

# Adaptation or recognition of the autistic subject? Reimagining autistic work life: Deconstructing the notion of “real jobs” in the Swedish autistic self-advocacy movement

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**Abstract.** Several researchers stress the importance of listening to autistic adults’ own experiences of work and related issues. This paper critically explores an ambivalent discourse of empowerment using notions of employment and work life in the Swedish autistic self-advocacy movement. The discourse analysis is based on articles from the Swedish autistic self-advocacy magazine *Empowerment*. In the data, three key themes linked to the notion of work are identified: alternative meanings of a “real job”, formulations of work-related problems, and solutions to these problems. We identify two storylines. The first, more dominant one, we call the recreated norm storyline. This storyline, in line with an individual/medical perspective on autism as deficit, represents autism as causing people with autism to have difficulties finding and keeping jobs in the open labour market and as entailing employment support. The second, counter narrative we call the challenged norm storyline. In line with the social model of disability, it focuses on structural barriers and discrimination against people with autism on the labour market.

Keywords: Adults with autism, empowerment, self-advocacy, work, labour market, real jobs, autistic self-advocacy movement

## 1. Introduction

We depend on getting the RIGHT support and adaptations based on our needs. What should we do to make people understand that we, although we have the same diagnosis, are all so different?<sup>1</sup>

The meaning of work is to feel needed and to do something significant. Therefore, voluntary work is

equally satisfactory. You will gain confidence from knowing what you can do. The worst thing you can do is to take a job that you do not enjoy just because it pays well.<sup>2</sup>

These quotations are taken from the Swedish autistic self-advocacy magazine *Empowerment*. They represent ambivalence when it comes to notions of work and work life among adults with autism involved in the Swedish autistic self-advocacy movement. On the one hand, these demands of adaptation to a neurotypical (NT)-dominated work life and workspace stress the

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<sup>1</sup> H. Danmo, Rätten till arbete, *Empowerment* 5 (2006), No 2, p 3.

<sup>2</sup> H. Danmo, Pensionären med makt över sitt liv, *Empowerment*, 2002 : 1, årgång 1, s.12.

importance of the “RIGHT support”; on the other hand, they stress the importance of doing something meaningful. The latter emphasis is more in line with autistic identity politics struggles for the recognition of autism as a neurological difference rather than deficit, and of autistic traits as things to be proud of rather than problematic behaviours calling for training [2]. This paper aims to critically explore an ambivalent discourse of empowerment in light of the notions of employment and work life conveyed in the magazine *Empowerment*. How are autism and work represented and imbued with meaning in the magazine’s articles? What assumptions underlie these representations? What types of power are constructed through these representations? What is not included in this way of representing autism and work?

To begin with this article starts with a presentation of research about autism, employment and the meaning of ‘real jobs’. After that a description of the concept of empowerment is made. Then the Swedish context for policy and employment support is described and this is followed by an account of the method and material that the article is based upon. Subsequently the articles findings and conclusions are presented and discussed.

### *1.1. Research into autism and employment and the meaning of real jobs*

It is well known that people with autism have difficulties finding and maintaining employment and that they need the right kind of support so that they can succeed in the workplace [4, 8, 12, 16]. Much less is known about workplace discrimination [18]. Over the past decade, research into autism and employment has stressed the meaning of work for quality of life (QOL) rather than merely the provision of certain forms of support [7, 8]. How people with autism experience various support systems has been highlighted when evaluating outcomes rather than simply measuring the level of behavioural adaptation [7, 12]. Several researchers stress the importance of considering how people with autism experience work and work-related issues [2, 12]. In a study that does just this, Müller et al. [12] note that people with autism requested the provision of a job coach “to assist individuals with ASDs in understanding and handling the nuances of routine workplace social interactions” on an everyday basis [11]. Another suggestion was “job matches that not only accommodated ASD-related weaknesses/deficit areas, but also exploited individuals’ ASD-related strengths” ([12] p. 173).

