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WHAT DO WE KNOW ABOUT IMPROVING EMPLOYMENT OUTCOMES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER?

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SUMMARY

Autism spectrum disorder (ASD) is the most commonly diagnosed neurological disorder in children. Adults with ASD have some of the poorest employment outcomes in comparison to others with disabilities. While data in Canada is limited, roughly 25 per cent of Americans living with ASD are employed and no more than six per cent are competitively employed. Most earn less than the national minimum hourly wage, endure extended periods of joblessness and frequently shuffle between positions, further diminishing their prospects. Poor employment outcomes result in lower quality of life and often lead to steep economic costs. Governments are wise to pay attention to the poor employment outcomes as the high numbers of children now diagnosed with ASD will become adults in the future in need of employment opportunities.

Improving employment outcomes for those living with ASD is an important policy objective. Work opportunities improve quality of life, economic independence, social integration, and ultimately benefit all. Adults with ASD can succeed with the right supports. Fortunately, there are many emerging policy and program options that demonstrate success. This paper conducts a review of studies and provides policy recommendations based on the literature, to help governments identify appropriate policy options.

Some key factors are both those that are unique to the individual and the external supports available; namely school, work, and family. For example, factors that contribute to successful employment for people living with ASD may include IQ, social skills and self-determination, but for all, even for the less advantaged, external assistance from schools, employers and family can help. Inclusive special education programs in high school that offer work experiences are critical as are knowledgeable employers who can provide the right types of accommodation and leadership. In the work environment the use of vocational and rehabilitative supports, from job coaching to technology-mediated training are a few of the work related factors that enhance success. Information in this paper provides policy makers with a way to move forward and enhance the current employment situation for those living with ASD ultimately improving quality of life and economic independence.

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INTRODUCTION

Autism spectrum disorder (ASD)¹ is a chronic lifelong condition that is one of the most prevalent childhood developmental conditions. While considerable investments have gone into research, development and implementation of early childhood interventions to support development, adults with ASD have had extremely poor employment outcomes. Employment has many benefits, not only for the individual with ASD but also for their family, the community and government. The opportunity to work may increase financial independence, a sense of purpose, social integration and self-esteem. Improving employment outcomes for those with ASD is a policy objective. In this light, the 2014/15 federal budget announced two complementary initiatives to enhance employment outcomes for persons with disabilities. The budget allocates \$15 million over three years to connect persons with disabilities with jobs via the Ready, Willing and Able Initiative, and by investing \$11.4 million over four years to expand vocational training programs for persons with ASD.

With the rising prevalence of ASD diagnoses for children since the 1970s, the scale of the problem of adult non-employment and lifelong dependence on families will grow. In contrast to sizeable investments in early childhood programs, adolescents and adults with autism face lower supports and are not easily accommodated in mainstream education and training programs. Is the lack of resources and training opportunities contributing to the poor employment outcomes of adults with ASD? Are there areas and/or interventions in which we could invest to improve employment outcomes? The purpose of this report is to examine the factors that contribute to employment success for individuals with neurodevelopmental disabilities like ASD. This report outlines what is known about employment outcomes and what factors help to explain the outcomes (both individual characteristics and external supports). It also provides recommendations for policy initiatives to enhance employment outcomes.

Even though many literature reviews were found that relate to employment outcomes and ASD, the general consensus among these reviews was that the existing research is not considered high in quality and for that reason the conclusions on best practices are unclear. Making good policy decisions on employment initiatives for those with ASD is difficult, given the lack of empirically based research for what contributes to success; this area should be considered a field of inquiry.² Still, enhancing and refining policy initiatives based on what is known is critical to improving employment outcomes.

WHAT DO WE KNOW ABOUT EMPLOYMENT OUTCOMES FOR ADULTS WITH ASD?

Employment enhances quality of life, cognitive functioning and the overall wellbeing of persons with ASD.³ Employment offers the opportunity for economic self-sufficiency, financial security, the opportunity for independent living, greater participation in the community and increased self-esteem.⁴ Employment is considered important in health-related outcomes for those with disabilities. Competitive employment, supported employment, volunteer work and purposeful daytime activity all provide structure and community integration which enhance quality of life.⁵

¹ Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition marked by deficits in social communication, social interactions, and restricted, repetitive behaviours or interests. The diagnostic category of Asperger disorder is no longer used in the DSM-V diagnostic manual, but throughout this paper the term Asperger disorder is used as this was the term used in research papers referenced in this report.

² Shattuck et al., 2012.

³ Walsh et al., 2014.

⁴ Joshi et al., 2012.

⁵ Holwerda et al., 2012.

Employment outcomes for those living with ASD are poor. In the United States, individuals with ASD have the lowest rates of employment in comparison to persons with other disabilities and over 50 percent of youth with ASD remain unemployed two years after leaving high school.⁶ Approximately 25 percent of individuals with autism are employed; most of this group is considered high-functioning and only six percent are competitively employed.⁷ ⁸ Another US study found that persons with ASD have limited opportunities for economic independence through their earnings as they work fewer hours per week and earn less on average than typical employees.⁹ The majority of Americans with ASD are paid less than the national minimum hourly wage.¹⁰

Individuals with ASD who are in the workforce (i.e., able and interested in working) often experience periods of unemployment, underemployment in jobs that underutilize their skills and education and mal-employment in jobs for which they are unsuited.¹¹ They hold jobs that are generally low-level, unskilled and low-paying; a few are able to secure higher level jobs.¹² Most experience high levels of job-switching that result in fragmented work histories.¹³

Vocational rehabilitation has improved over the past decade in the US and this seems to improve employment outcomes for adults with ASD. A recent review using the vocational rehabilitation (VR) database from the US for almost 6000 individuals with ASD found that 52 percent were competitively employed after receiving VR services. Although this trend is promising, most with ASD were underemployed (employed at entry-level jobs or overqualified) and had limited wages and hours.¹⁴

WHAT CONTRIBUTES TO EMPLOYMENT SUCCESS?

We conducted a literature review to identify factors that contribute to successful employment. We searched the peer-reviewed literature using the key words of autism or Asperger plus vocation/employment and success and then reviewed the references from these relevant articles to further the investigation. Where relevant, the general disability¹⁵ and neurotypical¹⁶ employment literature is referenced to consider the relevance of factors that contribute to employment success for these individuals in relation to ASD.¹⁷

⁶ Shattuck et al., 2012.

⁷ Competitive employment as it pertains to vocational rehabilitation is defined as work performed by a person with a disability in an integrated setting at minimum wage or higher and at a rate comparable to non-disabled workers performing the same tasks.

⁸ Holwerda et al., 2012 op. cit.

⁹ Smith and Lugas, 2010.

¹⁰ Chiang et al., 2013.

¹¹ Hurlbutt and Chalmers, 2004.

¹² Holwerda et al., 2013.

¹³ Balwin et al., 2014.

¹⁴ Chen et al., 2015.

¹⁵ General disability literature refers to literature that includes varying percentages of participants with ASD or where the participants have similar challenges to those with ASD (behavioural, cognitive disabilities). This literature must be interpreted cautiously because it is not clear that the findings in general disability research apply to those with ASD.

¹⁶ Neurotypical is a term used to define those who do not demonstrate autistic tendencies or display atypical patterns of thought or behaviour.

¹⁷ We acknowledge that important work not published in peer-reviewed journals can be found in grey literature. The large volume of grey literature, however, was not part of this review as some reports were based on solutions not yet confirmed in research and for this reason these documents were not included as foundations for policy creation.

A surprising number of systematic literature reviews was found specific to employment and ASD,¹⁸ as well as several general disability employment reviews.¹⁹ The majority of work comes from the UK and the US and this gap in Canadian research is a problematic limitation for our study, as the labour market institutions and contexts in the UK and US are very different from Canada's. These markets differ not only in regards to the rights and laws that protect and/or support persons with disabilities, but also in the methods used to provide income supports and unemployment insurance, and in the types of industries, types of jobs and the education systems.

Even though many reviews were found that relate to employment outcomes and ASD, the general consensus among these reviews was that the existing research is not considered high in quality and for that reason the conclusions on best practices are unclear. As such, the literature is best categorized as identifying promising practices as opposed to evidence-based practices.²⁰ Research findings were often based on small sample sizes, case studies and qualitative data. Even when large databases are used, the results do not reflect the vast heterogeneity of the condition of ASD. Conclusions about the influence and relative strength of individual factors to predict successful employment are difficult to make. As seen in this report, research findings on characteristics are underdeveloped and at times conflicting. For example, in one of the most relevant systematic reviews on predictors of work participation for those with ASD, Holwerda and colleagues²¹ report that IQ level was the only consistently significant factor to predict work participation. All other factors examined in this specific review (severity, comorbidity, speech, behaviour, social impairments, education, lack of drive and family) were inconsistent or had non-significant findings. Yet other researchers found that one's level of functional ability and independence in daily living skills had the greatest correlation to future vocational independence, even above IQ.²² This examples underscores the problem with current research, in that it does not give clear direction based on the heterogeneity of this condition.²³

Our review of the literature shows that success in employment appears to be a combination of factors that interact in a complex manner to either contribute to or impede successful employment. To help unravel the complicated issues that impact employment outcomes, the findings in this report are divided into three major sections: the influence of unique characteristics of the individual, the impact of external supports on employment success and the implications for policy.

