Becoming a member of the work force: Perceptions of adults with Asperger Syndrome

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\textbf{Abstract.} Objective: Research has shown that comparatively few adults with Asperger Syndrome (AS) participate in the competitive work force. The purpose of this study was to gain in-depth knowledge about contextual factors, which contribute to successful labor market participation in some adults with AS.

Participants: This study was conducted by indepth-interviewing six adults with AS working in the competitive job market in Switzerland.

Methods: A developmental and hermeneutic narrative approach was used for data collection and analysis. Two in-depth narrative interviews were conducted with each participant. A narrative analysis according to the theories of Paul Ricoeur was performed.

Results: Results showed that participants received pre-vocational requisites during their childhood through parents and friends that provided a feeling of security in social contexts. For participants, a supportive school setting resulted in academic achievements. The narratives reveal participants’ capacities for understanding and adapting to social norms. Participants’ understanding of their own needs was essential to the successful labor market participation. However, disclosure is rare and social stigma is still present.

Conclusions: This study showed that successful labor participation of adults with AS can be enhanced through adequate social support already in the early stages of an individual’s lifetime.

Keywords: Pervasive developmental disorder, competitive work, biographic narrative, pre-vocational requisites, occupational therapy

1. Introduction

1.1. The significance of participating in work

Already in 1932, Maria Jahoda investigated the psychological consequences of unemployment in an industrial Austrian district that suffered from high levels of unemployment (1981). Unemployment and its consequences has ever since remained an important issue. The United Nations (UN) pointed out only recently that the inclusion of people with disabilities in society is a human right and exclusion of people with disabilities is subsequently a matter of social justice [60]. In today’s society, participation in work is important not only for earning a livelihood, but also for developing one’s identity. As Watson [61] highlighted, “in looking at how people make a living, we are looking at how they deal with both the economic and the social or cultural aspects of their lives. Work occurs in society”
Baker et al. [6] further elaborated several areas that underscore the significance of work in one's life, including that, "work is a source of economic independence; (...) it entails certain rights and obligations; it promotes energy expenditure and activity; it imposes structure; it provides individuals with goals and meanings that transcend their own lives; it gets individuals involved in society; it provides existential meaning; and it provides personal status and identity" (p. 57).

Hence, being excluded from participation in paid employment has economic, social, and individual consequences. Disabled persons are more likely to be in households with lower incomes and would therefore lack employment-related qualifications as previous research has shown [52,57]. In addition, research in the field of intellectual disabilities shows that there is a positive link between quality of life and competitive work contexts [37].

1.2. The concept of context as theoretical underpinning

The necessity of including the social context in research and social and health care practice has been underscored by the World Health Organization (WHO), with the acknowledgement of the social context as a determinant of health [67], as well as in the area of disability research in particular [54]. Looking more closely into environments that create or prevent disability and enable participation in any type of paid and unpaid work, occupational therapists understand that any occupation (self-care, productivity, e.g., work, leisure activities, and rest) takes place in a context [66]. These contextual forces shape performance and engagement in any type of activity, as well as the meaning ascribed to it. In the Ecology of Human Performance Framework (EHP) [16], context is understood as having temporal as well as environmental aspects. Environmental aspects are physical, social, and cultural influences. The workplace itself constitutes a particular cultural context and requires adaptation to, and integration within, this context. The ability to adapt to traditions, customs, laws, rituals, dress codes, and rewards associated with work, is fundamental to maintaining one's presence in the workforce [31].

1.3. Work participation of people with Asperger Syndrome

Adapting to a particular work culture requires constant negotiation of these social and cultural values and norms, not only when entering a new workplace, but also when aiming to maintain one's position at work. Both however may constitute a challenge in particular for people with Autism spectrum disorder. Autism spectrum disorder is a continuous and lifelong condition [2] and has been included in the DSM-IV [2] under the umbrella categorization of pervasive developmental disorders. One typical feature of the autistic spectrum disorder is Asperger Syndrome (AS), which is a qualitative impairment in the development of reciprocal social interaction, communication, and imagination. Individuals with AS have normal or above-average intellectual capacity, and atypical or less well developed social skills. Although diagnostic criteria have been defined for diagnosing AS in childhood, the recognition that AS displays "persistence over time" is leading to a need for understanding the challenges of AS in transitional periods [55]. Despite great attention in research on the identification and treatment of people with AS at a young age (e.g., school-based interventions), limited focus has been given to their needs in adult life (e.g., their vocational needs) [59].

Research of adults with Asperger Syndrome reveals a generally poor though variable outcome [33], with the employment rate ranging from 5 and 55%. Cultural context, as well as possibilities of supported or sheltered employment was presumed as reasons for this variation. The vocational support needs of 18 individuals with AS revealed a great diversity in profession, but also showed major negative experience patterns for all participants. Obstacles to successful work were found to be mastering a job application process, adapting to new job routines, communication issues, and negative interactions with employers and co-workers [42]. Dropouts from educational settings at universities have also been reported to be a common feature in AS [22]. Currently, a variety of service options for supporting work entrants with Asperger Syndrome are discussed [14], such as job placement strategies, supervised on the job training, and supported employment. While initial evaluations of these strategies show promising results, the evidence remains to be developed [33]. However, the frequency of unsheltered, unprotected employment is reported to be low across different countries. Among 42 Swedish participants, only one had a regular job with a normal salary [17]. Hurlbut and Chalmers [32] interviewed six persons with AS about their work experiences in the competitive labor market. All experienced unemployment or underemployment. Social aspects of employment, including communication and social skills, as well as sen-
sory overload, were the primary culprits behind reported negative experiences. Participants also felt a lack of recognition of their competencies. These might be associated with reported traits in Asperger Syndrome, such as their sense of honesty, their highly developed logical deductive capacities [63], and their idiosyncratic humor, with which people with AS are often gifted, but which might appear unusual to others [62]. These traits might favor them in certain types of jobs (e.g., in the financial control sector). A promising tendency in the field of work for persons with Asperger Syndrome is the appearance of companies, which specifically hire employees with AS. Here the special capacities of persons with AS are prized for certain tasks that non-autistic persons would not as efficiently or as trustworthily perform [53].

