner informed the researcher that for FY 2000, 45 consumers with autism were served, 23 consumers with autism were rehabilitated, and 14 cases of consumers with autism remained open. For FY year 2001, the Assistant Commissioner informed the researcher that 63 consumers with autism were served, 29 consumers with autism were rehabilitated, and 21 cases of consumers with autism remained open. For FY 2002, the Assistant Commissioner informed the researcher that 80 consumers with autism were served, 28 consumers with autism were rehabilitated, and 25 cases of consumers with autism remained open. Over a three-year span, (FY 2000 – FY 2002), 188 consumers with autism were served, 80 consumers with autism were rehabilitated, and 60 cases of consumers with autism remained open.

According to the Alabama Department of Rehabilitation Services (2000) Annual Report, a total of 40, 695 Alabamians with disabilities were served by the VR program. Consumers with autism comprised 0.1% of total the number of Alabamians with disabilities served by the VR program in FY 2000. Also for FY 2000, a total of 7,687 Alabamians with disabilities were rehabilitated. Consumers with autism comprised 0.3% of the total number of persons with disabilities rehabilitated by the VR program.

According to the Alabama Department of Rehabilitation Services (2001) Annual Report, a total of 42,349 Alabamians with disabilities were served by the VR program.

Consumers with autism comprised 0.1% of total the number of Alabamians with disabilities served by the VR program in FY 2001. Also for FY 2001, a total of 7,692 Alabamians with disabilities were rehabilitated. Consumers with autism comprised 0.4% of the total number of persons with disabilities rehabilitated by the VR program.

According to the Alabama Department of Rehabilitation Services (2002) Annual Report, a total of 43,577 Alabamians with disabilities were served by the VR program. Consumers with autism comprised 0.2% of total the number of Alabamians with disabilities served by the VR program in FY 2002. Also for FY 2002, a total of 7,699 Alabamians with disabilities were rehabilitated. Consumers with autism comprised 0.4% of the total number of persons with disabilities rehabilitated by the VR program. For a three-year span, (FY 2000 – FY 2002) there was only a negligible increase in both the number of consumers with autism in Alabama who were served by the VR program and the number of consumers with autism in Alabama who were rehabilitated.

Implications of findings of this study are: (a) persons with autism are underserved in receipt of VR services in terms of VR services believed to be appropriate for persons with autism and VR services that are actually provided to consumers with autism; (b) the prevalence rate of autism is increasing (Autism Society of America, n.d.; Goin & Myers, 2004; Marcus, Garfinkle, & Wolery, 2001; NICHD, 2001; NICHD, 2005), indicating a crucial need for professional development of VR counselors to learn more about autism; and (c) to emphasize that federal rehabilitation mandates that "individuals with significant disabilities" have priority in the receipt of VR services which include persons with autism.

# Limitations of the Methodology

During the development of the survey instrument, care was taken to ensure that: (a) the participants' identities would remain anonymous; (b) questions could not be construed as ambiguous; and (c) participants would not have to reveal information that could be detrimental to their employment with the Alabama Department Rehabilitation Services or jeopardize their relationship with the Rehabilitation and Special Education Department at Auburn University. However, errors in the construction of the survey were noticed after reviewing the returned survey instruments. Discrepancies and ambiguity were revealed in Section II – Counselor's Knowledge About Autism. First, the researcher gave no criteria to VR counselors to prove whether or not they consider themselves knowledgeable about autism. Secondly, 47% of the VR counselors reported that they did not consider themselves knowledgeable about autism, yet 22% of those counselors reported that they had acquired knowledge about autism. Therefore, for those who reported that they did not consider themselves knowledgeable about autism, the researcher should have instructed them to go directly to Section III – Referral and Eligibility. Another alternative would have been to rephrase the second question under Section II such as: "If you consider yourself knowledgeable about autism, how did you acquire the knowledge?"

Another error pertains to the placement of questions in Section III – Referral and Eligibility. Questions and statements about *referrals* of persons with autism should have been placed together and questions and statements about *eligibility* of persons with autism should have been placed together. In addition, the researcher had requested the

VR counselors to give a percentage of those consumers found eligible for vocational rehabilitation services based on gender, yet the researcher failed to ask the VR counselors to give a percentage of those consumers *referred* for VR services based on gender. The researcher had committed a similar error by requesting the VR counselors to approximate, by race/ethnicity, the percentage of consumers with autism determined eligible for VR services, yet failed to request the VR counselors to approximate, by race/ethnicity, the percentage of consumers with autism *referred* for VR services.

