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On the outskirts of normality: Young adults with disabilities, their belonging and strategies

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Abstract

During the last decades, the living conditions for young people with disabilities have changed dramatically in Sweden, as well as in other parts of the Western world. The boundaries between what is considered normal as opposed to different have become less clear as a result of these changes. This has been followed by new problems regarding integration and changing patterns of marginalization. The aim of this study was to gain a deeper understanding of the ways in which young adults’ social identity is shaped by their dual belongings: to the category of individuals with disabilities as well as to mainstream society. In-depth interviews were carried out with 15 young adults with mental disabilities and mild intellectual disabilities occasionally combined with various forms of social problems. The analysis focused on the ways in which the young adults related to what they describe as normal and different as well as their strategies for navigating between them. The data was subsequently divided into three categories: Pragmatic Navigators, Critical Challengers, and Misunderstood Rebels, which reflect the ways in which the respondents describe themselves and the perspective they have developed to manage their existence.

Key words: Intellectual disabilities, mental disabilities, social identity, normality, stigmatization, strategies, social belonging.

Introduction

Society’s support and programs for individuals with disabilities have changed both in Sweden and in the rest of the Western world. Groups of people, who previously were isolated from society, now have access to the regular welfare institutions and participate in society on conditions similar to those of other citizens (Bradley, 1996; Brown & Smith, 1992). The boundaries between what is considered normal as opposed to different have become less clear as a result of these changes (Young, 1999). There is also a reverse development, which uses new and refined methods to classify and sort individuals into categories such as “normal” and “abnormal” (Gubrium & Holstein, 2001; Madsen, 2006; Sicakkan & Lithman, 2006). Previous general and stable organizational principles have been replaced by an increased emphasis on the responsibility of individuals to initiate, motivate and plan their lives, and create their social identity, both in their professional and their private lives (Beck, 1992; Castell, 1997). This is also followed by new problems regarding integration and changing patterns of marginalization (Deeley, 2002; Susinos, 2007). This article focuses on the ways in which young adults with intellectual and/or mental disabilities view themselves; how they manage their everyday lives and how they view the way in which they have been classified as disabled by society’s welfare system.

Swedish research on individuals with intellectual and/or mental disabilities has generally followed two tracks. Although both tracks have encountered significant difficulties with regard to diagnosing and classifying various groups, all research has been connected to the principals and institutions that treat or provide other kinds of support for each group. Today, we have reason to question the different tracks in light of the new situation that emerged after the Swedish reforms within the areas of disability and psychiatry. The responsibilities and organization of the various authorities have changed and optional contacts with them have become a central principle. In addition, problems of diagnosis have become...
Social identity, social classification and identification

The term social identity refers to something that is social and variable and may be described as a dynamic process related to everyday interactions and meetings in time and space, in which individuals may view themselves as similar and different from others (Allen 1994, Ekeland & Bergem, 2006; Gubrium & Holstein, 2001; Milner & Kelly, 2009). A social identity is formed and maintained through interaction with our environment and includes processes of involvement and resistance, but also through continuous change and renegotiations (Goffman, 1963; Giddens, 1991; Rapley, Kiernan & Antaki, 1998). Individuals are classified and classify themselves as belonging to particular social communities based on their interest and lifestyles. They also belong to general social categories such as men and women, or individuals with or without disabilities (Corrigan & Watson, 2002; Seale, 2001). Individuals may relate in various ways to the category in which they are placed: they may distance themselves from it as well as resist it (Goffman, 1963; Islam, 2008; Seale, 2001). The strength with which individuals identify with and feel that they belong to a particular social category may vary. From a weak identification in which individuals may describe themselves as having a disability in certain situations without feeling a connection to the group, to a strong identification in which the individual perceives a sense of belonging and community with the category (Corrigan & Matthews, 2003; Goffman, 1963; Islam, 2008). Shakespeare (1996) maintains that societal and political transformations have created new opportunities for identification for various minority groups. He uses metaphors such as "story telling" to describe the ways in which these groups express their experiences in stories about themselves and how we are able to distinguish a new way for individuals with disabilities to speak about themselves in terms that differ from the language that has been developed within the national welfare institutions.

