This is the published version of a paper published in *Nordic Social Work Research*.

Citation for the original published paper (version of record):

Narratives of ideal and second-option jobs among young adults with high functioning autism
https://doi.org/10.1080/2156857X.2018.1484385

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To link to this article: https://doi.org/10.1080/2156857X.2018.1484385

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Narratives of ideal and second-option jobs among young adults with high functioning autism

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ABSTRACT

The meaning of work is different for people in different social groups, and research exploring perceptions of meaningful work among adults with high-functioning autism (HFA) is scarce. The aim of this paper is to explore how narratives of satisfactory and meaningful future jobs are portrayed relative to two alternative discourses of work – the ‘obligation to work’ discourse, and the ‘disability rights’ discourse. This group of individuals are high functioning on the one hand, while at the same time holding legally-mandated special disability rights, an exploration of how this group reason about work-life and satisfactory jobs is particularly interesting. Through ethnographic fieldwork in Sweden, seven young adults with HFA were followed, and 17 interviews were conducted. The main findings and conclusions are that jobs that are individually assessed to be ‘ideal’, are put aside in favor of jobs that are more compatible with general labor market demands, as long as enjoyment and meaningfulness can still be experienced.

KEYWORDS
Citizen-worker; high functioning autism; meaningful work; vocational support; work-life

Introduction

The aim of this paper is to explore how narratives of satisfactory and meaningful future jobs are described by a group of young adults in a Swedish educational context for people with high functioning autism (HFA) in relation two alternative discourses of work, namely the rights and obligation discourses. This is an important question for social work and how we view this group’s abilities, social citizen-constructs, and ambitions in relation to work and work-life. We address this topic of crucial relevance in relation to social policies and professional encounters with individuals with HFA in diverse welfare provisional contexts.

One major Nordic contribution to social policy change for people with severe disabilities is ‘the normalization principle’ (see Nirje 2003). In addition to this, special disability rights legislation was enacted in 1994 (Tøssebro et al. 2012). The normalization principle addresses several key issues for achieving the vision of integrated citizens, and it is the basis for various normative processes that aim to make the lives of people with severe disabilities as similar to the majority population as possible; in other words, as ‘normal’ as possible (Nirje 2003). The ambition to include people with disabilities in a meaningful social context via working life has led to a variety of supported work interventions. Subsidized or supported employment is one of these interventions, either targeting individuals with the capacity to work in the general labor market, or providing ‘work-like activities’, in sheltered workshops for individuals with more extensive needs (Garcia-Villamisar and Hughes 2007; Lövgren 2013, 72–73).
Over the last 20 years, policy revisions focusing on social activation, participation, and stable labor market involvement for people with disabilities have been implemented in Sweden and throughout Europe (Rodríguez et al. 2014). These revised disability policies, from ‘passivating’ to ‘activating’ social policies (Cantillon and van Lancker 2013), create a tension between two different kind of discourses, which we have chosen to call the civil obligation to work and disability civil rights discourses.

Within the civil obligation to work discourse (henceforth shortened to ‘the obligation discourse’), participation in the labor market is expected of everyone and the importance of the productive and active citizen – the ‘citizen-worker’ – is stressed (e.g. Bertilsdotter-Rosqvist, Brownlow, and O’Dell 2014; Dahlstedt 2013; Friedman 2006; Graby 2015). We view the citizen-worker as a theoretical perspective (or component) within the obligation discourse that emphasizes that the responsible and well-equipped individual is a public asset who is ready to contribute to society through work. This component is also connected to issues of identity and citizenship (also see Lister 2003; Scourfield 2007).

The disability civil rights discourse (the rights discourse) includes two distinct ways in which individuals with disabilities might viewed, either by themselves or others. On the one hand, there is the ‘good enough citizen-worker’ perspective, which holds that individuals with disabilities are potentially able to have paid jobs like the general population if they are given the opportunity to work according to their individual capacities and are given the proper support in general labor market contexts (Bertilsdotter-Rosqvist, Brownlow, and O’Dell 2014), for example through supported employment or internships. On the other hand, there is the component of ‘disability-worker’ who is presented through a narrative of social inclusion and integration in the community (Bertilsdotter-Rosqvist, Brownlow, and O’Dell 2014; Graby 2015) by means of meaningful participation in society (Markström 2003; Barnes 2000) accompanied by economic maintenance. The ‘disability worker’ narrative dominates the Swedish special legislation for people with severe disabilities, in which the right to a meaningful daily occupation is a main aspect (cf. Markström, Nygren, and Sandlund 2011; Lövgren 2013) and placements within sheltered or segregated workshop contexts are common practices.

