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Toward the Successful Employment of Adults with Autism: A First Analysis of Special Interests and Factors Deemed Important for Vocational Performance

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Abstract

Background: Adults with autism spectrum disorders (ASDs) and with intelligence quotients in the normal range are disproportionately affected by unemployment.

Objective: We sought to assess special interests that could bear potential for employment as well as factors deemed relevant for work performance in adults with ASD.

Method: A newly compiled self-report online questionnaire was administered to high-functioning adults with ASD to assess special interests as well as factors that both interfere with and facilitate work performance.

Results: Participants reported that they spent an average of 26 hours per week on their special interests, and their average level of proficiency was rated as very good. Although special interests were reported to be in the social sciences and the creative fields as often as they were in the natural sciences and technology/engineering, the most common approach taken within those fields was systemizing rather than a creative or knowledge-acquiring pursuit. Social interaction problems with coworkers and superiors as well as sensory issues were most often rated as interfering with work performance. In addition, mental underload was rated as an important factor that interfered with work performance, whereas excessive demands were not. Among the factors most often reported to facilitate work performance were employers' and colleagues' awareness of the individual's ASD diagnosis.

Conclusion: Our data suggest that special interests among individuals with ASD may bear important potential for employment. Given the focus on systemizing in this population, recent efforts to create job opportunities in the information technology sector specifically for high-functioning individuals with ASD are a promising start. However, these efforts should be expanded into other fields.

Keywords: autism spectrum disorders, special interests, employment

Introduction

Autism was first described in the 1940s by Leo Kanner (1). The condition is characterized by early impairments in social interaction and communication and by a restricted repertoire of activities and interests (2). Although it was originally assumed that autism was a rare disorder, with approximately 2 to 4 children per 10,000 affected (3), recent studies have reported prevalence rates of approximately 1% for all autism spectrum disorders (ASDs) (4,5). Since Kanner's first description, enormous progress has been made in the area of

autism research, but only in recent decades has there been a shift in focus from children with ASD to adults with ASD.

Studies of outcomes in adulthood have shown that symptom severity often decreases with age (6); however, individuals with ASD seem to remain dependent on their families after their transition to adulthood (7,8), and their employment outcomes are poor (8-10). Shattuck and colleagues (10) analyzed data from the National Longitudinal Transition Study 2, wave 4, a nationally representative survey of young adults who had received

special education services during high school. Individuals with ASD had the lowest rates of ever having been employed during the first six years after high school (55.1%) as compared with individuals with other disabilities (i.e., speech/language impairments, learning disabilities, and mental retardation). Roux and colleagues (11) found comparable results when analyzing data from wave 5 of this same study. Approximately 50% of individuals with ASD between the ages of 21 and 25 years had the lowest rate of currently or ever having a paid job after leaving high school as compared with individuals with emotional disturbances, disabilities, speech/language learning and impairments. Furthermore, average wages and the variability of jobs were lower in the ASD group than in the comparison groups. At the time of the study, approximately one third of the participants were employed.

Howlin and colleagues (8) followed up with a cohort of individuals who were diagnosed with autism during childhood and reported that only nine out of 68 individuals (age range, 21 to 48 years) were competitively employed at the time of the follow-up study; most of the others were working in sheltered work environments. Studies of supported employment programs and vocational rehabilitation services are still limited and are often of poor research quality (12). Burgess and Cimera (13) found that approximately one third of participants with ASDs who participated in a vocational rehabilitation service were employed; however, rates varied between 25% and 50% across the United States. Another study by Howlin and colleagues (14) examined the outcomes of a supported employment service (NAS Prospects) for adults with ASD and intelligence quotients of at least 60 and found that, after eight years, approximately two thirds of the participants were employed, with most of their contracts being permanent. Mawhood and Howlin (15) conducted a quasi-experimental study that compared employment outcomes between an experimental group of high-functioning adults with ASD (n = 30) who received support with job finding, work preparation, and communication with their employers with those of a control group of high-functioning adults with ASD (n = 20) who did not receive any support. After two years, the experimental group showed significantly higher rates of employment (63%) as compared with the control group (25%).

Evidently, employment outcome varied considerably in these revised studies; however, results are difficult to compare due to the different elements of support offered, the duration of the studies, and the functioning levels of the participants. It has been suggested that especially

high-functioning individuals with ASD may be disadvantaged in terms of access to the support they need to find employment. Taylor and Seltzer (16) concluded that youths with ASD "in the mid-level of functioning—not severe enough to receive adult day services but too severe to function independently— (...) are 'falling through the cracks' during the transition to adulthood."

