Ways of Removing Social Exclusion of Young Adults With Autism Spectrum Disorder: Educational and Workplace Behaviour Pathways

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Abstract

Although public health policies emphasize the need for inclusive communities, the participation of young adults with autism spectrum disorder (ASD) in postsecondary education and work is particularly low. This study is funded by the Hellenic Foundation for Research and Innovation and aims to explore the educational and working experiences of young adults with ASD (age range:18-35 years) in Greece. Participants are selected from a cohort of 1220 individuals with a childhood diagnosis of ASD. This cohort was primarily assessed in the ASD focused clinic at Agia Sophia Children's Hospital. Longitudinal data derived from standardized instruments used for diagnostic purposes are available and will be used as prognostic variables in relation to outcomes. Quantitative outcomes are explored via the administration of parental and self-completed questionnaires. In the present paper qualitative outcomes are explored using 30 semi-structured interviews, where educational and working experiences are probed. The major themes of the semi-structured interviews that have emerged from the study are: (a) the absence of services and lack of proper dissemination with regards to already established initiatives/services, (b) the high level of parental involvement in job seeking practices, (c) the experience of bullying, especially during primary and secondary school. This is an ongoing study looking into the educational and working experiences of young adults with ASD in Greece. Preliminary results point to several barriers related to inclusion in work and educational settings and highlight the need for better dissemination of information regarding the available services.

Keywords: autism spectrum disorder, social inclusion of young adults

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Introduction

ASD is defined as a lifelong developmental disability that affects how a person communicates with, and relates to, other people and makes sense of the world around him (National Autistic Society, 2021). According to DSM-5, ASD is characterized by longstanding deficits in social communication along with stereotyped, restricted, and repetitive patterns of behavior and interests. ASD has great phenotypical diversity and considerable profile changes over the lifespan in comparison to other neurodevelopmental disorders (Lord et al., 2021). ASD is usually diagnosed during childhood and has had an increasing prevalence worldwide over the past two decades; prevalence estimates in most of the studies range between 0.8% to 1.5% (Fombonne, 2018; Helles et al., 2017; Lyall et al., 2017).

A recent study in Greece estimated overall prevalence to be 1.15% with a large variation between studied regions (0.59%-1.5%) (Thomaidis et al., 2020). The oft reported male to female ratio in ASD is 4:1 (Perez-Crespo et al., 2019; Theodoratou & Farmakopoulou, 2021). In adulthood the severity of symptoms and the level of functioning vary, ranging from autonomous young adults to individuals with restricted autonomy, Intellectual Disability (ID), and other comorbidities for whom continuous and substantial support is necessary. Between 73-81% of adults with ASD meet criteria for at least one co-occurring psychiatric disorder, the most common of which are depression, anxiety, obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) and personality disorders (Hossain et al., 2020; Vohra et al., 2017). Multiple diagnoses are also common (Howlin & Magiati, 2017; Lugo-Marin et al., 2019). A more recent study by Pehlivanidis et al. (2020) 33.3% of newly diagnosed adults with ASD received an ADHD diagnosis. Research has repeatedly demonstrated how the added impact of comorbidities can affect subjective QOL outcomes (Helles et al., 2017).

Social Inclusion in Post-secondary Education of ASD Transition-Aged Young Adults

One area where young adults with ASD lag in comparison to their typically developing peers and youth with other disabilities is post-secondary education (Griffiths et al, 2016; Lord et al, 2021). People with ASD and normal intellectual functioning face difficulties in degree completion, resulting in a high drop-out rate in this group (Helles et al., 2017). The postsecondary educational outcomes of young adults with ASD are worse than those of youth with other disabilities (Griffiths et al., 2016; Lord et al., 2021). The report commissioned by the US Department of Education found that students with ASD in the U.S. have one of the lowest rates of post-secondary education (44%) when compared to the general population (67%) and other disability groups (60%) (Newman et al., 2011). In a follow up study, Taylor et al. (2015) demonstrated the high risk of dropping out of university/college in this population with only 25% of young ASD adults maintaining their educational/occupational activities over a given period. Migliore et al., (2012) who examined the predictors of employment and post-secondary education outcomes for young adults with ASD found that high parental involvement during this transitional period and a higher socioeconomic status were positively associated with receiving college services and participating in post-secondary education.