Participants in this study have been diagnosed with Asperger syndrome or ‘high-functioning’ autism (HFA). Asperger syndrome is a diagnosis that previously was classified as its own category of autism, but was removed from the diagnostic manual of DSM-5 (APA 2013) and has instead merged with the wider autism spectrum diagnosis.

The term ‘high-functioning autism’ refers to the higher functional capabilities of these individuals compared to other conditions of autism (Richards 2015) which can include more severe intellectual and language difficulties. Common diagnoses-related hardships of the group with HFA are described as atypical neurological functioning affecting social interaction and understanding of abstract communication and information (see e.g. Richards 2012, 2015; Wing and Gould 1979). However, positive traits of people with HFA have been a quite neglected perspective where work abilities and skills may excel those of other employees. Examples of such positive traits are dependability, efficacy, trustworthiness and high attendance (Hendricks 2010; Krieger et al. 2012) and a high degree of self-advocacy (see e.g. Ward and Meyer 1999; Bertilsdotter-Rosqvist, Brownlow, and O’Dell 2015). Individuals with HFA consequently often have higher personal capabilities compared to many other disability groups, such as people with intellectual disabilities, who also are covered by the same Swedish disability rights legislation of the Swedish Act concerning support and service for persons with certain functional impairments, ‘LSS’ [Lag 1993:387 om stöd och service till vissa funktionshindrade]. Because they can be suited to the general labor market, individuals with HFA are therefore potentially more likely to be affected by dominant citizen-worker narratives, while at the same time they are explicitly included in disability rights legislation in Sweden. Even though the group of HFA are fit, or assessed as fit for regular work with the right support, they still have a right to claim disability rights provisions through LSS. It is therefore highly relevant to explore how the group of HFA reason about their ideas of satisfactory and meaningful future work, and also how their narratives can be understood through the lenses of both of the obligation discourse and the rights discourse.
The labor market situation for individuals with HFA

Internationally, high rates of unemployment among individuals with HFA have been highlighted (Howlin, Alcock and Burkin 2005; Hendricks 2010; Levy and Perry 2011), and studies have shown that this group still suffers from difficulties and disadvantages even if employed, including underemployment, lower wages, and job mismatches (Baldwin, Costley, and Warren 2014; Jones and Sloane 2010). Thus, while most people with HFA are deemed able to work under the right conditions and with the right kind of support, they are still an important target for work support interventions aimed at assessing and enhancing their fitness for work (García-Villamisar and Hughes 2007; Richards 2012). In line with the ‘good enough citizen-worker’ narrative, there is a risk for incentivizing vocational service providers to find any (paid) job for disabled people with any capacity to work, rather than finding an occupation that matches the individual’s abilities as well as their personal interests (Kaye 2009).

In Sweden, social welfare service provisions that aim to find suitable employment for people with HFA represent interventions for a group that is assessed as being able to work. Because the HFA population is very heterogenic (Taylor et al. 2012), there are also those with an autism diagnosis who are assessed as having difficulties too severe for work, and these are actualized for special disability rights support where meaningful participation in society is focused upon. In such cases, placements in segregated workshops as a ‘variation of work’ are a common practice. The notion of ‘meaningful participation’ is thus a key word in Swedish disability rights policies, and such occupations are provided for through the legislation of the LSS.

However, the theoretical basis of ‘meaningfulness’ is still a bit blurry. The concept is caught between the perspective of normalization – in which an occupation or a job is seen as a means towards a “normal life” (Nirje 2003) – and the perspective of the individual, where the idea of a ‘normal life’ might play no role at all; this tension has been demonstrated to be especially problematic for people with autism (cf. Rosqvist 2012). Albrecht and Devlieger (1999) stress that a good quality of life for people with disabilities can be achieved through balance between the self and the attainment and maintenance of (individually assessed) meaningful relations within the individual’s social context; this balance can conflict with conceptions of a good quality of life according to more normative perspectives. Renty and Roeyers (2006) also address the importance of targeting the individual needs of people with autism in all professional support provisions in order to achieve greater life satisfaction, and they emphasize the use of tailored support in active collaboration with the client.

Regardless of the dominant vision of work as a means towards meaningful participation in society, it is important to understand what is considered an appropriate and satisfactory job to achieve a sense of meaningfulness from an individual point of view. This is especially important for those who are on the high-functioning end of the autism spectrum if they are to attain and retain a job.

