Employment and adults with autism spectrum disorders: Challenges and strategies for success

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Accepted: August 2009

Abstract. Individuals with autism spectrum disorder (ASD) have the ability and desire to work, but there are still several obstructions. Research overwhelmingly demonstrates disappointing employment outcomes for this group. The vast majority is unemployed and for those who do have gainful employment, underemployment is common. The increased prevalence of ASD coupled with unique social, communication, and behavioral characteristics translate into the need for services to help them achieve employment success. Consideration of individual characteristics including strengths, needs, as well as specific interests, coupled with implementation of proper supports can result in successful and ongoing employment. This paper provides a review of evidence based research related to employment for individuals with ASD. Specific areas addressed include benefits of employment, state of employment, obstacles to employment, current service options, and an in depth review of supports needed for success. These supports focus not only on job tasks, but also the interpersonal skills needed to foster a positive work experience.

Keywords: Autism, ASD, employment for adults with autism

1. Introduction

Autism spectrum disorders (ASD) represent a distinct category of developmental disabilities that share many of the same characteristics. Individuals with an ASD have difficulties with reciprocal social interactions and interpersonal communication, and may demonstrate unusual or repetitive patterns of behaviors. We use the term "autism spectrum disorders" because the symptoms can occur in any combination and can range from very mild to quite severe [1, 58].

Autism spectrum disorders include autism and two related disorders; Asperger Syndrome (AS) and pervasive developmental disorder-not otherwise specified (PDD-NOS). It is often regarded that autism is the most severe of the three; however, any individual diagnosed with a spectrum disorder may be profoundly affected. Autism spectrum disorders are believed to be permanent developmental disorders that will continue

into adulthood, creating lifelong challenges for the individual [87].

The number of individuals in the United States diagnosed with an ASD has increased dramatically in recent years [18]. Current data from the United States Department of Education indicate this disorder is increasing at a rate of 10–17% annually [63]. This annual growth increase certainly impacts service delivery within the public education system; however, also extends to postsecondary services as these individuals leave high school. Despite a great deal of data and ubiquitous media reports publicizing an increase in numbers, there is currently still very little known about how best to provide support that will result in postsecondary success. The majority of research and programmatic efforts have focused on young children, with relatively little focus placed on adolescents and adults with ASD [55].

Successful employment is perhaps the primary aspiration for most individuals as they enter their

postsecondary years, whether such employment occurs directly after high school or following a training or educational program. According to the Individuals with Disabilities Education Act [34], the primary purpose of a public education is to prepare an individual for employment. This law clearly outlines post-school employment as the measure of accountability for individuals with disabilities. Postsecondary employment opportunities, however, have traditionally been very limited for individuals with ASD [62, 70]. Obtaining and maintaining employment can be difficult for any person, but is particularly complicated for an adolescent or adult with ASD due to unique communication and social impairments [56, 60]. While employment outcomes have received growing attention for many students with disabilities in the educational research (e.g., [74]), with the expanded numbers of individuals with ASD, there is a stark demand to assess what we know currently about their employment needs and understand better what services and supports may help facilitate employment success in the years after high school.

2. Purpose

In this paper we will review evidence based research related to employment for individuals with ASD. A spectrum of employment options is now available which include segregated workshops, supported employment, and competitive employment [80]. The outcomes of supported and competitive employment are far superior to sheltered workshop or other day service options in terms of financial gains, wider social integration, and worker satisfaction [12, 13, 67, 68]. Therefore, for the purpose of this paper, employment will refer to work within the natural community. Specific areas addressed in this review include benefits of employment, state of employment, obstacles to employment, current service options, and in depth review of supports for success.

Information on employment and ASD was obtained by conducting electronic and ancestral searches using ERIC and PsycInfo. Searches concentrated on research published from 2000 through 2009. Hand searches were conducted on six journals which frequently publish research involving persons with ASD (Autism, Education and Training in Developmental Disabilities, Exceptional Children, Focus on Autism and Developmental Disabilities, Journal of Applied Behavior Analysis, and Journal of Autism and Developmental Disorders). Because of the continuity across autistic disorders, this review addresses both the narrowly

defined disorder of autism and the broader range of autism spectrum disorders, including AS and PDD-NOS.