1. INDIVIDUAL CHARACTERISTICS

Underemployment and unemployment for individuals with ASD may be a result of a number of multifaceted problems, including the unique characteristics of the individual.²⁴ Some examples of individual characteristics that create challenges in finding and maintaining employment include

¹⁸ See Holwerda et al., 2012 op cit.; Bennett & Dukes, 2013; Hendricks, 2010; Hendricks & Wehman, 2009; Nicholas et al., 2014; Robertson & Emerson, 2006; Shattuck et al., 2012 op cit.; Taylor et al, 2012; Walsh et al., 2014 op. cit. and Westbrook et al., 2015,

¹⁹ See Kohler, 1993; Landmark et al., 2010 and Test et al., 2009

²⁰ Evidence-based practice: 1) Based on rigorous research designs; 2) Demonstrates a record of success for improving outcomes; 3) Has undergone a systematic review process using quality indications to evaluate level of evidence. Research based practice: 1) Based on rigorous research design; 2) Demonstrated a record of success for improving outcomes. Promising practice: 1) Based on research; 2) Demonstrated limited success; 3) Used 'weak' research design. Un-established practices: 1) Not based on research; 2) Have no data to support effectiveness; 3) Based on anecdotal evidence and/or professional judgment.

²¹ Holwerda et al., 2012 op.cit.

²² Taylor and Mailick, 2014.

²³ Shattuck et. al 2012, op. cit.

²⁴ Bennett and Dukes, 2013.

problems understanding facial expressions and social cues, difficulty expressing emotions, inflexibility with change and difficulty adapting to new routines and tasks.²⁵ In the published literature, the characteristics of cognitive ability, severity, functional ability/independence, social skills, age, gender, ethnicity, self-determination and unique abilities were found to play a role in explaining employment outcomes for persons with ASD.

Severity of the ASD Condition

An obvious starting point for understanding the variation in employment outcomes amongst persons with ASD would be to consider some measure of the severity of limitations with respect to employment attributable to the ASD condition. The term severity, however, is not used with consistency across the literature. Severity can be considered in terms of behaviours, co-morbid conditions, intellectual ability, adaptive functioning level and additionally as a level of independence in school.²⁶ Shattuck and colleagues²⁷ found in their review that severity as a variable in the research was measured inconsistently using standardized tests, adaptive behaviour scores, categorical descriptors (like severe or profound with no definition or reference as to how categories were determined) and several studies referred to verbal status. Regardless of how severity is measured, it is clear that severity influences employment and conversely the lack of severity contributes to employment success.

Severity can be measured by the presence of problematic behaviours. Adults with autism who had fewer maladaptive behaviors and autism symptoms have better vocational outcomes. Autism symptoms such as restricted interests, insistence on sameness and difficulty with change limit vocational opportunities.²⁸ In one study, researchers found that individuals who were competitively employed or in post-secondary education had significantly lower levels of maladaptive behavior in comparison to individuals who were in day services.²⁹ Lower IQ level has also been linked to more problematic behaviours. In a review of adult outcomes, researchers found that cognitively able individuals with ASD had fewer problematic behaviours and greater functional independence. Some research suggests that individuals with ASD will improve in severity over time, but the risk of behavioural deterioration was greater for those with lower IQ or for those who developed co-morbid conditions.³⁰

In the review by Holwerda and colleagues,³¹ co-morbid conditions were found to negatively impact employment outcomes of persons with ASD. In this review, the conditions of epilepsy and psychiatric disorders were included in the 10 studies reviewed. For example, Taylor and Seltzer³² followed 66 students with ASD who exited the school system and were followed post-high school for their education and occupational activities. One of the variables examined was a co-morbid condition of psychiatric nature. Those who had no daytime activities had extremely high rates of co-morbid psychiatric diagnoses. The authors suggest this factor is likely a barrier to employment and post-secondary

²⁵ Muller et al., 2003.

²⁶ In a general disability study, high school students with disabilities who participated in a school-to-work transition program were scored on severity. Severity was described as the amount of support each student would need in comparison to a peer without a disability. Severity was scored from level 1 (requiring less structure in academic work) up to level 3 (requiring considerable structure and attention in academic work). The amount of support required had a significant impact on employment outcomes despite job interest and job matching. The effect was seen specifically in the area of higher earnings. See Estrada-Hernandez et al., 2008.

²⁷ Shattuck et al., 2012, op. cit.

²⁸ Eaves and Ho, 2008; Howlin et al., 2004.

²⁹ Taylor and Seltzer, 2011.

³⁰ Levy and Perry, 2011.

³¹ Holwerda et al., 2012 op. cit.

³² Taylor and Seltzer, 2011 op. cit.

enrollment. Schaller and Yang³³ found that individuals with ASD who left vocational rehabilitation (VR) services for competitive employment were less likely to have a secondary disability (mobility or emotional disability) in comparison to a group who left VR for supported employment. Using the VR database, Chen et al.³⁴ found that co-occurring psychiatric disabilities showed a negative relationship with employment as individuals approach adulthood — more so than for those under the age of 18.

Lower IQ, as a measure of a co-morbid intellectual disability, appears to be the only characteristic that consistently predicts successful employment of persons with ASD, especially as it relates to competitive employment. Having an intellectual disability (ID is usually characterized by IQ <70) decreases the odds of participation in employment,³⁵ but IQ alone is not a guarantee of success. Persons with ASD with lower IQ can be employable with the right supports. In the Holwerda review, 18 research studies on predictors of work participation for individuals with ASD were located, but limited cognitive ability was the only significant predictor of low work participation consistently found in the research. Individuals with ASD who do not have an ID are more independent in adult work life and housing arrangements compared to those with an ID.³⁶ Howlin and colleagues³⁷ found that for those with IQ scores of less than 50, few were capable of employment. For those with an IQ of 50-70, employment was more variable, but even those with an IQ greater than 70 had only slightly higher employment rates than those with an IQ less than 70. In a study by Chiang and colleagues³⁸ using data from the National Longitudinal Transition Study 2 (NLTS-2), post-high school employment was significantly higher among a sample of 832 individuals with ASD who did not have an ID. The authors note that some individuals with an ID did participate in employment, which suggests they are employable but may have more difficulty finding and retaining jobs.

Functional Ability and Independence

The literature shows that higher levels of functional ability and levels of independence at home may predict employment outcomes. Taylor & Mailick³⁹ found that greater independence in vocational activities was correlated with individuals who had more independence in daily living. The ability to remain independent into adulthood may be one of the most important factors of continued engagement in vocational activities. In this 10-year longitudinal study of 161 adults with ASD (ages 18-52), researchers found that significant declines in levels of independence and engagement in vocational activities occurred and that those who had greater independence in daily living skills had greater vocational independence, even after controlling for unique personal traits, like IQ. It is possible that adults who initially have fewer daily living skills are on a path toward more limited vocational opportunities.

In a telephone survey with 500 parents or guardians of adults with ASD on employment outcomes, the results indicated that higher functional ability was associated with higher odds of participation in post-secondary employment. Functional ability was measured using a scale regarding ability to complete an activity varying from not at all well to very well. Examples of activities were: telling time on a clock, counting change, using a telephone, getting to places outside of the home, using public transit and buying clothing at a store. Those with lower functional skills had consistently worse outcomes post-high

³³ Schaller and Yang, 2005.

³⁴ Chen et al., 2015 op. cit.

³⁵ Chiang et al., 2013 op. cit.

³⁶ Eaves and Ho, 2008 op. cit.; Howlin et al., 2004 op. cit.

³⁷ Ibid.

³⁸ Chiang et al., 2013 op. cit.

³⁹ Taylor and Mailick, 2014 op. cit.

school as measured by disengagement from employment activities. This finding was consistent with other research on developmental impairment and increased risk of disengagement in adulthood.⁴⁰

In a smaller study of 15 youths with ASD, researchers implemented a program that taught functional skills and provided behavior supports (with some consideration of work-setting needs) to individuals aged four to 10 years over a 15-year period. In this program, a database of skills was created, with up to 600 programs to address skills like keyboard use, language development, money management, self-care, and telling time, to name a few. Skills were taught by life-skill coaches in a variety of settings. Ultimately, 11 participants found a job, and four people with severe behaviors were not employed. The authors recommend that vocational curricula and evaluation criteria for adults should be as comprehensive as they are for children.⁴¹

In the general disability literature, data from the NLTS-2 database indicated that for a sample of 450 individuals with severe disabilities, 36 percent of whom live with ASD, greater independence in self-care and more household responsibilities during adolescence increased the odds of employment after leaving school. The basic skills of toileting, hygiene and dressing are likely important skills to achieving better adult outcomes.⁴²

Social Skills

Evidence suggests that those with higher levels of social skills have more success in employment. In the review by Hendricks,⁴³ the author notes that the challenge of social interaction for those with ASD accounts for one of the greatest obstacles to successful employment. Communication and social interaction difficulties create obstacles to success in the interview process and in interactions with supervisors and co-workers. These challenges emerge as a primary hindrance to job success, in some cases even leading to job termination.

