

Employment and adults with Asperger syndrome

**A PHENOMENOLOGICAL STUDY WHICH
EXPLORES THE EMPLOYMENT EXPERIENCES OF
EIGHT ADULTS WITH ASPERGER SYNDROME**

by

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Abstract

This study presents and explores the employment experiences of eight adults with Asperger syndrome. People diagnosed with Asperger syndrome usually display problems understanding social cues, facial expressions and body language, problems forming peer relationships, difficulty expressing emotions in conventionally recognisable ways, inflexibility and discomfort with change and difficulty adapting to new tasks and routines. Even though more research is being published on adults with Asperger syndrome the area of employment has not been sufficiently addressed. This study adopted a phenomenological approach because it can take the reader into the life world of the participant in a much deeper way which other research methodologies cannot. In-depth interviews were used to capture the employment experiences of eight adults with Asperger syndrome. The eight adults interviewed described both positive and negative experiences they had within the workplace, identified major obstacles in obtaining and maintaining employment and recommended appropriate employment supports.

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Chapter One

INTRODUCTION

In recent years Asperger syndrome has received much attention (Mayes, Calhoun & Crites, 2001; Molloy & Vasil, 2002). Asperger syndrome was first discovered in 1944 by Hans Asperger (Freeman, Cronin & Candela, 2002). However, in the United States of America there was little awareness of it before Lorna Wing published her article in 1981 (Wing, 1981). An additional decade passed before Asperger syndrome was incorporated into the International Classification of Disorders - Tenth Edition (ICD-10) in 1992 (World Health Organisation (WHO), 1992) and into the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV) in 1994 (American Psychiatric Association (APA), 1994).

Asperger syndrome is generally considered to be a neurologically based condition characterised by stereotypical behaviour, challenges with social interaction, average to above-average intelligence and cognitive abilities and a limited understanding of verbal and non-verbal language expressions (Baron-Cohen, 2002; Khouzam, El-Gabalawi, Pirwani & Priest, 2004). There are some who would argue that Asperger syndrome is a distinct neurologically based condition (Freeman, Cronin & Candela, 2002; Frith, 1991), others would argue that it is a mild form of Autism (Howlin, 2003; Lozzi-Toscano, 2004; Mayes, Calhoun & Crites, 2001) and some would argue that Asperger syndrome fits into the Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) category (Klin & Volkmar, 2003; Szatmari, Tuff, Finlayson & Bartolucci, 1990). Finally, there are some who would argue that Asperger syndrome is a different cognitive style and not a neurologically based condition (Baron-Cohen, 2002; Happe, 1999; Molloy & Vasil, 2002).

These debates, regarding what Asperger syndrome is, have resulted in practitioners having a lack of understanding of the syndrome (Eisenmajer, Prior, Leekam, Wing, Gould, Welham & Ong, 1996; Fombonne & Tidmarsh, 2003; Klin & Volkmar, 2003). Furthermore, inconsistency in conceptualising Asperger syndrome is problematic because clinical research suggests that for adults with Asperger syndrome their quality of life can be greatly improved if they are diagnosed early (Khouzam et al., 2004; Lozzi-Toscano, 2004; Perry, 2004; Portway & Johnson, 2002; Safran, Safran & Ellis, 2003; Tsai, 2003). In addition, the inconsistent conceptualisation of Asperger syndrome by clinicians has resulted in a lack of published research regarding adults

with Asperger syndrome. Since adults with Asperger syndrome have not received much academic attention there is little published literature available to these adults, their family members or professionals. Even though more literature is being published on adults with Asperger syndrome the area of employment has not been sufficiently researched (Attwood, 1998; Bashe & Kirby, 2001; Meyer, 2001). Within the literature on Asperger syndrome there are only brief references made to the difficulties which those with Asperger syndrome have in finding and maintaining employment. The overall aim of this thesis is to present and explore the employment experiences of adults with Asperger syndrome. In doing so this thesis seeks to not only fill the current gap in the existing literature but to also add to the pool of knowledge about Asperger syndrome. What follows now is an outline of the following chapters.

