Document généré le 2 mai 2024 04:34

Développement Humain, Handicap et Changement Social
Human Development, Disability, and Social Change

Social Representations of Persons with Learning Disability or Autism Spectrum Disorder Among Rehabilitation Professionals in Sweden

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Volume 24, numéro 1, avril 2018

Représentations sociales et handicap : regards croisés sur le sens commun du handicap
Social Representations and Disability: Perspectives on the Common Sense Notions of Disability

URI : https://id.erudit.org/iderudit/1086204ar
DOI : https://doi.org/10.7202/1086204ar

Aller au sommaire du numéro

Éditeur(s)

Réseau International sur le Processus de Production du Handicap

ISSN

1499-5549 (imprimé)
2562-6574 (numérique)

Découvrir la revue

Citer cet article

Germundsson, P. (2018). Social Representations of Persons with Learning Disability or Autism Spectrum Disorder Among Rehabilitation Professionals in Sweden. *Développement Humain, Handicap et Changement Social / Human Development, Disability, and Social Change, 24*(1), 53–62. https://doi.org/10.7202/1086204ar

Résumé de l'article

Les individus avec des incapacités sont affectés par leur environnement de plusieurs façons, entre autres par la manière dont ils sont perçus des autres. Cet article se penche sur les représentations des professionnels de la réadaptation envers les gens vivant des difficultés d'apprentissage ou qui vivent avec le spectre de l'autisme, car les situations de vie de ces derniers sont grandement influencées par les professionnels avec lesquels ils travaillent au quotidien. Une étude par association, qui est une méthode établie dans la théorie des représentations sociales, fut entreprise afin d'approfondir les connaissances. Au total, 121 professionnels de la réadaptation ont participé au projet. Les résultats indiquent que, quand les professionnels pensent à leur clientèle, ils associent ce groupe au travail et au processus de travail. Une représentation de type relationnelle émerge où les personnes ne sont pas comme telle autonomes, mais plutôt associées aux tâches qu'elles réalisent. Malgré cela, les répondants avaient des attitudes sympathiques envers les individus et le travail. Cette étude montre aussi que les représentations sociales des professionnels envers les gens qu'ils aident diffèrent selon l'organisme auquel ils appartiennent et que les nombreuses dénominations par ces organismes à l'égard des individus ayant des incapacités ne sont pas appréciées par les professionnels.

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Social Representations of Persons with Learning Disability or Autism Spectrum Disorder Among Rehabilitation Professionals in Sweden

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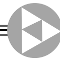
Article original • Original Article



Abstract

Individuals with disabilities are affected by their environment in different ways, and one important factor involves how these individuals are perceived by others. This article focuses on rehabilitation professionals and the social representations of people with learning disability or autism spectrum disorder, as this group's life situation is largely influenced by the professionals who work with them in their everyday lives. An association study, which is an established method in the theory of social representations, was carried out to gain more insight; in total, 121 rehabilitation professionals were included in the study. The results indicate that, when thinking about the target group, the respondents often associated the individuals in the group with work and the working process. A relational representation emerges where the individual is not perceived as someone with independent agency but rather as a person whose characterization is assigned in relation to the work tasks. Despite this, the respondents were sympathetic to the individuals and this work. The study also shows that the professionals' social representations of the target group differs depending on what organization they belong to and that the various denominations of the individuals used in the organizations are not appreciated by the professionals.