Determining eligibility (or ineligibility) of a consumer for VR services cannot be decided unless receiving referral of the consumer for VR services.

Errors were found in Sections II and III that applies to Section IV. For those VR counselors who considered themselves knowledgeable about autism (Section II) and those VR counselors who received at least 1-5 referrals on persons with autism and/or determined at least 1-5 consumers with autism eligible for autism (Section III), the researcher should have directed those VR counselors to complete Section IV of the survey instrument for a more accurate assessment of the provision of VR services to consumers with autism.

In Section IV – Services, another error was found which pertained to Milestones. The VR counselors were requested to state the advantages and disadvantages of Milestones. The request was made with one statement. The request should have been in two separate statements, one statement that requested VR counselors to state the advantages of *Milestones* and another statement requesting the VR counselors to state the disadvantages of *Milestones*.

# Social Importance of Study

In recent years, there has been intense focus on autism, especially regarding the suspected causes of the disability. Because autism is primarily diagnosed in early childhood, children diagnosed with autism receive greater attention than adults with autism; however, children with autism do eventually become adults. Since there is no cure for autism, having autism is a lifelong condition. Because autism has garnered so much attention and because persons with autism are no longer readily confined to institutions, it is time that persons with autism become accepted and contributing members of society.

## Summary

Nearly half of the VR counselors who participated in this study do not consider themselves knowledgeable about autism. The VR counselors reported that a majority of the VR services provided through the Alabama Department of Rehabilitation Services are appropriate for consumers with autism, yet less than half of the VR counselors actually provided VR services to consumers with autism. The implication of this is alarming because a lack of knowledge about autism and not providing the VR services that are appropriate for individuals with autism can and will be detrimental to achieving a successful employment outcome.

Since most of the VR counselors reported that school systems were the leading source of referrals of persons with autism, it is important to mention that from 2001–2002, it was determined that 1,233 Alabama students, ages 3–21, were classified as

having autism (Centers for Disease Control and Prevention, 2004). As these students prepare for transitioning from high school, for many of these students the VR program will be expected to take part in the transition process.

### IV. CONCLUSIONS AND RECOMMENDATIONS

To be determined eligible for VR services, federal guidelines stipulate that an individual (a) has a physical or mental impairment which constitutes or results in a substantial impediment to employment; (b) be able to benefit from services in terms of becoming employed; and (c) require VR services to prepare for, secure, retain, or regain employment (Title IV, 1998).

The American Psychiatric Association (APA) regards autism as a mental disorder of a medical nature. Published by the APA, the fourth and text-revision edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000) notes that the essential features of autism are impairments in social interaction, communication, and behavior development. Those impairments can result in a "substantial impediment" to employment. Due to significant developmental delays, individuals with autism meet the stipulations of the federal guidelines of having a mental impairment that result in a substantial impediment to employment and would require VR services to prepare for, secure, retain, or regain employment. However, VR counselors must determine whether individuals with autism can benefit from receiving VR services in terms of achieving an employment outcome. The purpose of this study, therefore, was to investigate whether VR counselors perceive individuals with autism as being able to benefit from receiving VR services.

It has been more than 60 years since Kanner initially introduced the term *autism* to describe the psychological state of 11 children. Decades ago, it was alleged that autism was caused by "refrigerator mothers", mothers who were allegedly cold, indifferent, and exhibited little affection to their children. This "refrigerator mother" cause has long since been discarded. Although the exact cause(s) of autism still has not been established, the general consensus among most researchers is that autism is a spectrum disorder, meaning that manifestations of the disorder range from mild to severe. No two people will exhibit characteristics of autism to the same degree. However, because autism presents with a host of challenging characteristics, those diagnosed with the disability are viewed as having a "severe" or "significant" disability, even if they exhibit minimal manifestations of the disorder.