Chapter two is a review of the literature on adults with Asperger syndrome and employment. I begin this chapter by discussing the Social and Medical Models of Disability. These models are then used to help discuss employment, labour market participation and income support for people with disabilities in Australia. This discussion will begin with the Commonwealth Invalid Pension and finish with the Howard Liberal Government's changes to the Disability Support Pension. I then briefly canvass the Rudd Labour Government's changes to disability support in Australia. I will then present an overview of the South Australian labour market and economy as all participants interviewed for this study only reflected upon their employment experiences in South Australia. Afterwards I introduce Asperger syndrome by first outlining the history, causes and prevalence of the syndrome in Australia. I then outline most of the characteristics associated with Asperger syndrome. I have decided to adopt a holistic approach and canvass most of the characteristics associated with Asperger syndrome as I believe it is a complex condition which should be viewed in its entirety. The characteristics associated with Asperger syndrome will then be summarised by presenting the diagnostic criteria for Asperger syndrome. I then challenge the diagnostic criteria for Asperger syndrome by outlining and discussing several areas of concern. I will then highlight several consequences arising from these areas of concern. Afterwards I summarise the gap in the literature and the research questions.

Chapter three describes the methodology and method used for this study and I begin this chapter by introducing phenomenology and in-depth interviewing. Afterwards I discuss the interview schedule and several concerns which need to be taken into consideration when using in-depth interviews as a basis for academic inquiry. The concerns I discuss are researcher bias, ownership

of the research and problems with the researcher's authority. After discussing these concerns I discuss how the participants were recruited and the sample composition. I then flag a note of caution about the results drawn from the sample. This will be followed by a section explaining how the data was collected and analysed. Afterwards I discuss several ethical concerns which need to be taken into consideration for this study. The ethical concerns I discuss are creating a comfortable interview environment for each participant, recording, obtaining written consent, counselling services, anonymity and confidentiality and data storage.

Chapter four uses a wide and detailed range of participant quotes in order to help discuss how the characteristics associated with Asperger syndrome can impact upon a participant's experiences of employment. The characteristics associated with Asperger syndrome, which I discuss in chapter four, are social skills, communication, sensory sensitivity and intense focus on special interests. By using elaborate and detailed quotes I hope to answer the following research questions: (a) In what ways do some of the characteristics associated with Asperger syndrome impact upon a person's experiences of employment?, and (b) How do the perceived life experiences of adults with Asperger syndrome impact on their work?

Chapter five summarises the main themes discussed in this thesis and makes several recommendations for helping people with Asperger syndrome succeed in their chosen occupations.

Chapter Five

CONCLUSION AND DIRECTIONS FOR FUTURE RESEARCH

5.1 INTRODUCTION TO THIS CHAPTER

In this thesis the participants discussed their experiences of employment and gave suggestions for helping other adults with Asperger syndrome to be successful in employment situations. Not being able to sustain employment on a constant basis was the biggest problem reported by each of the participants and this was often the result of the participants' intense focus on special interests and social skills deficits. Below I will review each of these issues individually and provide appropriate suggestions.

5.2 EMPLOYMENT SUPPORTS FOR ADULTS WITH ASPERGER SYNDROME

5.2.1 Social supports

The participants in this study reported that, while they acknowledged some difficulties with social skills, they were sometimes able to capitalise on their social strengths. However, this does not seem to reflect the experiences of adults with Asperger syndrome more generally. Adults with Asperger syndrome, including those diagnosed with Autism and PDD-NOS, experience a wide range of social challenges. Often adults with Asperger syndrome desire social friendships (Barry, Klingler, Lee, Palardy, Gilmore & Bodin, 2003). However, despite their desire for social friendships many adults with Asperger syndrome often have few friends (Ozonoff & Miller, 1995). Social isolation and vocational failure are often the result of these challenges (Tantam, 2000). Despite these social challenges, resulting in vocational hardships, few social support programs exist for adults with Asperger syndrome (Moxon & Gates, 2001). As the incidence of Asperger syndrome rises the need for social support programs is likely to increase (Fombonne, 2001) In addition, research evaluating the efficiency and effectiveness of existing social support programs is also scant (Rogers, 2000).

Often social skills influence employment success (Chadsey-Rusch, 1992). While socialisation in the workplace is important, employers often place the greatest value on the functional aspects of

the job. As a result, the social impairments adults with Asperger syndrome experience make obtaining and holding a job difficult (Barnard, Prior & Potter, 2000). Even if adults with Asperger syndrome have qualifications, employment levels are usually low (Barnard, Prior & Potter, 2000; Mawhood & Howlin, 1999). Often in order to find a job many adults with Asperger syndrome have to rely on their families for support (Howlin, 2000). A recent study of adults with Autism, for example, revealed that most of them remained highly dependent on their families for support (Howlin, Goode, Hutton & Rutter, 2004).