Keywords: Rehabilitation, social representations, professionals, learning disability, autism spectrum disorder

Résumé

Les individus avec des incapacités sont affectés par leur environnement de plusieurs façons, entre autres par la manière dont ils sont perçus des autres. Cet article se penche sur les représentations des professionnels de la réadaptation envers les gens vivant des difficultés d'apprentissage ou qui vivent avec le spectre de l'autisme, car les situations de vie de ces derniers sont grandement influencées par les professionnels avec lesquels ils travaillent au quotidien. Une étude par association, qui est une méthode établie dans la théorie des représentations sociales, fut entreprise afin d'approfondir les connaissances. Au total, 121 professionnels de la réadaptation ont participé au projet. Les résultats indiquent que, quand les professionnels pensent à leur clientèle, ils associent ce groupe au travail et au processus de travail. Une représentation de type relationnelle émerge où les personnes ne sont pas comme telle autonomes, mais plutôt associées aux tâches qu'elles réalisent. Malgré cela, les répondants avaient des attitudes sympathiques envers les individus et le travail. Cette étude montre aussi que les représentations sociales des professionnels envers les gens qu'ils aident diffèrent selon l'organisme auquel ils appartiennent et que les nombreuses dénominations par ces organismes à l'égard des individus ayant des incapacités ne sont pas appréciées par les professionnels.

Mots-clés : Réhabilitation, représentations sociales, professionnels, difficultés d'apprentissage, spectre de l'autisme

Introduction

Disability and its consequences for the individual are often discussed in various contexts. In the Nordic countries as well as in many other countries, an *environment-relative handicap model* is embraced. This model includes a social perspective and focuses on the impact of the surrounding society on the lives of individuals with disabilities. In contrast, the *medical model*, which involves a greater focus on diagnoses and individual difficulties, is seldom referenced in the public discourse. Research shows that individuals with disabilities are affected by their surroundings in different ways (Robey et al., 2006; Verdonschot et al., 2009; Vornholt et al., 2013). Negative aspects and consequences are often in focus, but in some cases, positive effects are also mentioned (Bell & Klein, 2001; Gouvier et al., 1994; Manchaiah et al., 2015). One important factor in the environment aspect relates to the perceptions people have about individuals with disabilities. Several studies have been conducted on this subject, and the results show that the negative attitudes of others toward people with disabilities leads to an increased risk of stigmatization and exclusion (e.g., Gilmore et al., 2003; Hall, 2004; Louvet, 2007).

The social psychological theory of social representations has been used in several studies of disease and disability (e.g., Herzlich, 1973; Zani, 1993; Morant, 2006; Linton et al., 2013). This theory suggests that our social representations – the everyday knowledge of phenomena or objects in our surroundings – affect our actions in various situations. Accordingly, this article focuses on rehabilitation professionals and their representations of people with learning disability or autism spectrum disorder (ASD). A learning disability affects a person's capability to learn new skills, understand complex information, communicate and act independently. ASD is a condition that affects social interaction, communication and behaviour, and often creates difficulties within these areas. The life situation for persons belonging to these groups is largely influenced by professionals that surround them in their everyday life (Ståhl et al., 2011; Stucki et al., 2007). Thus, the professionals' representations of these individuals are especially important, as their actions will affect the way in which these persons are treated and what rehabilitation measures are implemented. In line with this, the aim of the present study is to explore the social representations of persons with learning disability or autism spectrum disorder (ASD) among rehabilitation professionals in Sweden.

Theory and method

- Social representation theory

The theory of social representations (SRT) was developed by the social psychologist Serge Moscovici and was first formulated and published in the 1960s in his thesis "La psychanalyse, son image, son public" [*Psychoanalysis: Its image and its public*]. Moscovici defined a social representation as a system of values, ideas and practices which enables individuals to orientate themselves in their material and social world, and to communicate with members of a community by providing them with a code for social exchange and a code for naming various aspects of their world (Moscovici, 1973). Representations can be perceived as historically conditioned expressions of our contemporary culture, and the theory provides the possibility to describe and explain various groups' everyday knowledge, or in other words, their common mental images (Chaib & Orfali, 1995). It details how we, in social interaction with others, build our everyday knowledge and how this knowledge affects our worldview and subsequent actions[1].