Interpersonal difficulties have been identified in numerous studies as a major barrier to employment. Among a sample of 830 post-high school students with ASD, stronger social skills were found to be a significant predictor of post-high school employment participation.⁴⁴ For persons with high-functioning ASD (HFASD), weaker social skills specifically were found to be a barrier to success in competitive employment. In this small study six people with Asperger's syndrome were interviewed about their experiences with employment. Qualitative data analysis found that all struggled with obtaining and maintaining employment and that they were often underemployed. Challenges with social situations, communication and sensory issues were common themes. Repeatedly, challenges with social interaction led to lost work opportunities, as opposed to problems with work task performance. One of the participants stated that the most important rule of work was to get along with other co-workers, and that the job was 80 percent social and 20 percent work. He felt that for those with ASD, it would be better if it were the other way around.⁴⁵ In another qualitative study of 18 individuals with Asperger's syndrome, HFASD self-reports indicated that vocational success relied more on the social and communication aspects of employment rather than on completion of job tasks.⁴⁶

⁴⁰ Shattuck et al., 2012 op. cit.

⁴¹ McClannahan et al., 2002.

⁴² Carter et al., 2012.

⁴³ Hendricks, 2010 op. cit.

⁴⁴ Chiang et al., 2013 op. cit.

⁴⁵ Hurlbutt and Chalmers, 2004 op. cit.

⁴⁶ Muller et al., 2003 op. cit.

As a way to overcome the demands for social interaction in the workplace, one study found that having an avoidant coping style led to better success. Avoidant coping is defined as a coping style where one's response is oriented away from emotions or from the source of stress. 22 individuals with HFASD (IQ > 68) were matched on a number of traits (e.g., autistic tendencies, family support, age and years of education) and tested for an avoidant attachment style of coping. Those with an avoidant attachment style were significantly more likely to hold a competitive job for more than one year, in comparison to those who did not have this style of coping. The authors suggest that those with an avoidant style may have more success in obtaining better job adaptation—regardless of their autistic tendencies and perceived support—and recommend that supervisors of individuals with HFASD in competitive jobs be aware of this characteristic and not attempt to force socialization.⁴⁷

In the general disability literature, Carter and colleagues⁴⁸ studied 450 individuals with disabilities, of whom 36 percent had ASD, and found that two years after high school individuals considered to have a severe disability were more likely to be employed if they had stronger social skills. An individual was considered severe if by parent report they had a cognitive skill deficit in two or more areas like reading, understanding common signs, telling time, counting change or using a telephone. In the neurotypical work world, the importance of people skills in the labor market for underrepresented groups was shown to be the key factor that decreased the wage gap, in particular for women, between 1970-1990.⁴⁹ The authors described people skills as the ability to effectively interact with people, ranging from communicating with, caring for and motivating people. The trends in increased wages and employment of underrepresented groups mirror the trends in people skills in the labor market.

Age, Sex, Ethnicity

The influence of each of these factors is unclear due to a lack of research. Regarding age, Schaller and Yang,⁵⁰ in a review using the national Rehabilitation Service Administration (US) 2001 database with 450 individuals with ASD, found that age was related to successful competitive employment. Those with ASD who received services for competitive employment experienced greater successful entry into competitive employment as their age increased from 21 to 45 years of age. In another study using the VR dataset from the US of 5,681 individuals with ASD, researchers found that transition-age youth (under age 18) had significantly lower employment rates and hourly wages when compared to older age groups, which suggests that the younger transition-age individuals are at higher risk of unemployment during the transition to adulthood.⁵¹

Sex as a factor was found in numerous studies, but the research using this variable is mixed and should at best be considered a weak predictor. Taylor & Mailick⁵² conclude that not enough research on women with ASD and employment outcomes has been completed and thus this subject is not well understood. Some studies indicate that men will do better than women. Migliore and colleagues⁵³ examined predictors of employment for 2,913 youths with ASD who participated in the Vocational Rehabilitation Program and found that sex (being male) was among the eight predictors that contributed to integrated employment after exiting VR services, but that it was ranked as one of the weaker predictors. However,

⁴⁷ Yokotani, 2011.

⁴⁸ Carter et al., 2012 op. cit.

⁴⁹ Borghans et al., 2006.

⁵⁰ Schaller and Yang, 2005 op. cit.

⁵¹ Chen et al., 2015 op. cit.

⁵² Taylor and Mailick, 2014 op. cit.

⁵³ Migliore et al., 2012.

Chiang and colleagues⁵⁴ found that of the sample of 830 students post-high school, female youths with ASD were more likely to participate in employment after high school than male youths, leading the authors to recommend more research in the area of gender and employment.

In the general disability literature, using the NLTS-2, for a sample of 450 students who had severe disabilities including ASD, employment at two years after leaving high school was associated with being male, while age, race, ethnicity and primary disability were not. Overall if the individual was male with paid work experience during school, they had a better chance of post-school employment.⁵⁵ In another study of 1,393 special education students, being male for students with disabilities was a significant factor in successful employment one year post-school. Males were more likely to be employed than females, especially females from rural settings, except for females with a learning disability (where the type of disability was more important in employment success than gender).⁵⁶ In an analysis of predictors of employment outcomes for 422 youths with disabilities, females were significantly less likely to be in competitive employment post-high school than males; especially affected were females who exited high school with low self-esteem and from low-income families.⁵⁷

Ethnicity may influence outcomes but the research on this is limited. Schaller and Yang⁵⁸ found being white was a significant variable in employment success for those 350 clients with ASD who left VR services for supported employment, but this was not the case for those who left VR services for competitive employment. In the review by Shattuck and colleagues,⁵⁹ the authors note a relative neglect of issues related to ethnic diversity.

Self-Determination and Motivation

Self-determination is the ability to make decisions and determine action by oneself without outside influence. Higher levels of self-determination have been linked to future employment success in the general disability literature. In the general disability literature, researchers followed 94 students categorized as learning disabled or mentally retarded (no ASD specified) one to three years after leaving high school. Researchers rated students on their levels of self-determination. Students were divided into two levels of self-determination and those who were more self-determined fared better in areas of employment, financial independence and independent living.⁶⁰ The authors of these studies note that one must look beyond IQ test scores at the multiple variables that lead to successful adult outcomes, like self-determination. Self-determination has been linked to enhanced quality of life and positive adult outcomes for individuals with an intellectual disability.⁶¹

Motivation to work may be a driver of success, although this appears to be an understudied area for those with ASD. This area is not yet well researched as a factor for success. In a systematic review by Holwerda and colleagues,⁶² the lack of drive for those with ASD was a weak predictor of success, in part due to the lack of research and the poor quality of research found.

⁵⁴ Chiang et al., 2013 op cit.

⁵⁵ Carter et al., 2013 op. cit.

⁵⁶ Rabren et al., 2002.

⁵⁷ Doren and Benz, 1998.

⁵⁸ Schaller and Yang, 2005 op. cit.

⁵⁹ Shattuck et al., 2012 op. cit.

⁶⁰ Wehmeyer and Palmer, 2003.

⁶¹ Wehmeyer and Bolding, 2001.

⁶² Holwerda et al., 2012 op. cit.

One essential element of individual characteristics not found in the literature on employment success is the unique marketable skills and interests that some individuals with ASD possess. In relation to motivation it is reasonable to assume that the use of one's unique skills and interests at work results in increased satisfaction and success; this is discussed further in the section on external factors (an element of job placement). Here, however, we are referring to the presence of extraordinary skills that are marketable abilities that some possess. Researchers note there is a tendency in ASD research to use a deficit model of research that is oriented towards the major impairments of ASD and the view that individuals are broken or ill. This view has largely ignored the individual's strengths, diverse ways of being, talents and gifts.⁶³

Autistic traits that may be beneficial in work settings might include things like intense specific interests or exceptional skills in specific areas like computer programming or numbers. Examples of matching the unique skills and interests of an individual and employment success can be found in numerous media stories like the employment success of the son of Mike Lake (a Member of Parliament from Alberta) who has exceptional skills in coding and filing library books and has found success working as an assistant in a library.⁶⁴ Another example comes from the company Meticulon, which hires individuals with exceptional skills in computer-related work.⁶⁵ Still another news story tells of an Edmonton man with severe autism who is turning his love for LEGO into a business of building items.⁶⁶ It is likely that many of these individual stories exist where those with exceptional skills are linked with work success. Not everyone with ASD has unique skills or focused interests, but for those who do the opportunity to use them in combination with the appropriate supports may result in successful employment. This area warrants more research.