New stories are being told, and we are creating ourselves for ourselves, rather than relying on the traditional narratives of biomedical intervention or rehabilitation, of misery, decline and death. Doing it for ourselves, perhaps we can reconcile tensions and produce alternative, happier endings. (Shakespeare, 1996, pp. 95.)

Winance (2007) discusses boundaries between individuals with disabilities and others, between their perception of being different or normal, and she believes that the traditional separation is no longer relevant. The question is no longer how individuals with disabilities may be integrated into society, but rather how to create a society that includes both those who are "normally different" and those who are "differently normal". She believes that normality and difference are not objective categories that depend on the person's individual characteristics, but includes relative qualities that are created through interaction. Islam (2008) makes the same argument in his study of 13 young adults with disabilities from Pakistan and Bangladesh. He shows the ways in which multiple aspects of identity such as gender, ethnicity and disability affect the young adults' self-image and results in a cultural experience that differs from other individuals with disability in the same age group. According to Seale (2001), adults with intellectual disabilities sometimes present themselves in personal home pages. This way of self-presentation, allows them to express and manage multiple identities.

Madsen (2006) uses the term "threshold individuals" to describe those who live a double life on the border between different social and cultural areas. This situation applies to many individuals with disabilities, particularly those who are somewhat able to manage on their own, but who also need support to manage parts of their everyday lives. They may largely be said to live on the border and issues of belonging and participating are central to their lives. They have experiences of managing conditions of various social contexts and they have developed strategies for existing on the border between the normal and the different. Meeting the requirements and expectations of various environments requires flexibility as well as the ability to portray oneself in a way that reconciles the perceptions of other people with one's own self-image (Beck, 1992; Giddens, 1991; Molin, 2008). The group of young adults who were studied in this article consists of people with mental disabilities and/or mild intellectual disabilities, occasionally combined with various forms of social problems. The welfare
system's actors describe this group as “clients in the grey zone”: they are on the boundaries between the normal and the different.

**Purpose and research questions**

The purpose of this paper is to understand the ways in which social identity is shaped by the young adults’ dual belongings, to the category of individuals with disabilities as well as to mainstream society or the “normal”, and the way in which they navigate between them. Central research questions are:

- How do the young adults describe themselves and their difficulties?
- How do they relate to the ways in which they have been categorized as disabled?
- What strategies have they developed to manage the difficulties of their dual belonging?

**Methods and study group**

**Study group**

The study’s primary material consists of 15 in-depth interviews with young adults with intellectual or mental disabilities who are between the ages of 19 and 29: eight men and seven women. Interviewees were recruited with the help of counselors from adult habilitation centers and outpatient psychiatric services, based on the following criteria: interviewees’ previous contacts with these services; they have been diagnosed with either a psychiatric disorder or a mild intellectual disability. All the interviewees, however, are described as “grey zone clients” by representatives of the welfare system; they either do not clearly belong to their target group or they do not want to be categorized. Seven of the young adult interviewees have had contacts with various psychiatric services, eight have had contact with habilitation centers for adults and five have received support from both of these welfare institutions.

The living situations of the young adults vary: nine live in their own apartments, three live with their parents, three have no homes and one temporarily lives at a halfway house for people with mental disabilities. Two of the interviewees came to Sweden as refugees. They primarily support themselves with activity reimbursement which is a support specifically targeted at young people who are not part of the labor market due to illness or disability. Some also receive disability benefits, social welfare, and one of the young adults lack organized economical support. All of the young adults are outside the regular labor market and only six engage in some form of formally organized occupation.