- Data collection

To explore the professionals' perceptions and mental images of the target group, an *associa-*

[1] For a more detailed presentation of the theory, see e.g., Germundsson, P. (2015) *Inclusive Education in Sweden and social representations* in Hensen, G. & Beck, A. (Eds.) Inclusive Education. Internationale Strategien und Entwicklungen Inklusiver Bildung (Beltz Juventa) or Chaib, M., Danermark, B. & Selander, S. (Eds.) (2011) *Education, Professionalization and Social Representations: On the Transformation of Social Knowledge* (Routledge).

tion study was carried out[2]. This is an established method in SRT. During the association study, free associations were gathered. The *free association method* involves respondents being asked to enter the word or expression that comes to mind from a presented stimulus word or word series. The method is expected to give spontaneous answers which are less elaborated and controlled than those which are developed and linguistically formulated during an interview, for example. (Abric, 1994). It is assumed that the person's response depends on the stimulus word or phrase as well as the knowledge and images the respondent has of the object (Wagner et al., 1996). By analyzing the associations, the opportunity to expose our partly subconscious mental images arises, which in turn, affects our often unreflected actions especially in situations where quick decisions are required (Kahneman, 2011; Ratinaud & Lac, 2011).

- Participants

The association study was conducted in the form of an online questionnaire to be answered by the respondents consisting of professionals working in daily activities[3] or assisted living facilities in a major city in Sweden or within the municipality or region's rehabilitation teams. From a list of all workplaces in the city with daily activities (*n* = 42) or assisted living facilities (*n* = 86), 25 % of the workplaces *(n* = 32) were randomly selected using the *Microsoft Excel* software. Within the selected workplaces and the two rehabilitation teams, all of the professionals with rehabilitative work tasks were contacted. The respondents were contacted via e-mail containing information about the study and a link to the questionnaire. In addition to demographic data such as age and gender, the respondents were asked to associate about the users. Up to five associations could be given by the respondents, and they were also asked to indicate if the association was positive or negative on a five-point scale of values (--, -, 0, +, or ++). The questionnaire was sent to 189 persons, of whom 121 responded (response rate 64 %). This study follows the ethical principles as stated in the Helsinki Declaration.

- Data analysis

A total of 323 associations were gathered, and the collected associations were divided into 13 categories (see Figure 1). The categorization process followed a step-by-step synonymy procedure: Association items considered to be synonymous (i.e., having the same meaning) were grouped together and specified categories were established. During the process, an external person with experience in social work was consulted to discuss the categorization, and corrections were made following the discussions. If the association consisted of several words or whole sentences, significant keywords were identified to place the association in the right category. The positive or negative connotations were helpful in efforts to place the associations in the correct category, with the aim of being as specific as possible for the items included. Eleven of the associations could not be interpreted (as *used*, *long*, *EU*, and *assistant*) or placed into any specific category resulting in 312 associations being included in the study. The number of categories varied by the respondents' affiliation (see Table 2), and the stimulus word was adapted to the denomination used in the respective organization (*inhabitant*, *patient*, or *user*).

To show the distribution of associations a *similarity analysis* was implemented, where the *co-occurrence* of associations among the respondents is studied. The analysis is based on the mathematical *graph theory*. During the analysis, *Iramuteq* (Ratinaud, 2015) software was utilized, which uses *R* statistical software (The R Foundation, 2015). The result is presented (see Figure 2) as a *maximum tree* graph through which the strongest link between different categories is shown in the form of lines. The tree consists of categories which are linked to each other thus showing the tendency of people to mention these categories together. The size of the text in the tree is in proportion to the size of the category.

[2] The study is part of a research project in agreement for collaboration in the field of Rehabilitation for Individuals with Learning Disability or Autism Spectrum Disorder (ASD).

[3] Also referred to as 'regular educational–vocational activities'.