Research stresses the importance of real jobs, although it is unclear exactly what this means. Real jobs are defined by Ridley and Hunter [14] as “paid jobs in inclusive settings, thus demonstrating the capabilities and contribution of people with disabilities across the world”. Ridley and Hunter stress the positive outcomes for people with disabilities of having a real job, outcomes such as “access to socially valued roles, a purpose or structure to daily life, social links with the community, meaningful choices and opportunities, a sense of personal future, and last but not least, financial benefits” ([14], pp. 57–58). Critics, however, have pointed out the connection between the real job notion and principles of normalization as well as consequences of exclusion [20]. Wilson stresses the “importance of individuals attaining and retaining a ‘real job’ as “an effective means of normalizing their appearance” [20]. Wilson argues:

that pursuing the principle of a “real” or “normal” job for people with “learning difficulties” has, in some cases, led to their being expected to successfully negotiate all the tasks expected of non-disabled workers. It appears that some supported employment providers attempt to “normalize” people with cognitive impairments in employment situations using extensive support to compensate for their impairment. As “real jobs” are constructed around non-disabled workers it is often impossible to provide this support adequately. Attempting to withdraw the support often denies the nature and consequences of the impairment. While support is necessary for many people with cognitive impairments to find and sustain employment it seems, however, insufficient, in many situations to be able to compensate for their degree of impairment and, ultimately, their ability to perform all the required tasks of a “real job”. ([20], pp. 113–114)

### *1.2. Notions of empowerment in research*

The concept of empowerment is defined by Rappaport ([13], pp. 121–122) as “a process, a mechanism by which people, organizations, and communities gain mastery over their affairs”; furthermore, “empowerment conveys both a psychological sense of personal control or influence and a concern with actual social influence, political power, and legal rights”. The multiple levels of this construct are interdependent, according to Zimmerman [19]. The implications of this concept differ between contexts, periods, or groups of

individuals. Furthermore, empowerment supports individuals so they can influence changes at the community level. Zimmerman argues that psychological empowerment refers to a broader interpretation of the construct, since it includes both mental and behavioural aspects. Individual empowerment should be interpreted more narrowly as “what goes on in the mind” (p. 582).

Critics stress that our understanding of empowerment is both limited and confused [5]; it lacks theoretical clarity, particularly in the context of working organizations [17]. Many scholars often perceive empowerment as synonymous with supervisors sharing power or delegating it to subordinates [5]. The management and social influence literature considers power and control in two ways. The first is linked to perceiving empowerment as synonymous with delegating and participating activities. According to this view, power is a relational construct, a function of actor dependence or independence; therefore, “the relative power of one actor over another is a product of the net dependence of the one on the others” and the supervisor is considered to possess power when deciding to share it with subordinates [5, p. 472]. Conger and Kanungo see this view of power as problematic because, for example, an individual may not feel empowered when the supervisor delegates a task. The second view is that power is a motivational construct and that individuals need it. Power concerns an intrinsic need for self-determination, so “individuals’ power needs are met when they perceive that they have power or when they believe they can adequately cope with events, situations, and/or the people they confront” ([5], p. 473). The dividing line between these two views is whether empowerment concerns the sharing and delegation of authority and resources, or the individual’s sense of personal efficacy. There is a crucial discrepancy between the individual’s sense and perception of power and control and his or her actual power and control, i.e., whether or not the individual can actually exercise power [15].

Another important aspect underlying this issue is that psychology encompasses both behaviouristic and cognitive views of human nature [15]. The former holds that “reality creates the person” and is interested in the significance of contexts. The latter, which dominates American psychology, holds that “the person creates reality” and is therefore more interested in what goes on in an individual’s mind; Riger holds that a consequence of this is that situational or social structural factors will be ignored or downplayed [15]. Furthermore, she argues that “in the context of empowerment, if the focus of inquiry becomes not actual power but rather the

sense of empowerment, then the political is made personal and, ironically, the status quo may be supported” [15, p. 281]. Distinctions must be made according to whether individuals have power over, for example, their working situation, or whether they have power to act in ways that can change a situation. Another view is whether an individual obtains power from a situation and can thereby resist the power of others. Furthermore, another problem that Likert identified [15] lies in the ideology’s pre-assumptions about empowerment, namely, that it is constructed as a model of conflict. Different groups are supposed to have different levels of power and resources; according to the definition of the concept [13], empowerment is concerned with marginalized groups, for example, those with physical or emotional disabilities. The empowerment of all these groups could lead to competition for the same limited resources. The solution advocated by Likert is commitment to community through which both individuals and the community as a whole will be reinforced.