**Data collection**

The in-depth interviews were structured based on an interview guide that focuses on the following themes:

- Life-situation and everyday activities
- Social belonging and relationships
- Experiences of various contacts to provide help
- Perceived self-image
- Thoughts about the future

Data was collected through narrative interviews with open-ended questions (Kvale, 2007; Patton, 2002). The interviewees were asked to speak freely about the five themes and to give examples of concrete situations. Follow-up questions linked to each theme included: “How did you handle the situation?”; “How did you feel?”; and “Can you tell me more about it?” The interviews lasted for about 1–1.5 h and took place either in the homes of the interviewees, in a conference room in the adult habilitation center or in the offices of psychiatric services. One interview was conducted in a daytime activity center for homeless and one was conducted through an interpreter. All interviews were taped and transcribed verbatim albeit including language corrections.

**Ethical considerations**

Ethical matters were considered throughout the project and research ethics in accordance with the Helsinki declaration (World Medical Association, 2000) were thus followed. Information about the aim and procedure of the study was given verbally before the interviewees agreed to participate. In this study the principle of confidentiality and anonymity was central in the presentations of the results as the staff might recognize the participants. To avoid these problems, details, which might contribute to identification, are omitted and slightly changed. The interviewee’s dependency on various welfare actors may result in problems, which were solved by emphasizing that the research project is independent of the organizations that provide care and support. In addition, we emphasized that the interviewees’ decisions to participate would not affect their continued assistance. Questions about participation and voluntary participation are not viewed as solved when a respondent has agreed to be interviewed. As researchers, we have continued to relate to this issue and we have continued to reflect on it during the entire research process. An interview situation is not a meeting between equals. Interviewers have the advantage as they initiated the meeting and largely control the content of the conversation (Mishler, 1986). An additional complication is that several of the respondents have
intellectual disabilities which require researchers to provide the interviewees with clear and concrete information about the study’s purpose, focus and consequences, and to be aware of effects of interviewers (Barron, 2002; McVilly, 1995; Taylor & Bogdan, 1998; Rapley et al., 1998). We have in various ways tried to handle this issue by repeatedly providing as concrete information as possible. We focused on themes and questions that engage and interest the informants, and closely connect to their own experiences. We also tried to communicate our sense of involvement and interest in what they have to say and show respect for their roles as important informants for this study.

Data analysis

The data analysis followed an inductive model based on the interaction between theoretical concepts and the growing classification of the material, influenced by Taylor and Bogdan’s (1998) analytical model. The basic idea is to receive an in-depth understanding, where insights are grounded in and developed from the data themselves. The data analysis illuminates features of the contexts or people studied; and to be able to understand people on their own terms. Taylor and Bogdan (1998) describe the analysis process in several steps from discovery to coding and control including moving between empiricism and theory, between ideas, data, interpretation, categories, tests, and retest.

Using this approach the analysis consisted of following steps:

1. Emerging and tentative themes. In the first step all the interviews were transcribed, all together 160 pages, which were reread carefully several times. The first reading was done without any prior expectations while additional readings, guided of the research questions, were intended to catch the entirety of the text. The aim was also to identify tentative themes, such as self-image, life-situation, social relationships, belonging and strategies.

2. Case synopsis. In the second step the text was used as a tool for reflection in order to look for deeper meanings based on words and phrases of each interview. We also created an individual case synopsis for each of the informants, which highlighted the emerging tentative themes. Each of them was illustrated with narratives and quotations, which gave a deeper understanding of how the informants viewed their situation.

3. Sensitizing concepts. In the third step we looked for words and phrases, which highlighted how the informants talked about themselves. For example some of the participants described themselves as “slowly learners” but not in terms of disability. We also searched for sensitizing concepts that united themes with underlining similarities such as social identity, normality and difference. Sensitizing concepts provide a “general sense of reference and suggest a direction along which to look” (Blumer, 1969, pp. 148).