TABLE 1 : RESPONDENTS IN THE ASSOCIATION STUDY

	Number	Female/Male (%)	Age (average)	Post-Secondary Education (%)	Years in the Profession (average)
Daily Activities	52	83 / 17	45	68	13
Assisted Living	45	82 / 18	46	43	17
Rehab Team Region	14	86 / 14	42	100	14
Rehab Team Municipality	10	70 / 30	37	100	12
Total	121				

TABLE 2 : NUMBER OF ASSOCIATIONS AND CATEGORIES BASED ON THE RESPONDENTS' ORGANIZATIONAL AFFILIATION

	Associations	Categories
Daily Activities	142	12
Assisted Living	93	12
Rehab Team Region	43	13
Rehab Team Municipality	34	12

Results

1. The professionals' representations

1.1 Size and valance of categories

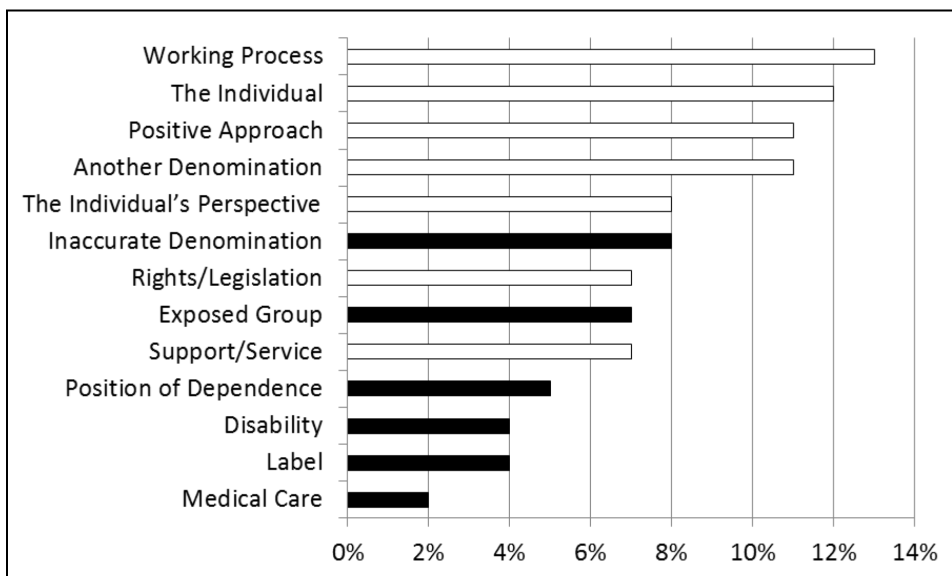
Figure 1 shows the categories and their size for all respondents. The figures indicate the percentage of the associations found in each category. The largest category (13 %) is 'Working Process', and contains associations such as *work*, *adapt*, *objectives*, *many meetings*, and *administration*. The second largest category, 'The Individual' (12 %), relates to the individual and individual characteristics, and includes associations such as *individual*, *personality*, and *fellow man*. Eleven percent of the associations are found in the category of 'Positive Approach' where, through their associations, the respondents expressed an overall positive attitude toward users (as *interest*, *joy*, and *consideration*).

Almost one fifth of the associations reflect references to the individual and that respondents give suggestions on 'Another Denomination'. In certain cases (8 %), the respondents expressed that the current denomination is inaccurate. Another four percent of the associations concern the same area; in this case, the respondents believed that the denomination is a label placed on the individual.

In addition to the 'Positive Approach' category, some associations (8 %) highlight the 'Individual's Perspective' (as *self-determination*, *independence*, *actor*, and *be like everyone else*). Overall, more than one in ten associations involve users being in an 'Exposed Group' (7 %) and in a 'Position of Dependence' (5 %).

In the collection of associations, the respondents were asked to state if the association was positively or negatively value-charged or had no charge (five values). In Figure 1, a black bar represents the categories containing predominantly negatively charged associations,

FIGUE 1 : CATEGORY SIZE AND PREDOMINANT VALENCE OF ASSOCIATIONS WITHIN EACH CATEGORY AMONG ALL RESPONDENTS



while the white bars indicate that the associations are predominantly positively charged based on a calculated average. The five largest categories are positively value-laden. Altogether, seven of the thirteen categories, containing 69 % of all associations, are predominantly positively charged. Among the six negatively charged categories 'Inaccurate Denomination' and 'Exposed Group' are the largest.