### *1.3. The Swedish context: Policy and employment support*

Since the early 1990s, Swedish act concerning support and service for persons with certain functional impairments (LSS) has specified the support and services to which certain disabled people are entitled (1993 : 387).<sup>3</sup> LSS sets standards for the rights of individuals with permanent, severe disabilities – including people with autism – to equal living conditions and full participation in society. The responsibility for providing necessary support and service is situated at both the municipal and county levels. The regional county council usually provides advice and personal support, while the municipality is responsible for ongoing practical support in everyday life. The support should be adapted to the individual, who should have a say concerning the support provided. The law establishes ten specific activities for the individual, covered by LSS, in addition to those to which they are entitled according to other legislation. If the individual is under 17 years old, some individual (usually the parent) should have an influence. Among these activities are “daily activities” (Swedish: daglig verksamhet) if the disabled person is professional and not working. The purpose is two fold, having an activity and a possibility in the long run of getting an ordinary employment. However, this type of activities seldom results in this.

<sup>3</sup> <http://www.socialstyrelsen.se/downloaded> 2011-04-14.

The Swedish employment office administers other types of interventions, such as “development employment” (Swedish: utvecklingsanställning) and “employment with employer wage” (Swedish: anställning med lönebidrag). The first addresses unemployed individuals with disabilities that affect their capacity to work. In this intervention, which lasts up to one year, the employer receives compensation from the employment office. During this period, individuals engage in both labour activities and skill development, such as education or guidance on how to apply for work. The second type of intervention aims to help individuals find or retain employment and to build their competence and skills with regard to working capacity and disability. In this intervention, employers who hire a disabled person are supported a great part of the salaries. The intervention is for both new employees and previously employed individuals returning from sick leave and can last up to four years.<sup>4</sup>

## 2. Method and materials

This paper is based on a discourse analyse of articles in the Swedish magazine, *Empowerment*, produced by and aimed at adults with autism.

All issues of the magazine were included in this analysis with the permission of the editor, Hanna Danmo. The analysis of the articles is inspired by a critical discourse psychological analysis [6]. Important concepts in this kind of analysis are the idea of interpretative repertoires and subject positions. Interpretative repertoires can be interpreted as culturally available resources or *storylines* from which members from a specific society ‘can both draw on and resist in order to produce their own accounts’ ([9], pp. 2). Similar to discourses interpretative repertoires are “distinctive ways of talking about objects and events in the world” ([6], pp. 202). In the article we understand and refer to interpretative repertoires as different, sometimes competing, ‘meanings’ within a (ambivalent) discourse. For example within a discourse of autism there are a storyline which stress autism as a neurological difference in the same time there are a storyline which stress autism as a neurological deficit or lack. The different storylines can be looked upon as competing meanings of autism within the same discourse of autism. Through invoking

different storylines the discourse of autism is made unstable and changing. The concept of subject positions is here defined as “locations within a conversation” or “identities made relevant by specific ways of talking” ([6], pp. 210). After a phase of reading and rereading the material to distinguish patterns both within and between the parts, an ambivalent discourse of autism and work life and employment issues emerged. Within it connections between different meanings (storylines) of work life and employment issues in *Empowerment* including patterns of subject positions connected to the different storylines was formulated.

Publication of *Empowerment* began with two issues in 2002; thereafter, four issues were published every year until 2009 as part of Projekt Empowerment (PE) by the National Society of Autism and Asperger in Sweden (RFA). Altogether, 30 issues of the magazine were published. *Empowerment* was sent to all RFA members with autism. PE and the magazine *Empowerment* are parts of an emerging self-advocacy movement in Sweden for adults with autism. PE sought to help adults with autism meet and discuss issues of importance to them, to foster participation in the organization and its external work. The project was initiated by adults with autism who found that RFA was dominated by parents of children with autism and often directly excluded adults with autism from its work and activities. The editing committee and writers of the magazine consisted of adults with autism and one supporting NT assistant. Forty-seven adults with autism contributed at least one signed article in the magazine during the publication period. The magazine ran interviews with adults with autism on various issues, coverage of events and issues of interest to adults with autism, letters to the editor, and pictures of adults with autism.

## 3. Findings

Key themes linked to the notion of work identified in the data are presented here. These comprise issues concerning alternative meanings of a real job, formulations of work-related problems, and solutions to these problems.

### 3.1. Competing meanings of a real job

Several passages in the magazine *Empowerment* emphasize the importance and positive meaning of employment. These describe several interventions aimed at adults with autism, the goal of which is to help

<sup>4</sup> <http://www.arbetsformedlingen.se/download/18.46ccfec5127ddcec778000476/lonebid.ag.pdf>; <http://www.arbetsformedlingen.se/download/18.46ccfec5127ddcec77800098/utvecklingsanst.as.pdf> (downloaded 15-12-2011).

people with autism get real jobs paying regular salaries so they eventually need less and less support. The magazine presents coverage of and interviews with people with autism who, in various ways, with effort, helped by their autistic strengths and despite their autistic weaknesses, “has finally succeeded in working life”.<sup>5</sup> Other passages focus on autism as a special asset or strength in work life. For example, the articles describe how people were able to combine their special interests with a dream job or in various ways use personal experience of autism as an asset in their work life [12]. In these passages, autism is represented as a resource if conducive work conditions are provided.