4. Coding. The third step was the coding processes, which involved bringing together and analyzing all the data bearing on major themes, concepts and interpretations. All interviews were reread and put into categories in a coding scheme (Miles & Huberman, 1994). The coding scheme changed during the process as it was found that some themes overlapped and, therefore, they were merged in one category. Other coding categories needed to be refined or redefined. The coding process was guided by questions such as, “How do the young informants describe themselves, other significant persons and daily activities?”, “What are the similarities and differences between the informants’ various perspectives?”, “How do the informants deal with the discrepancy between their view of themselves and the categorization as individuals with disability?”. Finally, the interviews were reread once more to control the relationships between the empirical data and the categories to make the codes fit the data and not vice versa.

5. Category construction. The final step of the analysis focused on comparing different pieces of data related to how the young adults described themselves in terms of normal and different, and their strategies of navigating between these positions. It also included a critical reading of all interviews to ensure that the different categories actually represented the whole as well as to discern specific characteristics. Patterns and similarities among the categories were identified. Finally the data was subsequently divided into three categories: Pragmatic Navigators, Critical Challengers, and Misunderstood Rebels, which reflect the ways in which the respondents describe themselves and the perspective they have developed in order to manage their daily lives.

Results

The results are structured so that the three perspectives, Pragmatic Navigators, Critical Challengers, and Misunderstood Rebels, are highlighted by a short case description which focuses on one person’s self-images and various strategies for managing his or her dual belonging. This is followed by a thematic description that summarizes the characteristics of each of the three perspectives and in which patterns, similarities, and differences are identified and discussed.
The pragmatic navigators

Self-image and life-situation. The viewpoint of the pragmatic navigators is characterized by the fact that they describe themselves in positive terms: They enjoy life, and strongly believe in their own ability to manage various situations in their daily lives. While some claim that they have problems with certain issues in their everyday lives, they do not believe that the difficulties are worse than they can manage with a little help from the people around them.

One young woman, Sofia lives in the countryside with her parents. The family has cows, horses, rabbits, guinea pigs, dogs, and cats. Sofia is responsible for the rabbits and the guinea pigs. She is proud of being a good rabbit and guinea pig breeder and she has been successful at various shows. When there are problems with breeding she solves them through contacts with various experts in the area. Sofia also has a dog that she describes as her best friend and that comforts her when she feels down or depressed. Sofia does not think that she has any problems and does not really understand why she has to go to the adult vocational rehabilitation center. She replied the following to a direct question: “Problem, if I have any ... I don’t have any that I know of.”

She dislikes that representatives from adult habilitation center are trying to encourage her to move away from home. She enjoys her life the way it is and she prefers to continue doing what she likes most, i.e. being responsible for the animals:

They say that I should move away from home, but I say: where should I go with my rabbits, my guinea pigs and my dogs? I can’t live in an apartment with that many animals. The question is where should I go?

Sofia is satisfied with her situation. She knows what she can manage and does not like new situations that she thinks might be difficult to handle. She does not worry about the future; she takes things one day at a time and hopes that some day in the future, she might be able to realize her dream about opening a pet store:

What I like to do, and what I do all day long is to take care of my animals. I can manage that, I can take care of small animals, and bigger animals, but I can’t handle really big animals so somebody else can take care of them

Belonging and strategies. The pragmatic navigators believe that people in general and various welfare actors in particular, focus too much on their shortcomings instead of on their resources. They do not view themselves as individuals with a disability, but describe themselves and their difficulties in more socially acceptable terms. Another interviewee, Sara, says:

I started in the special education school because I couldn’t keep up in school, but I didn’t have much in common with the others ... the handicap thing is not really for me.

Maria, another young woman, who also attended the special education school, was pregnant at the time of the interview. She is convinced that she has enough resources to take care of a child. However, she does believe that others often have a wrong and negative opinion of people who, like her, attended a special education school. Thus she does not tell anybody at the maternity clinic about her background:

No, I don’t tell them because I think that they will become afraid if I happen to say that I went to special ed., they might think that I won’t be able to manage, that I am weird. I don’t tell people that I have gone to special education, I don’t. People don’t know what it is, so they don’t think I can manage some things.