3. Benefits of employment

There are many reasons to examine factors related to employment success. Individuals with ASD should have the same rights and entitlements enjoyed by the rest of society. Employment enables adults with and without disabilities to earn wages they can use to support themselves and pursue their interests. Employment provides a forum that promotes personal dignity and has been demonstrated to improve quality of life in individuals with ASD [20, 21, 65] as well as improve cognitive performance [19].

Despite the humanitarian reasons, increased employment also provides a number of economic advantages. With employment, there is less reliance on government funds and more contribution to taxes [28, 35]. Jarbrink et al. [36] conducted a study looking at the societal cost-impact of adults with high-functioning autism and found that lack of employment results in lost work time and productivity that supports a society and helps keep it moving. Further, employment has a significant cost impact on the economy due to resource utilization. Jarbrink et al. reported that with employment, the cost of community supports would decrease creating less reliance on day programs and activities, such as adult day care. Wages would provide the means to pay bills decreasing the need for living support. Health benefits would cover the costs of medical concerns, a critical issue for this population, as increased health care costs are common due to a need for medication and psychiatric services that address comorbid disorders [3, 6, 15, 40].

There is also ample evidence to support the potential benefits to employers and companies when they hire individuals with ASD [25, 26, 28]. Employers often value the trustworthiness, reliability, and low absenteeism of this group [30]. Once employed, individuals with ASD often demonstrate particular strengths, such as attention to detail and intense focus that result in increased work output and may enjoy performing jobs often shunned by others due to social isolation or the repetitive nature of the task [80].

4. State of employment

Follow-up studies suggest that long-term employment outcomes are poor for the majority of this group [88]. It is estimated that 50–75% of adults with ASD are unemployed [29, 32, 52, 57]. Even for individuals who are considered to be higher functioning, employment results are appalling. Adults experience underemployment, switch jobs frequently, have difficulty adjusting to new job settings, make less money than their counterparts, and are much less likely to be employed than typically developing peers [10, 33, 37, 56], individuals with less severe language disorders, or individuals with learning disabilities [9]. Even for those individuals who have postsecondary educational experience, employment difficulties are common [27].

5. Obstacles to successful employment

Individuals with ASD have markedly different vocational needs than individuals with other developmental disabilities [5, 56]. Because each person demonstrates a variety of characteristics across the diagnostic criteria, each individual is unique. The spectrum of need and ability makes the provision of successful employment a great challenge indeed [38]. As noted by Simpson:

The countless permutations and combinations of social interactions, language, learning, sensory, and behavior deficits and excesses found in these individuals, in combination with their wide range of abilities, developmental levels, isolated skills, and unique personalities make autism an especially baffling disability ([73], p. 69).

Interactional difficulties associated with ASD account for the biggest vocational impact [25, 26, 64, 79]. In interviews with adults with ASD, communication and social difficulties with supervisors and coworkers consistently emerge as a primary hindrance to job performance [8, 56, 67, 83]. Bolman [6] found that such difficulties often lead to termination. Communication obstacles include difficulty understanding directions; inability to "read between the lines", read facial expressions, and tone of voice; asking too many questions; and communicating in an inappropriate manner [32, 33]. Social impairment involves a wide array of deficits intrinsic to successful interactions and may include inappropriate hygiene and grooming skills, difficulty following social rules, inability to understand affect, working alone, and acting inappropriately with individuals of the opposite sex [42, 84, 86]. Navigating social interactions are often problematic even before employment is procured and begins with mastering the job application and interview process [56].

There are areas of cognitive functioning known to be impacted in individuals with ASD which can affect job performance. Impairments in executive functioning are well documented [43, 48, 54, 85]. Many exhibit difficulties in task execution due to problems with attention, motor planning, response shifting, and working memory [31, 50, 56, 64]. Acclimating to new job routines and managing changes in the work setting often pose a challenge [38]. Individuals with AS demonstrate difficulties with both problem-solving and organization, despite having average or above-average intelligence [2]. According to Howlin [27], many may experience difficulty in fulfilling employment roles as they get older due to a deterioration in skills that may occur in early adulthood for those who have low IQs or develop epilepsy.