The characteristics of post-secondary students with ASD are diverse and unique to everyone; they may possess significant strengths such as a superior memory, a detail focused processing bias, and a single minded and determined nature (Van Hees et al., 2015). Due to the repetitive and restrictive nature of their interests, they may often have amassed an impressive amount of knowledge on a single topic (Drake, 2014). Some students made reference to their personal strengths to their academic success. (Van Hees et al., 2015) These included strong technology and self-advocacy skills, persistence, and an intense interest in the subject they were studying. Furthermore, students posited diligence and determination for degree completion related to and gaining future employment as important traits for academic success (Drake, 2014; Van Hees et al., 2015).

However, many students with ASD face difficulties within educational settings that relate to both academic and non-academic issues. For example, when posing a question in class, participation in group work, performing presentations, and understanding abstract or ambiguous concepts have all been reported as relevant issues by students with ASD. (Knott & Taylor, 2014) Moreover, challenges related to sensory overload and routine adherence tend to flare up in college/university where everything is novel and the individual is asked to make numerous choices (Van Hees et al., 2015) In addition, lectures are often held in auditoriums that can house many students, something that can prove very distracting for students with ASD. Finally, young adults with ASD report experiencing high levels of depression and anxiety during this period, which stems from the social demands placed upon them in this new setting.

Social Inclusion in the Workplace of ASD Transition-Aged Young Adults

Employment is a basic human right. It is associated with improved physical, psychological and social wellbeing and contributes to financial independence, thereby increasing one's probability of independent living and reducing one's dependence on benefits (Anderson et al., 2021; Griffiths et al., 2016). Although, globally, numerous public policies highlight the necessity of moving towards inclusive societies and the importance of social inclusion of people with disabilities, unemployment statistics reported by the National Autistic Society (NAS) in 2021 are disheartening with only 15% of young adults with ASD reported as working, while, 69% are reported as having the ability and willingness to work (National Autistic Society, 2021). Studies of young adults with ASD have repeatedly shown that these individuals have much higher rates of unemployment than the general population and individuals with other disabilities (Krumpelman & Hord, 2021).

Additionally, a considerable number of young adults with ASD who are employed on a part-time basis, are underpaid compared to their peers without ASD, and experience ongoing problems with maintaining work. (Taylor et al., 2015) They are also more limited with regards to the types of work available to them (Griffiths et al., 2016; Nord et al., 2016).

In the words of young adults with ASD and their parents/carers, full time work is associated with meaningful experiences, higher self-esteem, the provision of a daily routine, financial independence and constitutes a valuable springboard for social interaction. (Anderson et al., 2021) Therefore, understanding the predictors that can lead to full time employment in this group, and designing practices that can build on their experiences and personal strengths is essential for promoting inclusive practices at work for young adults with ASD. Services that include job finding, job maintenance, and on-the-job support as well as internship placement services are associated with the best occupational outcomes (Migliore et al., 2012).

Many young adults with ASD report difficulties with respect to the performance of multiple duties/roles within the work setting seeing as it challenges their predilection for sameness and routine. In terms of gaining employment, the interview process is stated as the biggest challenge for young adults with ASD as it partly revolves around an assessment of their social skills. Parental psychological and practical support during this time is reported to be of paramount importance for this population, mirroring results from the educational outcomes research (Lord et al., 2021). Parents of young adults with ASD have referenced the lack of careful matching between the job seeker's skill set and the offered position (e.g. placing young adults with ASD in front desk customer service positions).

Understanding the Facilitators and Barriers to the Development of Inclusionary Practices

Throughout history, adults with ASD (and those with other disabilities) have been excluded from educational and working opportunities and, thus, fail to fully participate in their communities, make their own decisions, and influence the power structures designed to support them. In response to this social phenomenon, the inclusion of ASD young adults into society is increasingly the focus of research and policy making. Working organizations are beginning to introduce changes to their establishments to make them more inclusive. However, they often do not follow through with the appropriate workplace adaptations necessary for young employees with ASD to succeed.