1.2 Similarity analysis

The result of the similarity analysis is presented in a maximum tree where the strongest link between the different categories is shown in the form of lines (see Figure 2). For instance, the number on the line connecting the two categories of 'Working Process' and the 'Individual's Perspective' indicates how many individuals mentioned both these categories. The conditions were thus created to determine how the associations are linked by studying the individuals' associations supplemented with information about what the persons *additionally* came to think of.

The tree clearly shows that 'Working Process' is the hub around which the other categories such as 'The Individual,' 'The Individual's Perspective,' and 'Positive Approach,' circuit. A strong link is also found between the categories of 'Working Process' and 'Rights/Legislation,' which in turn, is linked to the 'Position of Dependence' category. The tree also shows a link between 'Working Process' and the respondents' tendency to suggest 'Another Denomination' of the individual in this context.

2. Differences between professionals

2.1 Differences based on organizational affiliation

This section presents the categories based on organizational affiliation. The division is split into two groups based on the condition that the professionals working in daily activities and assisted living facilities meet the individual continually and regularly participate in everyday activities; in contrast, members of rehabilitation teams located in other premises meet the individual in specific cases and on more limited occasions. In Figure 4 the grey bar means that the associations within the category in total were neither positive nor negative.

FIGURE 2 : MAXIMUM TREE FOR ALL RESPONDENTS AND INDICATING NUMBER OF CO-OCCURRENCES

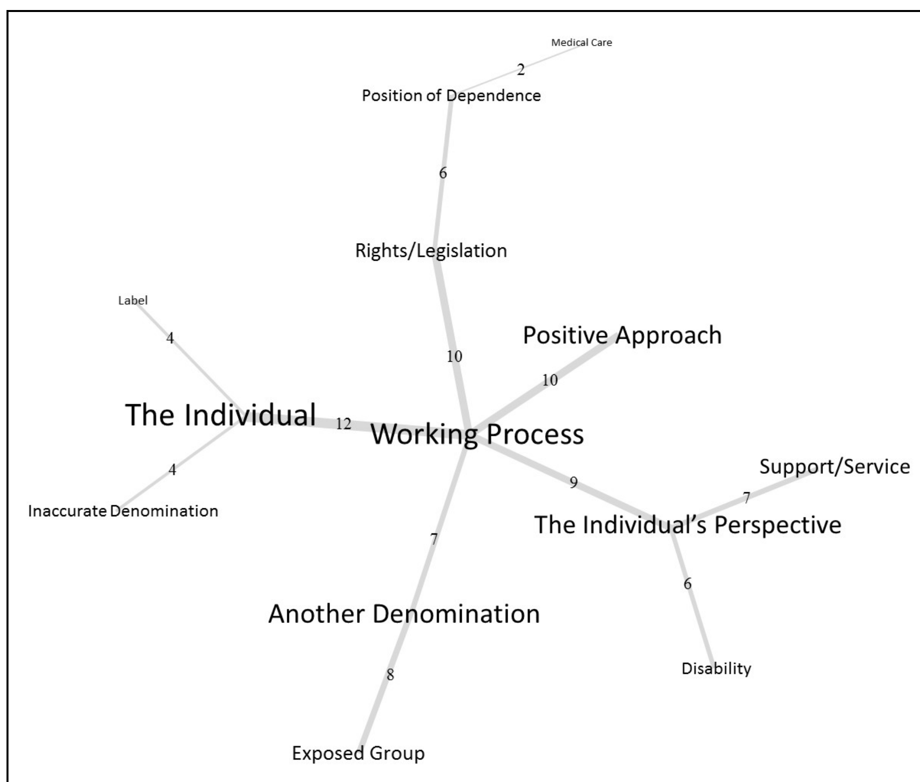


FIGURE 3 : CATEGORY SIZE AND PREDOMINANT VALENCE OF ASSOCIATIONS WITHIN EACH CATEGORY AMONG PROFESSIONALS IN DAILY ACTIVITIES AND ASSISTED LIVING FACILITIES

