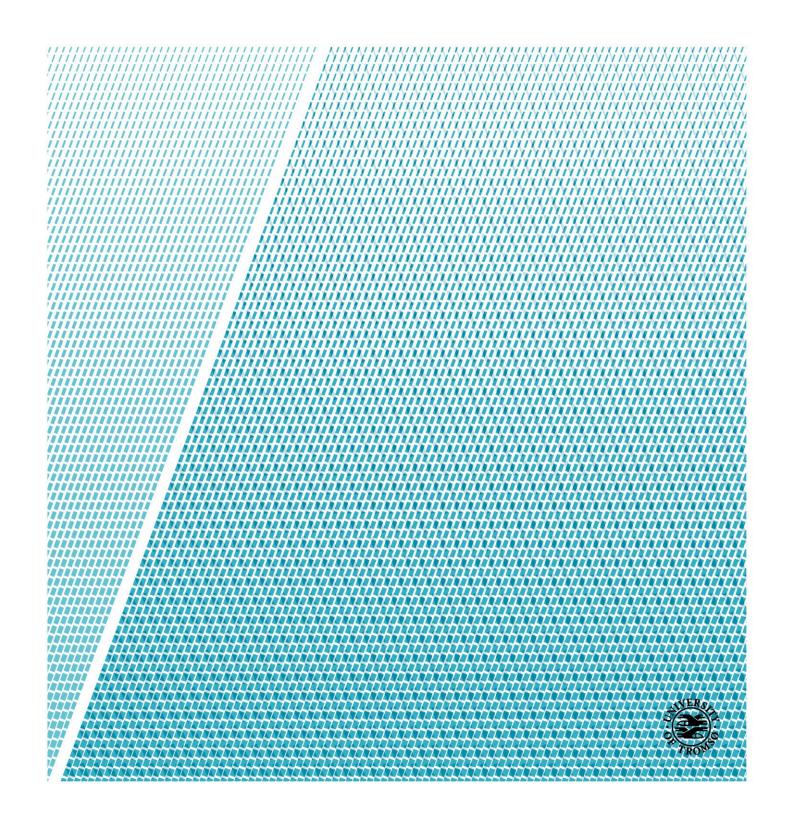


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Employees with Asperger syndrome – experiences and challenges

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Master's thesis in Psychology May, 2017





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Abstract

Asperger syndrome (AS) is a pervasive developmental disorder which is characterized by restricted, stereotypical, and repetitive behavior and interests with an abnormal intensity (ICD-10, 2016). Unfortunately, the vocational outcome for this population is extremely variable (Howlin, 2000). The aim of the present study was to retrieve information about informant's experiences and challenges in work-life and identify possibly significant factors that in the future may contribute to simplify facilitation and be helpful in better integration of employees with AS.

This was investigated through in depth qualitative interviews. There were 5 informants between the age of 18 to 67 who were diagnosed with Asperger syndrome and that had experiences as employees. The recruitment of the informants happened through a request via the homepage of "Autismeforeningen i Norge". The analysis used was Interpretative Phenomenological Analysis (Smith & Osborne, 2008).

The results were discussed in relation to relevant literature, psychological theories, and the characteristics of Asperger syndrome. There are large individual variations of outcome, hence large variations of special interests and abilities that reach from lower than normal intelligence to above average intelligence. It is important to take into account that the complexity of AS, requires a systematic investigation of each employee in order to find the appropriate facilitation. Labeling and diagnoses should be avoided at the workplace due to stigma.

EMPLOYEES WITH ASPERGER SYNDROME – EXPERIENCES AND CHALLENGES

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Forfatter: Kristina Nyvoll Pedersen

Tittel: Employees with Asperger syndrome – experiences and challenges

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Abstrakt

Asperger syndrom er en gjennomgripende utviklingsforstyrrelse som kjennetegnes av begrenset, stereotypisk og gjentakende atferd og interesser med en abnormal intensitet (ICD-10, 2016). Dessverre så er arbeidsutsiktene for denne populasjonen svært varierende (Howlin, 2000). Formålet med denne studien var å kartlegge informasjon om informantenes erfaring innenfor arbeidslivet og identifisere faktorer som kan forenkle tilretteleggelse og organisering av ansettelser og opprettholdelse av arbeidsforhold.

Dette ble undersøkt ved hjelp av kvalitative dybdeintervju. Det var 5 informanter mellom 18 og 67 år som hadde fått diagnosen Asperger syndrom og som hadde arbeidserfaring. Rekrutteringen av informantene foregikk gjennom en forespørsel som ble publisert på hjemmesiden til «Autismeforeningen i Norge». Analysen som ble brukt i studien var Interpretative Phenomenological Analysis (Smith & Osborn, 2008).

Resultatene er diskutert i lys av relevant litteratur, psykologiske teorier og karakteristika som er knyttet til Asperger syndrom. Det er store individuelle variasjoner på utfallet av symptomene og store variasjoner for særinteresser og evner som strekker seg fra lavere enn normalintelligens til øvre sjiktet av normalintelligens. Det er viktig å ta hensyn til at kompleksiteten av AS krever en systematisk gjennomgang av behovene, styrkene og svakhetene til hver enkelt arbeidstaker for å finne fram til riktig tilrettelegging. Diagnoser og merkelapper bør unngås på arbeidsplassen med hensyn til stigmatisering

Preface

Ever since my first job, I've been interested in different aspects with employment and organizations. How leadership and teamwork can make or break a company and the communication between employees and employer has always been fascinating to me. I've also had an interest for autism for many years, which developed through professional discussions with my mother whose profession involves individuals with Asperger syndrome. My wish was to somehow contribute to society within these two fields. Therefore, I tried to combine my two interests and eagerly decided on doing my master thesis on employees with Asperger syndrome.

First and foremost, I want to say thank you to all the informants for your time and willingness to share your experiences. You have inspired me so much with your stories and I am sincerely grateful for your participation. I would also like to declare my gratitude to my mother, Astrid Nyvoll. You have been so generous with your time, knowledge, guidance, and encouragement during this process. I am truly forever grateful for your help. I would also like to thank my family, my friends, and my fellow students for their continuous support.

I would like to express my appreciation to my supervisor Roald Øien for his advice and support. I am appreciative of your encouragement and belief in this project. "Autismeforeningen i Norge", thank you for your help with recruitment. "Koordinerende enhet for habilitering og rehabilitering" in Asker, and Allservice AS in Stavanger, thank you for making rooms available for interviews.

The research question, interview guide, recruitment, interviews, transcriptions, and analysis was developed and conducted by me. Roald Øien guided me in terms of relevant literature and valuable feedback when writing the thesis. I have learned a lot from this process and met with people that have affected me positively in so many ways. I will look back at this process with sincere gratitude.

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Employees with Asperger syndrome – challenges and experiences

Asperger syndrome (AS) is a pervasive developmental disorder that is part of the autism spectrum disorders (ASD), and occurs in approximately between 1 in 500 and 1 in 100 individuals (Müller, Schuler, Burton, & Yates, 2003). Research indicates that ASD is a permanent developmental disorder that will last throughout the lifespan (Volkmar, Stier, & Cohen, 1985). The ICD-10 (2016) includes Asperger syndrome as part of the pervasive developmental disorders, while DSM-V (American Psychiatric Association, 2013) only uses the term autism spectrum disorders with additional descriptions of level of function. In the DSM-V it is stated that patients who previously has been diagnosed with Asperger syndrome, should be diagnosed with autism spectrum disorder with further specification of additional impairments like language deficits or comorbidity. However, in this thesis, the term Asperger syndrome will be used due to the name of the diagnosis given to the informants at the time they were diagnosed.

Individuals diagnosed with Asperger syndrome or high functioning autism often experience challenges when confronted with situations that require skills or flexibility within communication, socialization, and rigidity. The symptoms are characterized by restricted, stereotypical, and repetitive behavior and interests with an abnormal intensity (ICD-10, 2016). The symptoms may cause the majority of this population to experience difficulties when doing things that are a normal part of life and development such as moving out from the parents, finding a job or getting married (Howlin, 2000). Despite the problems with social aspects, the interest for social interactions increases with age because of a longing to achieve the above accomplishments (Kanner, Rodriguez, & Ashenden, 1972). Unfortunately, the vocational outcome for this population is extremely variable (Howlin, 2000). But the majority

of the ASD population seems to have difficulties with long-term employment (Wagner, Newman, Cameto, Garza, & Levine, 2005).