To address the unique challenges facing this population, there is a need to document experiences as they relate to their successes and struggles at post-secondary education and working employment. Additionally, it is important to understand how individual (e.g. autism severity), family (e.g. maternal depression) and environmental (e.g. availability of transition services) factors affect the opportunity landscape for these young adults. In essence, what is needed is the creation of new tools that will be able to capitalize on our prior knowledge about the characteristics of ASD, e.g. known talents and weaknesses and match them to suitable degrees/jobs.

The next sections of this essay focus on an innovative research study which is funded by the Hellenic Foundation for Research and Innovation (ELIDEK) and aims to explore the educational and working experiences of young adults with ASD in Greece.

Mixed Methodology of the Research Study

Objectives of the Research Study

One of the major aims of the current study is to record the views of young adults with ASD, their suggestions for changes to the current educational and working practices, which we are hoping will lead to the design of better inclusion practices. As part of our study we would also like to explore the participants' own views about where their strengths (and weaknesses) lie. Thus, instead of focusing solely on the exploration of environmental facilitators and barriers (social, attitudinal, and institutional factors) relevant to educational and work participation for transition-aged young adults with ASD, the present research study will also take into consideration the participants' unique talents and strengths. Some of these talents can become valuable assets in educational and working settings given a well-designed support system. In other words, typical characteristics of individuals with ASD such as their "detailed oriented processing style" could be transformed into an asset by enrolling them in suitable jobs.

Overall, the present research study has four main objectives:

a) To identify early predictors of educational, employment and quality of life (QOL) outcomes in young adults with ASD (ages 18-35). This group can be rather heterogeneous with large variances in Intelligence Quotients and type of comorbidities.
b) To explore the educational and working experiences of this population the research team utilized semi-structured interviews. With this work the research team intended to investigate the environmental factors that act as facilitators or barriers to the educational and working inclusion of this population. It is important to state that no such study has been conducted in Greece. This is particularly important since socio-ecological factors vary tremendously from country to country.
c) Individuals with ASD regardless of cognitive ability often have particular strengths like paying attention to detail or rules following that are desirable in educational and workplace settings. Therefore, the research team included questionnaires that identified talents/strengths in the ascertained population to explore and promote the existence of different working profiles.
d) To introduce recruited participants to a newly developed tool *Jobslink* (https://asperger.gr/), the only platform for seeking employment for adults with ASD.

In comparison with most published studies to this field that typically report on a small number of participants (Scott et al., 2019) with rare exceptions (N = 123; Lord et al., 2021), the current Greek ASD cohort (370 young adults, 18-35 years of age) is one of the largest. This fact allowed the research study to go into depth exploration of factors that affect employability, educational prospects and overall QOL. Also, the collaboration between the ASD outpatient clinic and the Adult Neurodevelopmental Unit of the 1st Department of Psychiatry of the National and Kapodistrian University of Athens (NKUA), housed at Eginition Hospital, is among the very few examples of continuity of care in health system in Greece. The inclusion of the recently developed job seeking platform (Jobslink (https://asperger.gr/) for individuals with ASD without ID (formerly classified as Asperger in DSM-IV) the research team expects to actively promote the employment of young adults with ASD. Results from this endeavor will help to redesign novel platform features with the aim of maximizing employability.

In the present paper, we are reporting on the qualitative outcomes from the semi-structured interviews focused on work and educational experiences. (Objective B).

Study Sample

Participants are selected from a cohort of 1220 individuals with a childhood diagnosis of ASD. This cohort has been assessed in the ASD focused clinic at the “Agia Sophia” Children’s hospital. Longitudinal data, and, in many cases repeated measurements are available including results from standardized instruments such as the ADOS2, the ADI-R, the Vineland Adaptive Behavioral Scales and the Wechsler Intelligence Scale for Children. The assessment protocol has been derived from the research protocol adopted by the *International Molecular Genetics of Autism Consortium*. Outcomes are explored via the administration of parental and adult questionnaires. Young adults (18-35 years old) who have a childhood diagnosis of ASD, including those with ID and other comorbidities were eligible to participate in the present study. Upon completion of parental questionnaires, young participants with ASD having prior or current postsecondary education and/or work experience were identified and contacted.