While access to real jobs paying market-driven wages is a central theme in *Empowerment*, the discourse on work is ambivalent. In this discourse, there is tension between dominant and alternative notions of real jobs, which are seen as either meaningful or meaningless work. The relevant statements concern both the ordinary labour market and sheltered employment. From the dominant perspective on real jobs as meaningful, several authors argue that it is important that the individual with autism have a real job. From an alternative, more critical perspective, i.e., that real jobs are meaningless, some authors challenge the meaningfulness of real jobs and advocate the greater significance of alternative occupations.

From the perspective of the first understanding of real jobs, *Empowerment* asks the questions “Does one really have to work?” and “Why is it important to work?”<sup>6</sup> Real jobs are constructed in relation to various discourses, for example, concerning economics, adulthood, health, morality, and politics. In the economic discourse, work is stressed as a source of individual economic sustenance and as a precondition for national prosperity. At the same time, the adulthood discourse stresses work as part of being an adult member of NT society. Expressions of this emphasize the importance of a job in ensuring good quality of life [7], being an adult (including forging relationships), creating a home, and having the means to enjoy one’s leisure time. Having a job is construed as conferring independence, allowing one to live like other people, giving social status, leading to social contacts, contributing to structure in everyday life, making one

feel involved and needed, and a way to develop one’s social competence. Not working, from this perspective, means losing contact with one’s social surroundings. In the health discourse, a job is described as rehabilitation, as something that can be used for treatment purposes. In the moral discourse, employment is represented as “a moral boundary between those working, on one hand, and those not working, who in such a context are seen as lazy, sick, or too old”.<sup>7</sup> In the political discourse, a job is represented as “a political precondition, as the very foundation of the democratic system”.<sup>8</sup>

Along with claims that it is meaningful to have a job, counter-arguments assert the importance of having a job in which one feels at home, that is rewarding and fosters self-development, in which one’s capabilities are used and developed. Some authors question the reasonableness of forcing people at risk of poor health onto the open labour market and challenge the notion of jobs as meaningful. One writer, who states, “many have difficulties getting any job”, asks: “Do we also have the right to demand jobs in which we thrive and develop?”<sup>9</sup> Another statement, discussing the notion of “valuable work”, asks, “how many people can say they have that [valuable work]”:

... who know that they enjoy working full time, being social during lunches, breaks, and work. It seems to be what many prioritize. For those of us with autism and Asperger syndrome, the situation is different. Many of us want a job, but we need above all a peaceful environment. It is important that colleagues be aware of what autism and Asperger syndrome involve. We need to have clear job assignments and know who can give us help if we need it. When I was in adult education and studied psychology, there were often discussions. Disabled people and work were once discussed. One person imagined a disabled person as an office assistant. Then that person said that the disabled person would be so happy to get to copy paper, and then get a pat on the back as a reward. Is that all others think we disabled are capable of, I thought. Disappointed, I went home and pondered [the matter]. I know better, because we can handle as much as others if only

<sup>5</sup> H. Danmo, *Empowerment* 1, 2002:1, s.6-7, “Gunilla gör svagheter till styrkor”. Se även LW. Henrikson and L. Olsson, *Empowerment* 1, 2002:1, s.10-11, “Att äntligen lyckas i arbetslivet”; *Empowerment* 6, 2007:4, s.5, “Vad jobbar du med?”

<sup>6</sup> H. Danmo, *Empowerment*, 2003:4, årgång 2, s.11, “Erfarenheter av arbete”.

<sup>7</sup> P. Johansson, *Empowerment*, 2007:4, årgång 6, s.15, “Arbete och pengar – vad står det för?”

<sup>8</sup> P. Johansson, *Empowerment*, 2007:4, årgång 6, s.15, “Arbete och pengar – vad står det för?”