Today, employers in general don't hold sufficient information about Asperger syndrome. This may result in a wrong perception of the abilities of an individual with AS and thus the diagnosis might be perceived as a barrier for employment. This affects the opportunities of acquiring and retaining employment. Different employment processes require different skills. Previous to being an employee, one has to go through a job interview. This situation is stressful and demanding in terms of requiring extrovert skills and often ends in failure for individuals with AS (Barnhill, 2007). Social interactions often involve cues like body-language or metaphors and may be perceived as too ambiguous or incomprehensible for people with AS. They tend to interpret information literally and often fail to use and comprehend a pragmatic language (Barnhill, 2007). Work-related tasks that involve the use of social skills may therefore be perceived as stressful and could possibly end in saying or doing something that is considered to be socially inappropriate (Barnhill, 2007). This is reflected in the frequency of reports where employments end prematurely.

Chadsey and Rusch (1992) (as cited in Hillier, Fish, Cloppert, & Beversdorf, 2007) found that social abilities are directly related to employment success. This explains some of the reason why individuals with AS struggle with maintaining employment. Another obstruction for successful employment is sensory issues. Being oversensitive to noise and lighting is a concern in maintaining jobs (Hurlbutt and Chalmers, 2004). Other challenges that people with AS typically have to deal with is that they often spend longer time learning the procedures and tasks that are required at work, compared to a neurotypical person. This might be because of motor skills deficits. Fournier, Hass, Naik, Lodha, and Cauraugh (2010) found that motor coordination deficits are pervasive and a common feature of autism spectrum disorder (ASD). Motor coordination deficits combined with an impatient leader in this critical

period, is likely to lead to unemployment or missing the chance of being employed.

Although there are many limitations within this group that inhibits employment success, there are also many positive qualities and strengths that are considered valuable for employers. Work that require high levels of abilities within mathematics and computing or involve good memory for facts and dates, are more likely to lead to successful employment. Other qualities that is often characteristic for individuals with AS are focus on detail, honesty, punctiliousness, and reliability. They are often considered to be loyal employees as well (Mawhood and Howlin, 1999).

Work and comorbidity

Comorbidity is a widespread problem within the ASD population (Hillier, Fish, Cloppert, & Beversdorf, 2007). The additional features that are characterized as common are depression, anxiety and fear, and sleep problems according to Tsai (2001) (as cited in Barnhill, 2007). Various aspects of work can provide situations that increase the valence of these features. According to Ghaziuddin, Weidmer-Mikhail and Ghaziuddin (1998) depression is the most common additional feature among the adult ASD population. People with AS might experience depression as a result of awareness and insight regarding their behavior and difficulties (Attwood, 2008). Hedley and Young (2006) found that the depression rates were higher among the participants with ASD that contemplated themselves as more dissimilar to other people. One of the effects that are associated with depression is sleep disturbance (ICD-10, 2016).

During a lifespan, sleep problems will occur or have already occurred in between 40 % to 80 % of people with ASD (Volkmar & Wiesner, 2009). Sleep problems makes it hard to get up in the morning and may disturb activities during the day due to fatigue. Sleep problems often cause a lack of structure because of an uneven circadian rhythm. It appears that there is

a correlation between sleep problems and intensified symptoms of ASD, but this topic is in need of further research in order to make a conclusion (Schreck, Mulick and Smith, 2004). If intensified symptoms of ASD are accompanying sleep problems, there is a reason to assume that this would be problematic in an employment situation.

Anxiety can also lead to sleep problems, which indicates that comorbidity is complex (Richdale and Prior, 1995). Social anxiety is also a factor that can lead to possible challenges with employment. Kuusiko et al. (2013) explained that social anxiety often leads to a fear of public humiliation or avoidance of social interactions at work, school, and the store etc. Kuusiko et al. (2008) found a difference in social anxiety between participants with ASD and a control group. For these adolescents, there was an increase in social anxiety in the ASD group as they got older whereas there was a decrease in the control group. Although it is possible that anxiety interferes with an individual's social skills, it is also possible that difficulties with social interactions lead to anxiety – the direction remains unclear (White and Roberson-Nay, 2009). A general fear of change or situations that are unpredictable can also trigger anxiety (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). For many people, social interactions with colleagues are an appreciated and enjoyable part of the job or at least part of a curtesy. Interactions with colleagues or other situations at work sometimes require flexibility, and regarding the widespread of social anxiety or general anxiety, employees with AS may find social interactions and unclear situations at work as tiresome or perhaps stressful.

Vocational outcome - intervention

"Theory of mind" is described as an ability to predict, imagine and understand another person's beliefs, desires and feelings. It is the ability to understand how things might seem from another person's perspective (Kleinman, Marciano, & Ault, 2001). As pointed out

earlier, social skills are directly related to employment success. Interventions that include exposure to different social settings through role play targeting for example practice in taking turns in a conversation, making eye contact, making small-talk, dining etiquette and so can contribute to awareness of normative behavior. Normative behavior describes behavior that is considered to be the norm and is acceptable within a group of people (Christensen, Rothgerber, Wood, & Matz, 2004). There have been developed interventions like this that specifically deal with theory of mind. The effectiveness of social skills training for people with AS was evaluated in a study by Tse et al. (2007) and indicates that group practice and role-play regarding social situations will boost self-esteem regarding social skills.

Hillier, Fish, Cloppert, and Beversdorf, (2007) reviewed a program called the Aspirations program, which is a social and vocational skills support group program that lasts 8-weeks. They found that adolescents and young adults on the autism spectrum that participated in their social and vocational skills program intervention experienced reduced feelings of depression and anxiety. Given the complexity, pervasive and challenging part of comorbidity, this is an important finding that needs further research because it indicates that comorbidity like depression and anxiety can be reduced by increasing comprehension and skills regarding social situations.

Although, the effect size of this study was small, the participants met other people with AS which give a sense of fellowship. Being accepted in a group of likeminded people is a valuable and boosting experience. This could partly have been why the decrease in depression and anxiety occurred – being accepted and meeting someone in the same situation.

"Central coherence" theory is about understanding the big picture when presented with a mass of information (Happé, 1997). People with weak central coherence will only see the details, whereas people with strong central coherence will be able to see the global meaning of the information that is presented (Happé, 1997). It is known that people with autism often

have a weak central coherence; hence they have trouble seeing globally coherent patterns of information. In a work-related situation, not being able to see global meaning can cause problems in certain jobs. On the other hand, being detail oriented in jobs that include computing and mathematics may be a huge advantage because one might be able to discover errors or mistakes that the computer itself cannot discover.

Work can be beneficial in terms of an increased sense of contribution to society and belonging which is valuable in itself, but also for the motivation to work. It also provides economical income and structure in everyday life (Helsedirektoratet, 2011a). Employment has indeed a positive effect on the quality of life for individuals with ASD (García-Villamisar, Wehman, & Navarro, 2002).

NAV – The Norwegian Labour and Welfare Administration

The Norwegian Labour and Welfare Administration (NAV) is an organization that handles cases of social security, guidance, labour marked measures (translated from "tiltak"), pensions, sickness benefit etc. (NAV, 2017)

After a project by Oslo University Hospital, "Nasjonal kompetanseenhet for autisme", "NAV Senter for yrkesrettet attføring (NAV SYA), and "NAV Arbeidsrådgivning (NAV ARK), about development of method and increase of competence within NAV, a guide for individuals whose profession involves employees with Asperger syndrome was developed. This guide involves many aspects on how to integrate employees with Asperger syndrome in work-life (NAV, 2010).

NAV offer solutions for individuals with Asperger syndrome such as vocational rehabilitation companies which provides guidelines and trial within professions in order to examine skills for further employment. Although, this solution provides work-related tasks that occasionally are considered too easy, it has still proven to be valuable for individuals with

AS.

Long-term arranged employment (translated from "varig tilrettelagt arbeid") provides work-related tasks for individuals who aren't able to function in a normal employment situation. Enabling long-term arranged employment within a company is more complicated than labour marked measures.

NevSom ("Nasjonal kompetansesenter for nevroutviklingsforstyrrelser og hypersomnier – ADHD, autisme, Tourettes syndrom og hypersomnier) is responsible for controlling development of knowledge and competence within the specialized services (translated from "spesialisthelsetjenesten") and other relevant instances. They contribute with research and implementing of national guidelines etc. and are cooperating with instances like NAV in improving fields such as employees with Asperger syndrome.

The present study

Due to the poor outcomes of long-term employment for people with Asperger syndrome, it is important to do research on different aspects with employees with Asperger syndrome.

The aim of the present study was to retrieve information about employees with Asperger syndrome's experiences and challenges in work-life and identify factors that in the future may be significant in contributing with simplifying facilitation and maintaining employment.