SUMMARY OF INDIVIDUAL CHARACTERISTICS

The heterogeneity of ASD is apparent in the above review of characteristics of who is working and who is not working. However, what predicts success appears to be a complex combination of factors. Overall, the research indicates that those who work in competitive employment will most likely succeed if they have a higher IQ, greater functional ability and independence, better social skills (if that is required in the work), no unmanageable behaviours, no co-morbid conditions (unless they are managed), higher levels of motivation and higher self-determination. Some characteristics are more amenable to change with the appropriate supports (i.e., social skills and behavioral management can be taught) while other areas, like IQ, which remains fairly static over life, can be used more as a screening tool for employment. Then there are the examples of the unique strengths some possess that contribute to successful employment. The analysis of these characteristics underscores the heterogeneity of this condition and the resulting policy implications are discussed at the end of this paper.

⁶³ Robertson, 2010.

⁶⁴ Canadians with autism have 'untapped skills' when it comes to employment. CTV News, November 22, 2014. <http://www.ctvnews.ca/canada/canadians-with-autism-have-untapped-skills-when-it-comes-to-employment-1.2115018?hootPostID=6522e76abal6ccc616e47b7ccf6d6541>

⁶⁵ Calgary company aims to help reap rewards of autism. CBC News. November 7, 2013. <http://www.cbc.ca/news/canada/calgary/calgary-company-aims-to-help-reap-rewards-of-autism-1.2417157>

⁶⁶ Unique skill turns into a business for Edmonton man with autism. <http://globalnews.ca/news/1080425/unique-skill-turns-into-a-business-for-edmonton-man-with-autism/>

2. FACTORS EXTERNAL TO THE INDIVIDUAL

It is clear that the unique characteristics of the individual impact employment success, but so do the external influences on that individual. The key external factors that the literature identifies as impacting the employment outcomes of persons with ASD are the education system, the work environment and the family. Here we discuss the important role of each of these key factors and identify promising directions that may enhance employment success. Most of these factors were considered to be weak predictors of success in the literature, primarily because they were understudied in the field of ASD or were supported by research with small sample sizes and poor quality studies. However, these factors should not be interpreted as insignificant because they are classified as weak; rather, they should be seen as important but not yet well understood.

The Education System

The education system plays a critical role in laying the groundwork for success. Education professionals refer to the transition period as a critical time for high school students with disabilities, not only because transition programs could offer work experience, but also because transition is a period of planning and preparation for adulthood where specific skills can be taught in the school system.⁶⁷ In the United States, legislation based on the Individuals with Disabilities Education Act (IDEA) requires schools to implement a transition plan based on the student's goals.⁶⁸ But Westbrook and colleagues⁶⁹ state that given US federal regulations on transition programs for students with disabilities, it is "remarkable that such limited research attention has been paid to the effectiveness of interventions."

The term 'transition' is typically used by ASD researchers to refer to the period of time when one moves through the senior high school years into adulthood. So, although it is known that transition is a critical time, it is not known exactly what programming in this transition period produces the best employment outcomes for those with ASD. Westbrook et al. conclude after their review that no studies met their criteria for transition best practices for individuals with ASD. Research for the transition period is based on qualitative studies with small numbers of participants and is not ASD-specific. There is a paucity of research on the specific instructional skills offered in schools that result in employment success for students with ASD after leaving school.⁷⁰ Some promising factors that may contribute to ASD-specific employment success were: special education services that are inclusive, community integration, integrated work context, teaching self-management and functional community-based skills, modeling and behaviour-shaping techniques, social skills interventions and family-centered approaches.⁷¹

In the general disability literature, Landmark and colleagues⁷² published a review of transition best practices and found the most to least substantiated practices were: paid or unpaid work, employment preparation, family involvement, general education inclusion, daily living skills training, social skills training, self-determination skills training and community or agency collaboration. But it is important

⁶⁷ The transition period is a term used by professionals in the educational system to denote the major transitions a student encounters in the school system from junior high to senior high and from senior high to post-graduation.

⁶⁸ Banger, 2008.

⁶⁹ Westbrook et al., 2015 op. cit.

⁷⁰ Bennett and Dukes, 2013 op. cit.

⁷¹ Westbrook et al., 2015 op. cit.

⁷² Landmark et al., 2010 op. cit.

to note that transition practices have not yet been evaluated specifically for students with ASD.⁷³ As a result, the needs for those with ASD are often not appropriate or planned.⁷⁴

The Importance of work experiences in an educational setting

Some of the most substantiated work in the disability literature concerns the role of education-based work opportunities, as well as the impact of graduating (or not graduating) from high school. The impact of school-based work experience is well documented in the general disability literature as contributing to success,⁷⁵ but is understudied in the ASD literature. Work experiences offered through the education system could take the form of work-study programs, internships or apprenticeships.⁷⁶ Research on work-study, internships or apprenticeships specific to ASD is limited but what is available is promising. Wehman et al.⁷⁷ studied internship and employment outcomes using the Project SEARCH model⁷⁸ and found positive results. Following the program, 21 of 24 individuals in the treatment group (who benefited from this specialized program) were hired into competitive employment, whereas only one person out of 16 from the control group was competitively hired. Of the treatment group 78 percent were still competitively employed 12 and 24 months later. The treatment group also showed an increase in independence at work over the control group, and this was surprising to the researchers as some individuals in this group had significant behavioural and medical challenges. This study showed a successful transition from school to work using a business-based internship model.

In the general disability literature, a meta-analysis of evidence-based predictors of post-school success in transition found only six studies to have a moderate level of evidence; one of the predictor variables included targeting youth employment programs and work-study internships.⁷⁹ Researchers concluded that both paid and unpaid work experiences in school are significant practices in transition literature for those with disabilities. Internships, apprenticeships and work-study programs are important and beneficial across demographic characteristics and disability factors.⁸⁰ Lewis and colleagues⁸¹ reviewed the employment outcomes of those who completed an apprenticeship or traineeship program in Western Australia. 253 participants completed a program and were matched with a similar group who were registered and waiting for the program. The program offered 80 percent paid work experience and 20 percent study, with traineeships lasting one to two years and apprenticeships three to four years.

⁷³ Test et al., 2009 op. cit; Test et al., 2014.

⁷⁴ Koenig et al., 2014.

⁷⁵ See Kohler, 1993 op. cit.; Landmark et al., 2010 op. cit.

⁷⁶ School-based work experiences could include work-study, internships and apprenticeships. The definition of each of these is not well described in research. By definition, internships are a way to gain on-the-job training for white-collar and professional careers, and are similar to apprenticeships for trade and vocational jobs. There is a lack of standardization, which leaves the term open to broad interpretation. Interns may be college or university students, high school students or post-graduate adults. The positions may be paid or unpaid, but are usually temporary. Unlike a trainee program, employment at completion is not guaranteed.

⁷⁷ Wehman et al., 2012.

⁷⁸ This project is one example of a high school transition program for students with significant disabilities that provided real-life work experience through a nine-month internship model where the main goal is competitive employment. In this study, youths with ASD (n=40) were randomly assigned to a treatment group (Project SEARCH plus ASD Supports) for one year in their final year or a control group (services identified in their Individualized Education Plan, no added services or supports). The Project SEARCH model was modified for this project to include the original program of work-site experience, class time learning skills and supports from a job coach, plus ASD-specific modifications of: 1) On-site, intensive instructions using applied behavioural analysis; 2) On-site support and consultation from a behaviour autism specialist; 3) Intensive staff training in ASD and the Project SEARCH model.

⁷⁹ Test et al., 2009 op. cit.

⁸⁰ Landmark et al., 2010 op. cit.

⁸¹ Lewis et al., 2011.

Findings indicated that participants who successfully completed the apprenticeship programs were significantly more likely than those not enrolled in a program to have higher hourly wages, more hours worked and greater job durability. Better outcomes were also achieved for those completing the traineeship programs. Participants in this study were not specifically identified as having ASD, but had, among other disabilities, intellectual, sensory and neurological disabilities.

Other general disability studies have proven the positive impact of education-based work programs. Using data from the NLTS-2, Joshi and colleagues⁸² examined the employment outcomes of 62,513 high school students with mild intellectual disabilities (subjects had a learning disability, speech and language impairments, an intellectual disability, or emotional/behaviour disorders, but none were identified with ASD). Individuals were significantly more likely to be employed post-school when they had school-sponsored work experiences or engaged in paid-employment experiences while in school. Another study, a follow-up of 3,024 youths with disabilities (no individuals with ASD were identified) who participated in an internship program, found that paid internships in local companies for youths who were in their last year of high school resulted in almost 90 percent placement regardless of primary disability, gender or race of the student. In this study, those with learning disabilities were slightly more likely than those with other disabilities to be working at six months; at one year the students with emotional disabilities were half as likely to be employed as those with learning disabilities. Two factors —internship completion and an offer of a job— were highly predictive of future work success.⁸³

On a final note, even the predictor of work experience, as strong as it seems, may not operate alone in predicting future employment. In their review of transition services for youth with autism, Westbrook and colleagues⁸⁴ refer to a study from the National Center on Special Education Research, Institute of Education Sciences,⁸⁵ where in a follow-up study of youth with ASD (eight years after exit from high school) 63 percent of youths who had been employed at some point after leaving high school were not employed at the time of the interview. This underscores the need for longitudinal studies that include the impact of multiple factors on employment in the context of the heterogeneity of this condition.