Notions of ‘meaningful’ work

In general Swedish labor market policy, and in line with the European Commission, the picture of ‘the active citizen’ as a resourceful individual who is autonomous in diverse ways is encouraged. This picture of ‘the active citizen’ is imprinted in current Swedish labor market policies with an intrinsic emphasis on employability credentials. Concepts such as competence and competitiveness in relation to experiences and education (Lindberg 2009; Fejes 2009), individual responsibility, the desire for self-development, and flexibility in relation to taking diverse jobs (Nilsson 2010; Dahlstedt 2013) are some examples of such credentials. However, the employable citizen is also conditioned by normative frames of organizational and social conventions, such as being able to meet high psychological demands in the work setting and to manage stress in different forms (Gabel-Shemueli, Dolan, and Ceretti 2014; Sandlund et al. 2011).
In work-life, a high degree of job satisfaction is desirable, and that satisfaction can be measured in different ways. Wages and working hours are two factors regularly associated with job satisfaction (Clark 1998) although some studies stress that wages are less significant than other job factors (Wrzesniewski et al. 1997; Manuel and Hughes 2006). Wages and work hours are challenged by other more important factors for job satisfaction that ought to be accounted for, such as employees’ feelings towards their work, their individual desires, motivations, interests, and other psychological factors related to health and well-being (Wrzesniewski and Dutton 2001). Kinjerski and Skrypnek (2004) call attention to the importance of these psychological factors in light of the rampant organizational remodeling, downsizing, and uncertain employment conditions of the last several decades. Thus, employees’ needs for positive work contexts and meaningful work have increased in parallel with harsher employment conditions related to growing labor-market demands and calls for greater organizational productivity and efficiency.

As Wrzesniewski and Dutton (2001) show, organizational research usually is done from one of two alternative perspectives when studying job experiences. One of these perspectives focuses on external factors, targeting the job itself and its content. The other perspective focuses on individual factors like personal attitudes and expectations. However, these perspectives undermine the active subject who shapes and reshapes experiences of work in active collaboration with the social context at work – individual job-crafting.

In the theory of job-crafting, the subject uses social interactions and diverse work-tasks as the ‘raw materials’ for creating a psychological construct of the job. Job-crafting is triggered by three psychological factors/motivators. First, the concept of ‘control’ relates to a sense of control in life as in work where a lack of control leads to feelings of estrangement. Second, ‘positive self-image’ implies both the personally assessed image of the self and how one is looked on by others and the positive confirmation that is desired. The third and last motivational key to job-crafting is ‘connection to others’, which aims to ‘reframe the meaning of work and their work identities’ through meaningful relationships and interactions at work (Wrzesniewski and Dutton 2001, 183). By reframing the meaning of work, the formal borders of the job expand into an entity that personally feels meaningful, and this in turn affects the self-image in a positive direction. Job-crafting is thus an individual process that makes formal work tasks more subjectively satisfying by giving new meanings to the work performed, and by shaping a more satisfying identity at work regardless of job position or vocation.

The term ‘meaningfulness’ is also intimately connected to the concept of ‘calling’, which stresses self-fulfillment and meaningfulness. ‘Calling’ is one of three classification terms used in research targeting experiences and meanings of work where a sense of meaningfulness (not economical or career-related) can be achieved through feelings of enjoyment, self-fulfillment, and social usefulness (e.g. Dik and Duffy 2009). For example, within the teaching occupation, ‘engagement in the mission of making a difference’ is emphasized (Manuel and Hughes 2006), which is similar to ‘calling’, but is also connected to meanings of identity (Manuel and Hughes 2006; Laurence 2015). Consequently, several researchers have stressed that job compromises lead to decreased job satisfaction. Employees who have compromised often try to reduce the discrepancy between their ideal work and the work that they have. The identification of the inconsistency between the ideal self and the present job situation might lead to lower self-esteem, physical illness, anxiety, depression, and ‘burn out’ (Tsaousides and Jome 2008; also see Laurence 2015), thereby reducing self-assessed quality of life. Furthermore, work misplacements resulting from incentives for accepting any job that is offered might be counterproductive from the individual’s perspective (Kaye 2009), and might lead to both high degrees of absenteeism from work (Clark 1998) and a general distrust of society and social welfare institutions (Laurence 2015).

