

Educating adults with Autism spectrum condition as an international issue

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2013

Introduction:

The aim in this paper is to discuss autism spectrum condition (ASC) as an international issue. First, I explore the current definition of the condition and how research theories explain the underlying causes of its symptoms. Second, I discuss the difficulties faced by the individuals diagnosed with ASC, why ASC is becoming an international issue and why not only developing countries still face difficulties in meeting the needs of this population. Last, I will describe the services and support systems available for adults with mild autism who attend or plan to attend higher education institutions in their countries (the US, the UK and Saudi Arabia). I hope to clarify the image to service providers in Saudi Arabia by discussing the services internationally to help them reflect on their own practices. The reason for focusing on adults with ASC is that little if anything has been written about this topic in Saudi Arabia. Therefore, I will try to fill this knowledge gap. In order to maximize the value and benefits of this paper, I will avoid comparing the three countries in terms of services and support for adults with ASC. Each country has its own unique culture, policies, educational systems, health services, income levels and ideologies. Thus, what might be implemented and effective in one country may not work in other countries or for other populations. I have been a professional in this field since 2008 and have some personal experience with ASC. I work at King Saudi University as a researcher and lecturer, train teachers and paraprofessionals in schools and centres, offer consultation for parents, caregivers and charities, educate the public, raise awareness and support autism organizations, charities and associations internationally.

🕒 What is autism spectrum condition (ASC)? How does it affect one's thinking and behaviour?

Autism is one of the most common developmental disabilities (Tantam, 2012 and NewYork-Presbyterian Hospital,2012). It is a lifelong condition and a hidden disability that impairs socialization and verbal and non-verbal communication, and manifests in narrow interests and repetitive behaviours (Yollin, 2008; Al-Salehi and Ghaziuddin, 2009 and Taylor, 2005). It is often associated with sensory issues. Individuals with ASC may be under-sensitive and/or over-sensitive to stimuli (such as smell, touch, light, sound, tests) (ODA, 2010). It is one of the least recognized and diagnosed disabilities internationally. Things such as transitions, unpredictable changes in daily routine, disorganized environments can trigger stress and anxiety for those with ASC (Ozand et al., 2003). Behaviours such as rocking and flapping are also commonly associated with the condition due to individuals' communication and sensory deficit difficulties. Figure (1) illustrates common ASC behaviours.

**Figure (1): Common behaviours associated with autism spectrum condition (ASC)
(Tucker, 2010)**

Many studies show that with early and appropriate intervention, autism symptoms can become less distinct as a child develops into and during adulthood (VanBergeijk et al., 2008).

Thus far, autism theories have not fully explained all the causes of autistic behaviours, which are still subject to academic debate. Following are three common theories that have attempted to explain autistic behaviours.

1) The theory of mind:

The theory of mind refers to one's ability to ascribe mental states, such as beliefs, intents and desires, to oneself and to recognize these things in others. Deficits in this regard mean that an individual cannot recognize or understand that other people have different feelings and thoughts than him/herself. Consequently, he or she can appear to be less empathetic, tolerant and understanding of others' feelings. Such a deficit can also affect communication. A child or adult with ASC may assume that the people they talk with experience the same situations and feelings. Therefore, they offer little background or details about the subject of the conversation. Without understanding how ASC affects communication abilities, this can make interacting with autistic individuals more difficult (Mowat et al., 2011)

2) The central coherence theory:

The central coherence theory refers to the idea that those with ASC have a limited ability to see 'the big picture'. These individuals have difficulty understanding context. For example, young children with ASC may not be able to understand the function of a toy and may be preoccupied with its parts. This deficit can remain a lifelong impairment without appropriate intervention in childhood. An adult with ASC may have problems 'reading between the lines' and can be fixated on details rather than understanding the topic in general (Mowat et al., 2011).