Finishing High School, Participating in Post-Secondary

In a study to examine predictive factors for participation in employment for 830 students with ASD using the NLTS-2, Chiang and colleagues⁸⁶ found that graduating from high school had the greatest impact on participation in employment — more than other ASD student characteristics like social skills, gender or ID. Completing high school successfully is likely correlated with these factors and is not a predictor independent of them. Receiving career counseling and having the school contact post-secondary employment programs were also found to be significant factors in participation in employment post-high school.⁸⁷

In the general disability literature, completion of high school is considered one essential component of success in adult life. Students who did not graduate had high rates of unemployment or underemployment, with school dropout being one of the most serious and pervasive issues that face students with disabilities.⁸⁸ A study on labor market outcomes and transitions to adulthood for

⁸² Joshi et al., 2012 op. cit.

⁸³ Luecking and Fabian, 2000.

⁸⁴ Westbrook et al., 2015 op. cit.

⁸⁵ National Center on Special Education Research, Institute of Education Sciences, 2011.

⁸⁶ Chiang et al., 2013 op. cit.

⁸⁷ Ibid.

⁸⁸ Test et al., 2009 op. cit.

neurotypical youth indicated that a key marker of a successful transition, noted as the attainment of economic self-sufficiency and stability, was found to be the attainment of a high school diploma. For men and women without a high school degree, labor market outcomes were found to be poor.⁸⁹

Completion of post-secondary education was also found to be a factor in success. Using the Vocational Rehabilitation (VR) database of 2008, Migliore and colleagues⁹⁰ investigated predictors of employment for 2,913 youths with ASD. They found that receiving college services and participating in post-secondary education were the two strongest predictors of higher earnings, but only 10 percent of youths received college services. Researchers found that for youths with ASD who entered VR services with a high school diploma/certificate or lower attainment and exited with a post-secondary education (with or without a degree), having a post-secondary education was a strong predictor of better earnings. The authors conclude that their findings are supported by numerous other rehabilitation research reports across different disability groups, but that effects were moderate and future research that includes other variables is advised.

On a cautionary note, post-secondary education may result in employment, but the quality of employment may be less than optimal. In an Australian study of 130 individuals with HFASD or Asperger's syndrome, where no participants had an intellectual deficit, researchers completed a survey on employment experience and found that 85 percent had a post-secondary education, but 45 percent were overqualified for the jobs they were in. This rate of over-education was more than double that for the neurotypical workforce. Very few individuals worked in managerial positions (only six percent). Even with post-high school qualifications, many were unemployed and mal-employed. The authors speculate that job advancement opportunities may be impacted by uneven job histories, with periods of unemployment or underemployment leading repeatedly to entry-level jobs regardless of education level.⁹¹

The Work Environment

Work Experience (Paid Real-Life Experience is Best)

There is a substantial amount of evidence in the neurotypical and general disability literature to suggest that paid work experience in real-life settings while attending school is one factor that may lead to successful employment (these are jobs taken in addition to school, rather than work experiences offered through the education system). There was limited ASD-specific research in this area. It is unclear whether this aspect of success has simply not been studied, or whether individuals with ASD are less able to juggle a paid job while attending school.

If we use neurotypical youths as a normative benchmark for future employment success, then the lack of early work experience—in addition to attending school and periods of unemployment—could have a critical impact on one's future work trajectory. Researchers found that neurotypical adolescents who were employed during high school had better success finding jobs later in life. Using Canadian data from the Longitudinal Youth in Transition Survey (YITS), researchers found that the number of hours worked while in school was positively correlated with higher income during future years, with the highest number of beneficial hours being 25 to 31 per week.⁹² Youths working at age 15 were more likely to have higher incomes at 17, 19 and 23. All youths who worked while in school tended to find jobs that were a

⁸⁹ Danziger and Ratner, 2009.

⁹⁰ Migliore et al., 2012 op. cit.

⁹¹ Balwin et al., 2014 op. cit.

⁹² Houshmand et al., 2014.

better fit later in life. The authors argue that adolescent work intensity offers opportunities to learn about work situations and enhance life skills, and that skills gained through early employment experiences enhance future financial gain. The benefit of this intense work experience goes beyond the role of race, gender, socio-economic status and average high school grades.⁹³ Another study using Statistics Canada's School Leavers Survey from 1991, with a 1995 follow-up, found that work during school had a negative impact on the ability to graduate and did not impact future wages. This effect was primarily seen for those who worked a large number of hours.⁹⁴

Research also shows that the effects of early unemployment for neurotypical youths are serious. Neurotypical youths who endure early spells of unemployment have greater odds of future unemployment and lower wages in comparison to those who are employed as youths. Youth unemployment results in lower wages and the effect of lower wages can persist for at least 20 years, regardless of family income, educational attainment or individual characteristics.⁹⁵ These findings impact those with a college degree and for individuals without a college degree the prognosis is even grimmer.⁹⁶ To counteract this scarring effect of unemployment, the Governor of the Bank of Canada, Stephen Poloz, suggests getting unpaid work experience. Getting real-life experience, even without pay, is thought to enhance one's resume and is deemed to be better than not being vocationally engaged.⁹⁷ Although this comment was met with some controversy, it underscores the importance of getting work experience to ultimately secure paid employment.

Overall, general disability researchers for many years note that students with better post-school employment outcomes also had paid job experiences during school.⁹⁸ In a systematic review on general disability and employment, Kohler⁹⁹ notes that paid work experiences in the real world were the most important predictor of success. Work experience emerges as likely the most powerful contributor to employment success for youths with disabilities and appears to have more substantive research than any other single factor. Examples of some of the general disability research supporting this finding are noted below.

Using data from NLTS-2 over a 10-year period, researchers found that for 450 individuals with a severe disability, having held a paid community-based employment experience while in high school was strongly correlated with post-school employment success. Paid employment outside of school in the community, in summer, during school or both was found to be the most significant factor for future success. This factor was more important than other school-related work experiences like having a vocational plan, job search instructions or work-study experience (work for no pay). These factors were no longer significant when considered with the variable of paid work experiences. The authors acknowledge that the accumulation of work preparation activities during school may have influenced the outcomes of success.¹⁰⁰ In several general disability studies, where no participants had ASD, findings showed that having two or more job experiences while in high school was associated with better employment outcomes for both young men and young women with a disability.¹⁰¹ Rabren et al.¹⁰² found

⁹³ Ibid.

⁹⁴ Parent, 2006.

⁹⁵ Gregg and Tominey, 2004.

⁹⁶ Kahn, 2010.

⁹⁷ The Globe and Mail. Stephen Poloz on Youth Unemployment, November 4, 2014. <http://www.theglobeandmail.com/report-on-business/stephen-poloz-on-youth-unemployment/article21448687/>

⁹⁸ Test et al., 2009 op. cit.

⁹⁹ Kohler, 1993 op. cit.

¹⁰⁰ Carter et al., 2012 op. cit.

¹⁰¹ Doren and Benz, 1998 op. cit.

¹⁰² Rabren et al. 2002 op. cit.

that for 1,393 special education students with disabilities, having a job when exiting secondary school was a predictor of having a job one year later. In this study, 87 percent of those who had a job upon exiting from secondary school were also working one year later.

Supported Employment Models

In the reviews, supported employment¹⁰³ for those with disabilities was a common contributor to successful employment. But even though substantial literature exists for the value of supported employment programs for people with intellectual disabilities, the research was limited to adults with ASD.¹⁰⁴

More research was found for those with higher IQs and ASD that shows that supported employment results in significantly higher rates of employment, greater job satisfaction and higher employer satisfaction with supported employment, in comparison to generic disability employment programs. Data from a supported employment program created in 1994 were analyzed and participants were compared with a matched control group that received generic disability services. Follow-up of the two-year pilot showed significantly higher rates of employment for individuals receiving specialist supports; 63 percent found jobs while only 25 percent in the control group found jobs.¹⁰⁵ Eight years later, these levels of success were maintained. Of the original 19 individuals working at the start of the study, 15 were located and 13 of these people were still employed.¹⁰⁶ This longitudinal study focused on individuals with ASD (IQ 60 +). These individuals had a rise in salaries, contributed more taxes and claimed fewer benefits over the eight-year period. Mawhood and Howlin¹⁰⁷ found that an essential factor of success in maintaining long-term placement was job matching between the requirements of the job and the skills and abilities of the person with ASD.¹⁰⁸

Wehman and colleagues¹⁰⁹ followed 33 individuals with ASD who participated in a supported employment model with a one-to-one employment specialist. 27 of the participants obtained competitive employment positions. The supports offered by the specialist included: development of a job profile, guiding job development and the search for a career, on-the-job training and development of long-term supports for job retention. In another study on supported employment programs for individuals with ASD, 15 people with a mild to moderate cognitive disability were provided with employment-related skills over a four- to 10-year period and had positive employment outcomes. These individuals, who had a wide range of scores on adaptive and behavioural scales, were part of an adult life skills program that provided supports from childhood into adulthood and offered an array of community-based and home living skills delivered in a variety of settings. At follow-up, 11 of the 15 participants were employed

¹⁰³ Supported employment, described in the US Developmental Disabilities Act of 1984, was intended for persons with a developmental disability for whom competitive employment at or above minimum wage was unlikely and who need intensive ongoing support to function in a work environment. Supported employment programs offer a range of services and are defined as the “process of enabling a person with a disability to secure and maintain paid work that is in a regular work environment.” See Mawhood & Howlin, 1999 op. cit. Supports might include: interview skills, interest assessments, job placement and job coaching.