Through semi-structured qualitative interviews, this study may contribute in increasing knowledge about how employees with Asperger syndrome experience employment. It can provide insight in how they experience challenges or barriers during the working day. It can also identify interesting views from the employees with AS, and how they describe aspects that have been helpful and enabled them in maintaining employments.

Method

Recruitment

The aim was to recruit five to eight informants diagnosed with Asperger syndrome that held some form of work experience. It was desirable that the informants were an employee at the time of the study, but this was not mentioned in the inquiry nor was it a necessity. The employees could have any type of profession, but they had to meet the criteria of being between the age of 18 and 67.

The informants were recruited through an inquiry for participation through the main web page of "Autismeforeningen i Norge". Considering the possibility of large geographical differences between the informants, it was decided that the interviews were to be held at the informants' workplace or in a public place in cooperation with NAV, habilitation services or vocational rehabilitation companies. Participants contacted us by email and by phone if they wanted to take part in the study. Before each interview the informants signed an informed consent form that they also had access to prior to the interview.

Ethics

Prior to the project, Regional Committees for Medical and Health Research Ethics, Region North (REK) was contacted through applications for permission for the study. The evaluation from REK showed that there was no need for notification according to *hfl.* § 2, see Appendix "B". The Norwegian Center for Research Data (NSD) was also contacted in regard to personal data protection law (translated from "personveropplysninger"). NSD permitted commence of the project in regard to the personal data act (translated from "personopplysningsloven"), the health law (translated from "helseregisterloven") as well as the information provided in the application for NSD.

All the interviews were audiotaped to get a more thoroughly and complete comprehension of the descriptions provided by the informants. The audiotapes, notes, consent forms and transcriptions were stored at the University of Tromsø the arctic University of Norway which only the researcher and the supervisor had access to. In the coding system and in each transcription, the informants were given fictional names. Any statements that contained identifiable information like the informants name, company names or cities were made anonymous. After the thesis has been submitted and evaluated, the audiotapes will be deleted.

Table 1

INFORMANT	AGE	STATUS	POSITION	LAE*/LMM*	TYPE OF	DEGREE OF
				OR NOT	COMPANY	EMPLOYMENT
1. Siri	20-30	Job seeker	Former:	Former:	Grocery store &	None
			Shop assistant &	LMM	warehouse	
			warehouse worker			
2. Øyvind	30-40	Employee	Journalist	LAE	Newspaper	Fulltime (100%)
		& employer				
3. Jonas	40-50	Job seeker	Former:	Former:	Engineering	None
			Engineer	Not	companies	
4. Daniel	50-60	Volunteer	Cafeteria worker	Not	Nursing home	4 times a week
5. Åse	50-60	Employee	Consultant	Not	The Norwegian	Part time (25%)
					directorate for	
					children, youth	
					and family affairs	

The names in the study are fictional

^{*}Labour market measures (translatet from «tiltak»)

^{*}Long-term arranged employment (translated from «varig tilrettelagt arbeid)

Informants

Five informants were interviewed for this study. The aim was to recruit informants that had been diagnosed with Asperger syndrome and that held some form of work experience, either current experience or previous experience. Three of the informants were employees within different companies and two informants were job seekers. The informants initiated their participation through a request posted on the home page of "Autismeforeningen" where they evaluated themselves in terms of meeting the inclusion criteria. All five interviews were included in the study due to their relevance. The responses from the participation request were low, yet three additional inquiries regarding participation in the study were not included due to the timeframe.

Prior to the interviews there was email correspondence with each informant where information regarding the study and participation were given and additional questions were answered. The informants expressed that participation in the study was of personal interest due to their own situation but also regarding improvement of similar situations for other people diagnosed with Asperger syndrome.

Data collection

The aim of the study was to procure knowledge about employees' experiences in regard to having the diagnosis Asperger syndrome and how this effects their working-life. The interviews were conducted at different locations due to geographical differences. The interview with Siri was conducted at a vocational rehabilitation company, Jonas's interview was held at NAV through dialogue with "koordinerende enhet for habilitering og rehabilitering", and the interviews with Øyvind, Daniel and Åse were conducted at their workplace. It was requested that the interviews was held at the informant's workplace if they had work to get a broader understanding of their working environment, which all the informants approved of. Each informant participated in one interview which lasted from one

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to one and a half hours. The interviews were semi-structured with as described through guidelines by Kvale & Brinkmann (2009). The questions are clearer formulated than one would with a different population due to the characteristics of Asperger syndrome (NAV, 2010). An interview guide was used which sought to embrace the informants challenges and perspectives of being an employee with Asperger syndrome. Follow-up questions were prepared in case of themes that required elaboration.

In advance of each interview, the informants were given a consent form and were additionally informed orally that they could withdraw from the study at any time or choose not to answer questions if it evoked uncomfortable feelings. The interviews were audio-taped and subsequently transcribed verbatim.

The supervisor approved the questions and themes. The questions asked are listed in Appendix «B». The themes are listed below. Every theme had 1-3 main questions and possible follow up questions.

- Theme 1: Being a job seeker or an employee
- Theme 2: Facilitation
- Theme 3: The social aspect in the work-place
- Theme 4: Skills
- Theme 5: Managing routines at work
- Theme 6: Openness regarding the diagnosis
- Theme 7: Comorbidity
- Theme 8: Thoughts about the future

Analysis method

The analysis used was the interpretative phenomenological analysis (IPA) as described by Smith and Osborne (2008). The analysis is phenomenological in that it is concerned with comprehending how several informants experience a given topic in a given context, which in this case is the experience of being an employee with Asperger syndrome. IPA is considered to be a dual process in that it tries to get an in depth insight in individuals' perception of a subject, but also takes into consideration that the analysis process is somewhat colored by the researcher's conception of the topic itself and the transcriptions (Smith & Osborne, 2008). This is partially why IPA has reached more recognition within health psychology.

The interviews were transcribed verbatim including pauses, descriptions of gesticulations and mis-hearings, and subsequently analyzed according to the guidelines by Smith and Osborne (2008). The relevant quotes were translated from Norwegian to English and approved by the supervisor. However, linguistic fillers like "hm" and "eh" were removed in the presentation of the results. The analytic process included several steps and was conducted manually on paper and on computer by using relevant key words to thoroughly search each transcript. The process started by thoroughly reading each transcript several times to capture the essential qualities of the transcript, while taking notes in regard to possible themes. Key words connected to paragraphs were used as a coding system. If new themes arose during the process, all previous transcriptions were checked against the new theme to assure that relevant content were added if needed. A total evaluation of all identified themes were conducted which lead to weak themes being excluded and themes that featured similar content were either merged or included as sub-categories within a main category.

Results

The informants were eager and benevolent to share information about their experiences and challenges with processes related to work. They expressed a personal aspiration in terms of improving knowledge for relevant instances about barriers that individuals within the autism spectrum may be exposed to. Barriers like the process of finding appropriate work, applying for a job, managing the job interview situation, and being able to function as an employee over time were some examples that the informants mentioned. Facilitation or the lack of it was also a factor that they aspired to improve.

Some of the participants acknowledged the social disadvantages caused by the diagnosis and made several remarks on their ambition to improve what they considered to be weak skills. Despite the acknowledgement of the disadvantages, many participants mentioned that they tried to focus on the strengths of having the diagnosis Asperger syndrome, instead of focusing on their limitations. Throughout the interviews the informants expressed that work had a positive impact on their lives and that that they preferred to be employed rather than being unemployed. They considered employment to be helpful in terms of having a stable routine in their daily lives. But at the same time almost all of the informants made remarks that indicated frequently challenges in maintaining a healthy work-life balance.

Three categories were identified after deep analysis of the transcripts. The categories were as follows: *Openness, social challenges, and diagnosis in the workplace*. The categories and sub-categories enlighten some of the aspects that individuals diagnosed with Asperger syndrome may experience or feel in relation to work. The consequences of late diagnosis in relation to interacting with colleagues and functioning at work, and thoughts and experiences with being open about the diagnosis at work is described in the first category, openness. The second category attempts to describe the challenges, experiences and opinions the informants expressed regarding the social aspect of work. The third category "diagnosis in the

workplace" involves experiences and thoughts about facilitation and feeling excessive at work.

Social challenges

The informants described their perception on how they managed the social aspect of work. Some of them expressed difficulties during lunch time and social situations where small-talk was required. Although acknowledging their lack of strong social profit from attending conversations involving superficial or everyday subjects, many informants still attended lunch, tried to make small-talk and being active listeners. Siri and Jonas in particular expressed difficulties with the social aspect. Daniel described minor social difficulties, but mentioned that he frequently practiced on improving his social skills and stress management at work. Øyvind described that he had great difficulties with social interactions when he was younger, but that he through years of practice now was able to interact with his co-workers.