3) The executive function theory:

The executive function theory refers to the idea that the symptoms of ASC might be due to a crucial deficit in executive functions. This includes difficulties in generalizing and memorizing the order of things. Organizational skills (thoughts and behaviours) may also be negatively affected. Poor time management and a lack of organizational and prioritizing skills are also common among individuals with ASC. These skills are vital for academic achievement; however, with the appropriate support, students with ASC can overcome these difficulties and achieve just as much success as his/her peers (Graham, 2008).

🕒 Why is autism an international issue?

Autism is a global disorder (Al-Salehi and Ghaziuddin , 2009). The core deficits of autism exist in all cultures regardless of individuals' social state, economic class or race. There is no one specific cause of ASC and many studies indicate the cause could be genetic, environmental or a combination of those factors (Harmon, 2011). The prevalence of autism in the countries mentioned in this paper (the US, the UK and Saudi Arabia) is 1:100 (Al-Sibai, 2012 and Research Autism, n.d). Internationally, evidence-based interventions for adults with

ASC are very limited and little is known about good outcomes in terms of their participation in higher education (Howlin and Moss, 2012). It is expected that more students with ASC will attend higher education institutions worldwide, and there will be a greater need for scholarship funding to support them (University of Alabama, 2007). Professionals in the field believe that ASC has not received enough attention from policymakers and that public awareness and understanding are quite limited (Mowat et al., 2011).

🕒 **What are the common problems adults with mild forms of ASC face in higher education?**

The common difficulties faced by adults with ASC relate to their communication, emotional regulation and socialization abilities and to their academic progress. The needs of each individual in these areas are different, as no one size fit all (Robertson, 2007). In terms of communication problems, adults with mild forms of ASC have developed verbal communication. However, they will experience difficulties regarding the expressive and receptive language of non-verbal communication (e.g. body language and facial expressions). They may also show inappropriate use of verbal communication and lack conversation skills (VanBergeijk et al., 2008 and Schnepf,2008). As mentioned previously, anxiety and stress are also common among adults with ASC (Taylor and Knott, 2007). This is caused by poor emotional regulation ability, which can significantly affect the adults' quality of life and inclusion in mainstream settings (school, university). According to the literature, about 70%–80% of individuals with ASC will remain socially impaired in adulthood. They will lack peer relationships and social networks, and will have a limited social life due to their poor social skills (Trudeau, 2008; Minaya, 2007; Beardon et al., 2009 and Geller, 2005) strongly recommends that parents, family members and teachers redouble their efforts to help individuals with ASC acquire as many social skills as possible. He states that 'growing up without' such skills could negatively affect the quality of social life and damage one's physical and psychological health.

University students are often required to give presentations, participate in group projects and communicate effectively with teachers and other students. All these activities require reasonable communication and social skills for academic progress and achievement. Individuals with ASC may require some academic accommodations, such as extra time for tests, assistance with note taking, assistance in group activities and frequent reminders of due dates (Gershman, 2008; Perner, 2002 and VanBergeijk et al., 2008) also suggest the following academic accommodations:

1. Offering a copy of the lecture in advance
2. Allowing the use of a laptop for note taking or nominating a peer to assist
3. Offering written instructions
4. Offering training in organizational skills and time management.

According to Wilcox (2008) and Taylor (2005), some students have significant social impairment. Therefore, group assessments have to be replaced with individual assessments. Adult students with ASC typically have normal or above normal IQs. For bright and gifted students, it may be necessary to adjust the curriculum (York and Longden 2008). In terms of environmental accommodations, staff at institutions of higher education must consider students' need for a structured and predictable environment (Beardon et al., 2009; MacLeod

and Green, 2009). An autism-friendly environment is an environment that meets the sensory needs of students who are hypo and/or hypersensitive to stimuli (Yoder, 2008).

It is worth mentioning that research findings indicate the dropout rate among students with ASC attending institutions of higher education is often the result of unattainable social demands, emotional issues and communication difficulties rather than academic difficulties (Monsebraaten, 2012).

How are adults with mild forms of ASC being supported in US institutions of higher education?