¹⁰⁴ Robertson and Emerson, 2006 op. cit.

¹⁰⁵ Mawhood and Howlin, 1999 op. cit.

¹⁰⁶ Howlin et al., 2005.

¹⁰⁷ Mawhood and Howlin, 1999 op. cit.

¹⁰⁸ These studies were classified as poor in quality. In one review, for a number of reasons, they did not have random design, the diagnostic approach was not reported and coding was not completed by blinded assessors. See Taylor et al., 2012 op. cit.

¹⁰⁹ Wehman et al. 2012 op. cit.

in jobs like grounds maintenance, hotel housekeeping, data entry, laundry work, filing and factory assembly.¹¹⁰

Supported employment has other benefits and appears to be better than sheltered workshop¹¹¹ settings. Supported employment may improve cognitive levels over time. 44 adults with ASD who were in supported employment were tested and showed significantly greater improvements over time in cognitive performance in comparison to matched individuals who were unemployed.¹¹² In another study of 19,436 adults with ASD, researchers divided participants with ASD into two groups matched on gender, diagnosis and secondary diagnosis and placed them into two different settings: sheltered workshops or supported programs. Results showed that the rates of employment did not differ between the two groups, but that those who participated in sheltered workshops earned significantly less and cost significantly more to support than the matched non-sheltered peers.¹¹³ In a comparison of sheltered vs. supported employment programs, 51 adults with ASD were matched on characteristics like IQ, age and severity and divided into two groups. One group participated in sheltered employment while the other group was in supported employment. Those in the sheltered employment settings showed an increase in severity scores over time while the other group remained stable.¹¹⁴

Job Placement

Job placement, on-the-job supports (via a job coach) and technology were the most promising elements of supported employment, as noted in a number of the reviews.¹¹⁵ Using data from the Vocational Rehabilitation (VR) Program in the US, Migliore and colleagues¹¹⁶ found that the odds of employment success were greater for youths with ASD who received job placement services. In this study 2,913 youths with ASD who did not have integrated employment at application and received VR services were followed. Integrated employment was defined as work lasting more than 90 days and performed for a wage. Job placement services were found to be the greatest predictor of employment success. The authors note that these findings are consistent with most rehabilitation research across disabilities.

In a study of 450 individuals with ASD who left VR services and entered either competitive employment or supported employment environments, it was found that the case service variables of job finding, placement and maintenance were related to success in competitive employment. For the group who had successful supported employment, job placement was the only variable associated with success. Job placement and job finding historically have been the basis of VR services in the US.¹¹⁷

Job Coaching

Using the VR database from the US of 1,707 individuals with ASD, researchers found that the presence of on-the-job supports for those with ASD resulted in a higher likelihood of employment in the

¹¹⁰ McClannahan et al., 2002 op. cit.

¹¹¹ Sheltered workshops are settings that employ those with disabilities separately from others and are considered segregated and non-inclusive.

¹¹² Garcia-Villamizar and Hughes, 2007.

¹¹³ Cimera et al., 2011.

¹¹⁴ Garcia-Villamizar et al., 2000.

¹¹⁵ Nicholas et al., 2014 op. cit.; Hendricks, 2010 op. cit.

¹¹⁶ Migliore et al. 2012, op. cit.

¹¹⁷ Schaller and Yang, 2005 op. cit.

community, both in supported and competitive employment settings.^{118 119} As noted above in the research by Schaller and Yang,¹²⁰ job maintenance was a key case service variable found to be significant for competitive employment placement. In a smaller study, four adults with ASD were able to acquire work skills when on-site job training was provided along with simulation training.¹²¹ In a study by Hillier and colleagues,¹²² nine participants with ASD who had IQs in the normal range were provided with a range of supports on the job. The amount of job coaching varied from four to 20 hours per week depending on the need. Job coaching continued until the individual was independent in the job and this ranged from one day to six months. The researchers followed participants for two years and found that participants had higher employment rates and their income increased, but only after the introduction of a job coach. Seven of the original participants retained their initial job over the two-year period.

Media and Technology Augmentative Tools

Media- and technology-based augmentative tools are promising forms of intervention for enabling an individual to learn and complete a work task successfully. In the literature synthesis by Nicholas and colleagues,¹²³ one of the two key domains of promising vocational interventions for adolescents and adults with ASD was technology-related applications. The authors note that few studies on ASD-specific supports for vocational interventions exist and that much of the research is based on small sample sizes, so it is considered promising. In their review on transition practices for ASD, Westbrook and colleagues¹²⁴ concur that modeling and behaviour-shaping techniques using video, audio and positive reinforcement are promising practices.

As noted above, most research in the area of IT interventions and employment are based on small numbers of participants with ASD, ranging from one to six individuals, which is why this area considered promising. Some examples of the research available are noted here. In an intervention study, three individuals with ASD watched videotaped demonstrations of the work skills required over a four-month period and all participants learned the skills after watching the video. They were able to generalize the learning to a paid job, and comments from employers were positive.¹²⁵ Six adults with ASD used a personal digital assistant (PDA) to complete work tasks and five of the six participants were able to complete the tasks and the required behaviours after introduction of the PDA.¹²⁶ In another study, video modeling and positive reinforcement allowed five of the six participants with ASD who had a moderate intellectual deficit to master a target skill for work, and the skill was maintained by three participants for 1.5 to six weeks.¹²⁷ There were numerous other studies found in the review by Walsh and colleagues¹²⁸ that noted research involving one to six participants where each study demonstrated work skill acquisition with the use of video and audio technology to teach skills. In a recent review of

¹¹⁸ Lawer et al., 2009.

¹¹⁹ Taylor and colleagues (2012 op. cit.) classify this study as poor in quality for a number of reasons, including the fact that participants were not clearly characterized on IQ and developmental measures, as well as other concerns.

¹²⁰ Schaller and Yang, 2005 op. cit.

¹²¹ Lattimore et al., 2006.

¹²² Hillier et al., 2007.

¹²³ Nicholas et al., 2014 op. cit.

¹²⁴ Westbrook et al., 2015 op. cit.

¹²⁵ Allen et al., 2010.

¹²⁶ Burke et al., 2010.

¹²⁷ Alexander et al., 2013.

¹²⁸ Walsh et al., 2014 op. cit.

the VR system by Chen and colleagues,¹²⁹ one interesting finding was the limited use of rehabilitation technology services for individuals with ASD, especially given the importance of visual supports for people with ASD. There is a need for more evidence-based research on these interventions.

The Employer

One of the reviews found that supervisors and co-workers were important factors in strategies for employment success — in particular supervisors who were knowledgeable about ASD, supportive, and tolerant.¹³⁰ Leadership style¹³¹ was found to be a significant factor for employee work satisfaction, retention, and quality of life that led to a successful work environment for employees with ASD. In this study, 54 employees (rated as mild on the autism spectrum) who held a position for over one year described what type of leadership contributed to their success and how it did so. Authentic leadership was one style that led to success.¹³² In a survey of 18 individuals with high-functioning ASD or Asperger's syndrome who did not have an ID, analysis of the qualitative data found major themes in the area of employer awareness training and attitudinal supports that lead to success.¹³³ In a study of supervisors of 14 successfully employed workers with ASD, researchers found that accommodation strategies associated with successful supervision included: maintaining a consistent schedule, structuring the job, decreasing unstructured time, communicating in a direct manner and providing reassurance and support from the rehabilitation agency.¹³⁴

Awareness of ASD and the openness of organizations to employing those with ASD were examined by Nesbitt.¹³⁵ Using survey data, researchers analyzed questions around why organizations chose to employ those with Asperger's syndrome (AS). Two types of organizations were surveyed: organizations that used an employment model called Prospects¹³⁶ and employed those with AS (71 percent of organizations participated), and organizations that did not use Prospects and so had no employees with AS (29 percent participated). Researchers found that significant factors for hiring workers with AS were related to the employers' awareness of AS and the ongoing supports from Prospects to assist the employer. Several factors were found to be significant to organizations not employing workers with AS. These items focused on the ability of the person to interact and behave in certain ways.¹³⁷ There was limited research on employers' perceptions of hiring workers with ASD.