Those psychological factors regarding meaningfulness and calling align to the three concepts found in the theory of job-crafting, where ‘control’ relates to personal skills, ‘positive self-image’ relates to identity, and ‘connection to others’ relates to the desire to make a difference,
which is also closely connected to meaningfulness). Because those three concepts relate to individual experiences of being able to transform skills into labor resources, of having a positive self-image, and of having good relationships at work, we draw parallels to the concept of the 'citizen worker', which is a component within our theoretical concept of the obligation discourse that emphasizes the productive, flexible, and resourceful citizen. When the individual is not able to actively influence these factors and cannot affect the psychological crafting of work-life activities and identity, the 'disability-worker' concept is more applicable as a theoretical social citizen-state.

The explicit common denominator that the rights discourse and the obligation discourse share is the third factor in the job-crafting theory – ‘connection to others’ – in which meaningfulness is emphasized. The terms ‘meaningfulness’ and ‘meaningful social context’ are important for both the general public and individuals with severe disabilities who participate in segregated work-life activities, while the other two motivators (identity and control) are more explicitly related to work and are seen as the engines towards crafting a more satisfying and meaningful social context beyond the formal boundaries of the job.

Methods

The data analyzed in this paper is part of a broader study concerning experiences, thoughts and expectations of work and work-life among people with HFA.

Research setting and research participants

The research was conducted through ethnographic fieldwork in a Swedish folk high school setting. Folk high schools in Sweden provide programs that may, for example, be general education courses supplementing earlier studies, or lead to qualifications such as an upper secondary school equivalency certificate, or provide practical training and courses oriented toward occupational or working life. Students generally need to be 18 years or older to qualify. One of the folk high schools that provides specialized educational programs for people with HFA was selected for this study. The class consisted of seven students, with ages ranging from 19–27 years (three women and four men). Some participants had received their autism diagnoses recently (within the last 2–4 years), while some of them been diagnosed in early childhood. Most of the participants had no or limited experiences of work (such as summer-jobs or internships through school). All classes in the program comprised components of self-development and life-oriented-preparation (e.g. classes about relationships, economy, and work-life). Aesthetic classes and programs, like music, acting and arts were universally provided for all students with an interest in these subjects in the folk high school. There is a well-known understanding of the ‘special atmosphere of folk high schools,’ where individual development, democracy and autonomy in free thinking are key concepts (e.g. Åberg and von Essen 2013) summarizing folk high school as an especially accessible and inclusive educational context.

Design, data-collection and analysis

First, the principal was contacted regarding the study. She gave her consent to the study and access to the research site. Later, an oral presentation of the study was conducted when all seven students in the class were present by the first author (FA), providing information regarding the study. In addition, an informational letter about the study and consent information and forms were left after the presentation, and the informants were given time to think about this matter in the absence of the FA. Later, the head teacher contacted the FA and informed that all students had signed the consent papers. A couple of weeks later, the study began.
The study was conducted during six separate weeks over six months, November 2013 – April 2014. The data consists of observational studies, two focus group interviews, including two and four participants respectively, and 17 individual interviews. Observational studies were made throughout most of the study period, but for ethical reasons, no research activities were conducted during the first two weeks in order to get acquainted with the students first and gain their trust. The FA accompanied the participants the whole day. One school day equates to approximately 4–5 hours of lectures. The participants were interviewed individually 2–4 times, depending on personal interest in participating in the study. The interviews lasted between 25–75 minutes after school-hours, depending on how much they had to say about the topic at hand and also in respect to their planned spare time activities. All data collection was made by the FA who conducted the fieldwork.

The data used in this particular paper originated from interview material. The interview questions were based on a subject brought up by either the students themselves, or by the teacher at some point during the day or during class, in order to avoid constructions of new or unfamiliar elements of discussion (which is important in ethnographic studies, Hammersley and Atkinson 2007). In those cases where interview questions seemed too unfamiliar or incomprehensible to the participant, the interviewer ended the follow-up questions in that particular topic of discussion. Having six months for research allowed topics of discussion during interviews to be generated from observed situations during fieldwork. In addition, eventual processes could also be identified in narratives in relation to the different topics of discussion. The interviews never departed from an interview guide, and the topics were given to the participants before asking them for an interview, depending on what particular observation the FA wanted to follow up on. The place of the interview was chosen by the participants themselves, often in their own rooms in the dormitory. The interviews were transcribed and read thoroughly several times. Many topics were found in the impartial initial analytical process of the narratives, because of the diverse topics of discussion during interviews. However, narratives that implicitly and explicitly dealt with ‘future and past work-life’ were chosen for this particular paper and became items of a coding process. The coded extracts generated many different categories, but two of the largest categories were selected for this paper, the categories of ‘specific job interests,’ and ‘general ideas of future job positions.’ These two categories merged into the theme of ‘satisfactory jobs’ since clear patterns and notions were found in both categories. The theme was however eventually divided into two subthemes, ‘ideal jobs’ and ‘secondary jobs,’ which will be presented in the results.