Behavioral difficulties which may include tantrums, aggression, self-injury, property destruction, ritualistic behaviors, or pica can create an employment barrier [4, 7, 41, 75, 76, 81]. Interfering behaviors create a complicated issue as many are misinterpreted, have multiple functions, and require multi-faceted behavior management strategies [39]. Such behaviors are not well tolerated in the workplace and may prevent employment all together and lead to segregation [77].

Individuals with ASD report encountering high levels of stress and anxiety in the workplace which may interfere with performance. Hurlbutt and Chalmers [33] interviewed six adults with AS who reported high levels of anxiety due to the task of trying to fit in socially with the neurotypical world. Burt et al. [7] found that individuals with autism had increased anxiety due to sensitivity to workplace noise and other sensory stimuli. Camarena and Sarigiani [8] interviewed the parents of 21 high-functioning adolescents with ASD regarding postsecondary aspirations. Parents reported anxiety as a major obstacle for postsecondary success due to their child's fear of the unknown and navigating social interactions.

The comorbidity with a variety of psychiatric symptoms including depression, anxiety, and bipolar disorder in individuals with ASD has been widely reported [23, 40, 72, 84]. Further, the onset of epilepsy occurs in approximately one-third of the population [5, 18]. Such mental and physical health problems may significantly interfere with the capacity for positive employment outcomes. Schaller and Yang [71] used the 2001 Rehabilitation Services Administration database to describe the demographic characteristics related to employment by the 815 individuals with ASD who achieved competitive and supported employment outcomes. Absence of a secondary disability

was significantly related to successful competitive employment.

6. Current service options

Given the heterogeneity found in this group, for employment to be procured and maintained in the community, there must be a variety of services and supports provided. Vocational Rehabilitation (VR) programs provide supports and services designed to help individuals with disabilities meet their employment goals by assisting individuals prepare for, get, keep, or regain employment. The number of individuals with ASD utilizing VR services increased by more than 121 percent from 2002 to 2006 [14]. The small body of research evaluating employment outcomes of the VR system suggests that services provided through these programs are less than optimal for individuals with ASD and do not provide sufficient support [56]. Lawer et al. [47] examined the employment outcomes of 1,707 adults with ASD in the United States VR system whose cases were closed in 2005. Individuals with ASD were much more likely than adults with other impairments to be denied services as a result of being considered to have a disability too severe to benefit from services. Cimera and Cowan examined employment outcomes obtained by adults with ASD whose cases were closed between 2002 and 2006. The number of cases closed reached 41%. While this percentage was similar or higher to other disability groups investigated, those with ASD worked far fewer hours and earned lower wages. In addition to having limited efficacy, generic employment services and supports are not cost effective. Research indicates employment services offered through our current VR system for individuals with ASD are expensive and may cost more than services for other disability groups. Cimera and Cowan found service costs for those with ASD were among the most costly of nine disability groups served. Only participants with sensory impairments obtained services that cost more. Lawer et al. found services obtained by adults with ASD were the most costly of all groups served.

7. Strategies for success

Assistance provided through the provision of supported employment is often necessary for job success [47, 71, 78]. With a scheme providing on-the-job support services, employment outcomes for this population improve dramatically. Howlin et al. [28] tracked employment of adults with HFA and AS over an

eight year period and found that approximately 68% found permanent employment, jobs were commensurate with the individual's intellectual abilities and academic attainments, and salaries were increased. Hillier et al. [26] followed nine participants through two years of a vocational support program. Employment levels increased by 78% and income levels increased by 443%.

There is some evidence indicating programs specifically targeting the needs of this population may indeed be a more appropriate and cost effective solution [28]. There is limited research outlining the specific services and supports those with ASD require; however, examples of successful supported employment programs for individuals with ASD are described in the literature (e.g. [26, 38, 59]). Additionally, case studies conducted with adults with ASD provide tremendous insight regarding vocational needs [32, 33, 56]. From this research, recommendations for vocational supports can be ascertained and grouped into four major themes: (1) job placement, (2) supervisors and co-workers, (3) onthe-job provisions, (4) work place modifications, and (5) long-term support. The section to follow provides a summary of research for each area of workplace support and identified strategies.