Social withdrawal. This sub-category is based on the challenges characterized by Asperger syndrome and that many of the informants experience on a daily basis. Challenges with communication and socializing in the working environment led some of the informants to prefer avoidance of encounters. If avoidance wasn't available or preferred, staying in the situation and trying to contribute to the conversation, with different degrees of success, was the solution for most of the informants.

Some informants had received negative feedback from previous employers in regard to the social environment at work.

Siri: (...) It has kind of been one of the biggest complaints I have received from all of my workplaces, that I'm not particularly good at being social... I'm the kind of person that tries to avoid starting a social interaction, but if somebody else comes to me and tries to start, then I do try to keep up the best I can. But it doesn't always work.

They also expressed feelings revolving being an outsider. The awareness of being different seemed to influence the attendance in social settings. Although several informants seemed to have a fundamental wish to participate and be social with colleagues, the thoughts and feelings about the social aspect of work seemed to be ambivalent. Avoiding social situations that required participation appeared to be a valued opportunity, but they still stressed the contradictory negative feeling of withdrawing from a social community.

Jonas: I often let busy days be an excuse to go to lunch later after everyone else had eaten or I would sit outside, preferably alone, to get a real break. But it kind of felt like I was withdrawing from a fellowship in a way that was negative in terms of building relations and to be visible, a visible person in the work environment.

The informants accentuated that the feeling of not being part of a social setting was strong and that they sometimes felt like they were invading.

Siri: Because I don't want to feel like I'm intruding. And I often feel like that... as if I don't really fit in. I'm kind of forced into that position. It's a bit like a puzzle piece kind of... it's kind of like a piece that is supposed to fit in the corner that you try to squeeze in the middle. Push and push and push, but it never fits there. It will never fit; the piece will probably break before you are able to make it fit. That's kind of how I feel.

Uncertainty regarding possible subjects in a conversation was also a factor that affected withdrawal in social situations as well as level of feeling comfortable in the situation. Being prevented from speaking about special interests or subjects related to work was experienced as feeling vulnerable.

Jonas: (...) I kind of have to relate the subject to professional matters. If I can relate the subject to professional matters, I'm safe; if I can't relate it to professional matters I'm unsafe.

Practice. In this sub-category, it is argued that practicing social skills, being exposed to unexpected social situations, and relying on a predetermined social role, improves social skills. The informants stressed the importance of practicing social skills in order to succeed in socializing with others. They pointed out that by learning about their social skills and acknowledging the weaknesses, motivation for improving the skills appeared to be stronger. The attempt of improving social skills seemed to be driven by the aspiration of developing an implicit comprehension of normative behavior in social interactions, and was often executed in private during their working day. The informants explained different types of strategies to cope with interactions like stress management, using a predetermined social role, and the principles of active listening.

For one informant in particular, it was essential to have a predetermined social role, before he could expose himself to social situations. The social role involved predetermined guidelines for normative behavior. The guidelines involved when to approach people, a reason for why one was approaching people, how to start a conversation, and appropriate questions to ask. The informant explained that his profession enabled him to introduce himself with a certain role that provided a degree of safety and cover due to other people's knowledge about the role.

Øyvind: (...) It was hard to go out and meet people without having a role. So the paper, the role of being a journalist kind of became my acting role in order to get in contact with other people.(...) I would not have dared to do that if I didn't have a role.

The consequence of having a predetermined social role was being exposed to social situations that without the role would have been almost improbable. The employment also led to opportunities of observing other people's interactions, which the informants considered to be advantageous. Through years of applying the role in social situations, social knowledge about normative behavior developed.

Øyvind: Through the years since I started the paper, I have sort of become more and more socialized, how do I explain it... to be able to function socially with other people from the experiences I've made with the "role" that I have had. So today, I master it without having to have a "role" to sort of, be able to do it, because I have taught myself how a dialogue starts and how a conversation can start on the street without needing... I have learned a lot of techniques that help to say the least.

For some informants, social situations appeared to induce some level of stress. The stress was considered to be undesirable, uncomfortable and obstructive in interactions. Daniel mentioned that in order for communication to be optimal, he considered practicing stress management as being helpful.

Daniel: I've actually been practicing stress management at work in private. But the others don't know about that. But they know how I perceive the surroundings and they know how I handle stress. (...) I'm very... I'm not sensitive when I'm confronted with stress, but I get overwhelmed by context... working tasks that get focus, lose focus. It can vary from day to day, but overall I can handle almost anything. I have been taught a method from a specialist in the psychiatry, a clinician on the team. He's going to quit now because... I imagine a ski jumper, when he's at the top about to set in motion. He has to start planning the jump. When he has reached that far, when he's in the air, he has to start planning his style and the landing. He has to plan in the long-term. This has become a good methodological picture of how stress can be managed.

In retrospect, one of the informants talked about how practicing social skills had enabled progress in developing active listening skills. He had noticed that interactions often ended in misunderstandings, and therefore attempted to improve his listening skills.

Øyvind: I struggled with this before. To be able to listen to what people said, and hear what they were really saying and make conclusions. In the past I used to make conclusions before the conversation was over. But now, I have taught myself to listen to the conversation and to give myself some time to think that "ok, did it mean this and that, or didn't it". And I may dare to ask and say that I comprehend things in a certain way because often people say things to me that are explained in a complicated way. A lot of times I don't understand what they really mean and then I just ask. I've gotten better at asking; "I don't understand what you're saying now, can you explain in a different way so that I understand what it is that you're trying to say?"

Some of the informants worried that poor social skills affected other people's impression of them, and additionally obstructed performance at work. They worried about being perceived as rude or uninterested as an interlocutor. Øyvind mentioned that his profession required him to learn techniques about listening

Øyvind: (...) In the past, I wasn't able to pay attention during the conversation and I didn't make any contact with the other person. He clearly understood that I wasn't interested in what he was saying. That is something that I wanted to improve a lot because I felt that it was very rude. Therefore, I had to learn a technique on how to handle the handicap or the weakness that I had in these kind of settings and be able to function in an optimal way.

Openness

This category attempts to describe opportunities of being open about the diagnosis or the lack there of, the consequences of being open, and when it is appropriate to be open about the diagnosis in relation to employment. This subject evoked ambivalent opinions among the informants. They had polarizing feelings as to whether it was positive and necessary or pointless and even dangerous to inform people about the diagnosis. Only one informant

described openness as being solely positive. The informants highlighted that they feared that openness would result in stigmatizing because of inadequate knowledge or stereotypical perceptions of what Asperger syndrome is. They were apprehensive in terms of not being accepted, underrated, or excluded.

Receiving a diagnosis. This sub-category enlightens the experience of receiving a diagnosis. The timing of when the diagnosis was given is significant to whether or not the informants were given an explanation for their challenges, hence given an opportunity to be open about it in a professional way. Being diagnosed was described as liberating and calming due to improved comprehension about the reason for their challenges. It also evoked an awaited sense of fellowship

Åse: No, but it's great and... for me, it was very important that someone figured out that the way I function has a name and it harmonizes with what... with the challenges that many other people also have.

Several informants, who were diagnosed any time later in life, expressed that they had been suspicious of having Asperger syndrome. They experienced that receiving a diagnosis caused a significant change in their life. Opportunities of seeking relevant knowledge had provided relief and comfort.

Åse: Yes, one is able to understand things in a different way. I already had a lot of knowledge about autism without thinking that it concerned me in any way, before I could see it written on paper.

Another positive remark about receiving a diagnosis was the opportunity of mobilizing knowledge and identifying the strengths.

Øyvind: When I was 13 years old it was kind of far off. It didn't really matter, but as I got older, my mother and I started focusing more and more on finding the strengths with the

diagnosis instead of dealing with it like a weakness. And to use my diagnosis and explain and inform that I have a diagnosis like this in situations where it can be favorable to tell people so that they understand better.

Three of the informants received the diagnosis at any time later in life. Unreasonable extern expectations were some of the consequences the informants mentioned. A diagnosis results in practical solutions in regard to employment and receiving help.

Jonas: It was very liberating (...) well, my challenge is concretized and I get an explanation in regard to that there is a direct causation and that it is caused by... it is actually a handicap. So considering a couple of things that I used to feel.. were out of reach or beyond what has been realistic in terms of capability, I now look at it as a parallel to when you're asking someone who's in a wheelchair to just get up and start walking. It's kind of like that... I envision my childhood and that there have been expectations for me that have been completely unrealistic for me to fulfill. This being related to, let's call it a handicap, so it has been nice to see. It is also something that can be used with systems like NAV now that I'm unemployed.