1.4. Focus in treatment approaches for adults with Asperger Syndrome

Social deficits in autism have been targeted by various intervention models, mainly in the field of social skills training. These interventions involve teaching specific skills, like maintaining eye contact or initiating conversation through behavioral and social learning techniques [70]. Results of their review of social skills programs showed that improvements of certain skills have been confirmed in clinical settings, but are not necessarily applied in a child’s daily life and school setting. “Generalization and flexible skill use in natural environment continues to be a challenge” [70, p. 1868].

More recent research supports the adoption of a social model of disability with respect to persons with AS. The empathizing-systemizing model of Asperger Syndrome by Simon Baron-Cohen [8,9] seems to exhibit new aspects to be considered. It describes AS in a value-neutral way and characterizes it as a different thinking style. It refers to the concepts of disability and handicap with regards to the importance of particular environments that create disability.

1.5. Drawing on the perspectives of adults with Asperger Syndrome

Research drawing primarily on the perspectives of people with Asperger Syndrome is rare. A reason for this is that for a long time the scientific community saw persons with Asperger Syndrome as “unreliable informants due to the lack of self-reflection and inaccurate perceptions of their differences in relation to others” [56, pp. 87–102]. Despite relatively little in-depth research in AS [32,42], a wide range of autobiographic literature from persons with Asperger Syndrome has been published [20,23,69]. In reference to employment issues, Grandin and Duffy [24], both well-known and successful participants with AS in the first labor market, published a career advice book for people with AS. Based on their work, the most critical ingredient for job fulfillment seems to be career and work preparation during childhood.

1.6. Incorporating a temporal line in research about people with Asperger Syndrome

Other recent research also supports the application of a temporal line in investigating factors that affect work participation. Chapparo and Hooper [13] recommend shifting back to childhood and adolescence to further understand how a worker’s attitude and career decisions have developed. They examined in their study six-year-old children’s perceptions of classroom occupations, which were classified by children either as work or as play [13]. Results showed that children can clearly distinguish between these two categories, and that social and physical contexts are significant determinants of work. Beside schools, parents and peers provide the most influential social context to children. It is known that children benefit from observing positive role models for work in the significant adults of their lives [10].

Given the gap in current knowledge regarding factors influencing successful work participation in people with Asperger Syndrome, the purpose of this study is to gain in-depth insights about contextual factors that contribute to, and influence, successful labor participation of adults with Asperger Syndrome. More specifically, the aims of this narrative study are to explore (1) how adults with Asperger Syndrome assign meaning to, and perceive contextual and influential factors throughout, childhood and adolescence, and (2) how these factors enable or hinder them as adults in maintaining participation in competitive employment. Therefore the research question was: How do some adults with Asperger Syndrome perceive the meaning of past contextual influences as enabling or hindering their preservation of competitive employment?

For the purposes of this study, work is defined as “the carrying out of those tasks, which enable people to make a living within the social and economic context in which they are located” [61, p. 3]. Competitive work, mainstream labor market, or first labor market are used interchangeably to refer to jobs that pay market wages.
2. Methods

2.1. Design

A qualitative research design was chosen for this study. The interpretative character of, as well as the temporal-biographical aspects inherent in, the research question demand a hermeneutic and narrative approach. As a result, the design of this research was based on the French philosopher Paul Ricoeur’s theory of interpretation [49], modified and described for health sciences by Wiklund et al. [68].

Narratives give an understanding of the creation of identity, and its character of temporality and context. Ricoeur’s conception of historical time unites two elementary understandings of time. There is cosmic time and there is lived time. Cosmic time relates to the astronomical time scale. In lived time, some moments are more meaningful than others, and they will show up in narratives [49]. In a narrative, a lived sequence of two seconds may, in the example of an accident, result in a two-hour narrative about this moment.

Ricoeur’s narrative theory emphasizes that all narratives are created for a reader or listener [49]. Along with its hermeneutic tradition, interpretation is not the immediate understanding of a text, but an opening up of a new perspective.

2.2. Participants

For inclusion in this study, adult candidates were selected and had to have participated at the time of the study in the competitive labor market during the previous 18 months, with a minimum workload of 21 hours per week (42 hours per week is the standard workweek in Switzerland). The individuals identified themselves as persons with AS and having fluency in the German language. For purposes of recruitment, eight health care professionals or organizations, who were familiar with possible AS candidates for this study, acted as gatekeepers in forwarding invitation letters to the candidates. In the letters, research aims and inclusion criteria were explained. Interested persons were asked to contact the first author.

In accordance with the hermeneutic narrative tradition of this research [68], six persons were considered to constitute an adequate sample size. The first six persons who fulfilled the inclusion criteria were chosen. A demographic table of the six participants – Hannah, Jim, Paul, Celestine, Tom, and Kim – is shown in Table 1.

2.3. Ethics

Ethical approval was granted by the Medical Ethics Commission of the Canton of Zurich (Switzerland) to provide protection from harm and deception, and to ensure security of privacy. To address ethical considerations, approval from the Autistic Association of Switzerland was also obtained after its recommendations were fully addressed by adapting questions to the communication style of a person with AS. A psychologist experienced in counseling persons with AS was made freely available for helping participants to deal with any inconvenience arising from the study. Nobody felt the need to use this service. Lastly, participants submitted their informed consent to the study.

2.4. Data collection

The first author conducted two in-depth interviews within a time span of four weeks with each participant. The interviewer had previous experience in interviewing adults with Asperger Syndrome. After preparing a thematic and semi-structural interview guide [38] she conducted two pilot interviews with non-autistic adults to check if the questions were precise and clear. To accommodate the needs of people with AS, both interviews were prepared in either a semi-structured or open-ended way. Both interview types were used, as some participants felt comfortable with an open interview, while others preferred a semi-structured one. The topics were structured along the different aspects of lived context and can be summarized as follows: (1) Briefing and introduction, (2) description of workplace and duties, (3) meaning of work, (4) meaning of former physical context, (5) meaning of earlier social context, (6) meaning of experienced cultural context, and (7) debriefing. For the second interview, the participants were asked to provide further thoughts concerning the content of the first interview, or reflect again on the main question of the study: “What past influences do you perceive important for maintaining your position and participation at work?” The second interview was an adaption to the client group as new contacts and spontaneous reactions are reported to be rather stressful for persons with AS [42].