In general disability research, workplace attitudes towards those with certain types of disabilities had an impact on the employer. In a review of 37 studies on employer attitudes towards accommodating and hiring workers with disabilities, researchers found generally positive attitudes and affirmation of humane views, but some disabilities, like mental retardation and mental illness, were viewed more negatively than others.¹³⁸ In a Swedish study on employers' perspectives of hiring workers with disabilities, interviews with employers showed that positive early experiences with employees with disabilities

¹²⁹ Chen et al., 2015 op. cit.

¹³⁰ Hendricks, 2010 op. cit.

¹³¹ Authentic leadership (acceptance, transparency) was critical for employment outcomes, but was not found to be superior to other leadership styles, which suggests an array of leadership behaviors are needed.

¹³² Parr and Hunter, 2013.

¹³³ Muller et al., 2003 op. cit.

¹³⁴ Hagner and Cooney, 2005.

¹³⁵ Nesbitt, 2000.

¹³⁶ Prospects is a supported employment model for individuals with Asperger's syndrome developed in the UK by the National Autistic Society.

¹³⁷ Nesbitt, 2000 op. cit.

¹³⁸ Hernandez, 2000.

serve as one reason why employers were willing to hire people with disabilities. Characteristics of those with ASD might include analytical skills, computer skills, organization skills, loyalty and dedication as noted on the Meticulon website as the benefits of hiring their employees.¹³⁹ Furthering the research on employer attitudes and increased awareness of the positive attributes of hiring those with ASD may help enhance opportunities for employment.

In regards to the use of employer incentives to hire those with disabilities, a Canadian review by Jongbloed¹⁴⁰ of policy actions designed and directed towards the employer to increase employment notes that worldwide, the general approaches used to increase employment are: rights-based anti-discrimination legislation, obligatory quotas for hiring and incentive-based voluntary actions. Studies have found that anti-discrimination legislation has not markedly improved employment and Australian researchers have found no evidence that obligatory quota-based systems are effective. Wage subsidies to incent and support employers are available, but Canadian research shows that such subsidies are of mixed effectiveness. Wage subsidies when coordinated with other employer incentives, such as tax exemptions for accommodations, access to community-based expertise and grants to retain, hire or retrain employees work better than subsidies alone.¹⁴¹ A systematic review of literature from countries including Canada examined the effectiveness of return-to work interventions for people with disabilities, concluding that wage subsidies can be effective if they are sufficiently generous and that overall employer interventions favored the advantaged disabled worker who had already been in the labour market.¹⁴² Wage subsidy research and effectiveness reviews focus on those with physical disabilities and those with workplace disabilities. There was no ASD-specific research on wage subsidy effectiveness found and this area warrants further investigation.

The Type of Job

In the neurotypical literature, less stable jobs are associated with poorer employment outcomes. Researchers found that early employment instability contributes to low levels of employment. Holding a job that provides tenure (held for a length of time, employed in a permanent position) fosters future stability of employment for all skill groups.¹⁴³ In another review of labor market outcomes and transitions to adulthood for neurotypical youth, economists found that job churning, which includes the movement from employment to unemployment, results in negative outcomes on future employment and earnings. The movement between jobs for neurotypicals can be positive when it results in higher wages, but periods of unemployment negatively impact future work.¹⁴⁴

Constant movement between jobs and periods of unemployment for individuals living with ASD are not uncommon. Researchers confirm that a high level of job-switching for those with ASD exists and this results in fragmented work histories, which may contribute to limited career development.¹⁴⁵ The problem of unemployment, underemployment and mal-employment in this demographic has been confirmed by others.¹⁴⁶ If neurotypical work findings on unemployment and work instability apply to individuals with ASD, then a fragmented work history and periods of unemployment may lead to poor outcomes.

¹³⁹ <http://meticulon.com/our-stories/blog/supporting-employment-for-asd-individuals>

¹⁴⁰ Jongbloed, 2010.

¹⁴¹ Ibid.

¹⁴² Clayton et al., 2011.

¹⁴³ Holzer and LaLonde, 1999.

¹⁴⁴ Danziger and Ratner, 2009 op. cit.

¹⁴⁵ Balwin et al., 2014 op. cit.

¹⁴⁶ See Hurlbutt and Chalmers, 2004 op. cit.; Robertson, 2010; Muller et al., 2003 op. cit.

The Definition of Meaningful Work

One goal of employment for those with disabilities who want to work is that the work is meaningful and takes place in an integrated setting.¹⁴⁷ The historical development of supported employment is underpinned by the idea that work has meaning in our lives.¹⁴⁸ The term meaningful is appropriate when intended as that which is meaningful to the individual. Meaningful can and should mean different things to different people, but is there an issue in how society currently defines meaningful? Could this be a barrier to finding a job for those with disabilities?

What is meaningful work? How we define the meaningfulness of work could create barriers to employment for those with ASD. A Gallup poll of neurotypical workers in North America found that less than 30 percent were engaged in their jobs or psychologically committed to them. Experts believe that this is partially due to what is deemed to be the lack of a meaningful job as defined by a social discourse perspective. This could be seen as vocational snobbery that renders some jobs as more meaningful than others. A good job tends to offer stability, financial security, some challenge (in a desirable way), opportunity for growth, use of one's skills and interests and purpose and structure to one's day. But a meaningful job often implies that the value of prestige is important. For example, a job as a doctor is more meaningful than a job as a house cleaner. Thus, viewing dirty or hard labour (factory work or stocking shelves) as a job that should be avoided because it lacks meaning may contribute to labour shortages in some sectors of the Canadian labour market.¹⁴⁹ The emergence of this snobbery around meaning may be damaging to those with disabilities. How society defines meaningful vs. non-meaningful work may impact how an individual feels about their work. Does this prevent some from taking less meaningful jobs?

The Family

Family is another key factor that may be essential in the success of an individual and has been identified in the general disability literature as one of the three most important factors influencing transitional success for youths with disabilities.¹⁵⁰ However, it is considered an understudied area for ASD. In a systematic review of ASD pre-graduation practices and employment outcomes, researchers found that very little is known about family involvement during transition.¹⁵¹ Taylor and Mailick¹⁵² note that, although not measured empirically in their 10-year longitudinal study of adults with ASD and vocational independence, the case studies for most whose vocational activities improved over time were often the result of prolonged and fierce activity by parents to find employment and advocate for their children with ASD. Family likely plays a critical role in success but research is lacking in this area.

Family Navigation

Family supports could play an important role in the transition to the complex array of adult employment programs and eligibility that require networking. In a discussion paper on transition supports,

¹⁴⁷ Hendricks and Wehman, 2009 op. cit.

¹⁴⁸ Mank et al., 1998.

¹⁴⁹ Calgary Herald, November 3, 2014. Good Job/Bad Job: How We Judge Work Limits Our Ability To Find Meaning In It. <http://www.calgaryherald.com/Work+Progress+Good+versus/10292511/story.html>

¹⁵⁰ Kohler, 1993 op. cit.

¹⁵¹ Westbrook et al., 2015 op. cit.

¹⁵² Taylor and Mailick, 2014 op. cit.

McDonough & Revell¹⁵³ reviewed two case studies of individuals with ASD and transitional support needs. The authors note the important role of transition planners, who must navigate a complex system of adult services and employment programs to assist transitioning youths. It is likely that family, as part of the transition team, is a requirement for success especially in jurisdictions that do not provide significant levels of supports or assigned transition workers. Unique individual needs, variations on services available, funding, wait lists and service eligibility differences create fragmented employment programming opportunities and underscore the need for in-depth knowledge of community-based programs and the need for networking that is often orchestrated by family. In a study of 1,610 individuals, of whom the majority were learning-disabled (none had ASD), researchers found one of the two significant predictors for employment success was the self-family-friend network used to find a post-school job.¹⁵⁴

Family Expectations

Family expectations may also contribute to employment success. In the general disability literature, the impact of family expectations was found to be a significant factor in employment success, where employment was measured as having a job two years after high school. Higher family expectations of a young adult with a severe disability were associated with better odds of employment after school.¹⁵⁵ Family could also negatively impact success. In a small qualitative study with developmentally delayed participants, researchers found that family support was unhelpful when a family member dictates employment preferences over the individual's interests.¹⁵⁶

Family Income and Family Education

Family income may also play a role in success. Using the NLTS following 830 individuals with ASD to examine factors for employment participation for youths with ASD after leaving school, researchers found that annual household income (high income > \$50,000 and low income <\$25,000) was a significant factor associated with post-school employment. Students from families with high income were more likely to participate in employment than those from low-income families. Students whose parents had a bachelor's degree or higher were more likely to participate in employment than those whose parents had a high school degree or lower, but the impact of family income was greater than parental education.¹⁵⁷ In a national telephone survey of 500 parents or guardians of young adults with ASD, Shattuck and colleagues¹⁵⁸ also found that individuals from households with low incomes were significantly more likely to be disengaged after high school, even after measures of severity were considered. However, in a review of adult services Shattuck also notes the lack of attention to socio-economic position in ASD research.¹⁵⁹

¹⁵³ McDonough and Revell, 2010.