Like Sofia and Maria, the young people in this group avoid telling other people about their backgrounds and their experiences with contacts with authorities. It is a conscious strategy that these young adults have developed to protect themselves from the consequences of social classifications. They believe that people around them will not be able to understand what it means to live with a disability and will, therefore, underestimate their competence and abilities.

Many of the young interviewees prefer to be in places were they can meet other people with similar experiences. Some of them have family members with the same disabilities. Even those who don’t have those kinds of experiences and those who don’t view themselves as individuals with a disability, say that they feel more comfortable socializing with people who have similar difficulties. A young man, Linus, is one of them: He has regularly, and for some time, visited an activity center for people with mental disabilities. Even if he views it as a temporary free zone, he says that socializing with the other participants has qualities that he cannot get with other people:

Many people think that it is strange that I come to the activity center. The thing is that it has something for me too because there is no place like this anywhere. I have had a job before, but I feel more at home here, there are other people who know what it is like to feel bad, and there is not as much stress as in other jobs. It is great to take it easy, do things at your own pace; it is easier to relax
Self-image and life-situation.

Unlike the pragmatic navigators, the critical challengers express dissatisfaction with their existence. They are also more critical and challenging toward society and its welfare actors. Although they admit that they have certain individual difficulties, they believe that society’s excessive demands on formal competence and education are an equally large reason for their difficulties.

One informant, Julian, says that it may take him time to learn new things and that he reads and does arithmetic slowly. He still strongly maintains that if he had lived in a less complicated society or if he had received the right kind of help, his difficulties would not have caused him many problems in his everyday life. Julian is very interested in societal issues; he knows his rights and believes that society has let him down several times.

Another strategy that is common to members of this group is that they do not put themselves in situations that they do not think that they can manage. Sofia does not take care of the horses and the cows on the farm, because she thinks that they are too big and, therefore, too difficult for her to handle. She prefers smaller animals, and she views herself as a very competent caretaker. In this respect she seems to know her limitations as well as her qualities. Another of the informants, Lena, is a registered nurse who has had regular contact with psychiatric services for a long time. She used to work in the healthcare sector, but resigned because she felt that her job was too demanding. The employment agency helped her to get an internship at a retail store. She describes the way she changed her professional life:

I have changed professions, I wanted to work somewhere where I can still meet people, but not socialize as deeply as within the health care sector. I can’t handle the emotional part, and there is too much responsibility for me. I am afraid of making a mistake. Now I work in a store; it is a job I feel that I can manage.

The pragmatic navigators thus believe that they have a meaningful existence and that they have great opportunities to affect their own lives both now and in the future. While understanding their abilities and competence, they are also aware of their limitations and can navigate well between various social situations. They are thus able to avoid situations that they cannot manage.

The critical challengers

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During the days, Julian is busy with something he calls a “Dharma project” which is a house building project in the forest. His dreams about developing it into an alternative society inspired by the “new age movement” where he could gather people who, like him, are a little different and who do not fit into the majority society. Julian’s society would be characterized by simplicity and proximity to nature. Julian has no friends. His only regular contact outside the family is the counselor at the adult habilitation center. The reason he contacted the center was because he hoped that somebody there might help him to find an easier way of realize his dream of getting a driver’s license. He has tried, and failed, to get a driver’s license several times, and believes that the reason is that the demands are too high. He sometimes fantasizes about moving to another country where it is less difficult to get a license:

Sometimes I wish that I could live in Eastern Europe or Albania where it is pretty lawless and easier to get a license. Circumstances in a country are important for somebody like me. Sweden has such high demands, but down there it is probably much easier.

Julian envisions some possible future scenarios for himself. He hopes to be able to get a driver’s license and travel abroad with his own car to one of the countries where he thinks life would be easier for somebody like him.