Autism is primarily diagnosed in childhood and children with autism are *entitled*, by law, to special education and related services until age 21. Once they become 21 years of age, they are no longer entitled to services, but must be determined *eligible* for adult services programs. One such program is the vocational rehabilitation program.

Persons with autism have been historically underserved in the receipt of VR services. Due to the nature of autism, there were no expectations that persons diagnosed with autism could work; therefore, it was assumed that they were unable to benefit from vocational rehabilitation services. Therefore, once adults with autism reached adulthood, they were confined to their homes or placed into institutions because work was not considered a viable option.

It was mandated in the Rehabilitation Act of 1973 that "individuals with severe disabilities" take priority in the receipt of VR services. The Rehabilitation Act Amendments of 1986 mandated supported employment for those individuals who would need ongoing support services due to the severity of their disability. The Rehabilitation Act Amendments of 1992 emphasized VR services to persons with the "most severe disability", and the Rehabilitation Act Amendments of 1998 re-emphasized supports to "individuals with significant disabilities" (formally "individuals with severe disabilities").

The presumption of benefit clause in Title IV states that an individual shall be presumed to be an individual that can benefit in terms of an employment outcome from vocational rehabilitation services unless the designated State unit can demonstrate by "clear and convincing evidence" that such individual is incapable of benefiting in terms of an employment outcome from vocational rehabilitation services due to the severity of individual's disability. The presumption of eligibility clause states that an individual who has a disability or is blind shall be: (a) considered to be an individual with a significant disability; and (b) presumed to be eligible for vocational rehabilitation services provided that the individual intends to achieve an employment outcome consistent with the unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individual unless the designated State unit involved can demonstrate by "clear and convincing" evidence that such individual is incapable of benefiting in terms of an employment outcome from vocational rehabilitation services due to the severity of the disability of the individual. The "clear and convincing evidence" to determine if a

person with a disability would not benefit from VR services is based on the consumer undergoing a trial work period/experience. In relation to this study, the researcher requested that the VR counselors state the primary reason(s) for determining a person with autism ineligible for VR services. Only 15% of the VR counselors responded to the request, and only *one* respondent stated that the person with autism was determined ineligible after having undergone an unsuccessful trial work period. Other reasons that were given to determine a consumer with autism ineligible for VR services had nothing to do with consumers with autism having been unsuccessful during a trial work period such as: (1) a doctor did not recommend employment; (2) individual preferred to remain in a day program; (3) need constant supervision to perform tasks; (4) limited in self-care skills; (5) unable to express or appear receptive to directions/instructions; (6) facilities nor employers will provide one-on-one supervision; (7) a mother declined services; and (8) isolating behaviors were cited for determining persons with autism ineligible for VR services.

This study yielded three important findings: (1) nearly half (47%)of the vocational rehabilitation counselors reported that they lack knowledge about autism; (2) more than half of the vocational rehabilitation counselors reported that a majority of the vocational rehabilitation services provided through the Alabama Department of Rehabilitation Services were appropriate for persons with autism; and (3) significant differences exist between VR services believed to be appropriate for individuals with autism and those that were actually provided to persons with autism.

Rehabilitation legislation clearly mandates that VR programs should be providing services to those "individuals with significant disabilities." This study indicates that individuals with autism are underserved in terms of the VR services VR counselors reported were appropriate for consumers with autism and the VR services they actually provided to consumers with autism. In addition, VR counselors' lack of knowledge about autism would hinder the VR process for consumers with autism such as: (a) not knowing the appropriate vocational assessments utilized specifically for persons with autism that could present their vocational skills and abilities; (b) unaware of unique talents many individuals with autism possess and how those talents could be of value in the world-of-work; and (c) unaware that by placing consumers with autism in the inappropriate work environment could be disruptive to the sensibilities related to their disability. On the survey, VR counselors were given an opportunity to provide comments regarding serving consumers with autism. A majority of those that responded admitted that more training is needed in the area of servicing persons with autism.