During the last decade, there have been new efforts to create job opportunities for highfunctioning individuals with ASD by start-up companies in the information technology sector, such as Specialisterne (e.g., Denmark, Iceland), Passwerk (Belgium), and Aspiritech (United States), most of which train their employees as software testers and offer job coaching and other individual support. Software testing is believed to be a task that autistic individuals perform well as a result of a working style characterized by attention to detail (17), precision, an affinity for repetitive tasks (18), and a general interest in technology (19). This approach has been successful for the creation of jobs for autistic individuals, and there are similar start-up companies in numerous other countries (e.g., Germany, Japan, Switzerland). However, the number of jobs offered by these companies is limited, and they seem to match the strengths of only a subgroup of adults with ASD.

An appropriate job-match based on interests and strengths while at the same time considering weaknesses and offering long-term on-the-job-support seems to be the key to successful employment (20–22). Migliore and colleagues (23) found the probability of leaving a vocational rehabilitation program with employment to be four times greater among those who received job placement services than for those who did not. Hence, job placement is the strongest predictor of successful employment. That being said, little is known about the typical strengths and interests of individuals with ASD.

Surprisingly, the common presence of special interests in high-functioning adults with ASD, which could guide the search for employment strategies, has been mostly disregarded by the scientific community. Special interests have been estimated to exist in 90% of individuals with Asperger syndrome (24), and Asperger himself (25) claimed in his first descriptions that special interests can lead individuals with the syndrome to outstanding achievements in their chosen areas. To date, only a few studies have addressed special interests in individuals with ASD, and these have been limited to children and teenagers (26-29). Standardized instruments to assess special interests and their potential for employment in individuals with ASD are thus currently lacking.

The main goal of this exploratory study was to assess for the first time the areas of special interest for adults with ASD. In addition, we sought to identify more generally factors that are important for the successful employment of individuals with ASD.

Methods

Survey development

To assess information about employment from individuals with ASD for this exploratory study, a self-constructed questionnaire was used. The survey consisted of three parts: 1) background information and evaluation of the employment situation; 2) the special interests; and 3) factors individuals' interfering with and facilitating job performance. (The items of the questionnaire can be found in the Appendix.) There was no forced answering format (apart from the diagnostic items, which had to be filled out), and participants were allowed to skip questions. In the Results section later in this article, we indicate how many participants answered each item, and the results reported refer to that number accordingly. The questionnaire was developed in cooperation with a start-up company seeking to develop jobs for individuals with ASD and a focus group of adults with ASDs to ensure accessibility, respect, inclusion, and relevance of items.

Part 1: Assessment of autism diagnosis and background information

Autism diagnosis was assessed with the use of a two-step procedure. Participants were first asked more broadly if they were on the autism spectrum. Next, participants were asked if they had an official clinical ASD diagnosis and, if so, to indicate which one. Only those participants who reported that they had an official clinical diagnosis of ASD were included in the study. Additional background information (e.g., education, current job situation, satisfaction with job situation) was also obtained.

Part 2: Special interests

Special interests were assessed with the use of a two-step procedure. First, participants were asked to describe their special interests in an open-answer format. The information provided was subject to an analysis of the main approach by which the special (e.g., pursued programming, interest was categorizing). Second, each participant was asked to choose from a list the field of his or her special interest (e.g., mathematics, sociology). Although a comprehensive choice of fields was provided, participants could add additional fields if none of those provided matched their special interests.

Approach taken to the special interest. Thirty-one participants were included in the analysis, because only their answers provided enough detail for categorization according to the approach with which their special interest was pursued. In accordance with the principles of qualitative content analysis (30), as a first step, categories were built inductively on the basis of the content of the provided answers. After that, anchor examples were collected, and coding rules were defined to specify the assignment of the different answers to the categories (Table 1). In the next step, participants' answers (e.g., "searching for errors in software code," "collecting information about autism diagnosis and diagnostic system") were assigned to the four categories by two independent raters. The Cohen's kappa value for the assessment of interrater agreement was .94.

TABLE 1. Approaches

	Examples		
The creativity approach consists of all creative	Playing an		
activities, such as making music, painting, and	instrument,		
designing. The activity itself has to be creative, but	designing objects		
this criterion is not met by simply being in a creative field			
The systemizing approach contains all activities that involve analyzing, constructing, or controlling a system. A system is defined as something that follows repeated, lawful patterns. The focus can be on small parts of the system, such as numbers, or the overall purpose of the system, such as programming software	Categorizing photographs, analyzing mathematical problems		
The knowledge approach comprises those activities that are best described as accumulating knowledge about certain subjects	Acquiring information about plants, performing Internet research regarding historical events		
The "other" category should be assigned only if the			
approach to the special interest does not fall into any			
of the above categories			

Field of special interest. For analysis purposes, the fields were grouped into superordinate interest themes (29): human and social sciences, natural sciences and technology/engineering, and creative fields. See Table 2 for a list of the fields used and their correspondence with the special interest themes.