Belonging and strategies. The critical challengers are critical of society’s welfare organizations. They perceive that the help that they are offered is not what they want and believe that with the right kind of help and reasonable demands from the people around them, their individual problems would be negligible. Tom has extensive experience of contacts with both psychiatric services, and the social insurance office. He describes his experiences of the caseworkers in the following way:

I was one of the first people in Sweden who received activity reimbursement, which they started in order to reduce sick leave. I received full sick leave and had to be in an activity. What they did was, they reduced income: Mine went down by 30–40%, but they were supposed to pay for activities. But for a year and a half I got nothing.

Axel, another respondent who has had contacts with psychiatric services for a long time, also blames his situation on various factors in his environment and on the fast pace that is required in everyday life. He has qualified vocational training, but although he believes that he has the required know-how, it is
impossible for him to manage a job due to the high pressure. This is what he says:

There is always pressure and stress! It didn’t work. I could be one minute late from lunch and I would be yelled at. Even if I did a good job, they always wanted me to be quicker. You become clumsy and even if I wanted to do well I got nothing done. Then I was placed on sick leave. That was seven years ago, so it has been a while.

The critical challengers search for belonging. It may include anything from wanting some form of meaningful daily occupation to wanting to live with people who are in a similar situation and who have the same experiences. Julian prefers to take matters into his own hands, by trying to create an alternative social community. Mary who has a mild intellectual disability has the same desire for community, but she has more modest demands:

I am too well to live in a group home, but I need too much help to manage completely on my own. I often feel lonely. Maybe I should try something new, there has to be more people like me who have some problems and who feel lonely. If there were more of us we might live in a house together, we could help each other out; agree how things should be and how we would be and so on....

The critical challengers are that they often put themselves in challenging situations. Despite many experiences of shortcomings they do not become discouraged, but maintain that they have the same right to fail as other people. They fight continuously for recognition of their rights. Julian continues to try to get his much-desired driver’s license and a job. Emil, who has been in touch with the adult habilitation center and psychiatric services for many years, tells about his stubborn fight to get a place on the regular labor market:

They want us to go to an adult activity center, but I want a real job. I went to the Employment Agency even if they told me it was pointless.... I was thrown out, but I went back. Finally, they closed the door because I had failed too many times. I hadn’t got a job, and then you can’t join the Employment Agency.... They threw me out, but I want to work, and I can work so I have to try in a different way.

This group protests against the social consequences of the ways in which individuals with disability are classified. They do not view themselves as victims, or as “people to be pitied”, but claim their right to be different without being excluded from society. They maintain that if society and various welfare organizations would be able to take advantage of their competence and qualifications they would not be a liability, but a significant resource to society.

The misunderstood rebels

Self-image and life-situation. The young people who belong to the group misunderstood rebels live a difficult, almost chaotic life. Although they have no work and housing, they describe their difficulties as temporary and short-termed. While they freely admit that they need help with certain things or certain situations in life, they do not view themselves as different or as belonging to the category of individuals with a disability.

One of the informants, Bakur, has lived in Sweden for three years and is originally from Kurdistan. He first contacted the health care system because he wanted treatment for worry and anxiety, which he primarily attributed to his situation without work and housing. The health care system thus views him as sick, dangerous and unpredictable and, therefore, he was involuntarily transferred to an inpatient unit. He does not understand or agree with this classification. He does not view himself as different, dangerous or mentally ill, but as somebody who temporarily finds himself in a difficult situation, caused by external issues such as a lack of housing and work and the stress from his long wait for a residency permit. It is obvious to him that he should protest against medical treatments that he hasn’t asked for. He does not understand why he is receiving it and he feels violated. From his perspective, the treatment has turned him into a different person. He describes it as follows:

We humans interpret things differently. What the staff may have interpreted as positive, wasn’t positive for me, it was negative. Like getting shots, it might be interpreted as a good treatment for my symptoms, but I didn’t feel that way because I had lots of side effects from the capsules, my mouth was dry, I felt down, tired and sluggish. I couldn’t do everyday things like everybody else. Like today, everybody I know, all my friends.... I can’t live like them because of the medical treatment. My life is ruined. I am back to nothing! And the others are much much above and better than me, they are workers, they have their own lives, support themselves.