7.1. Job placement

Mounting research indicates supports related to job placement are the most impactful when it comes to successful employment [71]. Particularly crucial is ensuring an appropriate job match. In their description of the Treatment and Education of Autistic and related Communication—handicapped CHildren (TEACCH) supported employment program, Keel et al. [38] emphasized the need for job placement to be individualized and based on the person's strengths and interests. Research describing Prospects, a supported employment program for adults with AS, stresses the need to identify jobs that are appropriate to the individual's intellectual and educational background and that match his or her social skills and abilities [28, 51].

Placement also requires considerations regarding the job tasks and work environment [38]. An appropriate job is predictable and can be adapted to a schedule for the person with ASD. Work tasks are clearly defined and in areas with minimal distractions. According to personal opinion, jobs should require minimal social skills, allow adequate time for learning, and be void of excessive sensory stimulation [56].

To assist in ensuring an appropriate job placement, a variety of strategies have been highlighted in the literature. Job preference has been determined through exposure to a range of tasks in a variety of businesses [61]. Also effective are preference assessments. Lattimore et al. [44] found paired-item preference assessments determined more or less preferred tasks for workers with autism, while Lattimore et al. [45] found efficacy in multi-stimulus assessments. Nuehring and Sitlington described a formal process for using assessments to job match. These assessments took the form of behavior observations, situational assessments, and analysis of background information. The assessment data were used to determine individual interests, jobs the individual could do well, jobs requiring assistance and training, and work habits needing further development. In a vocational support program described by Hillier et al. [26] job placement skills, including job matching, were taught to adults with ASD. These skills covered job searching, identifying appropriate jobs, preparing resumes, and interviewing. Instruction was provided one on one for a minimum of one hour per week until employment was secured.

7.2. Supervisors and co-workers

Employment success can be contingent on employers and co-workers who provide a supportive environment. Employment retention may require flexibility and tolerance from individuals who supervise, interact, or collaborate with the person with ASD [7, 51]. Modifications to job tasks or the work environment, adjustments to communication exchanges, and assistance with social interaction will likely be required [25].

Both knowledge of the disorder as well as job supports available are important prerequisites for employing individuals on the spectrum [25, 26, 28]. Nesbitt et al. [59] surveyed employers to determine differences between those who did or did not employ an individual with high functioning autism or asperger syndrome. Differences were related to awareness or understanding of the disorder. Those not employing an individual on the spectrum focused on potential negative behaviors rather than the person's capabilities. These same organizations also failed to acknowledge the importance of employment supports that may be provided. Adults with ASD interviewed about employment described significant difficulty in the workplace due to insufficient knowledge. They recommended providing autism awareness training to employers and co-workers to help foster understanding of who they are and why they behave in a certain way [6, 56].

A primary component of existing supported employment programs is receptivity and knowledge of the employers and co-workers. TEACCH staff provides training to everyone at the job site who is willing to learn about ASD, resulting in an environment where the individual is more likely to be successful [38]. Informal training to supervisors on ASD characteristics and support strategies is a component of the Prospects program [28, 51]. In the program described by Hillier et al. [26], information was provided to supervisors and co-workers emphasizing how to interact socially and to maximize social integration for the individual with ASD.

7.3. On-the-job training

Experience has proven that with proper intervention and training, individuals with ASD can work in a variety of businesses and industries [26, 47, 80]. Workers may need extensive training and/or instruction using special methods to learn job tasks as well as other skills related to employment [25, 61]. For the individual with ASD, such skills may include communication, interpersonal skills, and management of stereotyped patterns of behavior that will foster a positive work experience [7, 16]. While it should be expected that the person with ASD enters the work place with a variety of skills intact, it is highly likely, the individual, regardless of ability level, will require on the job support [6, 16, 61]. Due to the unique learner profile associated with ASD, training may be most beneficial when provided on the actual job site. This allows for learning to take place in the natural setting where real jobs are performed increasing the chance for success [11, 89]. Lattimore et al. [46] demonstrated the importance of onsite training, when they increased skill acquisition in adults with autism by pairing simulation tasks with on the job training. An excellent example of providing onsite training is Project Search at the Cincinnati Children's Hospital [69]. Project Search provides a demand side employment model, where vocational training and placement occurs with a wide array of jobs within the hospital