TABLE 2. Superordinate interest themes and fields

Human and Social Sciences	Anthropology, education, ethnology,
	history, law, philosophy, politics, psychology, sociology, economics
Natural Sciences and Technology/Engineering	Biology, biochemistry, geology, agriculture, mathematics, physics, engineering, informatics
Creative Fields	Architecture, photography, graphic design, product design, fine arts. music

Time spent on special interests and skills. Participants were asked to indicate how much time they spent on their special interests in a typical week and to evaluate their skill level with regard to their special interests.

Part 3: Factors interfering with and facilitating job performance

A list of factors that potentially facilitate job performance and of those that may interfere with it was developed. The authors generated items based on a literature review (22,31) and on personal conversations with adults with ASD. A focus group of adults with ASDs then provided feedback on the items and added items that were deemed relevant. Study participants were asked to select from this list the factors that had interfered with their job performance in the past and the factors that they deemed important for facilitating job performance in general.

Data collection

The online survey was distributed through mailing lists and postings on bulletin boards for the autism community, and handouts were displayed in outpatient clinics. Participants received no incentive to participate. All surveys were completed anonymously. All parts of the study were conducted according to the declaration of Helsinki, and all subjects provided written informed consent.

Results

Part 1: Autism diagnosis and background information
The survey was completed by 108 adults. Those
participants with an official diagnosis (N = 76),
which was of Asperger syndrome in all cases, were
included in the analysis. For demographic data, see
Table 3.

TABLE 3. Demographic Information

	N	%
Gender (N = 76)		
Male	33	43.4
Female	43	56.6
		_
Age (N = 76)*	36.1 ± 11.1	Range:
		19 to 60
Education (N = 67)		
No school degree	2	2.7
Basic school degree (~9 years)	14	21
Vocational degree	12	18
Superior school education (~A	17	25.3
levels)		
University degree	22	32.8
Current job situation (N = 64)		
Employed	21	32.8
Self-employed	8	12.5
Currently studying	3	4.7
Disability benefits	3	4.7
Sheltered work	2	3.1
Internship or vocational training	4	6.3
Unemployed	23	35.9

^{*}Values are given as mean ± standard deviation

With regard to their current job situation (N = 64), 33% of participants reported that they were employed, 13% said that they were self-employed, and 36% reported that they were unemployed. Participants who were currently employed and those who were working freelance, respectively, indicated satisfaction levels with their employment situations to be more or less satisfying (N = 31; mean = 3.01; standard deviation [SD] =1.15). On average, participants indicated that they had not or had only slightly been able to use their vocational potential in the past, with unemployed participants scoring significantly lower (N = 23; mean = 1.74; SD = 1.1) than participants with jobs (N = 31; mean = 2.7; SD = 1.3; t(52) = 2.76; P <.01). Unemployed individuals (N = 23; mean = 4.3; SD = 0.93) scored as high as employed individuals (N = 31, mean = 4.26; SD = 1.03, t(52) = -0.17; P= .87) when asked to indicate whether they had relevant skills for the job market.

Part 2: Special interests

Approach taken to the special interest. The distribution of the categories was 55% for the systemizing approach, 28% for the creativity approach, 14% for the knowledge approach, 3% for other approaches. Two items on which the raters did not agree were excluded.

Field of special interest. Of the 54 participants who indicated their special interests, 38% reported a special interest in the natural sciences or technology/engineering, 34% had a special interest in the human and social sciences, and 28% had a special interest in creative fields.

TABLE 4. Approach and field of special interest

Approach (N =31)	N	%
Systemizing	17	55
Creativity	9	28
Knowledge	4	14
Other	1	3
Field (N = 54)		
Natural sciences and	21	38
technology/engineering		
Human and social sciences	18	34
Creative	15	28

Time spent on special interests and skills. Participants (N=51) reported that they spent an average of 26.2 hours per week (SD=16.3) on their special interests. There was no significant difference between participants with or without jobs. Participants rated their average levels of skill regarding their special interests as very good (mean = 4.2; SD=0.91).

Part 3: Factors interfering with and facilitating job performance

Social factors such as problems with colleagues (76%) and superiors (74%) as well as sensory issues involving smell (60%) and background noise (64%) were most often rated as interfering with job performance. With respect to intellectual challenge, mental underload was rated by two thirds of the participants (70%) as an interfering factor, whereas excessive demands were only indicated by a minority of participants (23%). Among the factors most frequently rated as facilitating job performance were employers' (78%) and colleagues' (66%) awareness of the individual's autism diagnosis, quiet surroundings (76%), and an undisturbed working space (74%). Complete results are displayed in Figure 1, \mathcal{A} and \mathcal{B} .