The interviews lasted between 90 and 270 minutes. The places of the interviews were chosen by the participants. Some interviews were held either in private settings, such as in homes, or in one case, in a music practice room; or in public spaces, such as in restaurants, or in the Zurich botanical garden. The development
of a mutual rapport was essential for conducting the interviews. The environments of the interview, as well as the researcher’s intuition, were important factors in achieving this. One example of how the environment influenced rapport in a positive way, was that one participant who worked as a gardener, could display his broad botanical knowledge during a walk through the botanical gardens while the researcher shared observations of flora on a recent visit to a tropical forest. The follow-up interview was subsequently conducted while sitting next to tropical aquariums. It turned out that the subject was an amateur diver. According to the participant’s feedback, the second interview was much more relaxed.

The primary author kept a field journal that included observational and introspective notes; these were used to supplement and validate information obtained during the data analysis. All interviews were audio-taped and transcribed verbatim.

2.5. Data analysis

Within a narrative analysis, four main steps of the procedure described by Wiklund et al. [68] guided the interpretation process:

1. For each interview, the first researcher formulated an initial core narrative, which was a distilled, chronological story of four pages’ length, deriving from the interview data. For Polkinghorne [46], a plot includes (1) a specification of the problem to be solved, (2) an organization of actions and events into a beginning, middle, and end, and (3) a clarification of lessons to be learned from the story. A plot of each narrative was extracted mainly from the first and last parts of the interviews. Celestine for example started the interview with the phrase: “That mankind can progress is part of my lifestyle and my life experience”, and she ended the second interview as follows: “[My] scars can be healed the same way as in neurotypical people: Good relationships must be built up, as only these can restore and sometimes cure souls. Life is shaped by relationships, and only functions because of them. As an autistic person, the unwritten conventions of relationships are hurdles.” Her way of expressing the problem as the unwritten conventions of relationships with accompanying learning experiences and scars, her emphasis on building good relationships, and her recognition of life as shaped by those relationships and that mankind progresses, justify the extraction of these phrases from Celestine’s narrative to become part of her plot. The language of the participants was used whenever possible, and each participant was invited to review their story and plot and to suggest amendments. All changes were accepted; there were corrections, more explanations, and alterations to protect privacy. After each participant agreed fully to his or her core narrative, these were translated into English by various native English speakers (who were knowledgeable or had personal experience about autism) to enhance the validity of the translations. The translation process also served to enable discussion throughout the analysis among the co-authors.

2. In the next step, a first naïve interpretation clustered meaningful experiences of each core narrative along the theoretical framework of the EHP into physical, social, cultural, and temporal contextual aspects [16]. Naïve interpretation was first conducted by the first two authors independently,
and then the interpretations of both authors were compared and discussed.

3. In the third step, the structure of the narrative and its plot were analyzed by identifying the structure of the recounted drama. This method, which was proposed by the historian Hayden White in referring to Ricoeur [65], asked whether a storyteller tells a story as romance, as comedy, as tragedy, or as irony/satire. The question behind this is: What does a person, who employs his/her narrative in this way, want to tell about himself or herself, as well as about the meaning of hindering or enabling influences to achieve labor participation?

4. Finally, the last step in the hermeneutic process was to merge the suggestions for all the different interpretations, including the researcher’s journal, for triangulation, and to derive the inherent meaning from the sum of the narratives. This process again involved much discussion among the co-authors until agreement was achieved.

Because the work in steps one, two, and four revealed the analysis of the core issues concerning context, the results of these steps are presented as results. The authors however acknowledge that the findings gleaned throughout all four analysis steps may have influenced their opinions about these findings.

2.6. Trustworthiness

Steps to ensure the trustworthiness [29] of this study included (1) prolonged engagement of the first author to understand the culture, language, and views of the group under study, (2) review of the questions by the Autistic Association of Switzerland, (3) establishment of a free flow of information from participants, (4) usage of member checks to verify information and to validate interpretation, (5) usage of native English speakers with experience in autism to translate the core narratives into English, (6) devising of explicitly different analysis tools, (7) usage of nuanced linguistic approaches as recently demanded by researchers [19], and (8) engagement in ongoing audits between the first two authors and with other peer researchers throughout the study.

3. Results

The findings of this study illustrate the importance for persons with Asperger Syndrome to be socialized in well-caring social contexts, and to learn culturally im-
portant competencies already in their early childhood, as Tom for instance expressed it: “The best support is socially secure parents and an understanding school setting.” Following the temporal line, well-caring social contexts supported successful social participation in adulthood, as became evident in the narratives of the participants in this study. The results are presented according to the four aspects of the EHP framework [16] that guided the analysis: Social, cultural, physical, and temporal context. As shown in Table 2, each of these four contextual aspects was complemented with themes. Underneath each theme, subthemes are presented that originate from a quotation of a participant, expressing what all participants have said about the theme.

3.1. Social context: To feel socially secure and be familiar with social environments

As illustrated by the two subthemes, this theme describes what participants felt to be meaningful about their relationships to their parents, as well as how different ways of experiencing peer relationships shaped their social competencies.