Supported employment programs serving this population emphasize providing individualized on the job training that targets job tasks, acclimation to the job site, and social integration [26, 28, 38]. Typically, intensive training is provided upon commencement by a job coach who slowly and systematically lessens support. Hillier et al. provide a description of common training objectives targeted by the employment specialist. These objectives include ensuring the worker

with ASD: understands his or her job tasks; can complete all job tasks to the satisfaction of his or her supervisor; understands workplace rules; knows the start time, end time, and break times; understands sick leave and vacation policies; is aware of emergency procedures; knows his or her way to pivotal areas in the building; and knows how to get to and from work.

The uneven cognitive and social abilities in those with ASD require a diverse set of specialized interventions and treatments [22]. Research on instructional strategies with adolescents or adults with ASD is scarce. Even more uncommon is research on teaching skills to this group in the workplace. Available research supports the use of strategies derived from the principles of applied behavior analysis and include modeling, structured reward systems, video modeling, errorless learning, graduated guidance, and systems of prompts [7, 80]. These strategies are not new, but are essential to teach individuals with a variety of disabilities in the workplace.

More recent research has utilized visual supports implemented via low-tech and high-tech modalities. Riffel et al. [66] used a palmtop computer to teach an adult with autism to roll silverware. The program enabled the worker to view step-by-step pictures paired with auditory instructions on the screen at his own pace. Foley and Staples [17] increased communication skills through the use of augmentative and alternative communication interventions. Adults were taught to use a voice output system to greet, name coworkers, request, comment, give directions, and make choices. In this same study, social stories [24] were used to increase appropriate conversational interactions. Targeted literacy instruction using written text was used to increase language comprehension and reduce perseverative commenting and questioning.

The literature promotes the use of behavior management strategies to reduce inappropriate behavior, including aggression, self-injury, property destruction, and pica in the workplace [4, 39, 75, 76, 81]. Kemp and Carr reduced inappropriate behaviors in three adults with autism when they conducted a functional behavior assessment (FBA) in the workplace. A multicomponent intervention package was implemented that included functional communication, building rapport, making choices, imbedding demands, and increasing tolerance for reinforcement. Other successful strategies have included teaching the worker to take a short break when upset [7] and implementation of a picture schedule [17].

7.4. Work place modifications

In addition to training and instruction to learn job tasks and other skills related to employment, the worker with ASD may also require workplace modifications and adaptations [25, 61]. A variety of strategies may be employed to make the job a better match for the employee by adapting work areas and work tasks. Due to difficulties individuals with ASD experience in modulating sensory input, the actual work site can prove to be an obstacle for success. Environmental stimuli can be distracting and disorienting. Supported employment programs for individuals with ASD incorporate the use of environmental assessments to identify distractions and determine ways to lessen their impact in each relevant work area [38]. Hillier et al. [26] recommend that at a minimum, assessments should evaluate noise level, interruptions, crowding, lighting, and space navigation and should be conducted with the individual's unique needs in mind.

The worker with ASD will likely benefit from clearly defined work tasks and may require restructuring actual job duties or the way a job is performed [16, 56]. There are many types of modifications highlighted in the literature. Providing a consistent schedule for completion of work tasks has increased job predictability [7, 17]. Organizers have been utilized to help structure and keep track of work. Simple organizers have included the use of instruction sheets, notebooks, labels, and checklists [7, 17, 25]. McClannahan et al. [53] utilized activity schedules based on a task analysis of work assignments while Hume and Odom [31] used a structured work system to organize the job task. Idle time in the workplace may prove to be problematic and also require restructuring. Down time alternatives including taking a walk or playing a computer game successfully reduced the amount of unstructured time for adults with autism [25].