Semi-structured Interviews

The thirty (30) semi-structured interviews who were conducted with young adults with ASD were split into two main themes (education and employment experiences). Participants who agreed to take part were sent a zoom link and a time and day for the interview was set. A degree of thematic overlap was present in the two types of interviews, since to build up to one's working experiences, one must also interrogate broader educational experiences.

The main subthemes of the interview guide that focused on the educational experiences of the young participants with ASD were the documentation of their: a) experiences from their primary and secondary education, b) transitional period from school to postsecondary education, c) experiences from their student life, d) exploration of educational support systems, e) strengths, talents and gifts in education and f) proposals for more inclusive educational settings. Regarding the central subthemes of the interview guide of the working experiences of the interviewees, special emphasis was given to the reporting of their: a) schooling and studying experiences, b) transitional period from studying to job searching, c) documentation of their previous and current working experiences, d) inclusive practices of the working environment, d) exploration of strengths, talents and gifts in workplace, e) recommendations for more effective inclusiveness in working employment for young people with ASD. Participants were often asked to expand their answers by giving specific examples, which were proved to be very illuminating. Responses were transcribed automatically by the recording software and were then checked for consistency between the audio and the transcription. Analysis of the qualitative data used a narrative approach due to the opportunity that it offers to listen to the voice of young people with ASD documenting their experiences. As an approach it reinforces the concept of self-advocacy and active participation. Twelve young males and three females with ASD participated in the semi-structured interviews for the documentation of their educational experiences and similar number of males and females were interviewed to report their working experiences.

Findings From the Semi-structured Interviews With Young Adults With ASD

As has already been mentioned due to the restricted extent of this paper, the focus is placed on the presentation of the findings of the qualitative data, which included thirty (30) semi-structured interviews with transition-aged young people with ASD. It is crucial to be mentioned that for first time in Greece it was given the opportunity to young people with ASD to express their views, concerns and recommendations for ameliorating their educational and working conditions.

Many of the findings of this research study are consistent with those of previous related studies. However, several unique results emerged, which are likely due to cultural issues and particularly the fact that in Greece informal networking is well developed and the families are child centered. Another important element that highlights the Greek reality is that stigmatization of people with disabilities continues to be apparent, especially to those who live in remote places such as provinces and islands. This unfavorable situation often leads to incidents of bullying during primary and secondary education of pupils with ASD as well as to adaptation and socialization difficulties during their education at colleges and universities. Also, the severe lack of services offered to young adults in general, and especially to people with disabilities and young people with ASD, seems to play an important role.

Results Related to Educational Experiences of Young Persons With ASD

A finding that is consistent with previous research studies is that young people with ASD, even those with normal intellectual functioning, face various difficulties in completing their studies, resulting in a high drop-out rate in this group (Helles et al., 2017). Most participating young people with ASD reported several bullying episodes -particularly during their childhood- which decreased in intensity and frequency during their adolescence. Some participants explained that they had been or continue to be victims of school bullying during their studies period. Typically, one participant reported:

> Nobody wanted to become my own friend at primary school. Some of my classmates called me ‘crazy’ and others ‘stupid’ because in the first grades I didn't speak clearly or because I had great difficulty in grammar and math’s. I always felt like an outsider and this adverse situation continues at the university I attend, where no one is sitting next to me in the auditorium during lectures. (MEE12) (Male Educational Experiences, 12)

Most participants explained that they have not graduated for several reasons, mainly due to their lack of participation in the exams because of their fear of failure. Some other interviewees reported that although they took part in the exams on several occasions they indeed did not manage “to pass” the courses undertaken. One participant recounted his overall negative educational experiences saying:

> I went to a mainstream school where I attended a special classroom for pupils with special educational needs for a few hours daily. My classmates constantly made fun of me for it and called me 'the retarded' or 'the weird one' and I recall that I often cried and being isolated in a corner in the school yard. Also, at the University period no one bothered to inform me that there was a Student Support Office and so several professor's slides seemed incomprehensible to me, and I felt embarrassed to ask for further explanation. Thus, during exam period I used not to learn adequately each subject and gradually to start having several courses that I have not passed it, and this situation discouraged me and made me to drop out from my studies. (FE2) (Female Educational Experiences, 2)

Another participant talked about the great difficulty he faced in his student life in establishing friendships with his fellow students:

> I felt like I was invisible, professors asked us to split into groups for working on assignments and no one suggested to join their group and sometimes when I suggested going out for coffee with one or two of them they lied to me that they would not go out but it happened to meet them in a cafe nearby being together having fun. (ME4)

Of course, positive educational experiences were also recorded, especially regarding the student life of some young adults with ASD, where according to their reports they had no difficulty in establishing and maintaining friendships with 2-3 fellow students. A few participants stated that they found their studies very interesting and graduated in four years and carried on doing postgraduate studies which they have also successfully completed on time. Most young people with ASD claimed that they preferred studying at colleges to universities since it was less demanding and lasted for a shorter period (2 vs 4 years).

However, several interviewees reported that although they enjoyed their studying period, they considered their exams difficult and therefore they finally did not get the college certificate.

Results Related to Workplace Experiences of Young Persons With ASD

As has already been analyzed in the first section, work is a fundamental right for every human being and is associated with improved physical health, contributes to the employees' mental health and self-esteem. It also increases the likelihood of independent living and promotes socialization and relationship building (Anderson et al., 2021; Griffiths et al., 2016). However, several research studies have found that young adults with ASD have much higher rates of unemployment than the general population (Krumpelman & Hord, 2021) and individuals with other disabilities (Wei et al., 2018). This study confirms the above-mentioned findings, since many of the participants stated that they have met a variety of obstacles both in managing to get a job but also to maintain it. An often complaint from the interviewees was the lack of support services for young people with ASD. Several participants mentioned active parental involvement, and one said:

> I honestly don't know what I would have become if I hadn't had the constant help of my parents, especially my father's assistance. He showed me how to make a resume (CV), we did role plays where he asked me possible questions that employers would ask me in a job interview. I strongly believe that this is the State's role, but they do not seem to care about people with disabilities. (MWE1) (Male Workplace Experiences, 1)

An interesting comment that several participants have made is that even if there are a couple available Support Services for young people with ASD, they are not aware of them, or they learn about it by coincidence. For example:

> A social worker recently informed my mother that there is a non-governmental organization called 'Asperger Association' that specializes in the needs of people like me, and it operates an employment platform called 'Jobslink' that helps you get a job matched to your own assets. I intend to get in touch with them, and I will try to get a better job. (FWE2)

Moreover, another interviewee explained that a neighbor informed him about another new non-governmental organization called "routes/diadromes" that is funded by a European Union Program (KISPE) which aims at helping young people with ASD to get a job. He said:

> I will definitely address this service because I want to find a full-time job where I will be well-paid as my goal is to try to rent a flat and achieve eventually my independent living. (MWE3)

Previous research studies have also put emphasis on the type of jobs offered to young people with ASD and especially the fact that the transition-aged people with ASD are usually on a part-time basis and get low-paid jobs and rarely acquire jobs tailored to their strengths and capabilities. In addition, half of the interviewees claimed that in the provinces and islands that they live in most people tend to gossip, to have bias and stereotypes for people with disabilities like themselves. One male interviewee said:

> Although I have tried hard to find a job that is related to my studies, since I have failed to find an appropriate one, I work at a part-time sales assistant post. If I dared to tell the truth about my disorder (ASD) I am certain that they would never have hired me. At my first job I made this 'silly' thing and talked to my employer about my disorder since we have had a very good relationship and he immediately changed his attitude towards me and within the end of that month he found an excuse and fired me. (MWE11)

On the other hand, a few participants stated that they were very satisfied with their current job, and they have found a workplace that matched their qualifications. However, even in these cases they explained that they got this job due to their parental involvement. Their father usually knew the employer and highlighted the strengths of the employment of their son/daughter such as that they are hardworking, they seldom make a complain and that they are devoted to their work, have exceptional ability to memorize and process numerical data.