Many of the VR counselors reported that a majority of the VR services provided through the Alabama Department of Rehabilitation Services were appropriate for consumers with autism, yet less than half of the VR counselors actually provided VR services to consumers with autism. On the survey instrument, VR counselors were asked to state job-related strengths of consumers with autism. Those who responded stated that consumers with autism: (1) have good visual skills; (2) have good long-term memory skills; (3) are reliable and dependable; (4) have a desire to work/motivated; (5) are good at performing repetitive tasks; (6) are willing to learn new things; (7) are thorough and

meticulous; (8) stays on tasks/focused on tasks; (9) attentive to details; (10) do not require frequent breaks while at work; and (11) good physical health. If more VR counselors were aware of the abilities that persons with autism possess, those abilities can be promoted to prospective employers. But that cannot happen if persons with autism are underserved in the receipt of vocational services.

It is crucial that the reader understand that autism not only affects the person diagnosed with the disability, but also their family members as well. This study revealed that persons with autism and their families are not well informed about the VR program. Four percent of the VR counselors reported that persons with autism initiated their own referrals for VR services. Seventeen percent of the VR counselors reported that referrals of persons with autism came from their parents/guardians. This study also revealed that five percent of referrals of persons with autism came from community agencies and two percent of referrals were from healthcare agencies. The low percentage of referrals from human service agencies in referring persons with autism indicates a greater need for human service providers to inform persons with autism and/or their families about VR services. This also indicates a greater need for interagency collaboration among human service providers' agencies and VR agencies.

To learn more about autism, there are a number of websites VR counselors can visit such as: http://www.agre.org (Autism Genetic Resource Exchange); http://www.autismresearchinstitute.com (Autism Research Institute); http://www.autismservicescenter.org (National Autism Hotline); http://www.autismsociety.org (Autism Society of America); http://www.cdc.gov/ncbddd/autism/asd

(Centers for Disease Control and Prevention); http://www.cureautismnow.org (Cure Autism Now); http://www.nationalautismassociation.org (National Autism Association); http://www.nichd.nih.gov (National Institute of Child Health and Human Development); and http://www.nimh.nih.gov (National Institute of Mental Health). There are also numerous books and articles written about autism from researchers, educators, parents, and individuals (e.g., Temple Grandin) who has autism. There are local, state, and national advocacy organizations that VR counselors can contact to learn more about autism. The researcher is aware that many VR counselors have large caseloads (200 or more) persons with disabilities in their caseload. However, it must be reiterated that the prevalence rate of autism is increasing. There are those who assert that autism is no longer a low-incidence disability, that the prevalence rate of autism has reached epidemic proportions (Rogers, 1998; Simpson, 2004). Vocational rehabilitation counselors need to be prepared to assist persons with autism and their families in obtaining VR services.

Although the nature of autism can be challenging, it does not mean that persons with autism cannot work. The researcher found literature regarding persons with autism working (Edwards, 2001; Smith et al., 1990; & Smith et al., 1995) yet in regards to persons with autism receiving VR services, literature was scarce. Vocational rehabilitation counselors must take care not to generalize about every individual with autism as being unable to work. As stated previously, autism affects no two persons the same.

Every developing human being, with disabilities and without, needs an environment, which encourages trying. Everyone must have an environment

which offers positive opportunities to learn from mistakes, instead of negative warnings of what can't be done. Everyone needs an opportunity to try and an opportunity to fail – in other words, an opportunity to learn (Excerpt from The Opportunity To Fail, PEAK Parent Center, Inc., 1988).

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### **APPENDICES**

# $\label{eq:appendix} \mbox{APPENDIX A}$ $\mbox{SURVEY INSTRUMENT}$

#### VOCATIONAL REHABILITATION SERVICES for CONSUMERS with AUTISM

COUNSELOR'S DEMOCRAPHIC INFORMATION

The purpose of this survey is to assess vocational rehabilitation services for consumers with autism. The results of this survey will provide information regarding services appropriate for persons with autism. Findings may also be useful in developing training programs to assist rehabilitation counselors in working with consumers with autism.

Please place a check  $(\mathscr{A})$  by categories that apply to you. Thank you for your time and participation.