<sup>9</sup> U. Andersson, *Empowerment*, 2003:4, årgång 2, s.9, “Ulricas krönika”.

we find what feels right for us and work on how to make it work.<sup>10</sup>

The discourse on real jobs can be seen as part of a general discourse on occupation. If real jobs, as an aspect of this discourse, primarily represent the meaning of work in economic terms, the more general discourse centres on plurality when it comes to choices and opportunities, adulthood, quality of life, occupation adapted to individual needs and competence, and perhaps most importantly, the experience of meaningfulness. In the discourse on occupation, various occupations are repeatedly constructed in relation to each other. In addition to real jobs, there is employment with wage subsidies, employment in daily activities, and voluntary work, which several statements represent as similar or supplementary to real jobs. For example, having both a paid job and routine daily activities are described as “important prerequisites for living a meaningful life”.<sup>11</sup> People’s individual needs are described as “greatly varying, so a variety of activities suited to the disability is required”.<sup>12</sup> Internship is described as one possible way to the job one would like to have. Sometimes, the differing economic conditions between occupations are challenged through invoking a narrative of similarity. For example, one statement challenges the meaning of work life in an economic discourse by arguing that the writer, in her current daily activities, performs the same tasks, though for less financial compensation, as when she was engaged in paid employment.<sup>13</sup> In another statement, the writer suggests changing the name of the position from “internship” to “apprenticeship”:

There seems to be a jinx on that word, as an “intern” is considered a free, temporary, and unskilled worker, in most cases. If you instead go out and find *apprenticeships*, then you have told the employers that *here* you have people who intend to learn, work their way *into* the *real* labour market, and who are fully educable, *although* they do not receive proper wages to start with.<sup>14</sup>

Several statements stress the differences between occupations, these differences being primarily represented in talk about meaningfulness:

The meaning of work is to feel needed and to do something significant. Therefore, voluntary work is equally satisfactory. You will gain confidence from learning what you can do. The worst thing you can do is to take a job that you do not enjoy just because it pays well.<sup>15</sup>

One statement challenges the supposed meaningfulness of a job by relating it to experiences of the meaningfulness of voluntary work:

Contrary to what some other speakers said, Thomas thinks that a profession is not important to having a sense of community. However, it is important to be involved in club activities if you don’t have a job. Thomas thinks that the voluntary work he does now feels more meaningful than the work he did as a paid employee.<sup>16</sup>

One statement describes a job as both “a right and an end in itself”.<sup>17</sup> At the same time, it is stressed that:

the right to work can sometimes be replaced by “meaningful employment”. In this context, the meaningfulness might replace a decent wage.<sup>18</sup>

### 3.2. *Individual responsibility or structural barriers?*

In the magazine *Empowerment*, the meanings of jobs are connected to two problem formulations and therefore solutions: a dominant one in line with a medical or individual model of disability (i.e., disability as a burden, pain, and personal tragedy [10]) and an alternative one in line with the social model of disability (i.e., the burdens of disability are caused by social structures of inequality and discrimination [10]).

According to the first formulation, the problem is a combination of individual difficulties caused by impairments connected to autism and the meaning of

<sup>10</sup> L. Tegemark, *Empowerment*, 2003 : 4, årgång 2, s.3, “Vi kan mer än folk tror”; LW. Henrikson & L. Olsson, *Empowerment*, 2002 : 1, årgång 1, s.10-11, “Att äntligen lyckas i arbetslivet”.

<sup>11</sup> *Empowerment*, 2006 : 2, årgång 5, s.10, “Rätten till systerställning”.

<sup>12</sup> *Empowerment*, 2006 : 2, årgång 5, s.10, “Rätten till systerställning”.

<sup>13</sup> *Empowerment*, 2007 : 4, årgång 6, s.9, “Krönika”; c.f. also *Empowerment*, 2005 : 3, årgång 4, s.17, “Anslagstavla”.

<sup>14</sup> *Empowerment*, 2006 : 2, årgång 5, s.16, “Insändarsida”.

<sup>15</sup> H. Danmo, *Empowerment*, 2002 : 1, årgång 1, s.12, “Pensionären med makt över sitt liv”.

<sup>16</sup> H. Danmo, *Empowerment*, 2003 : 4, årgång 2, s.11, “Erfarenheter av arbete”.

<sup>17</sup> P. Johansson, *Empowerment*, 2007 : 4, årgång 6, s.15, “Arbete och pengar – vad står det för?”.

<sup>18</sup> P. Johansson, *Empowerment*, 2007 : 4, årgång 6, s.15, “Arbete och pengar – vad står det för?”.

individual and social adaptation and social support. The suggested solution is a combination of individual responsibility to adapt (i.e., empowerment in a psychological sense) and social support to make that adaptation possible. The problem is summarized in several statements as difficulties finding and keeping a job. Here the problem is treated as something connected to autistic people's special difficulties in relation to the open labour market.