3.1.1. Mom left me alone without accusations

Parents and family were described in all six narratives as clearly enabling. Four dimensions: (1) Acceptance, (2) having space and time for themselves, (3) having practical experiences, and (4) having a broader social context – were frequently mentioned by participants:

(1) Acceptance: Parents helped their children by accepting them as being different and as having different needs than normal children. “As a child I hated to be hugged and kissed and my parents accepted it quickly and seldom gave me a hug” (Kim). This acceptance mediated a sense of protection when overwhelming demands originating from the outside would block these children. “Again I had to leave school. For months I stayed at home and locked myself in my room... She [Mom] left me alone without accusations” (Jim). Through their care and nurturing parents of the participants in this study were able to deflect societal pressures. Parents showed their children that their needs and pleasures could be shared and enjoyed.
### Table 2
Thematic overview of contextual features, themes and subthemes

<table>
<thead>
<tr>
<th>Context</th>
<th>Themes</th>
<th>Subthemes</th>
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<tbody>
<tr>
<td>1. Social context</td>
<td>To feel socially secure</td>
<td>“Mom left me alone without accusations”</td>
</tr>
<tr>
<td></td>
<td>To be familiar with social environments</td>
<td>“Through her I met other children in the neighborhood.”</td>
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<tr>
<td>2. Cultural context</td>
<td>To achieve cultural competence</td>
<td>“Teachers are for learning and not for relationships”</td>
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<td>“I am open for new ideas but in the end, I have to experience them as my own”</td>
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<td></td>
<td></td>
<td>“This is not my world but I know the rules of the game”</td>
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<td></td>
<td></td>
<td>“I like my job but I need enough to do to not feel bored”</td>
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<td></td>
<td></td>
<td>“Working behind a window in the post office protected me”</td>
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<tr>
<td>3. Physical context</td>
<td>To feel protected or offended</td>
<td>“It became clear: My strange needs are legitimate”</td>
</tr>
<tr>
<td>4. Temporal context</td>
<td>Receiving and disclosing diagnosis</td>
<td>“There is a subtle black and white thinking in Swiss society.”</td>
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</table>

(2) Having space and time for themselves: Participants valued having free time in their childhood for discoveries or being allowed to spend days in a room and listen to music or fairytales. “[During] holidays on the farm of my grandfather. . . . there was plenty of space, time, and material to discover and construct things. I remember that once I tried to construct an automatic door opener with bales of straw and pulley systems. This was paradise for me” (Paul). As illustrated in the narratives of participants, autistic children need things to do independently. In moments of outbursts, parents were the first to understand their child’s needs to be alone to calm down. “My parents told me later that they sought professional advice when I was around three years old and started to display outbursts of rage. They were advised to just leave me alone in those situations, which they duly did” (Kim).

(3) Parents played a pivotal role in providing practical experiences of daily living as Kim underscored: “Dad liked to garden... being a calm and quiet man and no one could disturb him during that time. . . [he did] a bit of planting and weeding. I loved to work with him and simply copied what he was doing. [We did it] together in peace and quiet without talking.” It became evident in the narratives, that the education styles of parents were different. Nevertheless, all parents were able to adapt to their children’s needs. “I believe my mother had the most influence on me. An autistic child of 15 needs the same instructions as a normal child of five. For instance, they need to be shown how to use deodorant and to be told how often to take a shower” (Jim). Structure in practical learning was highly valued as highlighted by Celestine: “My mother ran the house like a military commander. She could never complete a task alone and insisted on giving orders to everyone in the house. The orders became structure. As a result, I learned a lot of practical things.”

(4) Participating in a broader social context: Most of the participants valued their parents’ social engagement and their sharing of their own social contacts and relationships. This allowed them to observe, and become familiar with how people interacted in groups. Allowing children to listen to adult discussions was positively regarded. “I loved to listen to adult conversation, but unfortunately I was often sent off to look after my younger sisters. Children had to play with children. I always invented new strategies that allowed me to eavesdrop and observe the adults” (Celestine). Social family routines, such as spending holidays with grandparents in the mountains or other family encounters were positively meaningful for participants.

3.1.2. Through her I met other children in the neighborhood

Even more important for achieving basic social skills was naturally developed peer friendships with “normal” children. With one exception, five of the participants experienced intensive one-to-one peer relationships during childhood. These relationships were never facilitated by parents or through social skill groups. It seemed that they evolved rather naturally through common interests. “Most of all, I recall a friendship with a boy from the neighborhood. This boy seemed to me like a book. So we studied technical books together and tried to reconstruct inventions we saw in the TV program,” Star Trek “. Paul expressed how, as a child with Asperger Syndrome, he could share his interests, knowledge, and fascination with technology.

Such friends often served as a kind of “door opener” to social networks. “In this new school, I quickly made a friend called Marc. To Marc I seemed a bit strange, but we were “on the same wavelength”. Together we listened to hard rock and were interested
in science fiction. Together with another boy and girl we played pranks and annoyed adults. We were never bored. I pierced my ear with a safety pin and felt secure and accepted by the other classmates” (Jim). In these friendships, participants described that they experienced mutual acceptance which resulted in shared joy, fun and opportunity to learn social behavioral patterns as expressed by Hannah: “Through her I met other children in the neighborhood. For them I was a bit odd... they laughed with me but not at me. Biene made sure of this. Yes, I owe a lot to Biene!” Hannah could observe and learn to bring herself in, as she elaborates: “In the group, I observed how easy going my friend was. I learned how to talk without verbally expressing something. I imitated her spontaneity and tried to say whatever came to mind.”

Participants in the study narrated that feedback from rejection was often helpful, as for instance Celestine stated: “I once asked a group of children why they didn’t play with me. They called me bossy. Today, I understand this. I needed structure and so I outlined the plans while playing with others. I also talked a lot so the others had no chance to lead”.

All six participants still value single friendships over membership to a peer group. Friendships are long lasting and are maintained through mutual understanding. Some participants mentioned that an expressive, outgoing person is easier for them to relate to. For all participants, groups are still more challenging than single-person encounters. Hannah remembered the setting in kindergarten: “Believe me, this was pure hell... there seemed to be so many children... at least fifty... I attempted to block them out. Today I realize that there were no more than 20”.” Celestine reflects rather accurately “I find groups disturbing. It is as if emotions have a smell... I can perceive it like a perfume. If one person is in the room, I can smell him... when there are two people, it becomes difficult to distinguish them from each other and with three it is not possible anymore.”

Some of the six participants also attended formal groups during childhood, which nourished their interests and preferences. “From early on, I attended a dance theater group for children. I loved to dress up and to move to the music. I had to take part in several performances... but they allowed me to play minor roles... twice I was a tree in the background. I could never say a line. But standing there was enough for me” (Kim). In this context, observing quietly and without a need to react was a highly meaningful experience for some participants. In these groups, their role and place appeared to be rather clear. “It is often said that scouts are organized in a military way, but I appreciated the clear expertise and decision-making structures. This is a sign of good leadership. ... In this group, I learned to solve problems and to discuss possible solutions with others” (Tom).