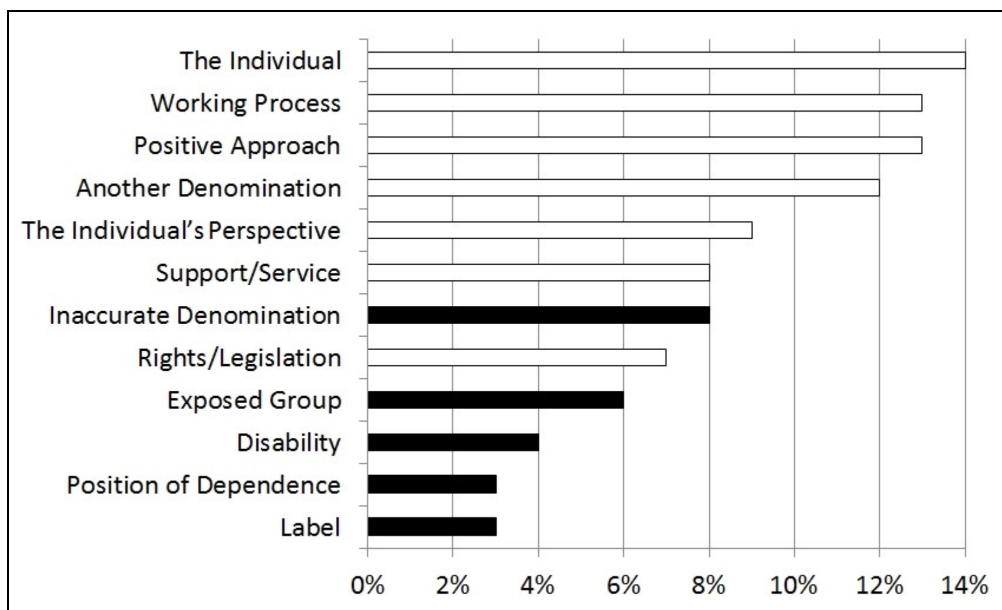


FIGURE 4 : CATEGORY SIZE AND PREDOMINANT VALENCE OF ASSOCIATIONS WITHIN EACH CATEGORY AMONG PROFESSIONALS IN REHABILITATION TEAMS