Timing. The dilemma of informing the company of the diagnosis and risking negative consequences versus being open and contributing to improvement of the company, was truly upsetting for several informants. If they decided to inform their colleagues or employer about the diagnosis, then finding the appropriate time to do so was experienced as stressful. Two of the informants mentioned that they had decided to write about their difficulties in their Curriculum Vitae. Øyvind said that he had been open from the start and that he recommended others to be open at the beginning of employment because personal strengths could be very beneficial for the company.

Øyvind: I think that the best way is to be honest from the start and inform the employer like, listen; I have this diagnosis, and considering this job that I have applied for I'm going to be able to add this and that to the company, and I'll be extra qualified for these things and other employees may not be able to do the same things with the same kind of effectivity and the same type of precision. I'm just speaking of my own experience now, I know that there are different aspects and function levels, but this is the way I would have done it if it was me that was standing there being a job seeker today, I would have emphasized those things in terms of being open with the diagnosis instead of hiding it and then let people know after you've been hired. That could be more negative than telling people from the start because today, from what I've heard from employers, the skills and the strengths that someone with autism have is actually sought after.

In the process of applying for a job and be hired, there are several times where one could inform about having Asperger syndrome. Two of the informants had decided to write about their challenges in their Curriculum Vitae, to inform possible employers about their weaknesses. However, they were still skeptical of doing this because it could result in being rejected immediately.

Daniel: I don't mind sharing it orally. I write a CV that currently is updated and it actually says specifically that ever since I was a little boy, I struggled with understanding relations, you know. So I don't necessarily write a diagnosis with a number and a name because soon there is no such thing as Asperger, you know. It is going to be "autism spectrum" again, you know. Then it's going to be harder to understand, you have to explain more.

Jonas also decided to write about his challenges in the Curriculum Vitae.

Jonas: It is sort of something I as a job seeker have tested in terms of what kind of degree I should say that I have Asperger in the applying for jobs process or not. Now I have come to terms with a phrasing saying that I'm reserved in unpredictable social situations, but I communicate well if the subject is related to the field.

Stigmatizing. In this sub-category, the informants expressed stigmatization through fear of change in treatment by co-workers and employer. The category starts by describing the informants fear of the consequence of employers' and co-workers' inadequate knowledge about Asperger syndrome. The final paragraph in this category will elaborate on the informants experience with diagnosis being abused as a justification for being unequally treated by family members.

One of the informants seemed very reluctant with informing her colleagues and employer about the diagnosis. She feared that society is changing in the wrong direction in terms of acceptance. She insinuated that the knowledge in society about Asperger syndrome isn't good enough and that it affects her willingness and wish of being open.

Åse: I have not seen any reason to inform anyone about it, no. (...) I think there is a lot of prejudice against being different and I think these prejudices are growing fast right now. Against any form of discrepancy. It has kind of been a little bit tolerance, we have tolerated homosexuals to a certain degree, we have tolerated immigrants, and we have tolerated different skin colors. Now, I believe that we are moving into a different landscape where the tolerance is no more; I think we are entering a seriously dangerous landscape. I think that it's unwisely to inform anybody if you don't have to say anything because humans have a lot of prejudice and it colors how we meet each other more than how people actually appear. That is my experience.

Fearing generalization of being a stereotype of someone with autism generated reluctance in wanting to tell people about the diagnosis.

Jonas: I would like to be able to be open about it. But I understand that not everybody.. how do I explain it... understands it, they do not know enough about Asperger to be able to allow it, so it can quickly become more dangerous than it is in reality. It can also be that, if somebody knows someone that are diagnosed with Asperger, then I'm sort of put in a box and they think that I'm like that because that's the kind of stereotype perception of what Asperger is. So I'm a little concerned about that.

In what way one is perceived by others seemed to concern most of the informants. One of the informants experienced that the strengths he had because of the diagnosis caused negative rumors in the community. Therefore, he felt like there was no choice but to be open about it. But he also mentioned that he could not see anything negative by being open about it.

Øyvind: Everyone knows today and I have been open and honest about it here in the company and externally in the media that I have the diagnosis that I have and that I have... this is about what I talked about earlier, that I have gone out and talked about who I am because I felt like the community around me needed to know because people didn't understand how I could be the first one to get a hold of news. People thought that I was using drugs because I was too fast, "he is too fast to be able to do these things, he is too effective". That's why it was important for me to clarify to people that I have a diagnosis that allows me to handle things that I'm interested in very quickly. It makes me seem odd, but I still have a resource.

One informant in particular felt like his family used the diagnosis as a justification for treating him unequally compared to the treatment of other family members. The lack of acknowledgement was painful and frustrating. Daniel described that being treated like a patient caused vulnerability and a relationship that was skewed

Daniel: (...) They consider me as a patient... most of the time. When we discuss, they look at me like I'm an idiot. Not as a professional within my subject. Not by any means a professional within my subject. But I have experience. "No". I only have a perception (laughs). Why should it be like that? I have a dream of getting, what is it called... acknowledgment. It's not an unfamiliar word; it's an appreciation of a social role (...)

Diagnosis in the workplace

This category describes some of the factors that the informants reckoned as problematic during the working day. The category will also describe some of the challenging stages of employment situations that were highlighted by the informants. Finding the right profession, being accepted as an equal employee, and provision of sufficient facilitation were mentioned as important factors to function in an optimal way.

While talking about Asperger syndrome and employment, the informants continually spoke of the interview situation as a possible deal breaker. Interviews often require extrovert strengths which concerned many informants.

Jonas: (...) I absolutely think that Asperger has an important place in working life...

At the same time working life is driven by the fact that one is measured in an extrovert scale.

The interview and the process of getting into a company is often through interviews where you have to talk about yourself and yes, that's where people with Asperger face challenges so, what can I say, the modern working life is more of a fashion thing when it comes to what you're looking for in employees. That is going to be a challenge for people with Asperger in general.

Øyvind: (...) The problem is that when you meet as an employee and employer in an interview situation, then you're both, or at least one side is afraid that they're not going to be good enough and you lose an important part of the communication in order to be able to

inform and emphasize the things that actually could've become a success. These are my thoughts about this.

Focusing on the positive aspects by having Asperger syndrome as an employee, there were many qualities that were mentioned.

Jonas: It is a lot of positive things about it. Focus... you know someone with Asperger who works with knowledge that is really interested in specializing in subjects... That's actually a dream situation for an employer. The fact that I'm quite antisocial on a workplace gives the right type of company... It's actually positive. There are too many employees that are talking away their workday, that I've seen in workplaces where I've been. I'm superb at being able to think structure and troubleshooting. So there are a lot of things that I consider being very positive skills for an employer. But at the same time it isn't really a subject in a hiring process at all. You are often measured on how you are face to face with a group of people that are interviewing you, and yes...

Øyvind described his difficulties by being both an employee and employer and how the chosen solutions to his weaknesses and utility of his strengths had strengthened the company. Tasks that are connected to problems related to Asperger syndrome was handled by other employees. His strengths, like being persistent with working tasks, made the company better.

Øyvind: Maybe the staff related tasks are a big challenge in terms of accepting that normal... then again, what is normal... that normal employees in their daily routine can have different needs than I do. Or that one isn't able to function with a task as long as I can. This aspect, understanding that other people are different in this area, is hard for me to understand in many settings. Well, I understand it, but I cannot relate to it. I'm not able to have individual staff meetings and understand the part about "this is how it is and this is the

reason for it". This is why I don't have responsibility for the staff. Yes, I'm an employer and yes I'm the owner and leader of this company, but I have other employees that are responsible for the staff and business matters. So other people compensate for the weak skills that I may have.

Facilitation. This sub-category is mostly based on the informants experience with facilitation, but it will also elaborate on what kind of facilitation they wished for in future employments.

Siri: I'm not the best at demanding it myself, but I do feel like there hasn't been a lot of facilitation within the jobs that I've had. The only thing I feel like I've asked for is a little bit extra help in getting an overview.

In retrospect, not all facilitation was considered to be positive or even wanted. For Siri, having a contact person at the job became degrading and vulnerable. It became a relationship where the status of the individuals involved, were not the same. One of them was there to take care of the other individual; one of them was weaker than the other. The thought of having a contact person led to memories of feeling obstructed in being independent. Other people's perception of one's ability or inability instantly evoked insecurity.

Siri: Because it takes me back to my childhood. It ended up with me not being allowed to join any kinds of excursions without having an extra person there with me, kind of like a babysitter. (...) I think it's very unfortunate and degrading, especially at junior high, and I felt that it stole a lot of opportunities from me when it comes to being independent and growing up in my childhood. Last year was the first time I travelled abroad without a parent or someone who was requested only to take care of me. So that tells you a little bit about how independent I've been.