SECTION I

| 1. Gender:                | ☐ Male   | ☐ Female  |
|---------------------------|--|---|
| 2. Age Group:             | 20 - 29<br>50 - 59   |   |
| 3. Race/Ethnicity:        | ☐ Asian Amo<br>☐ Caucasian<br>☐ Hispanic/I                     | merican Indian/Native American erican or Pacific Islander American /Euro-American atino American use specify):          |
| 4. Educational Attainme   | ent:  Bachelor's   | degree (Academic Major)   |
|                           |  | egree (Academic Major)  |
|                           |  | (Academic Major):   |
| 5. Certification/Licensur | ☐ Certified C<br>☐ Certified V<br>☐ Licensed I                 | Rehabilitation Counselor (CRC) Case Manager (CCM) Vocational Evaluator (CVE) Professional Counselor (LPC) use specify): |
| 6. How long have you be   | cen a rehabilitati  Less than Greater th Greater th Greater th | on counselor?   |

| SECTION   | II. COUNSEL   | OR'S F               | KNOWLEDGE AB   | OUT AUTISM   |  |
|---|---|----------------------|--|--|--|
| 1. Do you co  | nsider yourself knowl   | edgeable             | about autism?  | _YesNo   |  |
| 2. How did y  | ou acquire the knowl  | edge? (Pl            | ease check all that apply                              | y.)  |  |
|   | ☐ Counseling Session ☐ Relative ☐ Other (Please Spec                                    |                      | Friend/Acquaintance<br>Training Workshops              | ☐ Journal articles                                     |  |
| SECTION   | III. REFERRA  | L and E              | LIGIBILITY   |  |  |
| Please approvocational rehaute  | oximate the number of publication services betw   | ersons wi            | th autism that have been<br>and 2002. (Please check th | referred to you for<br>ne applicable category.)        |  |
|   | □ 0<br>□ 11 - 15  | □ 1 - 5<br>□ 16 - 20 | ☐ 6 - 10<br>☐ 21 or m                                  | nore   |  |
| with autism did   | per of persons with auti<br>I you determine were <u>el</u><br>check the applicable cate | gible for v          | ve been referred to you,<br>vocational rehabilitation  | how many of those persons<br>services between 2000 and |  |
|   | □ 0<br>□ 11 - 15  | □ 1 - 5<br>□ 16 - 20 | ☐ 6 -10<br>☐ 21 or m                                   | nore   |  |
| <ol> <li>For those persons with autism you determined to be <u>ineligible</u> for vocational rehabilitation services<br/>between 2000 - 2002, please state the primary reason(s) for determination of ineligibility.</li> </ol> |   |                      |  |  |  |
|   |   |                      |  |  |  |
|   |   |                      |  |  |  |
|   |   |                      | -  |  |  |
|   |   |                      |  |  |  |
|   |   |                      |  |  |  |
|   |   |                      |  |  |  |
|   |   |                      |  |  |  |
|   |   |                      |  |  |  |

| 4. Of those consumers with autism found eligi 2000 - 2002, what percent were: Female Male                          | ible for vocational rehabilitation services between                                     |
|--|---|
| 5. What has been your source of referrals for check all that apply.)   | persons with autism between 2000 - 2002? (Please  |
| ☐ Self-referral ☐ Parent/Guardian ☐ School system ☐ Community agency ☐ Healthcare agency ☐ Other (Please specify): |   |
| 6. Please approximate below, by race/ethnicit determined eligible for vocational rehabilitation                    | y, the percentage of consumers with autism that you<br>on services between 2000 - 2002. |
| % African American   |   |
| % American Indian/N  | ative American  |
| % Asian American or  | Pacific Islander American   |
| % Caucasian/Euro-An  | nerican   |
| % Hispanic/Latino An   | nerican   |
| % Other (Please speci  | fy):  |

#### SECTION IV. SERVICES

1. Listed in the middle column are services provided through the Alabama Department of Rehabilitation Services. At the left column titled "Appropriate", please put a check (\$\notings\$) in the box next to the service that you believe to be appropriate for consumers with autism. (Please check all that apply.)