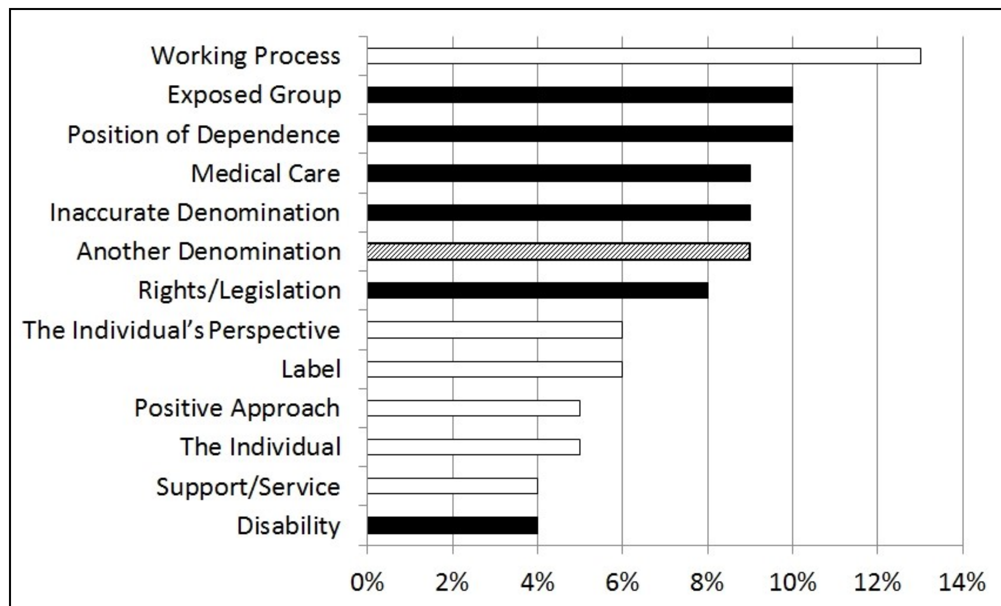


Figure 3 shows that the category which includes most associations among professionals in daily activities and assisted living facilities relates the user to an *individual*. This category is positively value-laden, which also applies to the next two categories, 'Working Process' and 'Positive Approach'. Overall, seven of the twelve categories which, when combined, contain 76 % of all associations, are predominantly positively charged. The largest negatively charged category is 'Inaccurate Denomination'.

Among the rehabilitation teams (see Figure 4), the distribution is different. The largest category is 'Working Process,' which is positively value-laden. Six of the other categories, which together contain 50 % of the associations, are predominantly negatively charged. The 'Another Denomination' category had neither a positive nor a negative response among respondents in the rehabilitation teams.

The denomination (*inhabitant*, *patient*, or *user*) varies between the organizations, and the stimulus word in the association study was adapted accordingly. In particular, this is reflected in the negatively value-loaded category of 'Medical Care' (stimulus word: *patient*) and is found only among the professionals who work in rehabilitation teams where this denomination is used. The figures show that the categories of 'Exposed Group' and 'Position of Dependence' are more prominent among the professionals in the rehabilitation teams. A difference in the value of the charge between the groups when it comes to the category 'Rights and Legislation' was also noted. The positively value-loaded category of 'Working Process' is proportionately equal in both groups, while the 'The Individual' and 'The Individual's Perspective' categories are more prominent among the professionals working in daily activities and assisted living facilities.

2.2 Significant differences between and within organizations

The difference between the groups is significant only within the category of 'Medical Care' (x^2 = 12.47, p < .01), which is not present in the group of respondents from daily activities and assisted living facilities. When testing significant differences, the calculations are made at the individual level, for example, if an individual has more than one association in the category of 'Working Process,' then they are only count-

ed once. A significance level of .05 was used for interpretation.

Significant differences within the groups were tested based on demographic variables: gender, age, educational background, and number of years in the profession. The only significant difference was that the respondents with a higher level of education associated with the category 'Rights and Legislation' ($x^2 = 6.01$, $p < .05$)[4] more often than those without.

Discussion

The study indicates that the respondents largely associate with work and the working process when they think of the users and that they are sympathetic to this work. Many of the associations are linked to the individual and the individual's perspective, and a positive picture emerges which is reinforced by a relatively large proportion of associations which more directly express a positive approach. From the SRT perspective, this may be interpreted as the professionals' everyday knowledge of the users being positive, where both their own work and the individual are at the center. The variations within the groups are small; however, differences between occupational groups based on organizational affiliation do exist. Of the persons who work within the rehabilitation teams, a representation appears that is more influenced by the perception that the individuals belong to an exposed group who are in a dependent position. This image is reinforced by the negatively charged associations that come to mind when the members of the rehabilitation teams think of rights and legislation. The opposite is found with those who work in daily activities and assisted living facilities.