Facilitation that seemed to be acceptable and helpful often included having a desk located where it wasn't likely for disturbances from colleagues or sounds from coffee machines or printers.

Jonas: I would like to ask for an office where it's calm. Not necessarily an office that's located separately from the others, but not a desk in an open-plan office that's close to a coffee machine or a copier or a passageway.

Sensitivity of lighting was also mentioned as a minor issue that easily could be solved.

Jonas: For an employee within a knowledge department it is primarily sound and lighting. You can fix sound issues with noise cancelling headphones or earplugs. And lighting, well, I'm not that bothered by it, so it's not a big problem, but if I'm able to do something about it... at my previous workplace, I never turned the lights on. I only used lighting from the window and that sort of thing as lighting in the room.

Øyvind described that he was allowed to decide his own working time, as long as he worked 7,5 hours a day. He also had an assistant who took care of the things that he weren't able to or found very difficult.

Øyvind: I'm supposed to be at work 7,5 hours every day, but I have the liberty of deciding when I want to start my day and when I want to end it. I get payed 25 kroners an hour anyway. It has never been a problem that I don't work those hours, and people can see the result, what we do every day, online (...) The municipality has facilitated an assistant for me in my work. A personal assistant who works with me 70 % during my working day and helps me with the things that aren't my strengths, like math, accounting, economical matters and that kind of thing.

Underestimation. This sub-category describes how the lack of knowledge about the diagnosis can lead to judgmental thinking about which qualities the individual with Asperger syndrome hold. The informants experienced that the belief in their abilities were impaired. They sometimes felt or previously had experienced feeling underrated or unimportant.

Åse: (...) In a way you're kind of unnecessary, you know, there's no one that rely a lot on me being here, except from when I'm sitting in the reception. Then it is actually important that I'm here, but yes...

One informant experienced being left with tasks that were too easy or being prevented from doing certain tasks in disbelief of capability, which left him feeling underrated.

Daniel: I was with labour market measures where I was studying for social education. I was working there with labour market measures for 4 years. It didn't lead to anything in the library because I only got jobs that a 12 year old could do. They wouldn't let me work the register, with disposal, grading or in regard to ordering things. The woman who was the leader in the library said straight up that she didn't understand... she took samples of us... she didn't understand that I was able to learn a new system in no time. The system that the library had, I learned that by heart in a couple of days, and she just couldn't understand that, so she became unsure. And when she became unsure, she didn't think straight.

Discussion

The aim of the present study was to investigate the experiences and challenges of employees with Asperger syndrome through qualitative in depth interviews. Three categories, openness, social challenges, and diagnosis in the workplace, were identified and will be discussed in relation to relevant literature and the characteristics of Asperger syndrome according to ICD-10 (2016) and DSM-V (2013).

Social challenges

The challenges with the social aspect at work were described through two sub-categories; "social withdrawal" and "practice". The informants seemed to have different current experiences with the social aspect of employment. When reasoning about their past they mentioned more similar struggles. The age of the informants and the time at which they were given the diagnosis, may have had an impact on the different social experiences. Further studies need to consider the impact of late versus early diagnosis and how it affects managing of social interactions.

When the informants talked about their past, they mentioned similar difficulties with lacking understanding for certain interactions and not being aware of the impact of their own social behavior. But the present perceptions of the informants own management of the social aspect at work was divided. Siri and Jonas described the social aspect at work as difficult, and they mentioned social withdrawal as a common solution when in doubt of normative behavior. Øvvind, Daniel, and Åse seemed to have less trouble with the social aspect of employment in their current situation, but still mentioned aspects that they struggled with which involved communicational aspects.

Both Øyvind and Daniel were also the two informants that had practiced social skills and handling different social situations the most. They described employment as an opportunity to be exposed to social situations they normally wouldn't seek out. They had to speak with co-workers frequently and had the opportunity of observing interactions between colleagues. Work is known to be an excellent arena for social skill practice for individuals with Asperger syndrome (NAV, 2010). Øyvind also emphasized that having a social role with predetermined rules for social behavior was essential for him towards developing the level of social abilities that he holds today. His profession as journalist became his social role and guidance for behavior. The literature describes the use of scripts as helpful in development of

social skills. In a study by Krantz and McClannahan (1993) scripts were used in peer interaction amongst children to enhance and increase social interaction. The scripts included appropriate questions and answers and did indeed increase the initiation of contact by the autistic children.

The other informants accentuated that although they struggled with social interactions, they wanted to be part of a fellowship at work and be able to participate and function well in social contexts. They were aware of being an outsider and it affected the attendance to social situations. Withdrawal or avoidance of social situations such as lunch time or small-talk in the hallway was preferred in these situations.

Theory of mind is explained as the lack of ability to understand the perspective, thoughts, and feelings of another individual. It enlightens the fact that other people have unique beliefs and motivation for performance (Kleinman et al., 2001). Some of the informants had trouble with understanding why others had different needs than themselves. Øyvind's company had solved this by giving the responsibility for staff related tasks to other employees because he found it hard to relate to the fact that other people had different needs than himself.

Stress management was also practiced in order to improve social skills. Situations that are unpredictable may contribute to stress. A systematic investigation of how the individual with AS handles situations such as communication, teamwork, independency with work-related tasks etc. can be helpful when facilitating for employees with Asperger syndrome.

NAV can provide this form of systematic investigation of these factors through measures like labour marked measures in the form of work trial (translated from "arbeidsutprøvning")

(NAV, 2010), which can lead to improvement of stress management and avoidance of situations that triggers stress.

Openness

Three of the informants were diagnosed with Asperger syndrome at any time later in life. Late diagnosis in relation to opportunities of being open about it requires more research, but there may be a possibility that a late diagnosis can lead to missed opportunities of being open about the diagnosis. Lack of diagnosis may lead to a lack of comprehension of how strongly one is affected by the symptoms and what they actually mean.

The informants highlighted timing of when to inform an employer of the diagnosis as a process of feeling upset and vulnerable. Risking negative perception of abilities by informing the employer from the start or risking the employer finding out after employment and take the following consequences was considered as a very difficult dilemma.

The informants also described fear of stigma as strong. It affected their willingness to be open about the diagnosis. More discrepancy from what is considered as "normal" is associated with higher occurrence of stigma (Westbrook, Bauman, & Shinnar, 1992). A diagnosis can also induce stigma (Martz, 2004). According to Shtayermman (2009) stigma of individuals with Asperger syndrome, that may have discreet signs of their disability, is because of the label of having a diagnosis. The informants fear of being treated differently if they were to inform their employer or co-workers about their diagnosis are eligible.

Diagnosis in the workplace

The individual outcome of the diagnosis decides what sort of profession is suitable for each individual. In general, individuals with autism spectrum disorders often succeed within professions like engineering, computer science, and translators. Other jobs that seem to work are librarians, programmers, or other areas within IT (Dalferth, 2011).

From the informants perspective, many abilities that individuals with AS often hold

were considered as strengths. They mentioned several strengths that could be beneficial for an employer such as systemizing, focus, endurance, and being antisocial.

Individuals with Asperger syndrome often find the interview situation in employment very difficult. They will experience difficulties with conveying their skills through an interview (NAV, 2010). This was reflected through the descriptions given in the category "diagnosis in the workplace" where the informants stated that the interview situation was very challenging. The informants reasoned about the cause of the difficulties with the interview being related to the characteristics of Asperger syndrome and feared this situation in future employments.

Facilitation. A company that has succeeded in facilitation for individuals with Asperger syndrome Is "Unicus AS". They present themselves as follows: "Unicus AS is a Norwegian consulting company that focus on the special features of autism" (Unicus, 2017). The company has competence on testing and quality assurance of IT, which is based on the employees special interests such as details, precision, structure etc. Unicus AS has succeeded in facilitation in relation to work-tasks that are suitable for each employee. This involves taking problem areas like communication, socializing, and rigidity into consideration. The informants in this study have different experiences with facilitation.

Two of the informants, Øyvind and Jonas, had received several facilitations such as long-term facilitated work (translated from "varig tilrettelagt arbeid"), a caps to avoid issues with lighting and sound cancelling headphones to deal with sensory issues. In addition to this, Jonas expressed that he had thoughts about which facilitations to ask for in a future employment.

It is often suggested that having a contact person at the workplace can be beneficial in terms of getting an overview (NAV, 2010). Siri was the only one who had experiences with having a contact person. She emphasized that she was very reluctant to having a contact

person in future employments because she felt that it was degrading and obstructive for independent behavior.