As these results show, participants who reported engaging in peer groups during childhood expressed feeling greater confidence in group settings; provided the group structure is clear and the interests of the person with Asperger Syndrome are fulfilled.

3.2. Cultural contexts: To achieve cultural competence

This theme deals with the ways that cultural contexts provided opportunities to enable participants to adjust to cultural demands. It is divided into subthemes connected to cultural context at school, aspects of experiencing possibilities and limits, and ways of comprehending and adapting to cultural norms. The theme ends with a subtheme about how, when mediated by cultural contexts, participants have learned to understand their own needs for work.

3.2.1. Teachers are for learning and not for relationships

Four of the six participants were enrolled in regular school settings during their entire education. One participant changed from a private school that was based on the premises of the German philosopher Rudolph Steiner to a regular one, while another participant experienced as least eight different schools in various kinds of settings. Most participants experienced bullying and teasing at mainstream schools. “I once protected myself by putting tacks under my shirt, in case somebody approached too close” as Paul stated; or as Jim remembered, “during breaks I used to hide in the toilets”. Teachers of participants were seen as an important buffer to soften these experiences and protected them from severe repercussions. But more importantly, teachers were considered primarily as people who transferred knowledge. “After kindergarten it was a relief to me to go to a normal school. I had tried to love the horrible teacher and now I realized that I did not have to love [her]. Teachers are for learning and not for relationships” (Hannah).

In the narratives, those teachers who showed an interest in their students and in their learning needs were well regarded. “At that time, I was totally overburdened by this experience [entering a new big class (ed)] and
missed things. I just waited for the lessons to be over. Sometimes the lessons' contents spilled over into my thoughts. One teacher encouraged me to just note down what I knew, a technique that still functions today" (Hannah). Such teachers were remembered as having successfully found individual ways to approach students. As fellow classmates often associated the participants' ways to ask questions, or their behavior, with oddness or stupidity, it was important for all participants to show they were not stupid. "My husband was the first human being who acknowledged that I am not stupid, but am highly intelligent. I had nearly believed it myself [that I was stupid]" (Celestine).

Participants described difficulty in concentrating and memorizing when they had no interest in a subject, or when the aim of learning was not clear. For four years, Jim attended a home for children with special needs. There, teachers “bullied, battered and humiliated us. They tried to break our will. Once I dared to ask an educator during a walk what he knew about comets. This angered him and he insisted I write the word “comet” a hundred times. His hope was obviously that I would learn not to consult people about such eccentric topics. After this, I stopped asking.” The consequence of pressure was in most cases withdrawal into an inner world of thoughts and imagination. Paul explained that “under these hostile conditions, I withdrew and started to read adult encyclopedias. I occupied myself with sequences of numbers and knew by heart the 30 decimal places of pi, and the 17 decimal places of the Euler numbers. Sadly, the encyclopedia didn’t tell more.”

All participants reported handwriting problems and difficulties in sport games that still persist today. Teachers who did not try to change these traits were highly regarded by participants. Similarly supportive were teachers who were not easily offended by these children. Participants described how their knowledge, their questions, and their way of talking, was similar to little adults, and was often misinterpreted. “The accounting teacher understood that I was different. He was not easily offended. He permitted me to be right. As I was not graded and missed classes, the headmaster wanted me to quit. But this teacher insisted that I be assessed on my performance. The headmaster was even surprised by my extraordinary results and suggested that I pursue a higher degree.”

So in this case, a courageous teacher made a major contribution to enable Jim to remain at school and finish with a grade. Participants perceived it as beneficial, when teachers were able to adapt to the learning styles of pupils with AS.

3.2.2. I am open for new ideas but in the end I must experience them as my own

The quest for knowledge, and the desire to perform meaningful occupations in a broad sense, is a major motivating factor for participants to do work. “As long as I can remember, I was thirsty for knowledge. Discovering how things worked gave me a kind of “buzz.” For this to become real, I needed time, a calm atmosphere, and opportunities. Working with others to reach a goal is inspirational. I consider myself extremely fortunate to have been able to obtain these conditions without having had to plead for them” (Paul). Only Paul was able to directly transform his interests into his professional activities. “My professional success can be explained in the choice of an introverted profession in a technical field and a knowledge-intensive environment.”

The other participants had made an odyssey to finally arrive at the professions they are performing today. Having experienced differing work settings and professions allowed them to learn about themselves and about the conditions required to feel satisfied at work. “Time and time again I dared try out something new. I thought if others can do it so could I. My strategy has been to verify whether or not I could do something, and if not, to refrain from doing it in the future. This trial and error attitude has provided me with many learning experiences. I am, believe me, a relatively stubborn person. I am open to new ideas but in the end I must experience them as my own” (Kim).

The meaning of work is closely connected to participants’ acceptance of, and satisfaction with, their existing working conditions. “My biggest wish is to work independently. It is hard to work within the constraints of a clinical setting, but I have to accept it. My profession gives me a sense of fulfillment and stimulation, and allows me to meet other people, thus reminding me of my place in the world” (Hannah). Performing activities that correlate with their personal interest and identity calm them, provide inner order, and console them despite the vagaries of life. For Tom, on the other hand, work is no longer fulfilling due to perceived changing conditions: “I’ve been a gardener for 15 years. But I don’t enjoy this job as much as I used to. Everything and everyone has turned against me. I feel like I am going off the rails. If I have to do tasks I am not really cut out for, it means less to me.”