¹⁵⁴ Doren and Benz, 1998 op. cit.

¹⁵⁵ Carter et al., 2012 op. cit.

¹⁵⁶ Moon et al., 2011.

¹⁵⁷ Chiang et al., 2013 op. cit.

¹⁵⁸ Shattuck et al., 2012 op. cit.

¹⁵⁹ Ibid.

SUMMARY OF EXTERNAL FACTORS

Education, work environment and family all influence employment success, but in each of these areas further research will be important to clarify best practices specific to ASD. Quality research that embraces the heterogeneity of this condition and also the integrated efforts of employers, adults on the autism spectrum and family members in partnership is needed.¹⁶⁰ Given what is currently known about employment, what are the next steps in policy directions that offer the best likelihood of improving employment outcomes?

3. POLICY IMPLICATIONS

Recommendation 1: Research on Persons with ASD in the Canadian Labour Market

Although a number of studies were found on employment success and ASD, the consistent message is that not enough is known to form best practices and in some key areas (i.e., family involvement, wage subsidies, exceptional skills) there is virtually nothing known. For this reason the first policy recommendation concerns furthering research into employment success overall and specifically a better understanding in a Canadian context. There is a large amount of general disability literature related to employment, but whether this research can be fully applied to ASD is questionable. The challenges and opportunities for those with ASD in the workplace are substantially different than for those with a physical disability, auditory or visual disability, or disability related to workplace injury.

A few critical areas missing are: the role of exceptional skills and success, best practice models in transition (given the critical role of the education system), work-study and internship models, the role of a job coach in sustainable employment, successful employment for lower functioning individuals, the role of family and what they need, employer incentives and the effects of wage subsidies and technology for workplace accommodations.

Recommendation 2: Address Individual Characteristics that Limit Success

From the research it is clear that a lack of social skills, limited independence, limited self-determination and unmanaged behaviours are factors associated with work challenges. Life skills for independence, social skills programs and supports for behavioural management are required across the lifespan, not just in early childhood. The importance of intensive supports at a young age to address these issues is accepted practice as seen in early childhood interventions, but many adolescents face a support cliff at age 18 where services are lacking. In the education system programs may be offered in an inconsistent or non-existent manner, leaving students unprepared to enter adulthood. Those who have higher IQs are often disqualified from adult service supports at age 18 based on IQ scores, while those with lower IQs enter into a support system that is unprepared, with a lack of structured daytime programming and access to behavioural specialists.

Better social skills, functional independence and behavior management programs are key elements of employment success. In a recent Canadian review on the needs of people living with ASD, at least half of survey respondents noted the need for social skills programs, life skills training and employment or day programs.¹⁶¹ Ensuring that education systems in all jurisdictions offer these programs and that adult supports exist based on need, regardless of IQ eligibility, will enhance employment success and

¹⁶⁰ Shattuck and Roux, 2014.

¹⁶¹ CASDA, 2014.

contribute to quality of life.

Recommendation 3: Improve Treatment and Access for Mental Health

Mental health conditions prevent some from participating in work. Individuals with ASD are at high risk for added mental health issues and often as adults lack access to knowledgeable professionals and treatments. Until these conditions are better managed many, even those who have high IQs or those with exceptional skills, will continue to struggle to succeed in employment. From the CASDA survey,¹⁶² the highest of the top five needs was mental health treatment. Policy initiatives that enhance access to psychologists and psychiatrists who are trained in the complex issues of neurodevelopmental conditions and mental health issues will help increase access to qualified professionals and appropriate treatment, which ultimately may enhance employment success.

Recommendation 4: Increase Opportunities for Work Experiences

Work experience is one of the most substantial best practices found for individuals with disabilities. The education system (both secondary and post-secondary) could be enhanced to offer employer links in the form of traineeships, internships and work-study programs with ASD-specific supports. Even though ASD-specific transition best practice research is underdeveloped, the role of early work-related experience and having a job when one graduates may offer an important entry into adult employment. Education policies to increase work-related experiences (with ASD-specific supports) made available across school boards cannot be overlooked as a critical policy recommendation. Supporting a pilot of the employment model Project SEARCH described in this paper is one example of a next step towards enhancing successful education-based employment programs.

Recommendation 5: Incent and Support Employers

Employers play a key role in employment success. There is evidence that supports are required to enhance employment success, but less is known about the role of employer incentives specific to ASD. Based on Canadian research for general disabilities, it seems reasonable that a comprehensive employer support and incentive program may also be required for those with ASD. Jongbloed¹⁶³ recommends a comprehensive program of incentives and supports that include wage subsidies, plus other forms of employer supports like tax exemptions for workplace accommodations, access to community-based expertise on accommodations and grants to retain employees. Current ASD research suggests that employer awareness and training, the ongoing role of the job coach, job placement and workplace accommodations specific to the needs of the individual (media and technology supports) are key elements of a comprehensive program. As previously noted, more research on the impact of wage subsidies for this population is suggested. A multi-dimensional approach to employer incentives and supports may be particularly important for those with ASD who require unique, flexible and diverse accommodations.

¹⁶² Ibid.

¹⁶³ Jongbloed, 2010 op. cit.

Recommendation 6: The Essential Role of Family

Possibly one of the most understudied areas that may be critical to successful employment is the role of family. In many cases, successful employment is likely in part due to the intense efforts of parents who network and advocate on behalf of their son or daughter with ASD. Not all families have the vision for success, the intensity or the capability to manage this task.

Pilot project for an employment clearinghouse

Networking has been shown to promote successful employment outcomes, but networking takes time and effort. For school personnel, employers or family who do not have the time to seek out the right fit between the individual and the opportunities, the facilitation of a convenient link to jobs and individuals may help.¹⁶⁴ A pilot project for a clearinghouse of work connections to support families and individuals to find the right job and to connect employers with employees is a reasonable investment. A provincial employment site could also profile successful employment examples that would not only give parents ideas and hope, but also raise awareness in the business community of the unique skills and abilities offered by some individuals with ASD. In particular, where individuals have a unique and exceptional skillset, this could be profiled and serve a function to promote matching skills and jobs. The Alberta Employment First Strategy identifies the need to enhance collaboration between persons with disabilities and employers with the use of technology to develop and share employment opportunities.¹⁶⁵ A clearinghouse would fit well into this plan.

Increase Supports for Small Business and Entrepreneurs

Families are often the drivers behind the creation of small business opportunities. Connections with families and increasing supports for small business ventures will help. The Entrepreneurs with Disabilities Program offered through Western Economic Diversification Canada¹⁶⁶ offers business loans (in some locations) plus mentoring, business training and identification of special equipment needs. Although the loan portion of this program is important, the other aspects of the program are truly essential for the ASD population. Unlike physical disabilities, those with neurodevelopmental disorders often lack the executive functioning skills to plan, coordinate and sustain a complex financial situation and so rely lifelong on others.

Solid and ongoing supports to help families and individuals plan, market and maintain their businesses are essential. In particular, for families who do not have the capacity to initiate these ventures, providing significant startup support and a plan to sustain the business is critical. The needs of those with neurodevelopmental disabilities and sustainable small businesses could require unique approaches within this program.

CONCLUSION

This report summarizes the peer-reviewed literature for factors that predict or contribute to successful employment for persons with autism spectrum disorders. It is clear that the current employment situation requires attention and options for enhanced or new policy directions do exist. Persons with disabilities continue to struggle to secure employment and those living with ASD have some of the worst employment outcomes across all disabilities. Autism spectrum disorders are now the most commonly

¹⁶⁴ Luecking and Gramlich, 2003.

¹⁶⁵ Alberta Employment First Strategy, 2015. humanservices.alberta.ca/documents/alberta-employment-first-strategy.pdf.

¹⁶⁶ Entrepreneurs with Disabilities Program, Western Economic Diversification Canada. <http://www.wd.gc.ca/eng/13643.asp>

diagnosed neurological disorder in children;¹⁶⁷ high numbers diagnosed as children have major implications for future employment challenges as these children become adults.

In conclusion, individuals with ASD are starting out in life with major challenges; as they enter into adolescence they often diverge early on from neurotypical youth on the work trajectory. Most struggle to achieve complete independence, understand social interactions, manage a job in addition to attending school and complete high school. This different entry into work life may be so significant that it is a challenge to catch up. Add into this the individual characteristics and heterogeneity of co-morbidity and ID, plus the history of job instability, and there is no wonder why the outcomes are so poor. Although outcomes are poor and evidence-based research is lacking, much can be done to continue to move ahead to enhance employment outcomes and quality of life. The answer is not straightforward and it will require a vision that recognizes the unique characteristics of the individual and the role of external influences (education, employer and family) — all factors in employment success.

¹⁶⁷ Fombonne, 2009.

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