Since 1990, an increasing number of individuals have been diagnosed with mild forms of ASC (Srakocic, 2008). According to Harmon (2011), people with autism ‘typically disappear from public view after they leave school’. She also found that students who graduate from institutions of higher education often end up unemployed, socially isolated and living with their parents. In 2012, Athanasidy published a study showing that 35% of students with ASC who leave high school do not hold jobs or attend college or university. She also found that most support systems and services are limited to children with ASC and little is offered for adults with the condition. (Shattuck et al., 2012) reviewed the literature from 2000–2010 relating to services for adults with ASC in the US. They found that evidence-based services for these adults are less developed compared to services for children with ASC. Service providers are still not thinking beyond secondary school. Transitioning from high school to college or university is another issue adults with ASC face; unfortunately, services to help deal with this are lacking. In some cases, the transition is unsuccessful and in others it takes a long time (Athanasidy, 2012).

The economic impact of ASC on families and countries is also significant. (Shattuck et al., 2012). Ari Ne’eman, an autism rights advocate, and Michael John Carley discuss the need for more funding for adults with ASC in the US. They believe that current government and organizational funding is misused. According to Ne’eman, adults with ASC need services, communication devices and increased family support. However, funding currently goes to research, which has little impact on the quality of life of adults with ASC (Williams, 2012).

In terms of higher education institutions, there is little evidence about the efficiency of current services for students with ASC. The majority of disability service centres have experience in supporting students with mobility disabilities, sensory disabilities, Attention deficit-hyperactivity disorder (ADHD) and Learning disabilities (LD), and few are familiar with the needs of students with ASC (VanBergeijk et al., 2008). The Individuals with Disabilities Education Act (IDEA) is a public law to ensure that students who are not progressing well academically due to a disability receive appropriate services. In secondary education, the services have to be free, individual, based on comprehensive data, and required according to the student individual educational plan the (IEP). An IEP includes educational objectives and the necessary accommodations to help a student achieve his/her academic goals. At the university level in developed countries, such as the US, students with ASC are offered different types of services by disability service centres. These services are based on civil rights, not educational rights. The rights of individuals with disabilities are obtained from section (504) and the American with Disabilities Act of 1990 (ADA). Both sections are intended to ensure equal access to higher education in the admission process and to ensure any necessary accommodations are provided. Employees must ensure that students with ASC receive appropriate accommodations, such as extra time for tests and a separate place for exam taking. According to section 504, employees do not necessarily need any special

training in special education. Many such employees work part time at disability service centres (Madaus, 2005).

Services for students with disabilities must be free of charge. However, the quality and practicality of services vary from university to university. Some institutions may offer comprehensive disability programs, which can include help with learning and writing skills, and one-to-one tutoring. These additional services may cost extra. In terms of admission requirements and course content, students with ASC should not be subject to any change in US colleges and universities in both aspects. However, because section 504 and the ADA are not educational laws, they do not detail the need to modify teaching methods. In higher education institutions, it is expected that students advocate for themselves. If a student does not self-disclose and later struggles in the course, the institution is not responsible for any negative consequences (Madaus, 2005).

How are adults with mild forms of ASC being supported at UK institutions of higher education?

Diagnosing individuals with mild forms of autism is still difficult and less recognized in the UK. The lack of diagnoses means a lack of support and a reduced quality of life (Research Autism, n.d). Generally, 40% of students with special needs are less likely to enter higher education institutions in the UK (Goodley and Madriaga, 2010). Students who successfully enter higher education institutions are not fully supported. According to Taylor (2005), higher education institutions are less equipped to teach students with ASC. Staff and students alike are less aware of and knowledgeable about ASC compared to other disabilities. Professionals in the field sometimes lack the ability to link theory with practice when working with adults with ASC (Morgan, 1996). Although the UK is known to have a wide variety of services for adults with ASC, there is lack of data about the number of individuals who benefit from these services. In addition, there is a significant need for research to evaluate the effectiveness of current support systems for this population. As in the US, there is a lack of transition planning, and individuals with ASC have indicated that the quality and quantity of services need to be improved (Taylor, 2005).