This analytical approach aligns to conventional content analysis, in which a primarily inductive systematic approach is used to form categories and themes via a coding process, where an individual interpretation of text data is utilized in order to gain and extend knowledge about human thoughts and experiences (Hsieh and Shannon 2005). Text data is interpreted on a manifest level of content analysis where the level of abstraction is low (Graneheim and Lundman, 2004). The narratives were found to be closely connected to research on job satisfaction as well as the obligation discourse of work. In the presented extracts, pauses in speech during the interview are marked by (…) regardless of the length of the pauses. Places in the transcripts where the authors have made an edit by cutting in the narratives are marked by/.../.

This study has been approved by the Regional Ethical Review Board in Umeå, Sweden [ref number 2013–167-31Ö].

Results

Here, the theme of satisfactory jobs and the subcategories of ideal jobs and secondary jobs will be presented. All names used in the results are pseudonyms due to informant confidentiality and were chosen by the participants themselves. The names are followed by their approximate age in the narratives presented, which may differ ± 2 years, to ensure additional participant confidentiality.
Ideal jobs – satisfaction and enjoyment

In the interviews, the participants were asked to talk about their future plans in relation to jobs and their preferred choice of job. Their narratives varied both in relation to the choice of preferred future job-positions, and also the reasons behind the preferred jobs. However, a common denominator that the narratives share is that ideas about ideal jobs are driven by perceptions of satisfaction (meeting their expectations of a suitable place in work-life) and enjoyment (in which personal feelings of happiness and motivation were addressed in different ways). All participants described their initial ideas of ideal jobs as driven by the two concepts:

Damon (23): … Yeah. First of all, I like music. There’s different sides to the story, music makes me feel good… and I need it to… yeah feel good. I’ve been acting since I was little and played parts in musicals/…/and that has led to my growing interest/…/it makes me happy/…/but if we speak about becoming an actor, that’s what I want, more than anything…

Damon addressed feelings of well-being and happiness, along with a narrative of past experiences and practices of acting, drawing on a timeline to his childhood when he participated in musicals, and he continues to speak about his engagement and participation in musicals and acting to date, which had occupied Damon to a great extent. By the argumentative usage of past experiences, he introduces what part ‘acting’ has taken in his life so far, positioning his choice of an ideal job as an already-present element in his life. Damon’s argument of why he perceives musicals/theater as his ideal job is based on the repertoire of ‘well-being’, when he says that music is needed in order to ‘feel good’ He also positioned his idea of a future job as the job he wants the most by using the term ‘desire’ in his narrative.

Another participant, Agnes, did the same when being asked to talk about her ideal type of job:

Agnes (27): Yeah, singing… because I have been singing since I was little. I sang on many speech days, and that kind of thing./…/I feel so good when I sing/…/it has been chaos throughout my whole life, so music in particular and singing has been… well, kind of my medicine/…/that’s what makes me feel good, even today.

In Agnes’ narrative, there are plenty of arguments relating to what the music means to her. Past experiences and interest accompanied by feelings of well-being were addressed. Like Damon, Agnes also uses arguments that are grounded in her upbringing when motivating her choice of ideal job, not only from the aspect of practicing music in different ways, but also from the experience of using music as a coping strategy, positioning her choice of ideal job as favorable due to the well-being it brings.

Five out of the seven participants strictly positioned their narratives in line with satisfaction and enjoyment, with no references to hardships connected to their diagnosis. There were however two participant narratives that differed a bit from the others. While addressing notions of enjoyment in relation to their idea of preferred/ideal job, they simultaneously also invoked implicit references to their disabilities, which is absent in the other participants’ narratives when talking about ideal jobs:

Leo (20): Arts is about… maybe creating something beautiful, not being so locked down into myself… I feel introverted… I have a hard time expressing myself… I can talk and hold a conversation, but quite shallowly… in particular when I express myself in words./…/maybe I could even be recognized through my arts.

Here Leo described his ideal job as a position in work-life that is suitable for his personal characteristics of being an introvert. To work with art would be a means to express himself and make ‘beautiful work’. Leo never explicitly mentions his characteristics as being part of his diagnosis, or his preferred choice of job as being a result of it. We identified this passage as a possible expression of the diagnosis; however, since being an introvert and shallow talker don’t necessarily emphasize disability, we rather interpret his narrative of future job position as an expression for Leo’s idea of self-assessed personal fitness for future jobs.
Similarly, implicit references to disability when talking about ideal jobs were also made by Amy:

*Amy* (19): I really love handling animals and I believe it is *that* direction I feel most safe/. . ./maybe I could also work with a lot people in Kolmården [zoo] too, who knows?