It should be noted that the results should not be interpreted as meaning that the professionals in the rehabilitation teams necessarily have a more negative perception of the individuals they care for compared to those working in daily activities and assisted living facilities but rather that the individual is often perceived to have a weaker position and is more dependent on others than the perceptions of those who work in daily activities and assisted living facilities. Within these organizations, the associations are more often linked to the individual and personal qualities, and these are often perceived as positive. This study cannot answer why this is the case, but one reason may be that these professionals, by the nature and organization of their working activities, will be more closely linked to the individual and this more personal relationship is reflected in the study's results. Similarly, the professionals' role in rehabilitation teams, one based on defined contributions to assist and facilitate for the individual, may cause the representation to be more colored by a sense of dependence and vulnerability.

The largest category is about the working process, which also forms the hub around which other categories are formed in the maximum tree. This is somewhat surprising, as the stimulus word was the denomination of the user that each organization uses. This indicates that when the professionals associate with the target group, the individual and the work are closely interlinked. A relational representation emerges where the individual is not perceived as an independent entity but as a person who is essentially characterized in relation to the working tasks. This relational approach could possibly be influenced by the environment-relative handicap model which emphasizes the role of the surrounding environment in the lives of persons with disabilities and is the dominant model in the public discourse in the Nordic countries. Also, very few associations are connected to medical or disease aspects. It can be assumed that the respondents included in the study adhere more often to the environment-relative model than to the medical model that focuses more on diagnoses and individual difficulties.

The association study shows that the different denominations of the individuals used in the organizations are not appreciated by the professionals. The way in which we term phenomena in our surroundings has been shown to affect how we perceive them (Philogène, 1999), and this study shows an example of

[4] One expected value less than five.

this; in the organization that names the individuals as patients, the representation is linked to medical care while, in the other organizations, this link did not occur. Although it is not expressed in the form of representations by the respondents, this can be interpreted with the theory of social representations through which where one question arises: If we speak of individuals in what is perceived as negative terms, which in turn, affects the representation, how will that affect the way we perceive and respond to them? Although we are often unaware of our representations, they are the basis of how we interpret the world around us and treat others (Howarth, 2006; Moscovici, 2000). Social representations can be perceived as indicative of the professional when interacting with others (Jovchelovich, 2007). It is believed that these representations can affect the activity of the daily professional practice (where many quick decisions are often required) because, in such moments of quick decision-making, primarily unreflected thoughts and interpretations of the world affect one's behaviour (Kahneman, 2011).

Rehabilitation is an activity characterized by the need for collaboration between professionals and organizations; no single profession alone can respond to the needs of the individual, as these needs can be social, psychological, and medical in nature. Therefore, collaboration between professional groups is important for the rehabilitation process to work well. However, research shows that it is often difficult to establish well-functioning collaboration between various organizations and professions (Huxham & Vangen, 2005; Sullivan & Skelcher, 2002). For the collaboration process to be successful, a common view of whom (or what) you collaborate on (Danermark et al., 2013) is required, among other things. The partially differing perceptions of the individuals are likely to complicate the desired collaboration. Another aspect relevant to the collaboration process is linked to different organizations denominating the individuals in different ways. In the case of other organizations' denominations being perceived as improper or even disparaging, how does this affect the involved parties' views and understanding of each other? These questions are best discussed across organizational boundaries. If our representations (or our everyday knowledge of each other) have positive overtones, then this provides a good basis for good collaboration.

This study is not without its limitations. First, the sample was collected in only one city, so the results cannot be generalized to all professionals within the rehabilitation field. It should be noted that the categorization process could have led to alternative interpretations and categories if implemented by other researchers. Also, alternative methodological choices (e.g. to conduct focus groups) could have led to partly different results.

Conclusion

Overall, this study shows that, although few significant differences were found, the professionals' social representations of the target group differed depending on what organization they belonged to. Several factors may form the basis for these differences; in this study, the differences in working conditions and how the individual is denominated are especially focused on. Also, the study shows that the professionals' representations of the users are closely linked to the working process. From an organizational perspective, the representations are assumed to affect the activities, especially in matters related to collaboration with other parties. Continued and more in-depth studies are required to further understand and explain these differences and the impact they may have on rehabilitation work.

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