Staff at higher education institution disability service centres rarely engage directly with students with disabilities at secondary schools to inform them about what services will be available at college or university (Martin, 2003). Students with an official diagnosis of ASC who attend higher education institutions are eligible for the Disabled Students' Allowance (DSA) if they show evidence of a disability (such as a letter from a doctor or psychologist, or a statement of special educational needs). The DSA covers the cost of equipment, travel, a personal helper and other services that may be necessary to help a student with ASC cope with university life (Martin, 2003 and student support services, n.d)

How are adults with mild forms of ASC being supported in Saudi Arabian institutions of higher education?

The level of awareness about ASC has risen in Saudi Arabia during the last few years (Al-Salehi and Ghaziuddin, 2009). However, the quality and quantity of services is still limited. The financial aid that is being offered is insufficient for individuals with ASC. The government offers SR 20,000 annually to those with ASC, but the cost of rehabilitation and treatment is almost seven times more than this (over SR 130,000); this would put most families with members who have ASC in economic crisis.

Children are diagnosed and receive treatment at an older age due to the long waiting list. Psychologists and paediatricians who diagnose autism may deal with some families who are less educated and less aware of ASC. Some parents may believe that they themselves or a vaccine caused their child's autism. Some parents may also believe ASC is a result of the evil eye or black magic (Al-Qahtani, 2012). In terms of intervention and treatment, the majority of parents follow the medical model of disability, which considers autism a disease. They often seek medical treatment, such as a special diet or oxygen therapy (Al-Qahtani, 2012). Although the research findings emphasize that educational programs and behaviour interventions such as applied behaviour analysis (ABA) are more effective in the long run, few parents are aware of this.

Adults with ASC in Saudi Arabia tend to disappear after secondary school. Services to help with the transition from high school to higher education institutions simply do not exist. For the first time, a group of students with ASC entered higher education institutions in September 2012. It is expected that more students with an official diagnosis of ASC will enter higher education institutions over the next ten years. Unfortunately, Saudi professionals know little about the best practices to support adults with ASC. According to a study conducted by Al-Khashrami in 2011 at one of the largest universities in the capital city of Riyadh, the disability service centre only supports students with motor and sensory impairments and no services are offered for students with hidden disabilities such as ADHA or ASC. Unlike in the US, the admission requirements of Saudis universities accommodate students with disabilities. All Saudi students who plan to obtain an undergraduate degree are required to:

- pass the General Aptitude Test (GAT) (40%)
- have a secondary school Grade Point Average (GPA) of 60%
- pass the achievement test (biology, physics, chemistry, English and mathematics).

Students with disabilities are exempt from the last condition.

Based on personal experience, I can say that higher education institutions in Saudi Arabia are not fully prepared to accommodate students with ASC. For instance, the staff and students are offered no training or awareness programs. In addition, it is very challenging to find a mentor to support ASC students academically. In a case in which I was involved, the student's father was at the university for the first week, neglecting his job in order to support his son during his first days at university. Another significant issue is equal access to higher education. The student in question was excluded for four years after he graduated from secondary school. Moreover, his parents were not aware of foreign scholarships for students with special needs and thus missed many opportunities. The lack of laws and advocacy services are now part of autism history in Saudi Arabia. Currently, there are about eight advocates specializing in ASC who speak for people with ASC. They have successfully claimed the attention of local media (newspapers, television and radio) to advocate for equality and improved public services.

What are some international best practices for adults with mild forms of ASC?