Amy expressed a desire to work with animals as a zoo-keeper – a childhood dream. She spoke about animals as being there for her in contrast to people, and expressed views on how to handle animals well. In the above quote, she addresses her love for animals and motivates her preference for a job with animals rather than with people by referring to a need to feel safe and be in a comfort-zone. Diagnosis-related hardships based on social interaction are at play in her narrative without being explicitly conveyed. Thus Amy’s narrative aligns with Leo’s by balancing ideas of the ideal job driven by individual perspectives emphasizing personal job-match, satisfaction and desires, and the disability perspectives, where ideas of future jobs are formulated as a choice based on hardships and limitations.

These examples demonstrate that there was a consensus that preferred/ideal jobs were thought of first as individually driven ideas of satisfactory jobs. Narratives illuminating concepts of ‘desire’, ‘beautiful work’, ‘wellbeing’, and ‘happiness’ were informed concepts aligned to the notion of ‘calling’ and meaningfulness (e.g. Manuel and Hughes 2006; Wrzesniewski et al. 1997).

As initially presented, personal feelings of satisfaction and enjoyment dominated all participants’ narratives when they were asked to describe their ideal job. However, these ideas were not left uncontested. Reality was encountered when the participants declared their awareness of barriers and the improbability of obtaining a job in their preferred choice of field or job role, and back-up plans or second-option jobs were declared through what we identify as internal negotiations. Hence, another perspective to work and work-life was introduced through these narratives of second-option jobs, which we call the ‘citizen-worker narratives’.

**Negotiating second-option jobs; disability and citizen-worker perspectives**

In this second section, we want to illuminate our findings in relation to citizen-worker notions of work in contrast with disability perspectives on work. By ‘citizen-worker’ we mean ideas of the active citizen that is generally expected, where a job is seen as a natural daily activity in life and where education, job experience and credentials are important resources for accessing work-life (obligation discourse). This access is also conditioned by labor market demands. Since most of the presented ideal/preferred jobs were niched in their character (musician, actor, artist, manga-painter, zoo-keeper, author, floorball-coach) which may be hard to match with labor market demands, second-option jobs were presented by all participants. Hence, diverse citizen-worker perceptions are present to different degrees in all participants’ narratives. As the disability perspective is relatively absent in the narratives of preferred/ideal work (rights discourse), it was however introduced implicitly by one participant, Amy, and explicitly by another participant, Agnes, when motivating second-option jobs.

Agnes was the oldest participant among the interviewees and has had the longest experience of work through both supported-employment programs and trainee-positions:

*Agnes* (27): Yeah, I’m very interested in music, I think that is really fun… but it’s very hard to get a job in the music business, so that’s more leisure-time. But what I feel certain of otherwise, is cleaning/. . ./that I feel safe doing, it’s not a dream job, but it’s a job that I am able of doing and can handle, if I get the job accommodated after my needs/. . ./so yeah, that would. . . work.

Here, previous working experiences are exhibited as a ‘safe card,’ where a previous cleaning job was experienced as safe and matched Agnes’ abilities, addressing the theoretical component of
'control' in the job crafting theory. She also positions her ideal job of working with music as a hobby due to labor market demands, where success within the music business is perceived as difficult and inaccessible. Therefore, she prioritizes the striving to obtain paid work over a job that matches her interests and perceptions of joyful activities (see Section 1). Agnes also addressed this type of paid work as 'not a dream-job', but a manageable one, if she receives accommodations in the workplace, putting the disability perspective on the map through emphasizing her ability to work under the right conditions by vocational support, positioning herself in the 'good enough citizen-worker' narrative.

Similar to Agnes, Amy also presents her perceptions of second-option jobs from a disability perspective when addressing citizen-worker notions with regard to education and credentials:

Amy (19): I really want to continue my studies… for further development… I am mostly interested in becoming an environmental scientist…/And then, I am not ready for a work environment, so that's why I feel that it's better to study and self-develop, rather than to begin an internship and then work…/I will get sick and end up in the hospital again, because there were a lot of hospital stays when I was in high-school. Amy had rough years in school which led to psychological distress, medications and frequent contact with a psychologist. Amy here presents academic goals of studying environmental science. She describes that her case manager, who is in an authority of the Swedish Social Insurance Agency (Försäkringskassan) that manages issues concerning income maintenance for young adults with disabilities, had suggested that Amy should either work or take on an internship (universal labor market support intervention) after the end of the folk high school program. The results of this suggestion is shown in Amy’s narrative, where she invoked the term of 'hospitalization' and positions herself as not being ready for work-life, and would prefer to pursue her second-option plan regarding education.