3.2.3. This is not my world but I know the rules of the game

In this study, the assimilation of norms inherent in culture in general and work culture in particular was re-
vealed as an important factor in keeping a job. “Changing countries allowed me to be more objective and to develop a theory about the essence of culture. The rules of behavior and culture are arbitrary and one must work out how to conduct oneself in the context of these rules.” As Hannah illustrates here, this adaptation to new cultural contexts was enabled through both a highly cognitive process of understanding inherent norms, as well as an intuition for limits, which one sometimes was able to experience in childhood. “Once, I saw the other children playing in the sand and pretending that it was a cake. I found this rather silly but suddenly understood the logic of kindergarten – learning to pretend! I started to play with the others and attempted imagining that the sand was a cake but found it somewhat stupid and futile” (Hannah). Most participants described the reality of culture and the world as being different from their own perceptions. Through observing and experiencing, most came to a similar conclusion: “This is not my world but I know the rules of the game” (Celestine). Assimilating multiple cultural contexts can be seen as a protective strategy because observers cannot be sure if particular behavior is attributable to culture or to personality. “I find it difficult to adapt to Swiss culture. There are so many rules and regulations guiding all aspects of life. Working together with foreigners has a certain advantage. It is impossible for them to know whether the way I behave is because of my culture or my personality” (Jim).

Swiss German culture, with its perceived restrictions and its low tolerance toward people with dissimilar cultural traits, was seen by some participants as generally hindering. “I like to play music with Africans. Some of them are not as bright in mathematics, but they know a lot of things, for example, they know a lot about friends and friendship. Their moods are stable. They can express themselves emotionally and I learn from them” (Jim).

Workplaces with clear structures and explicitly communicated hierarchies were preferred by participants as for instance Celestine said: “I worked for 13 years at the post office. The relationships with people are straightforward and the tasks are well defined. It was not expected that the employees should greet by kissing. Everything followed a routine, and the expectations of everyone were clear”.

3.2.4. I like my job but I need enough to do to not feel bored

The analysis of the narratives in this study provided a clear picture that understanding one’s own needs at work, and looking for strategies to fulfill those needs, exhibit a highly developed understanding of the rules and norms inherent in a cultural context. To feel socially accepted and tolerated was essential for the work environment. “I appreciate people’s tolerance at my workplace, especially when I behave badly and throw things across the room. My work colleagues always took this in stride. They let me know that this kind of behavior is not acceptable but don’t condemn me for it either” (Kim). Participants became aware during certain periods of their lives that they needed to enter social settings and could not succeed alone. “Due to my talks with God and my reading of religious books, I know that my soul needs relationships with people. It is nutrition for the soul” (Celestine). This need, as well as knowing their strengths, enabled collaboration with others. “After the clinic, I started at a university and found a small study group. Some used their social competencies to get exams in advance. I contributed my statistical knowledge and analysis of the examiners’ personalities. Together we succeeded more easily” (Hannah).

When participants knew their own needs but these did not match workplace expectations, the narrative expressed hindering contexts and revealed tragic plot: “I like my job but I need enough to do and not feel bored. I also find it difficult to follow rules that dictate how I have to do things. Working from eight to five with exactly one hour break in the middle is hard. I also cannot leave earlier if I finish my work. So I become bored and agitated. I really don’t need this stress” (Jim). As part of knowing their needs, three participants regularly attend sessions with psychotherapists to analyze their work experiences. None of the participants ever attended a social training group and would not do so if invited.

3.3. Physical context: To be protected or offended

Influences of physical contexts in form of sounds, lights, space or touch affected participants’ behavior and learning patterns in different ways.

3.3.1. Working behind a window in the post office protected me

While physical context played a minor role in the narratives of some participants, other participants discussed stress because of their particular sensory perceptions. “The old school building, high halls and terrible acoustics were terrifying” (Hannah). Situations that did not provide an overview were felt as being
hinderings. Similarly difficult were loud surroundings. Crowds of people with the related possibility of being touched unexpectedly were clearly perceived as negative. Often participants expressed feeling offended but had no chance to withstand these influences. But physical context could also be experienced as enabling as Celestine stated. "Working behind a window in the post office protected me". A clearly structured workplace with few distractions and reduced noise to promote concentration and calm was essential for adults in this study to ensure successful inclusion in the workplace.

3.4. Temporal context: Receiving and disclosing a diagnosis

The two subthemes of this theme elaborate on the most meaningful temporal issues for participants. The moment of diagnosis with AS, and disclosing the diagnosis to others in the context of work.

3.4.1. It became clear: My strange needs are legitimate

After having been diagnosed with other kinds of disorders, for example, ADHD, special needs disorder, depression, dyslexia, and autism, nearly all participants eventually came across Asperger Syndrome in the Internet, and sought to be officially assessed. Most were diagnosed while they were in their 30s or 40s. For participants in this study, the diagnosis came not as a shock or a disappointment, but as a relief, since they were aware of being different but could not explain why "A week after the diagnosis, most of my regular nightmares vanished. I was hoping to have Asperger Syndrome" (Kim).

The diagnosis helped them to become more patient with themselves and to explain their condition better. "The result was more important for those around me than for me. It became clear: My strange needs are legitimate. I am not hard any more with myself when things go wrong. Instead, I say to myself: "Aha, my Asperger Syndrome" (Celestine)." Furthermore, as Paul highlighted, it also serves future decisions: "Understanding myself as Asp helps me to reason why I am more talented in some fields than in others." Finally, the diagnosis helped participants to accept their differences. They did not necessarily see this as a disability, but instead saw the challenges and advantages of having a different personality.

3.4.2. There is a subtle black and white thinking in Swiss society

In this study no common pattern of disclosure at the workplace was found, since the practicalities and consequences of disclosure varied among participants. For instance, the legal secretary felt no need for it, while the university professor only disclosed his condition to his secretary. The psychologist fears she would lose credibility as a psychotherapist. The office worker communicated his diagnosis to his supervisors. "My psychologist convinced my employer to reduce my weekly workload from five to four days a week. But since then, my working conditions have worsened. I get less interesting work to do, which in fact makes work more boring than before" So for Jim, disclosure has not yielded the hoped-for advantages. The gardener reflects on the legal advantages of disclosure, under the pressure of an economically driven boss. He explains: "There is a subtle black and white thinking in Swiss society. I also notice this in official disability politics in Switzerland. I am not ashamed to talk about being an Asperger. But as long as the word "autistic" is used as an insult, I don’t believe in progress after disclosure" (Tom).