Lifelong learning opportunities are a civil right for individuals with ASC. Equal access to education is a basic human right for all individuals, including those with disabilities (Cancro, 2009). Therefore, self-advocacy must be taught to students with ASC in an age-appropriate manner. This is the responsibility of parents, caregivers and educators. Self-advocacy is a necessary lifelong skill. Developing this basic skill will lead to greater independence and a better quality of life for individuals with ASC. According to the UK Disability Discrimination Act (1995), people with ASC are considered as being discriminated

against if educators, employers or governmental bodies fail to provide certain services, as listed in the following table.

| |
|--|
| 1. Provide opportunities to demonstrate through practice, on the job |
| 2. Provide a host to navigate the pre-entry and admission processes |
| 3. Provide materials and information in a manner the person can understand |
| 4. Make adaptations to communications |
| 5. Provide time to acclimatise to other people and situations |
| 6. Provide help to manage and acclimatise to new tasks |
| 7. Provide explicit information, explanations and signposts |
| 8. Provide opportunities to rehearse and practice |
| 9. Arrange managed transitions |
| 10. Give clear and explicit expectations and rules |

Table (1): The rights of adults with ASC (Graham, 2008, p.15).

Two hundred years ago, normalization ideology emerged as a result of poor quality services for people with disabilities. Normalization does not mean making individuals with special needs ‘normal’. It means adapting the environment to help them function as normally as possible, taking into consideration the degree of the disability, competence and maturity and the need for appropriate services (Morgan, 1996). High quality practices and services are associated with government action, positive attitudes among the public and services providers and a positive ideology. They are also associated with the quality of the relationship between service providers and individuals with ASC (Robledo and Donnellan, 2008). In addition, good autism practices are focused on individual needs and desires, especially in adulthood (Morgan, 1996). If foreign professionals are willing to offer their services to other countries, it is strongly recommended that they take the culture, beliefs and values of individuals with ASC into account and modify their support accordingly (Hussein et al., 2011).

Supporting adults with ASD must receive the same amount of attention as supporting children with ASC. Good practices, supportive services and success stories can positively impact the services offered. Closing the gap in services that exists in both developed and less developed countries will have a significant effect on student welfare.

The basic models for educating children with autism can be classified into three categories 1) home-based, 2) centre-based and 3) school-based. These also apply to educating adults with autism. Home-based services can focus on encouraging flexibility in behaviour by increasing the less structured environments and encouraging more socially complex interactions (VanBergeijk et al., 2008). Centre-based services are offered by disability service centres at higher education institutions. This includes social, communication and academic skills that are learner-centred (VanBergeijk et al., 2008). School-based services will be more diverse at the college or university level in terms of settings. Support will be given in seminars, lecture rooms and other areas on campus. (VanBergeijk et al., 2008) state that peer training has had a noticeable impact on ASC students in higher education settings, similar to secondary school settings.

Choosing the right university may not be an easy decision for adults with ASC. A university that can meet the needs of one student may not be the right choice for another. Students must find the university or college that can meet their social, communication, emotional and academic needs. The size of the institution is also fundamental in the decision making. (Hussein et al., 2011) compares small and large universities/colleges in terms of their ability to meet the needs of adults with ASC. Table (2) is a summary of the comparison.

| Elements | Small university/college | Large university/college |
|----------|--------------------------|--------------------------|
|----------|--------------------------|--------------------------|

| | | |
|--|--|---|
| 1. Lectures rooms | Small “Less sensory stimulations ” | Large “More sensory stimulations ” |
| 2. Social demands | Less | More |
| 3. Services provided by the disability service centre | Few students benefit from the centre Service is limited | More students benefit from the centre Wide variety of services according to the type of disability |
| 4. Developing students’ social skills | Little attention | More attention |
| 5. The structure and predictability of the environment | More | Less |

Table (2): Comparison of small and large colleges and universities

Conclusion:

In this paper, I discussed ASC and related theories. The difficulties adults with ASC face were also examined. The services available for adults with autism in three countries (the US, the UK and Saudi Arabia) were briefly investigated. The particular aim is to help service providers and professionals in Saudi Arabia reflect on their own practices and work toward a better outcome and life for adult students with ASC.

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