Bakur describes his situation as chaotic and expresses a feeling of powerlessness, but he has not given up his fight to change it and he expresses strong confidence in his own ability to affect and restore his
dignity. He tells his story at every chance he gets and he has met professionals who agree that he received the wrong treatment due to misunderstandings and unlucky circumstances. In dreams about the future he sees himself living a normal life; being a worker, having a home and being able to support himself.

Belonging and strategies. This group’s attitudes toward the actors of the welfare system are characterized by expressed beliefs that their situation, which the health care system views as individual, is the result of structural or institutional circumstances. They often have negative experiences of contacts with various health care providers. Bakur believes that his treatment is hurting rather than helping him. His statement also expresses his attitude toward the health care system’s view of him: we humans interpret things differently, he says. He thereby acknowledges the good intentions of the health care system, but also gives himself the right to have a different opinion of what would be best for him. Some of the other informants also refuse help when they cannot get the help they want, based on how they define their problems. Erik has a psychiatric diagnosis, but describes himself as unemployed, homeless, and generally troublesome:

I want my own place where I can try to heal and become a part of society. But I want a real place to live, not a hostel, hotel or a group home, but a real home. The way I live now I have my freedom, which is something I appreciate.

However, Erik believes that his contacts with representatives of the welfare system have complicated rather than facilitated his ability to establish himself in society:

When I go to the social welfare office and tell them that I don’t have anywhere to live and that I need help they tell me that they unfortunately can’t help me, but that I have to find housing myself and they will help me pay the rent. Then I say ‘please, I have debts with the collection agency, and no references, I have nothing, I won’t get any housing; you have to help me in some other way. I’ll take anything as long as I can close the door and sleep in peace and quiet at night, so I can start to change my life’. But they say they can’t help me. Well, to hell with it!

The misunderstood rebels don’t view themselves as individuals with disabilities and don’t need contacts nor do they feel that they have anything in common with other people with similar difficulties and experiences. Sara who used to attend a special education school says:

I have epilepsy, but I am not disabled. I am not a person like that… I have nothing in common with them.

Although the misunderstood rebels view themselves as normal and non-different, they do not deny that they need support and help in certain situations. However, they do fully reject all efforts to classify them as disabled which would provide them with a specialized form of help and support particular to a defined group of individuals with disabilities. Their strategies are characterized by protests and rejection, both against being cowed and categorized and against being refused what they consider their obvious rights. They confront the system, circumvent the rules and use them in their own way. Many members of this group pull away and reject all contacts that imply control, adaptation and being parts of a system to which they feel they do not belong. They still have hopes for the future, however, and believe that they will be able to find their place in society with or without the help of the welfare society’s actors.

Comprehensive understanding

The young adults who belong to the group the pragmatic navigators transcend boundaries and move between different communities. They may be said to have a multicultural identification: they have experiences of managing conditions in different kinds of communities and have thus acquired the ability to manage division and create contexts. They appear to view their movements between what is considered normal and different as relatively unproblematic and avoid situations that they cannot manage. Their social identity is complementary in that they provide an image of themselves as “different but normal”. A self-identification which is simultaneously normal and different is however, not mutually exclusive. The way they describe themselves does not emphasize their differences as a problem of being an outsider and neither of them talks about discrimination and exclusion due to their differences. To borrow Goffman’s (1963) terms one might describe it as the “normal different”. He assumes that all people deviate somewhat from the norms of their cultural environments. The young adults present themselves as different in the sense that they are slower or more sensitive to stress than other people are, but they do not view it as a big problem either for themselves or for others.