Several statements use the word *despite* in relation to competence and personal resources. For example, despite vocational qualifications, education and personal traits that should make the person very appreciated in most workplaces, the individual is described as someone who has mostly been living on temporary disability pension. Several statements position people with autism as people who "repeatedly experience failures at work and never get a chance to do themselves justice"<sup>19</sup> and who "could well do a proper job if only the conditions are right".<sup>20</sup> Employers and others are urged to focus on strengths rather than weaknesses.

According to this problem formulation, the problems are stress, lack of appropriate support and adaptation, lack of knowledge and understanding in the social environment, and difficulties interpreting certain signs. As a result, people with autism are not encouraged to apply for relevant jobs at the employment agency. Other results of this problem formulation, at the workplace, are; the occurrence of misunderstandings and conflicts at various workplaces, the person does not learn the ways of the workplace or is incorrectly introduced to invisible workplace rules and demands; the person is exposed to excessive social demands and becomes 'socially overloaded' in relation to colleagues and the person experiences bullying and ostracism and displays sensitivity to stress.

From the perspective viewing people with autism as having a "disability within the autism spectrum"<sup>21</sup> and as having "different ways of perceiving and interpreting the world around [them]",<sup>22</sup> the lack of "good models to validate our knowledge, that is, to identify our strengths and weaknesses based on the specific

impairments caused by our disabilities"<sup>23</sup> is represented as a problem:

A major dilemma is that people often think that we who have AS/HFA [Asperger's syndrome/high-functioning autism] are "high-enough functioning" for daily activities, but too "poor functioning" for the regular labour market. Instead, we are often passed from agency to agency, with the result that we often "fall through the cracks" and end up unemployed. That there is no place for us in the labour market creates exclusion. If we are not given access to meaningful employment that meets our own abilities and difficulties, we cannot achieve a good quality of life and sense of belonging in society.<sup>24</sup>

A similar statement<sup>25</sup> stresses the importance of a holistic view and of coordination between responsible institutions, for example, when it comes to various supports and adaptations. The result of this lack is that "we who have a work disability become 'draining' instead of 'productive' members of society".<sup>26</sup>

The second, alternative problem formulation stresses structural changes and barriers in terms of discrimination facing people with autism on the labour market. Structural changes in the labour market have consequences for people with neuropsychiatric disabilities. Cited changes include greater demands for flexibility, stress resistance and social interaction, interpersonal skills, efficiency, concentration, and ability to independently organize and plan work.

The statements refer both directly and indirectly to discrimination, such as descriptions of people being fired without explanation and being treated unfairly by the employer. In more radical discussions of structural barriers in work life, labour market problems are defined manifesting the oppression of "people who are different" and a lack of openness to diversity.<sup>27</sup>

### 3.3. *A individual perspective and individualized interventions*

If we get to work in the right place with the right support tools, we can be as productive as people without impairments.<sup>28</sup>

<sup>19</sup> LW. Henrikson & L. Olsson, *Empowerment*, 2002 : 1, årgång 1, s.10-11, "Att äntligen lyckas i arbetslivet".

<sup>20</sup> A. Mård, *Empowerment*, 2006 : 2, årgång 5, s.5, "Andreas väg till arbete". Seäven *Empowerment*, 2006 : 2, årgång 5, s.9, "Krönika".

<sup>21</sup> A. Sjölund, *Empowerment*, 2006 : 2, årgång 5, s.7, "RFA planerar nytt arbetsprojekt".

<sup>22</sup> A. Sjölund, *Empowerment*, 2006 : 2, årgång 5, s.7, "RFA planerar nytt arbetsprojekt".

<sup>23</sup> A. Sjölund, *Empowerment*, 2006 : 2, årgång 5, s.7, "RFA planerar nytt arbetsprojekt".

<sup>24</sup> A. Sjölund, *Empowerment*, 2006 : 2, årgång 5, s.7, "RFA planerar nytt arbetsprojekt".

<sup>25</sup> *Empowerment*, 2006 : 2, årgång 5, s.9, "Krönika".

<sup>26</sup> *Empowerment*, 2006 : 2, årgång 5, s.9, "Krönika".

<sup>27</sup> *Empowerment*, 2005 : 1, årgång 4, s.11, "Annons".

<sup>28</sup> *Empowerment*, 2007 : 4, årgång 6, s.4-5, "Att hitta det man är bra på".