Here, the phrase 'not being ready for work-life' is not interpreted as related to disability since young adults of 19 often want to pursue higher education, so this section is rather addressing a citizen-worker narrative focusing on employability credentials. Invoking the term of 'hospitalization' aligns to the disability perspective, but this term is not linked to her assessment of work ability or position in work-life. Thus, the barriers standing between Amy and her plan are presented as both the lack of credentials/grades (a component of the obligation discourse) and organizational problems that have to do with her diagnosis and managerial aspects around that issue.

Other participants whose narratives provide good illustrations of the citizen-worker perspective are Mariah, Johan and Max:

Mariah (20): It’s hard to get a job as a writer… it is hard to become an author. But then, I care about people a lot, and when I notice that people are in distress… I think I could use that…

Johan (22): Yeah… I am thinking in different tracks… in order to try and combine work with floorball, teacher would be an alternative, or some work that I can leave on the spot, so there is time for other things. For example, teacher, carpenter, yeah… Administration or anything like that.

Max (20): I would like to paint and write books…/but it’s this kind of thing you can’t economically rely on in case it doesn’t work out…/I have a friend who makes a living on doing programming, I could create art-styles and stuff like that.

Mariah spends much of her spare time writing story-manuscripts, even at the dinner table or sometimes during class. However, to become an author is not an option according to her, since it is not compatible with the prevailing labor-market demands. Her second-option job is to work with the elderly, which is motivated through emphasizing notions of meaningful work through ‘caring’ and wanting to help, which also are suitable personal traits for her second-option job. Her words when saying 'something I could use' highlights the importance of personal belief in individual resources in relation to a potential job, but also, considering when Mariah uses the repertoire of caring, she also highlights the importance of a job that feels meaningful. Personal
conviction is needed to justify this second-option job since it’s not her preferred choice, but rather a choice encouraged by dominating labor market policies. Mariah provides an example of a narrative where all components of ‘control’, ‘identity’ and ‘connection to others’ comprised within the job-crafting theory are present in the creation of a ‘meaningful job’, simultaneously positioning herself as a citizen-worker.

In Johan’s case, he presents several job options that are compatible with the possibility of practicing his leisure activity. Johan, who initially had presented his dream/ideal job as working with floorball full time, has now via negotiating his dream job with labor market demands, transformed his ideal job to a leisure-time activity. Similarly, Max also actively invokes meaningful secondary job options to his narrative when negotiating his ideal job by using the citizen-worker discourse of self-sufficiency as the main motivator. These kinds of patterns are found frequently in the data, where motivations/justifying second-option jobs are presented through internal negotiations of this type – where personal feelings of satisfaction or meaningfulness can take place during work-hours, or after work in Johan’s case.

In this section, we have presented how the citizen-worker perspective aligns with the ‘obligation discourse’ of work, accompanied by references to flexibility, credentials and self-development (e.g. Fejes 2009; Lindberg 2009; Dahlstedt 2013; Nilsson 2010). Citizen-worker narratives are prioritized over strict ideas of joyful or meaningful occupations, as informed through the rights discourse, where disability support interventions found in the Swedish disability rights legislation (LSS) is emphasized. However, perceptions and notions of meaningfulness, satisfaction and enjoyment in different forms are not abandoned in favor of paid work or active participation in the labor market, and associations to the three motivators in job crafting theory are present in all narratives, in different forms and to different degrees.

**Conclusions**

These narratives provide knowledge about how a group of young adults with HFA think and reason about work and work-life in relation to individually driven ambitions, thoughts, and ideas, as well as more citizen-worker navigated ones. Notions of the citizen-worker, the ‘obligation discourse’, are noticeably present among the participants where labor market demands are focused upon from different perspectives, such as the importance of credentials and education in relation to future work, but especially regarding the importance of paid/general work. Citizen-worker narratives are found where social norms and expectations are addressed through the frequent usage of different repertoires related to the obligation discourse. Due to the relative absence of the disability rights discourse in the narratives, the participants positioned themselves as able citizens that want to take on work-life, are willing to self-develop and contribute through work as the general public. This presented will and ability can be regarded as the counter-position to the perspective of ‘disability-worker’, in that preferences for segregated work-like environments with economic maintenance were totally absent from the narratives. Even perceptions of ‘good enough citizen-worker’ were relatively absent, where issues regarding subsidized employments or support-to-work on the ordinary labor market were alternatives left unspoken by all but one participant who had had similar support in the past and invoked the term of ‘accommodations’ in her narrative of future work-life. These narratives illustrate how the participants’ perceptions of work are aligned to general expectations of work and work-life along with a desire to pass as ‘full citizens’ (see Bertilsdotter-Rosqvist, Brownlow, and O’Dell 2014). Thus, to have a paid job through active participation in work-life was presented as a natural element in life, putting ‘ideal jobs’ aside, which aligns more to the research on general labor-market demands and theories about job-matching and meaningful work than to the disability rights discourse.