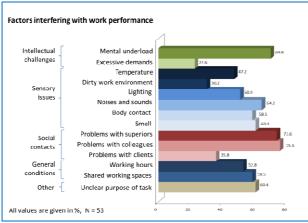


FIGURE 1A

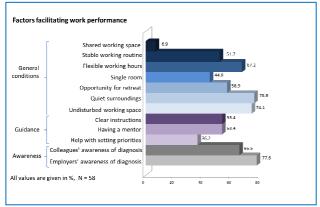


FIGURE 1B

Discussion

We found that, despite high levels of education, more than one third of the participants with ASD in this study were unemployed. This number is well above the current general unemployment rate in Germany of 6.6% (32), but it is in line with other studies that have reported high unemployment rates among individuals with ASD (8,10,33-35). We

carefully suggest that, despite predominantly high levels of education, individuals with ASD seem to not be able to fulfill their full potential. Given that unemployment is associated with emotional-behavioral issues and health problems (36) and that it has a negative impact on life satisfaction (37), this is alarming. Moreover, several researchers have pointed out the high cost to society that arises from the high number of unemployed individuals with ASD (38,39).

Special interests

This article is the first to assess special interests with the use of a two-step procedure that focuses on both the approach and the field of interest. Although an effort is made to relate our results to previous research, this is somewhat hindered by the different approaches taken to examine interests among individuals with ASD by prior studies (26,27,29) and the fact that study participants were children and teenagers rather than Furthermore, concepts and associated terminology vary across studies, with some focusing on (26), others on "circumscribed "obsessions" interests" (28), and still others on "repetitive behaviors" (27).

Special interests in the fields of natural sciences and technology/engineering were most commonly reported (38%), but interests in the human and social sciences (34%) and in creative fields (28%) were almost as common. This seems surprising given that autism has traditionally been mainly associated with the natural sciences. That being said, our data involving the different approaches with which special interests were pursued are able to shed some further light on this unexpected finding. In fact, we found systemizing to be the most common approach when pursuing special interests (55%), including in the social sciences and creative fields. This was followed by the creative approach (28%) and the collecting knowledge approach (14%). This is in line with other studies, which found high rates of special interests that were based on systemizing skills (27,28). Moreover, systemizing has been described by Baron-Cohen (40) as a common trait among individuals with ASD.

Only limited research exists regarding creative interests pursued by individuals with ASD. Some authors have reported music and art-related activities in their studies of special interests among children and adolescents with ASD (26,29). Although collection of knowledge was the least common approach taken to pursue a special interest in our sample, other studies (27,28,41) reported high levels of learning, reading, and memorizing facts to be associated with the special interests assessed in their participants.

Participants in our study reported that they spend a remarkable amount of time—26 hours per week, on average—pursuing their special interests. Furthermore, they evaluated their own skills with regard to their special interests as being very good. Both of these factors are important indicators that it would be of value to consider special interests when developing employment strategies. Interestingly, unemployed participants evaluated themselves as possessing relevant skills for the job market to the same degree as employed participants did, which indicates that unemployed adults with ASD also bear potential for employment.

We consider the jobs that have recently been created in the information technology sector as an important first step toward more employment for individuals with ASD. Software testing evidently meets the strengths of individuals with ASD whose special interests are characterized by a systemizing approach that lie in the and technology/engineering. However, individuals who have interests in technology/engineering but who like to engage in a creative manner would be likely to perform better at software development rather than software testing, whereas an individual who approaches his or her interest in technology/ engineering through collecting knowledge may enjoy working as an author of computer handbooks. This example indicates the importance of assessing the approach to and the field of special interest independently to inform employment strategies. Nye and colleagues (42) found interests to predict vocational performance in neurotypical individuals, thereby underlining the importance of the match between a person's interest and his or her vocational setting. Although this finding awaits replication in individuals with ASD, we predict associations to be equally high or stronger in these individuals, because pronounced interests are more prevalent among those with ASD than in neurotypical individuals. However, the success of a job placement strategy is also determined by the characteristics of the corresponding job market. Specialists in professions in the fields of technology/engineering and the natural sciences are more sought after and may be offered better conditions than those in the fields of human and social sciences or the creative field. Jobs in the latter fields are usually rarer and hence more competitive. They are often characterized by short-term contracts or freelance employment.