The quotation above illustrates the meaning of 'right support' for success in the open labour market. In relation to the two problem formulations, two kinds of solutions are proposed, individual and structural. Proposals for individual solutions occur most frequently in the material. Among the individual solutions mentioned, we can distinguish between those stressing that somebody else (e.g., employers, employment agencies, and support people) is responsible for the individual solution or that the individual with autism is responsible, as an expression of the need for psychological empowerment. Right support represents the most common individual problem solution, and is one for which somebody else is responsible. It can also be understood, as part of a reformulation process in which right support is contrasted to support not experienced as such.

Right support means both more general support, applicable to autistic people more generally, as well as support adapted to the individual. Several statements stress the importance of a combination of external support and of the individual with autism taking responsibility and exerting effort (i.e., psychological/functional empowerment). This is exemplified by one statement emphasizing that the individual "accepts and understands autism/AS and his/her difficulties. One must be motivated and willing to have a job".<sup>29</sup> Several statements articulate the ideals of self-knowledge and of individuals actively changing their situation in order to find and keep a job. Individuals are usually urged to use and develop their strengths and to find and develop strategies for dealing with difficulties. The importance of the individual receiving a diagnosis and, through it, obtain self-knowledge is stressed in several statements.

Although statements highlighting the importance of receiving a diagnosis occur frequently in *Empowerment*, some statements challenge this. Parallel to narratives of diagnosis as a path to increasing self-knowledge, the possibility of living "a whole life without knowing one's diagnosis"<sup>30</sup> is stressed; similarly, it is claimed that the absence of diagnosis early in life may prompt the individual to go further in work life, because she/he has been "stimulated to fight so hard".<sup>31</sup> Discussion of discrimination is also connected with ambivalence regarding the somewhat contradictory ideals of being open about one's diagnosis and trying to

pass as an NT person (i.e., adapt to the NT-dominated workplace environment) in the Swedish autistic self-advocacy movement (cf. [1]). Being open about one's diagnosis ironically facilitates both special support and discrimination. In the few statements in which openness is discussed more directly, ambivalence regarding it is expressed through discussions of the disadvantages and advantages of living a "double life"<sup>32</sup> versus coming out. For example, one statement gives the following advice:

If you want to tell people about your disability when looking for work, think carefully about how. Talk about your strengths. "Be prepared to be disqualified immediately", Hans warns. Many employers believe that autism/AS means that one cannot handle a job. Opinions differ on whether or not it is best to tell. If you know you need special adaptations to cope with the work, then of course you have to say that you have autism/AS. Otherwise, the employer will not receive a wage subsidy, for example. But if you do not need support, you can gain by not revealing that you have the disability – or at least by waiting until you have started working and showed that you can do the job.<sup>33</sup>

As a complement to individual solutions, writers criticize deficiencies in society and propose changes to address these, as well as providing more general advice concerning courses of action for people experiencing discrimination. Various alternative employers are mentioned. More direct proposals for structural-level changes represent alternative, less frequently suggested problem solutions. Only one statement directly criticizes the current labour market, which is depicted as exclusionary and inaccessible for people with autism. The statement stresses the significance of going from being "patients to being citizens".

It's time to change the rules of the game. It's time to create a labour market in which we all fit. It's time to change the statistics and make everyone winners instead of losers! It's time for you who make the rules to rewrite them, so that we can become agents in the "team play" of the labour market. Then we can relieve our teammates, who are playing without substitutes in Sweden today. For us to go from being "patients to citizens" and to participate in an accessible Sweden before 2010,

<sup>29</sup> L. Tegemark, *Empowerment*, 2003 : 4, årgång 2, s.12-13, "Vägar till arbete".

<sup>30</sup> H. Danmo, *Empowerment* 1, 2002 : 1, s.6-7, "Gunilla gör svagheter till styrkor".

<sup>31</sup> H. Danmo, *Empowerment* 1, 2002 : 1, s.6-7, "Gunilla gör svagheter till styrkor".

<sup>32</sup> M. Hellström, *Empowerment* 6, 2007 : 4, s.10-11, "En aspie inom omsorgen".

<sup>33</sup> *Empowerment* 6, 2007 : 4, s.6-7, "Att tänka på när man söker arbete".

policy makers must begin to think beyond the fiscal year.<sup>34</sup>

#### 4. Conclusions

According to Rappaport [13], empowerment includes both a psychological sense of personal control or influence as well as actual social influence, political power, and legal rights. The primary aim of Project Empowerment was to develop a model enabling adults with autism to meet and discuss issues of importance to them. Another aim was to explore what adapted support might be like, to enable adults with autism to achieve greater influence and participation in the labour market or at work, within organizations. This illustrates how the aim of Project Empowerment encompasses both a relational, functionalistic approach to power and an individual, motivational approach. The project aim suggests that through being motivated, adults with autism should be able to influence questions of interest at the organizational and societal levels.