Adults with Asperger syndrome can learn social skills but they do not know how to apply those skills. Social skills must be learned in conjunction with social situations (Meyer, 2001). Previous research, undertaken by Barnhill, Cook, Tebbenkamp and Myles (2002), has shown that learning social skills in a group allows participants to develop social skills which will help them form social relationships. Furthermore, during a social skills program, participants often value the friendships they gain more than the skills they learned. A group specifically designed for people with Asperger syndrome would avoid the high social and communication demands of a typical group, creating a greater sense of belonging and safety (Mishna & Muskat, 1998), and therefore providing an environment in which social risks could be more easily taken (Marriage, Gordon & Brand, 1995).

5.2.2 Utilising an intense focus on special interests

Employers could consider utilising the intense focus on special interests of employees with Asperger syndrome. Harnessing the employees' intense focus on special interests can help improve their behaviour within the workplace and motivation to complete work tasks. Employees with Asperger syndrome do not consider their intense focus on special interests to be merely hobbies but instead they consider them an innate part of themselves. Thus, there is clearly an untapped source of drive and passion within employees with Asperger syndrome when they are engaged with their special interests. The employer's challenge is to discover how best to utilise the employee's passion. The intense focus on special interests is so important to an employee with Asperger syndrome that they are utterly focused on their special interest and want to learn more about it. Attwood (2003, p.131) described this consuming drive as "the almost insatiable thirst for access to the interest". From the study I propose that employers integrate their employees' intense focus on special interests into the workplace.

An employer may wish to incorporate the intense focus which an employee with Asperger syndrome has on a specific topic into their work day by interviewing them about their intense interests. Not only will this interview strengthen the relationship between the employee with Asperger syndrome and their employer but it will also demonstrate the employer's interest in the employee. Furthermore, the information gleaned by the employer will reduce the possibility that they will have misperceptions about their employee's interests. An employee who works in an automotive mechanical shop, for example, may seem thoroughly interested in cars. Upon talking to them, however, it may become apparent that they are not actually interested in cars as such but may instead have a passion for brakes and fuel injection systems. Talking with the employer also provides an opportunity for the employee with Asperger to converse freely about their interests and gives the employer an opportunity to assess the employee's oral communication skills. As Grandin and Duffy (2004, p.vii) write, "Society loses out if individuals with Autism Spectrum Disorders are not involved in the world of work or make other kinds of contributions to society". Adults with Asperger syndrome must be encouraged to pursue their intense focus on special interests in the home, school, community and work environments. Grandin and Duffy (2004, p.xi) support this claim by stating that "To build success, parents should help their children develop their natural talents". Grandin and Duffy's (2004) view is also supported by Asperger (1944) who first proposed that the special interests that a person with Asperger syndrome has may form the basis of a meaningful career. As he wrote, "We can see in the autistic person, far more clearly than with any normal child, a pre destination for a particular profession from earliest youth. A particular line of work often grows naturally out of his or her special abilities" (Asperger 1944, p.88).

Adults with Asperger syndrome may have a high level of job satisfaction if they work in careers which are related to their specific interests. Holding a job which is directly related to a specific interest gives these adults the opportunity to use their innate abilities. A job which is based on an individual's specific interests could mean the difference between either unemployment or high job satisfaction (Attwood, 2003). In addition, there are other benefits to having a job which relates to an intense focus on special interests. In the context of such employment, an adult with Asperger syndrome would likely demonstrate strengths in social, communication and emotional skills. For example, a person with Asperger syndrome who likes cataloguing books might have a satisfying career working as a librarian. As Grandin and Duffy (2004, p.ix) emphasised, "For those on the Autism Spectrum, finding a satisfying job also provides social opportunities through

shared interests.” Attwood (2006, p.174) added to this view by stating that “The special interest can also provide a valuable source of intellectual enjoyment and can be used constructively to facilitate friendships and employment.”

Earlier on in this thesis it was argued that the voices of adults with Asperger syndrome were not heard within the research literature. In this study, the participants’ voices were centralised in order for their experiences in the workplace to be highlighted. The literature focuses significantly on the difficulties and deficits of adults and children with Asperger syndrome, and in doing so fails to address the strengths which people with Asperger syndrome bring to society. The findings of this study indicate that a focus on the strengths inherent in the diagnostic categories of Asperger syndrome can lead to significant occupational success for people with Asperger syndrome. The challenge lies in matching workplaces and employment opportunities to the specific skills of this population. The results of this study strongly suggest that adults with Asperger syndrome should be included in future research efforts to define appropriate employment interventions. Future research efforts would also benefit from including the voices of family members, work colleagues, employers, career counsellors and job coaches.