Contributions of this study

This study has contributed in research within the field autism, specifically in relation to employees with Asperger syndrome. The study has improved the knowledge about experiences and challenges that employees with Asperger syndrome in Norway may encounter from the employees' perspective. Their perception of the content of the working day and descriptions of individual successful solutions at the workplace is useful.

Valuable information has been found about the employees views of the facilitations provided by NAV or the lack there of due to the informants withholding diagnosis information from the employer.

Limitations

The analysis of the transcriptions was conducted by the author of this paper. According to Malterud (2017), the strength of the analysis will increase if more than one researcher conducts the analysis. Therefore, the analysis may be biased in terms of the authors' expectations and knowledge prior to the study, as well as subjective perception of the results. Two of the informants were job seekers which may cause the memory of previous employment experiences to be vague to some extent. It is possible that it has affected the quality of their answers. Although, there were nearly equal distribution of men (n=3) and women (n=2) in the study, the sample size was quite small which limits the possibilities for generalization of the findings. It must be noted that the different ages of when the diagnosis were received is also something that may have an impact on the informants' answers.

It is a possibility that the choice of qualitative interviews and the Interpretative Phenomenological Analysis by Smith and Osborn (2008) has affected the results.

Future studies should take sample size into consideration when conducting similar studies. Possible directions can be studies that involve mixed methods designs or a quantitative study that investigates factors that help integrate employees with Asperger syndrome in a workplace.

Conclusion

There are many reasons for conducting research on this area. Employment leads to income, independency, and creates a feeling of belonging as well as being able to contribute to society.

Individuals with Asperger syndrome are likely to be in needing of different vocational facilitations than neurotypical individuals. Pervasive developmental disorders like Asperger syndrome involve individual differences within symptoms (ICD-2016). Therefore, there are large individual variations of outcome, hence large variations of special interests and abilities that reach from lower than normal intelligence to above average intelligence. This population will experience difficulties with social aspects, communication, and rigidity. For an employer, this will require profound knowledge about each employee's weaknesses and strengths. There are also expectations about having knowledge about the diagnosis and willingness for facilitation for the employee.

If the employer and employee succeed in cooperating on this, then the development and expansions of companies like "Unicus AS" where exceptional competence within IT is beneficial for each employee and society will perhaps be easier. Therefore, it is essential to investigate the employees' own experiences of how they perceive work-life in relation to social integration on premises that harmonize with the needs of individuals with Asperger syndrome. Another step towards succeeding with this is an improvement of competence on a national level, where knowledge is implemented locally through public instances, and preferably also through private companies.

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Appendix A

Consent form



20.09.2016

Arbeidstakere med Asperger syndrom

Forespørsel om deltakelse i forskningsprosjektet

Bakgrunn og hensikt

Dette er en forespørsel til deg om å delta i et forskningsprosjekt som har til hensikt å kartlegge erfaringer og utfordringer til arbeidstakere med Asperger syndrom. Studien inngår som en del av en masteroppgave i regi av Institutt for Psykologi ved Universitetet i Tromsø, Norges Arktiske Universitet. Studien vil kunne bidra til forbedringer av organisering og tilrettelegging i ansettelsesprosesser for denne populasjonen, i tillegg til å øke forståelsen omkring Asperger syndrom hos arbeidsgivere. Forespørselen henvender seg til deltakere mellom 18 og 67 år som har fått diagnosen Asperger syndrom og som fungerer som arbeidstaker eller arbeidsledig.

Hva innebærer prosjektet?

Deltakelse i denne studien vil omfatte et intervju om dine utfordringer og erfaringer som arbeidstaker med Asperger syndrom. Lengden på intervjuet vil være på omkring 1-1/5 time. For å sikre en korrekt gjengivelse av informasjonen som gis av deltakerne under intervjuet ønsker vi å benytte båndopptaker under intervjuet.

Mulige fordeler og ulemper

Deltakelse i denne studien vil ikke medføre noen særlig form for risiko. En mulig ulempe ved deltakelse kan være at deltakeren blir oppmerksom på negative tanker eller emosjoner som er knyttet til eventuelle barrierer ved det å lykkes i arbeidslivet. En mulig fordel ved denne studien er økt forståelse omkring egen situasjon i tillegg til at informasjon om utfordringer og erfaringer i positiv og negativ forstand kan føre til en forbedring av dagens situasjon for arbeidstakere med Asperger syndrom.

Hva skjer med informasjonen om deg?

Informasjonen om deg skal brukes i en masteroppgave i tillegg til en mulig publikasjon i et relevant vitenskapelig tidsskrift. Identiteten til deltakerne vil ikke fremgå av masteroppgaven eller en eventuell publikasjon i et tidsskrift. Alle personopplysninger vil bli anonymisert i presentasjonen av resultatene fra studien. Underveis i prosjektet vil det kun være studenten og veileder som har tilgang

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til datamaterialet, og ved prosjektets slutt vil lydopptak og kodenøkler som kan identifisere deltakerne slettes (31.05.2017).

Frivillig deltakelse

Det er frivillig å delta i denne studien. Deltakeren kan når som helst trekke sitt samtykke til deltakelse i studien uten å oppgi noen grunn.

Dersom du ønsker mer informasjon om studien eller studiens utfall, kan du gjerne ta kontakt med oss.

Studien utføres ved: Kristina Nyvoll Pedersen

Tlf: 95946709

E-post: kristina.nyvoll.pedersen@gmail.com

Prosjektleder:

Roald Øien, Stipendiat ved Institutt for Psykologi, UiT – Norges Arktiske Universitet

Tlf: 93099994/77644344

E-post: roald.a.oien@uit.no

Samty	kke	til	delta	kelse	i	studien
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Samtykke til deltakeise i studien
Ved å signere på dette skjemaet samtykker du til deltakelse i studien, at lydopptak tas i bruk og at du har lest og forstått informasjonen i dette skrivet.
(Underskrift og dato)

Appendix B

REK - Application



Region: REK nord Saksbehandler

Telefon:

Vár dato: 02.11.2016 Vår referanse: 2016/1777/REK nord Deres referanse:

Deres dato: 20.09.2016

Vår referanse må oppgis ved alle henvendelser

Roald Øien Hugingbakken

2016/1777 Arbeidstakere med Asperger syndrom

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 20.10.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: Universitetet i Tromsø

Prosjektleder: Roald Øien

Prosjektleders prosjektomtale (original):

Formålet med denne studien er å kartlegge informasjon omkring erfaringer og utfordringer som personer med Asperger syndrom opplever i møte med arbeidslivet. Det er ønskelig å identifisere faktorer som kan kategoriseres som barrierer i forhold til suksess i arbeidslivet, i tillegg til faktorer som kan bidra til at denne populasjonen i større grad mestrer prosesser som omhandler ansettelse og det å forbli ansatt i en bedrift. Det er manglende kunnskap omkring Asperger syndrom som diagnose blant arbeidsgivere, noe denne studien kan forandre ved å bidra til økt forståelse omkring styrker ved arbeidstakere med Asperger syndrom og forhåpentligvis bidra til forenkling av tilretteleggelse og organisering av ansettelser for denne populasjonen. Problemstillingen til denne studien er: Why do some people with Asperger syndrome succeed in working-life, while others don't? Forskningsspørsmålet skal besvares ved kvalitative dybdeintervju av arbeidstakere og arbeidsledige personer med AS.

Vurdering

REK har vært i kontakt med Instituttleder ved IPS, Ingun Skre, og fått bekreftet at hun skal stå som kontaktperson for forskingsansvarlig i prosjektsøknader fra IPS.

Framleggingsplikt

"Medisinsk og helsefaglig forskning er i helseforskningsloven § 4 bokstav a definert som: «virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er forskningens art og natur som må være avgjørende for hvorvidt den skal regnes som medisinsk og helsefaglig forskning som faller inn under loven. Begrepene" helse og sykdom" må tolkes vidt. Forskning på rehabilitering vil for eksempel falle innenfor. Videre betyr det at flere samfunnsvitenskapelige prosjekter vil falle inn under lovens virkeområde, så fremt de tar sikte på å fremskaffe ny kunnskap om helse og sykdom".

I en klagesak behandlet i NEM med tittelen «En registerstudie av inntekts- og trygdeforhold hos menn med prostatakreft (Saksnr. 2013/97)» uttalte NEM at «studien i vesentligste grad skal studere yrkeslivet til

Besøksadresse: MH-bygget UiT Norges arktiske universitet 9037 Tromsø Telefon: 77646140 E-post: rek-nord@asp.uit.no Web: http://helseforskning.etikkom.no/ All post og e-post som inngår i saksbehandlingen, bes adressert til REK nord og ikke til enkelte personer Kindly address all mail and e-mails to the Regional Ethics Committee, REK nord, not to individual staff

..