7.5. Long-term support

The intensive individualized training provided by a job coach should slowly and systematically lessen over time. However, workers with ASD may need extended support to avoid later deterioration in work performance which can lead to employment failure [38]. Long-term support services are especially important to this group since unexpected changes can be disruptive. Personal accounts by adults with ASD recommend ongoing vocational services that would help prepare for and negotiate the types of challenges that arise from day to day [56].

Supported employment programs serving this population implement both natural and external long-term supports [38]. Natural supports include identified supervisors and company employees [80, 82]. As the job coach fades, active strategies are employed to transfer relationships and support responsibilities to these individuals resulting in sustained and continual assistance [90]. The importance of onsite support was stressed by supervisors of individuals with ASD who were interviewed regarding their experiences [25]. Specifically, they reported natural supports being essential for explaining and helping the employee deal with changes in the workplace.

Some individuals may need intensive external supports for continued success. External supports often include follow-up and close monitoring by supported employment staff [89]. The TEACCH program provides extensive long-term support indefinitely through the provision of site visits, phone calls to the employer, contact with families and/or residential staff, and retraining when needed [38]. Long-term supports may extend beyond the work day since factors in the whole life of the individual with ASD could potentially influence job performance. Certainly, residential, social, and medical matters may have an impact. Therefore, support staff may also act as a liaison for relevant non-work issues. Other long-term supports may include the provision of targeted instruction in areas of deficit outside of the workplace [26, 28, 38]. Areas of instruction have included social groups to address difficulties in social interaction and/or individual counseling services which focus on developing appropriate coping strategies for the work situation.

8. Discussion

This paper provided a review of evidence based research related to employment for individuals with ASD. There are many reasons to examine factors which lead to improving employment outcomes. First and foremost, meaningful integrated employment should be an option for all individuals with ASD who wish to work [49]. Employment enables adults with and without disabilities to earn wages they can use to become self-sufficient. Further, employment provides a forum that leads to improvement in one's quality of life. While personal factors are a sufficient motive, employment also provides a number of economic advantages as it leads to less reliance on government funds and more contribution to taxes [36].

Research overwhelmingly demonstrates disappointing employment outcomes for this group. The vast majority is unemployed and for those who do have gainful employment, underemployment is common. The increased prevalence of ASD coupled with unique social, communication, and behavioral characteristics translate into the need for services to help them achieve employment success. Services provided through the traditional VR system are less than optimal and do not provide sufficient support [14, 47]. Furthermore, most individuals with ASD, because they do not have an intellectual disability, are ineligible to participate in state and/or federally funded programs designed to assist individuals with other types of developmental disabilities [56]. Such inadequacies in services, both because of quantity as well as quality, result in a tremendous shortcoming and a waste of human potential.

It is clear that vocational outcome is highly dependent upon the adequacy of the facilities that are available to adults with autism [71]. Fortunately, there is a burgeoning body of research outlining efficacious supports and strategies designed to increase vocational success. This literature has major implications for this population, since many cannot obtain or keep a job without the appropriate assistance and oversight [16]. While this body of research gives shape to this critical topic there are many limitations worth noting. The number of peer reviewed articles on this topic is sparse and is hampered by limited sample sizes and restricted population ranges. Research that does exist covers a wide array of topics, yielding few solid conclusions in any given area. Much can be learned from vocational support programs describing successful supports implemented with individuals with ASD; however, there are only a handful of such descriptions.

Despite these limitations, the research outlined in this paper provides direction as we move to improve employment outcomes for a significant and growing number of people. Further, the research provided here sets a course for future study on this topic. There is a substantial need for rigorous evaluation of methods of intervention and the means for implementation within the workplace. Such studies should focus not only on job tasks, but also the interpersonal skills that will foster a positive work experience. Longitudinal studies documenting strategies that lead to favorable outcomes and create lasting effects are essential for furthering knowledge and delivering services that are both beneficial and cost effective.

Individuals with all levels of ASD, and all levels of cognitive, social, and behavioral functioning, have the

ability and desire to work. Consideration of individual characteristics including strengths, weaknesses, as well as specific interests can lead to an appropriate job placement. This careful match between the individual and the environment, when coupled with implementation of proper supports, can result in successful and ongoing employment.

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