An interesting quotation for a satisfying young female working person with an ASD is as follows:

> I am very happy at my own job. When my employer or my colleagues are stuck at various job stages, they often call me to solve the various problems, and I always succeed in this. They often call me 'number magnet' because I am very good at math's. (MWE3)

However, when the same interviewee was asked about his socialization experience in her job she mentioned:

> They often say that we will all go out together as a team to drink wine to celebrate our successful work outcomes, but so far, we have not been able to do it. I do not know if they go out by themselves and forget to tell me. I am thinking to ask a colleague to go to watch a movie together. (MWE3)

Discussion

Several studies have found that the postsecondary educational outcomes of young adults with ASD are worse than those of youth with other disabilities (Griffiths et al., 2016; Nord et al., 2016). In addition, young adults with ASD and normal intellectual functioning face difficulties in degree completion, resulting in a high drop-out rate in this group (Helles et al., 2017). This research confirms these findings since many participants faced a variety of educational difficulties and have not graduated, even those who studied at college, mainly due to their exam related stress.

Moreover, several research studies have found that young adults with ASD have much lower rates of getting and maintaining a job compared to the general population (Krumpelman & Hord, 2021) and individuals with other disabilities (Wei et al., 2018). The present study confirms this trend. Previous research studies have also put an emphasis on the type of jobs offered to young people with ASD. Namely, they are usually employed on a part-time basis, have low-paid jobs. Similar conditions were reported in our cohort. Nevertheless, some of our participants reported feeling satisfied with their current position and working conditions since their strengths and talents were not only noticed by their employers and employees but have also been appreciated by them.

The lack of awareness about available services was a recurring theme when participants were asked about employment and educational resources. A specialized governmental platform that presents such information all in one place needs to be created and at the same time there is a need for awareness campaigns that can reach even those families that are not fluent in the use of technology. Many participants also alluded to the actual lack of services aimed at facilitating their inclusion in the workplace and educational settings. Parental association initiatives such as the one developed by the Hellenic Association of Asperger, whereby a mentor is assigned to each new person who signs up on their job seeking platform, are steps in the right direction. It is important that such initiatives are supported, advertised, and become inspiration for many more such endeavors.

As has been shown many of the findings of this research study are consistent with those of previously published studies. However, several unique results have emerged, which are likely the result of cultural differences between the various countries. One such difference is the level of parental involvement in the lives of young adults with ASD and their active role in job scouting and maintenance. Many participants reported that they found a job due to their parents using their personal connections (i.e. informal networking).

Another important finding is that our participants reported experiencing continued bullying, especially those who live in the province. Incidents of bullying during primary and secondary education were reported by most participants, which however, seemed to subside as they grew older. This may be partly the result of older children's ability to exercise more self-control and refrain from bullying someone else in comparison to younger children who cannot. Psychoeducation can play an important role in lowering bullying incidents and there are many such initiatives that Greek policy makers can take inspiration from. Wang and Susumu (2024) have argued for a zero-tolerance attitude with regards to bullying in schools and at the same time assessing teacher's and staff's beliefs on ASD and its characteristics.

Conclusion

The thorough understanding of work-related challenges, environmental facilitators and barriers is expected to aid educators, clinicians, service-providers, employees, researchers, and policy makers as they develop interventions and improve systems designed for the educational and occupational inclusion of young people with ASD. The research team expects that this research will lead to designing a more inclusive educational and working model that addresses important flaws in the current system.

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Declaration of Generative AI and AI-Assisted Technologies in the Writing Process

I declare that the research team has not used AI and AI-assisted Technologies in the Writing Process.

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