Appendix C

NSD - Application



Roald Øien

Institutt for psykologi UiT Norges arktiske universitet

9037 TROMSØ

Vår dato: 02.01.2017 Vår ref: 51281 / 3 / KH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 24.11.2016. Meldingen gjelder prosjektet:

51281 Employees with Asperger Syndrome

Behandlingsansvarlig UiT Norges arktiske universitet, ved institusjonens øverste leder

Daglig ansvarlig Roald Øien

Student Kristina Nyvoll Pedersen

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 02.05.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Kjersti Haugstvedt

Kontaktperson: Kjersti Haugstvedt tlf: 55 58 29 53

Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

NSD – Norsk senter for forskningsdata AS Harald Hårfagres gate 29 Tel; +47-55 58 21 17 nsd@nsd.no Org.nr. 985 321 884 NSD – Norwegian Centre for Research Data NO-5007 Bergen, NORWAY Faks: +47-55 58 96 50 www.nsd.no

Kopi: Kristina Nyvoll Pedersen kristina.nyvoll.pedersen@gmail.com

Personvernombudet for forskning



Prosjektvurdering - Kommentar

Prosjektnr: 51281

Personvernombudet legger til grunn at taushetsplikten ikke er til hinder for rekrutteringen av utvalget.

Ifølge meldeskjema informeres utvalget skriftlig og/eller muntlig om hva deltakelse i studien innebærer. Vi finner at det gis tilfredsstillende informasjon til utvalget. Vi anbefaler likevel at det tilføyes i skrivet at det er sendt ut via Autismeforeningen, og at Nyvoll Pedersen ikke er kjent med deres identitet med mindre de selv tar kontakt med henne.

Personvernombudet har lagt til grunn for vår vurdering at det ikke behandles taushetsbelagte opplysninger i forbindelse med studien. Vi legger videre til grunn at data sikres i tråd med UiT sine retningslinjer for datasikkerhet.

Ved prosjektslutt anonymiseres data ved at verken direkte eller indirekte personidentifiserbare opplysninger fremgår. Eventuelle lyd-/bildeopptak slettes.

Appendix D

Intervjuguide

Intervjuguide

Presentasjon:

Jeg går på masterprogrammet ved Institutt for Psykologi ved Universitetet i Tromsø, Norges Arktiske Universitet. Jeg skal fortelle deg litt om hva vi skal snakke om i dag. Personer med Asperger syndrom opplever ofte vansker med det som kalles for triaden, det vil si kommunikasjon, gjensidig sosial interaksjon og rigiditet eller spesielle interesser. Disse problemene kan føre til at noen faller utenfor, det vil si at de opplever det som vanskelig å skaffe seg en jobb eller forbli i en jobb de er ansatt i. Men så vet vi jo at personer med Asperger også har mange sterke sider som gjør at de kan være fantastiske arbeidstakere. Det jeg vil snakke om i dag er hvordan det var for deg å begynne i arbeidslivet. Så da skal jeg stille deg noen spørsmål.

Jeg setter stor pris på din deltakelse og dine svar er viktig for hvordan vi kan forbedre dagens situasjon når det gjelder tilrettelegging og organisering av ansettelsesforhold.

(Informer om lydopptak og samtykkeskjema) Har deltakeren noen spørsmål?

Yrke:

- Kan du fortelle litt om yrket ditt og bedriften du er ansatt i?

(Hva er dine arbeidsoppgaver på jobben?) (Hva er bedriften på jakt etter i forhold til den stillingen du har?) (Hva ønsker din bedrift fra deg?)

- I hvor stor grad er du i jobb for øyeblikket?

(Kan AS misforstå og tenke «akkurat i dette øyeblikk»? Hvor stor stillingsprosent har du, er det 50% eller mer?)

(Hvorfor er det ikke 100 % stilling?)

(Er det du eller arbeidsgiver som har bestemt at det ikke skal være 100 % stilling)

- Hva tenker du om det å være arbeidstaker/arbeidsledig?

(Opplever du det som positivt eller negativt å være i jobb?) (Er det viktig for deg å være i jobb? Hvorfor?) (Hvorfor vil du være i jobb?)

Tilrettelegging:

- I hvor stor grad har arbeidsgiver lagt til rette for deg på arbeidsplassen? (Har du klare avtaler om arbeidstid?)

(Har du eget kontor?)

(Har du en kontaktperson på jobben?)

- (Har *«denne tilretteleggingen»* vært til hjelp for deg?) (Hvordan hadde arbeidshverdagen din vært dersom du ikke hadde *«denne tilretteleggingen tilgjengelig?»*
- (På hvordan måte?)
- (Hva innebærer tilretteleggingen?)
- (Har dette vært til hjelp for deg? På hvordan måte?)
- (Var det du eller arbeidsgiver eller noen andre som foreslo den tilretteleggingen du nå har nevnt?)

Sosialitet:

- Det sosiale aspektet ved en arbeidsplass kan dreie seg om øyekontakt med kollegaer, small-talk, klemmer osv. Som du vet så er kjennetegnet på AS den triaden jeg nevnte i sted. Vansker med kommunikasjon, gjensidig sosial interaksjon og rigiditet.
- Føler du at du mestrer det sosiale aspektet ved jobben?

(Spiser du lunsj sammen med kollegaene dine?)

(Hilser du på kollegaene dine i gangen?)

(Drikker man kaffe sammen på jobben?)

(På hvilken måte?)

(Kan du gi et konkret eksempel på en situasjon hvor du følte at du mestret det sosiale på jobben?)

- Kjenner du til noen regler eller samtaleemner for sosiale situasjoner som for eksempel i lunsj og pauser?

(Hva gjør de andre kollegaene dine i lunsjen?)

(Hva pleier kollegaene dine å prate om i lunsjen/pausen?)

(Føler du at du kan ta del i samtalene?)

(Lytter du på hva kollegaene dine snakker om hvis du deltar i lunsjen?)

Ferdigheter:

- Hvilke ferdigheter må man ha for å lykkes i ditt yrke?

(Kan du forklare litt nærmere hva du mener med.....?)

(Hvilke ferdigheter har du som gjorde at du fikk denne jobben?)

- Hvilke ferdigheter må man ha for å lykkes generelt i arbeidslivet?

(Utadvendt, lojal, punktlighet, osv. Gi eksempel om de spør?)

Rutiner:

Nå skal vi snakke litt om rutiner på jobben.

- Er det vanskelig for deg å omstille deg ved nye rutiner på jobb? For eksempel hvis det kommer nye arbeidstider eller et nytt dataprogram.

(På hvordan måte?)

(I hvilken grad må du være forberedt på at det kommer en ny forandring?)

(Kan du gi et konkret eksempel på hvordan du har omstilt deg?)

(Når du sier at du synes det er vanskelig/OK med omstillinger, er det noen spesielle emosjoner du opplever når en forandring kommer?)

- Hvorfor er det vanskelig å omstille seg?

(Trenger du en muntlig eller skriftlig oversikt over at det kommer en ny rutine?) (Hvor lenge opplever du ubehag/stress?)

Informasjon om diagnosen:

- Er det av betydning for deg at dine kollegaer er informert om at du har diagnosen Asperger syndrom?

(På hvilken måte?)

(Opplever du det som positivt eller negativt om de er informert/ikke informert?)

(Kan du gi et eksempel på hvorfor det er av betydning?)

Komorbiditet (angst/depresjon):

- Har du opplevd noen negative emosjoner (stress, angst eller depresjon) i forbindelse med jobben?

(Kan du fortelle litt mer om dette?)

(Kan du gi et konkret eksempel på dette?)

(Hvilke situasjoner er det som framkaller negative emosjoner?)

- I hvilken grad har dette påvirket deg som arbeidstaker/arbeidsledig?
- (Kan du si litt mer om dette med....?)

Fremtiden:

- Hvilke tanker har du angående fremtiden når det gjelder å bli ansatt i en bedrift eller forbli ansatt i en bedrift?

(Når du tenker på fremtiden i forhold til jobb, har du positive eller negative tanker i forhold til dette?)

Avslutningsvis:

- Er det andre aspekter ved det å være arbeidstaker med Asperger syndrom du ønsker å få frem?
- Takke for deltakelsen.

Oppfølgingsspørsmål:

- I forhold til dette med ____
- Hvordan opplever du dette?
- Kan du si litt mer om det?
- Du nevnte dette med ____
- Kan du utdype det litt?
- Du fanget interessen min når du nevnte dette med ___
- __ hvordan er din opplevelse i forhold til dette. Har du opplevd dette som vanskelig/utfordrende?