Interfering and facilitating factors

Among the factors rated most often as interfering with work performance, participants reported a lack of cognitive challenge; excessive work demands were reported much less. Together with the oftenreported social problems at work (31), the dilemma of many individuals with ASD becomes evident: although they are often proficient with respect to work-related demands, social problems may impede their ability to get or to keep jobs (31). Consequently, high-functioning individuals with ASD often work in lower-level job positions (7). However, even in those positions, the social demands may still be overly challenging, whereas the lack of cognitive challenge adds to dissatisfaction with the employment situation.

Another important finding of the current study is that many participants report perceptual problems as interfering with work performance. These include irritations and negative reactions in response to body contact, noise, specific sounds, temperature, and lighting. The new Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition allows for sensory abnormalities by including hyper-reactivity to sensory input in the diagnostic criteria for ASD (43). Employers should therefore carefully assess the sensory issues of individuals with ASD and adjust the workspace accordingly. Instruments for the assessment of sensory issues, such as the Adolescent Adult Sensory Profile (44), can serve as inspiration for the design of checklists. Alternatively, sensory issues are also among the factors deemed important for facilitating work performance, because many participants indicate quiet surroundings and an undisturbed working space to be desirable. Another crucial factor that is deemed important for facilitating work performance is employers' and colleagues' awareness of the employee's autism diagnosis. This may partly explain the success of companies in the technology sector that employ individuals with ASD, which deal with the diagnoses of their employees openly.

Limitations

Our study has several strengths, but it also has limitations. This research is the first to assess special interests in adults with ASD and to discuss their potential as part of employment strategies. However, the size of our research sample was relatively small, which limits the generalization of the findings. In future studies, we plan to collect data from more participants. In addition, the online procedure may have influenced the sample composition (i.e., only those individuals with ASD who have access to the Internet and who are especially interested in work opportunities may have taken part in the study). The results we obtained are based on variable sample sizes, and we did not include a comparative group in our study. We believe that our approach was warranted given the exploratory nature of the study and given that no research to date has assessed this type of employment-related information. Future studies should compare the interests and needs of individuals with ASD that are relevant to employment with those of neurotypical individuals and other clinical groups.

Conclusions

The special interests of individuals with ASD are pursued intensively and lie in a wide range of fields. Participants estimate their competencies in their fields of interest to be good as well as suitable for employment. Thus, our data suggest that special interests among individuals with ASD may be valuable sources to rely on when developing employment strategies for autistic individuals. Social interaction problems and sensory issues were most often rated as interfering with work performance, whereas employers' and colleagues' awareness of the individual's autism diagnosis was most often reported to facilitate work performance.

Given the German Code of Social Law, which postulates equal rights to employment opportunities for individuals with disabilities, there is a great need for more research efforts to target employment strategies for individuals with ASD.

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APPENDIX

Questionnaire assessing special interests and factors that facilitate and interfere with work performance in individuals with autism spectrum disorders

Part I

- 1) Do you consider yourself to be on the autism spectrum? Yes/No
- 2) Do you have a clinical diagnosis of autism? Please indicate which one No/Yes, Asperger syndrome/Yes, Kanner autism/Yes, atypical autism/Yes, other, please specify/I'd rather not say
- 3) Please indicate your highest level of education (A list of German levels of education was provided)
- 4) Which of these options best describes your current situation?

I am a freelancer./I am employed./I am employed in a sheltered workplace./I am doing vocational training in a sheltered workshop./I am studying./I am doing an internship./I am unemployed./I receive disability benefits

- 5) How satisfied are you with your current work situation?

 1 (Not satisfied) 5 (Very satisfied)
- I believe that so far I have been able to use my vocational potential according to my skills

 1 (Not true) 5 (Very true)
- 7) I believe that I possess skills that are relevant for employment 1 (Not true) 5 (Very true)

Part II

Many individuals on the autism spectrum possess strongly pronounced interests or "special interests." In the following section, we want you to describe your special interest. Please choose the one which, in your opinion, would be the most fitting for vocational use.

1) Please describe your special interest (e.g., programming websites, rebuilding antique guitars, filing historical street names)

Open question format

- 2) Please indicate your level of knowledge of your special interest 1 (Basic knowledge) 5 (Excellent knowledge)
- 3) In a typical week, how many hours do you spend on your special interest?

 Open question format
- 4) Please label your special interest with one of the following categories that best matches it

 The list of categories is provided in Table 2

Part III

1) Please indicate which factors you perceive as interfering with your work (or your work in school in the past)?

The list of factors is given in Figure 1 A

Which factors would you consider to be necessary to facilitate an ideal working environment?

The list of factors is given in Figure 1 B