4. Discussion and practical implications

The study centered on contextual aspects that both hinder and foster competencies and work attitudes for succeeding in competitive employment, by using a narrative approach to analyze the experiences of six adults with Asperger Syndrome. The analysis of the data showed that contextual aspects played a vital role in achieving vocational prerequisites for competitive work. The following discussion reflects the structure of the findings.

4.1. The social context

For acquisition of basic social competences, parents and peers seemed to be the most important environmental factors. Parents provided basic acceptance, protection, and space and occupational security. In child psychology, these needs collectively are referred to as attachment [11]. Children who feel securely attached are able to use this as a safe haven, and in times of distress, this enables them to calm down, explore, and play. Attachment influences security, feelings of trust, and the emergence of self-regulation skills. First developed with parents, attachment is later generalized to others. However, there is little research on attach-
ment in autism. Some authors found that children with high functioning autism seemed to develop secure attachments [12], whereas anxiety and social worries in children with AS are more frequently reported [51].

Parents’ willingness to accept their children, and to not load additional demands on them, was highly valued by all participants. And, despite the call for structures in the daily lives of children with autism [39], participants highly valued having plenty of space and quiet time at home. Hence, the findings of this research point to the need for more collaboration between health professionals, parents, and the child with AS, to find the appropriate balance between structure and “loose” time. When adequately balanced, both of these dimensions potentially enhance successful work participation of adults with AS.

The aggression that disrupts family life in conjunction with children with high functioning autism, as described in previous research [25], did not appear in the narratives of this study. One possible explanation for this is that members of a family with a child with Asperger Syndrome develop different expectations of a “normal” family life [26]. Families in this research did not know about the diagnosis of Asperger Syndrome of their child during childhood, but tried to adapt to their child’s needs as best they could. Through their way of enabling attachment in a broad sense, the participants reported a positive and meaningful memory of social environment around their families. Given these findings, social and health care practitioners, and researchers, are encouraged to consider the social environment of their clients with AS, and to provide a context that contributes to fostering these environments even further.

Another striking result is that participants valued their parents for having prepared them for collaborating in social groups. Observing social contexts without the need to be the center of attention seems essential, not only in family life but also in peer relationships and social groups. This is consistent with results from a large Australian survey that demonstrated a strong correlation between social participation by mothers, and a subsequently high social participation by their autistic children [48]. This finding challenges and contributes to current knowledge on the concept of social participation, and directs our attention to the subjective dimension of participation. While an observer may note that this child is not really participating as she is not actively interacting, she may be still perceived subjectively as having a high degree of participation.

Inherent to the diagnosis of AS is the combination of special interests and reduced reciprocal social relationships. The question remains however, how these two relate to each other. A qualitative study on restricted interests of adolescents with AS outlined changes of interest patterns in a context of sustained social involvement. Social integration and demands were a decisive factor in the process of “normalization” of their restricted interests [41]. The current study shows again that a sense of social competence and mastery, which can be positively influenced and thus developed within a supportive, secure, and familiar social context in people with Asperger Syndrome, leads to a widening of interests, and is one of the most important preconditions to participating in future social situations such as work.

All participants rejected the idea of participating in a social training group with other AS persons to learn social adaptive behavior. They expressed that understanding and intuition is not learned mechanically but only in real life situations. This finding is in contrast to frequently used social skills training [70]. One explanation could be that attempting to learn while isolated from context seems to be difficult because of the need to understand purpose and practicability.

Another clear result concerns naturally developed peer friendships with “normal” children. These relationships were never facilitated by parents or teachers. The pattern of single-peer relationships that were based on common interests is observed to be very strong. In these friendships, mutual acceptance was experienced, and resulted in shared joy and fun. Authors in the field of social development consider experience sharing as one part of social competence that involves the desire and skill to be a good reciprocal playmate, to value others’ points of views, develop friendships, and to conduct emotionally based transactions [30]. This was also illustrated by all participants of the current study.

Participation is a consequence of the interaction between a person and the environment [16,18]. The conditions for qualitatively meaningful participation are not yet defined objectively. It is “the great property of lived experiences that is best known to those who experience it and therefore most accurately report it” [18, p. 278]. In narrating their various friendships during their life spans, participants in this research revealed the meaning these friendships had for their preparedness for social adaptations. This preparedness is confirmed by other research as well [48].

Observing and analyzing real-life situations, or continuing a few but nevertheless intense one-on-one relationships, may enable a qualitatively high level of social participation for persons with Asperger Syndrome.
This also has implications for health practitioners, providing therapists with possibility of treating children and adults with Asperger Syndrome in a natural social environment. Furthermore, families should be encouraged to provide the necessary space and time to their child with AS for building such relationships.

4.2. The cultural context

The results of this research reveal that participants got to know themselves in different cultural contexts, and developed competencies to adapt to these. School experiences played a vital role. Looking for predictive factors for competitive employment in persons with sensory and physical disabilities, Pack and Szirnoy [44] found that a completed college education resulted in a 215% greater likelihood of attaining competitive employment. The academic period of the participants of this research lay 15–25 years in the past, when educational sensitivity was different and fewer possibilities were offered to them compared with today. Finally, against great odds, all finished their college or university studies. Academic achievements of those with Asperger Syndrome are seldom [28]. The participants of the current study positively remembered the intuition and empathy of a few teachers. Their preparedness to adapt to individual learning needs provided the base for subsequent academic success. The different learning needs of children with AS can be explained by their ways of perceiving the world [45], as well as by a weak central coherency [35]. All participants reported handwriting and coordination problems, a well-known phenomenon in AS [7,27]. These weaknesses never disappeared but they could accept them as they developed strengths in other areas. This research supports recent shifts that educational programs have made in adapting school curricula to the learning style of persons with Asperger Syndrome [5].

The results showed that participants were able to analyze culture at workplaces, and to seek those work environments that matched their own ability to adapt. As long as norms and work culture were formalized and transparent, participants expressed fewer difficulties for integration. A balance between clearly expressed norms, and a tolerance for behavior that deviates from those norms was needed as well. A lack of such a balance is reported in other studies to be the main hurdles in work participation of persons with AS [32,42]. Informal social encounters posed a special challenge for all participants, as they preferred structured relationships.