Meaningfulness and satisfaction were nonetheless found to be highly important for the participants in relation to well-being, which was mostly addressed through expressions of these notions as
allocated by either the job *per se*, or (in one case invoking after work-hours) where the job played an important part of not taking time and energy away from free time activities. This pattern emphasizes the importance of an individually fit job. A personalized match should consider (although not be limited by) credentials or levels of ability to work, but equally important are aims towards an individual match from a life-perspective, which is an important issue in relation to experiences of life satisfaction (e.g. Albrecht and Devlieger 1999). We see the personal match as especially important when it is not possible to obtain the ideal/preferred job for one reason or another, because negotiations relating to ideal job positions might already have taken place previously, in reducing one’s own desires and will in favor of more labor-market compatible second-option jobs. Additionally, in research there is the issue of unwanted discrepancies between the ideal and attained job-situation leading to psychological distress (Laurence 2015; Tsousides and Jome 2008). This possibility for distress makes the personal job-match even more important for individuals with HFA because, as illustrated in our data, notions of satisfaction and well-being never leave the argumentative context in the narratives regarding both ideal jobs and second-option jobs. What people with HFA enjoy doing in their spare time and their communities is important (García-Villamisar, Wehman, and Navarro 2002) and must be accounted for if the individual is being actualized for vocational support in work-life (Renty and Roeyers 2006).

Our main finding is that there is a general lack of disability perspectives among young adults with HFA when speaking of future work. The context of the folk high school, a democratic and inclusive educational institution, might have played a role in the absence of the disability perspective. However, narratives addressing disability perspectives were present in conversational subjects not dealing with ideas of future work positions, so the disability perspective is present, but only in other interview contexts. We asked ourselves how this could be and offer three ideas. First, this finding could possibly result from an unawareness of the potential hardships related to their (dis)abilities that they might find in work-life, due to their inexperience. Second, these ideas could result from their youth and lack of awareness about existing disability rights policies. A third possibility could be their will to position themselves as citizen-workers as a countermeasure against stigmatizing preconceptions of the ‘disability-worker’, and as a way to assert a positive self-identity by addressing their ‘ableness’.

We prefer to interpret these findings as demonstrating that these young adults with HFA find themselves able to work on the general labor market, as long as the job is experienced as satisfactory and joyful from an individual point of view. This view is similar to that of young individuals without disabilities when talking about ambitions and future plans. This result confirms the conclusions of other studies like that of Ineland, Molin, and Sauer (2015), which also showed that young disability groups gave narratives that were opposed to unsatisfactory jobs that could be provided through disability provisions.

Limitations of this study include a small participant group. A larger group might have contributed more diverse data, which could also have been achieved by using a larger pool of discussion topics with regard to work and work-life. Although, an ambition with the ethnographic approach was to minimize new unfamiliar elements in the form of unfamiliar topics, the researcher did not explicitly ask questions that might have been comprehended as unnatural in the participants’ natural contexts. Although that ambition might have resulted in a limited number of discussed (work-related) topics, we stress that the employed ethnographic approach also strengthens the credibility of the study.

We encourage future research to widen our knowledge of how individuals with HFA reason about individually assessed ideal jobs, since research in this area is scarce. It is not enough to lean on social policies that aim to ‘normalize’ individual living standards, where *any* job might do, since individual experiences and assessments of meaningfulness might be lost. We stress that this matter is important for practitioners and policymakers alike to consider, if the goal is to find satisfactory and sustainable positions in work-life for people with HFA, in order to both increase individual well-being and welfare and decrease public expenditures resulting from job-mismatches and psychological distress.
Funding

This work was supported by the Forskningsrådet om Hälsa, Arbetsliv och Välstånd [Research Council for Health, Work, and Welfare] [2012-1111];

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References


APA. 2013. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Washington, DC: APA.