At the right column titled "Actually Provided", please put a check (1) in the box next to the service that you have actually provided for your consumers with autism. (Please check all that apply.)

| APPROPRIATE  O  O  O  O | EVALUATION and ASSESSMENT General Medical Examinations Speciality Examinations Aptitude and Interest Testing Vocational Evaluations Psychological Examinations Employability Assessments On-the-Job Evaluations | ACTUALLY PROVIDED        |
|-------------------------|---|--------------------------|
| APPROPRIATE  O          | COUNSELING and GUIDANCE<br>Disability-related Issues<br>Vocational Planning<br>Job-Readiness Preparation  | ACTUALLY PROVIDED        |
| APPROPRIATE  O  O       | PHYSICAL RESTORATION Medical Treatment Surgery/Hospital Care Purchase of Assistive Devices  | ACTUALLY PROVIDED        |
| APPROPRIATE  O  O       | TRAINING and RELATED SERVICES<br>Specific Skills Training in School<br>Facility Training<br>On-the-Job Training   | ACTUALLY PROVIDED  □ □ □ |
| APPROPRIATE             | EQUIPMENT and TRANSPORTATION As needed for Training or Employment   | ACTUALLY PROVIDED        |
| APPROPRIATE  O  O  O  O | JOB DEVELOPMENT and JOB PLACEMENT Labor Market Data Job Leads Job Analysis and Job Matching Job Site Coaching Job Clubs Rehabilitation Engineering Technology   | ACTUALLY PROVIDED        |
| APPROPRIATE  □ □ □      | POST-PLACEMENT ASSISTANCE<br>Follow-up After Employment<br>Job Modification or Restructuring<br>Job Accommodations  | ACTUALLY PROVIDED        |

| 2. Please approximate the percentage of your consumers with autism placed in sheltered workshops between 2000 - 2002 %   |  |  |  |  |
|--|--|--|--|--|
| <ol> <li>Please approximate the percentage of your consumers with autism placed into competitive<br/>employment <u>without</u> job site coaching between 2000 - 2002 %</li> </ol>  |  |  |  |  |
| <ol> <li>Please approximate the percentage of your consumers with autism placed on a job by means of<br/>supported employment between 2000 - 2002%</li> </ol>  |  |  |  |  |
| 5. If placed on a job by means of supported employment between 2000 - 2002, which of the supported employment models, listed below, were utilized to place your consumers with autism? (Please put a check (%) next to the supported employment model(s) utilized for your consumers with autism.)   |  |  |  |  |
| SUPPORTED EMPLOYMENT PLACEMENT MODELS  |  |  |  |  |
| ☐ <u>Individual Placement Model of Competitive Employment</u> : One employment specialist training one person on the job, in community-integrated competitive employment. This model is considered the least restrictive and most normalizing of supported employment placement models.  |  |  |  |  |
| □ Enclave: A group of individuals, usually three to eight, who work together in a group with the assistance of a permanent full-time supervisor. Employment occurs within a regular, community-based industry called the host company with participants' earnings based upon production rate results.  |  |  |  |  |
| □ <u>Dispersed Group or Cluster Option</u> : This model of supported employment is characterized by the business hiring up to eight individuals, all of whom work in different positions but closely with the on-site supervisor. Wages are commensurate with co-workers performing the same or similar duties.  |  |  |  |  |
| ☐ Mobile Work Crew: Includes between three to eight employees with significant disabilities and one or two supervisors. A mobile work crew usually travels through the community performing specialized contract services. People with disabilities work with people who do not have disabilities in a variety of settings, such as offices and apartment buildings. |  |  |  |  |
| Entrepreneurial/Small Business Model: People with significant disabilities are<br>joining family and friends in owning and operating businesses. Success is<br>dependent upon on the ability to attract customers.   |  |  |  |  |
| 6. Was the outcome-based payment system known as Milestones (incremental payments to supported employment providers when clients accomplish goals in sequential order) utilized for consumers with autism?Yes orNo   |  |  |  |  |

| 7. If Milestones was utilized, please state it advantages and disadvantages.    |
|---|
|   |
|   |
|   |
|   |
| 8. Please state job-related weaknesses that your consumers with autism exhibit. |
|   |
|   |
|   |
| 9. Please state job-related strengths that your consumers with autism exhibit.  |
|   |
|   |
|   |
| 10. Do you have additional comments regarding serving consumers with autism?    |
|   |
|   |
|   |
|   |
|   |

### APPENDIX B

## PERMISSION LETTER TO CONDUCT THE STUDY

### Clarence Brown - (Fwd) Survey

From:

"Jim Harris III" <jharris3@rehab.state.al.us>

To:

<brownc8@groupwise1.duc.auburn.edu>

Date:

3/24/2003 10:26 AM

Subject: (Fwd) Survey

······ Forwarded message follows ······

From: To:

Jim Harris III < jharris 3@rehab.state.al.us> brownc8@groupewise1.duc.auburn.edu

Subject:

Survey

Date sent:

Mon, 24 Mar 2003 09:55:57 -0600

#### Clarence,

I have reviewed the survey regarding autism to be sent out by Margie Cannon.

looks good. The only concern I had was the inclusion of questions requiring a narrative response. My experience is that this may tend to decrease the number of responses. Hopefully, not by very many. Please let me know how I can help with distribution process. I'll be glad to send them out from here ( I have the location and number of counselors) and have them returned directly to Margie. My number is (334) 281-8780. Direct line is (334) 613-2204. Jim 3 ..... End of forwarded message ......

James Harris III, Assistant Commissioner Alabama Department of Rehabilitation Services

# APPENDIX C $\label{eq:local_energy}$ INFORMATION SHEET



Auburn University, Alabama 36849-5226

Department of Rehabilitation & Special Education

1228 Haley Center

Telephone: (334) 844-5943

#### INFORMATION SHEET FOR

#### "VOCATIONAL REHABILITATION SERVICES FOR CONSUMERS WITH AUTISM"

You are invited to participate in a research study to assess vocational rehabilitation services for consumers with autism. This study is being conducted by Margie Cannon, a graduate student majoring in rehabilitation counseling, under the supervision of Dr. Clarence Brown, Associate Professor in the Department of Rehabilitation and Special Education at Auburn University. The purpose of this study is to learn about the provision and delivery of vocational rehabilitation services for consumers with autism. You were selected as a possible participant because you are a rehabilitation counselor employed by Alabama Department of Rehabilitation Services.

If you decide to participate, you will be given a survey instrument constructed by Ms. Cannon. The survey has been approved by Mr. Jim Harris, III, the Assistant Commissioner of Adult Vocational Rehabilitation Services for Alabama Department of Rehabilitation Services. Your participation will require approximately 30 minutes of your time. Upon participation, please complete and return the survey instrument within 10 days of receipt.

The results of the survey returns should provide information about the status of provision and delivery of services for consumers with autism. The findings from the survey would be beneficial in determining counselors' awareness of assisting individuals with autism seeking vocational rehabilitation services. Information collected through your participation will also be used to fulfill a thesis requirement for a master degree in rehabilitation counseling.

Any information obtained in connection with this study will remain anonymous. Please know that by filling out the survey and returning it indicates your willingness to participate in this project. Once your information is sent, you will not be able to withdraw the information since the information collected is anonymous.

Your decision whether or not to participate will not jeopardize your future relations with the Department of Rehabilitation and Special Education Department at Auburn University or Alabama Department of Rehabilitation Services.

If you have any questions, please contact:

Margie Cannon, Principal Investigator (334) 844-5943 cannoma@auburn.edu or Dr. Clarence Brown, Faculty Advisor (334) 844-5943 brownc8@auburn.edu

Page 1 of 2

HUMAN SUBJECTS
OFFICE OF RESEARCH
PROJECT # 03-025 EX 0305
APPROVED 5/3/03TO 5/4/04

A LAND-GRANT UNIVERSITY



Department of Rehabilitation & Special Education

1228 Haley Center

Telephone: (334) 844-5943

For more information regarding your rights as a research participant you may contact the Office of Human Subjects Research by phone or e-mail. The people to contact there are Executive Director E. N. "Chip" Burson at (334) 844-5966 (bursoen@auburn.edu) or IRB Chair Dr. Peter Grandjean at (334) 844-1462 (grandpw@auburn.edu).

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER TO PARTICIPATE IN THIS RESEARCH PROJECT. IF YOU DECIDE TO PARTICIPATE, THE DATA YOU PROVIDE WILL SERVE AS YOUR AGREEMENT TO DO SO. THIS LETTER IS YOURS TO KEEP.

Page 2 of 2

A LAND-GRANT UNIVERSITY

HUMAN SUBJECTS OFFICE OF RESEARCH PROJECT #43-085 EX 0305 APPROVED 5/3/03 TO 5/2/04