We identified two competing meanings (storylines) within an ambivalent discourse of autism, work life and employment issues in the studied material. The first and dominant one are what we call the recreated norm storyline. Invoking this storyline *Empowerment* magazine – in line with an individual/medical perspective on autism as deficit – represents autism as making it difficult for people with autism to find and keep a job in the open labour market; to do so, they need external employment support. In light of Rappaport's [13] definition, this storyline represents an individualistic and motivational approach producing an autistic subject position where adults with autism have to revise or correct themselves to achieve acceptance in the NT work world. This process is accordingly constructed in relation to the predominant norm within society. The assumption underlying this representation is equivalent to liberal individualism compared with the Calás and Smircich [3] mapping of feminist organization studies. Liberal individualism is based on a liberal view of society and organizations. The points of departure of this perspective are that individuals have equal opportunities and can, by their own strength, shape their own lives and careers. The solution according to liberal individualism is therefore to reduce differences and, when opportunities are the same, individuals can compete on an equal footing. In our findings, this storyline maintains the discourse of real jobs and with it the ideal of

“the effective worker”, i.e., in relation to other kinds of daily occupation, such as state-supported sheltered employment or “daily activities”, unemployment, disability pension, and non-profit work in organizations, as well as possible alternative subject positions for adults with autism.

These findings concern individual difficulties caused by impairments connected to autism and the meaning of individual and social adaptation and social support. When invoking this storyline, autistic adults do not become empowered [13], but rather subordinated to the predominant norm. This is because the responsibility has an individualistic perspective: it is the individuals who ought to change while the determining factor that constructed the unequal conditions and power relationships remains intact.

The second identified storyline represents an alternative, counter narrative [c.f 9] in *Empowerment* challenging the idea of the meaningful real job in the open labour market, and the importance of people with autism finding and keeping jobs there. This storyline is called the challenged norm storyline. In line with the social model of disability, it focuses on structural barriers and discrimination against people with autism on the labour market. The assumption underlying this representation is based on ideas that Calás and Smircich [3] call socialist feminism, in which the focus shifts from an individual to a structural perspective. From this perspective, the problem are considered to be deeply rooted in social structure, not in individuals. The opportunities and structural power individuals have in their positions are crucial. Different positions segregate the structural power, reproducing the problem. If structural barriers or processes containing bias are eliminated, equal opportunities are created and conditions can be considered socially equal.

But is the norm challenged through invoking this storyline? The findings indicate that this storyline produce an autistic subject position where autism and autistic traits are regarded as opportunities rather than weaknesses and the open labour market, rather than the autistic individual, as the problem. The first storyline regards the individual as in need of behavioural change in order to find and keep a (real) job. In contrast, in the alternative storyline, it is the labour market, its constituent workplaces, as well as the meaning of various daily occupations – among them real jobs – that are in need of change. The individual is instead urged to find out what would be a meaningful daily occupation, and to discover how to make the best out of his/her individual strengths and

<sup>34</sup> *Krönika, Empowerment* 5 (2006), No 2, p. 9.

interests. Thereby, both the individualistic/motivational and relational/functionalistic perspectives on power are included, and the prerequisites are created for empowering adults with autism [13].

The power relationships within this storyline will unfortunately remain unchanged as long as the conditions that construct and maintain social inequity do not change substantially. When highlighting autism and autistic traits as opportunities rather than weaknesses, the norm is visualized. A consequence is that autism and autistic traits are marginalized since they are constructed as “the other”. Therefore, the power relationships will remain intact as long as the organizational and societal mechanisms that reproduce them remain the same.

The alternative, counter narrative of autism and work gives rise to collective empowerment that includes people with autism as a counter-political group, rendering discrimination visible and deconstructing structural barriers to the inclusion of people with autism in the labour market. From this perspective, society’s values and norms must change and the ideal notion of the “effective worker” must give way to a more nuanced and complex view of the worker. This view includes, through the storylines of individual or psychological empowerment, adults with autism gaining power over their situation – power to act and maybe even power from their situation – and thereby gaining the possibility to resist inequality [15]. Consequently, the organizational or societal mechanism that reproduces social equality will change.

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