All participants developed these skills during a process of constructing an identity, which included the view that they were capable of adapting to the demands of a socially complex culture such as the workplace. This participants’ development happened despite a mainly negatively driven discourse about disability (especially concerning autism) [4]. This author concluded that construction of identity in persons with AS is challenged by limited experiences in the social world and restricted opportunities for participation. Participants of this research did not suffer these kinds of limitations as they had adequate experience in social contexts.

4.3. The physical context

Results concerning physical contexts reveal for these six participants a clear division between enabling and hindering contexts. Physical agents such as visual tactile or auditory stimuli seem to have a strong effect on their perceptions. A majority of autism-specific research and interventions of occupational therapists focuses, mainly on the field of children on sensory modulation problems [45]. There is preliminary evidence that children, both with and without autism, score differently on sensory profiles [15,58]. Connections between sensory modulation and emotional disturbances in children and adolescents are also reported [45]. The present research reveals the role these influences play in adult lives as well. Although the meaning of physical context did not turn out to be as strong as social or cultural context, hindering aspects such as unwelcome sensory perceptions of physical stimuli gave some guidance for contextual adaptations. The authors of this paper are not aware of any research on how these sensory argents influence actual work performance in persons with AS.

The expertise that occupational therapists have gained over the last years in treating children with sensory integrative problems, and the findings of this study, indicate that increased attention in research and practice needs to be given to how occupational therapists’ expertise can be carried forward across the life span of people with AS, and transferred into environmental adaptations in adults with AS.

4.4. The temporal context

In challenging a late diagnosis, one might argue that this might also be a reason for successful work participation of adults with AS in this study. Disability is of-
ten associated with low self-esteem and the experience of barriers erected by social stigma. It might be rather common that AS is diagnosed relatively late, or after the manifestation of many difficulties [21]. The participants in this study were diagnosed later in life. Analysis of the narratives revealed each person’s struggle to become normal. Hence, the question arises whether an early diagnosis would have supported these struggles or rather hindered them. All participants perceived or experienced the official diagnosis to be a relief, since this provided a reason and explanation for their differences, and sometimes oddness. But it was also combined with a strong sense of pride that they could become who and what they are, despite their challenges. The stigma of being autistic, and the claim of having different needs, still comprise strong negative consequences for disclosure in the competitive workplace [47]. Allan and Carlson [1] categorized reasons to conceal a disability condition. One of the results of their research was that if conditions are socially less-acceptable and stereotyped as reducing productivity, it seems better to conceal them. Reasons to disclose are to obtain assistance from one’s social network, or as a reflection of a personal ethical preference for honesty [1]. The latter point may be a unique one for persons with AS, as they tend towards a preference for honesty. So to conclude, if therapists aim to support clients with Asperger Syndrome in obtaining and keeping a work position, the decision on how to handle disclosure must be carefully considered [47].

5. Limitations and directions for future research

Critical reflection about research results must take into consideration the varying employment rates of adults with AS across different countries. These employment rates may be more dependent on social, political, and commercial factors than on the disability itself [17]. This opinion encourages discussion on whether there are even more contextual reasons (e.g., legislative or economic conditions) that explain the workforce participation of these six persons in Switzerland. Hence, further research in other contexts is recommended to gain an understanding of how various national contexts influence successful work participation of people with Asperger Syndrome.

Another weakness of this research is that the six participants disclosed their conditions without the benefit of official diagnostic criteria. Considering the variety among autism spectrum disorders, we would recommend the application of official diagnostic criteria in future research to be able to draw further conclusions on the relation between study results and specific severities of AS.

As this study focused on persons in the competitive workforce, it does not clarify whether other persons with AS, who do not have a job, also had a positive social context as children or not. This study does not reveal whether there is a direct link between a well-caring social context in childhood and the ability for persons with AS to find competitive work.

The translation from the spoken Swiss dialect into the written German language, and subsequent translations into written English by native English speakers with knowledge of autism, was intended to encourage dialogue and discussion between the first and second authors throughout this analysis. At the same time, it implies a simultaneous loss of the linguistic richness of a participant’s statements.

A narrative analysis according to the theories of Paul Ricoeur was utilized to study subjective experiences of contextual factors for contribution to successful participation in the labor market. Why participants were able to maintain a presence in the labor market can only partly be interpreted as the narrative approach in this study was not tailored to distinguish between going to work, desiring to work, and staying employed. So the question of how individuals managed to adapt to their workplaces remains to be investigated and should be explored by means of other methods.

Furthermore, it should be kept in mind that competencies achieved in a certain context are not only used for one performance area exclusively. It was the conscious choice of this study to focus on work participation. The way in which participation in one performance area, such as paid and unpaid work or social relationships, may influence participation in another area, requires further research.

The researchers put particular emphasis on positive and enabling factors. This is probably a result of the long-held and stigmatizing medical view of individuals with Asperger Syndrome, and the attempt to go beyond this deductive approach. The main researcher is also an occupational therapist working in clinical practice, where she is contacted by people with AS, who are seeking or may need help. Hence, she must critically ask herself to what extent the medical view shapes her perspective on people with AS. This study was a valuable means to go beyond the dominant medical view and explore resources within the context of individuals with AS, which can easily become neglected when adhering uncritically to the long-held dominant view of Asperger Syndrome.
6. Conclusions

This study highlights the heterogeneity of trajectories, strategies, and models of social integration developed by six people with AS throughout their lives. It takes a strong stance on a variety of contextual influences on lifelong experiences providing pre-vocational competences of persons with Asperger Syndrome. If contexts are shaped in these ways, this research highlighted, persons with Asperger Syndrome may empower themselves to adapt to the ‘worlds’ around them.

Despite studies that question the ability of persons with Asperger Syndrome to process coherent narratives, this research illustrates the need to listen to persons with Asperger Syndrome, as they are the experts concerning their own lives. Based on the author’s experiences, it was a positive and memorable experience to meet and collaborate with these six fascinating, shy, and humorous people in the framework of this study.

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