The critical challengers view themselves as a minority group and their strategies involve challenging the boundaries of the normal. Rather than viewing themselves as different, their stories indicate that they view themselves more as a variation of the majority society. They look for alternative ways to
find a place in society or a society in which they are valued and respected based on their particular uniqueness. They talk about experiences of discrimination and feeling like outsiders, but believe them to be the result of other people's ignorance or inability to tolerate differences. From their perspective, the boundaries of normality are too narrow, and they want a school, a job market and a society that has room for all kinds of people. They may be viewed as "voluntary different" as they are proud and demand recognition for their uniqueness.

The misunderstood rebels, however, view themselves as excluded and oppressed particularly by actors in the welfare system. Although they fulfill many aspects of society's criteria for different, they refuse to accept that identity. While they understand and are able to reflect on the ways in which other people view them, they assign themselves the right to interpret their own situation. By telling their story about who they are and what has happened to them they reinstate and confirm their identity and their image of themselves as normal, but misunderstood. Another strategy that they use to defend themselves against the stigma of being different is to distance themselves from other people in the same situation. They fight to manage the division between the ways in which they are viewed by others and how they view themselves and use strategies, confrontation and negotiations with their environment to get their interpretation recognized.

Discussion

The results of the study clearly show that the informants challenge the welfare organizations as they are difficult to classify and do not fit into accepted categories. The welfare actors describe the informants as clients having different kinds of disability identity and social problems (Gubrium & Holstein, 2001). The young adults, however, do not describe themselves in terms of problems, but relate to varying demands in different situations and contexts (Allen, 1994; Ekeland & Bergem, 2006). They believe that they can manage specific activities in everyday situations, but also believe that their difficulties become obvious only in their interactions with various institutional practices such as school, the employment agency, and the child health center. The young adults' discussions also clearly indicate that they find structural rather than individual explanations for their difficulties, which is particularly obvious with regard to the critical challengers and the misunderstood rebels. In contacts with various societal institutions such as schools or the employment agency, attitudes and barriers have signaled that the boundary between the normal and the different is sharp and unambiguous thereby making it almost impossible for them to penetrate it (Barnes, Mercer & Shakespeare, 1999). Another such barrier is created as the respondents are excluded from general support services from the employment agency or other service organizations and referred to special services for people with disabilities.

The interviewees all have in common that they have not internalized their diagnoses or classifications as individuals with disabilities. This might be viewed as a consequence of the interview situation as they want to present themselves in a way that hides the fact that they belong to the group of young adults with disabilities (Radley & Billig, 1996). However, the interviews clearly indicate that several of the respondents also use this strategy in other situations. While they do not deny their difficulties, none of them describes him or herself as an individual with disability, nor mentally or intellectually disabled. When talking about themselves and their difficulties they use everyday terms and describe themselves as difficult, odd, sensitive to stress, slow or bullied, as home- less or unemployed, but not as different or abnormal (Winance, 2007).

The young adults consistently communicate a trust in their own abilities to affect their situation, albeit to a varying degree and with the help of different strategies. The social identities of the young adults is the result of the way in which they relate to and adapt to various social contexts, but also how they practically manage various situations in their everyday lives (Goffman, 1963; Islam, 2008; Seale, 2001). By identifying and interacting with others and by participating in various social contexts, the young adults have found their own ways to create alternative strategies. Their social identity can change and it can be renegotiated through social interactions. Developing an identity and identification becomes successful and universally valid when others support the norms (Goffman, 1963). Several of the young adults are parts of groups or want to be part of a community of individuals whose difficulties and experiences are similar to their own. This is particularly true for the pragmatic navigators, who often seek out and participate in contexts with other individuals with disabilities. The critical challengers, however, view themselves as different from the society in which they live, but express an idea about imagined communities where they can meet likeminded people. The misunderstood rebels distance themselves from the discourse of disability and signal their belonging to mainstream society.

The social identity of the young adults with disabilities is dynamic and constantly recreated through interactions with other people. It is obvious that the participants have developed different strategies to avoid being identified as disabled, a social category of which they do not want to belong.
Conclusions

The results from this study show that the social identity, which the young persons have constructed, differs from the images that the professionals have of them. They avoid seeking professional help for as long as possible as they perceive this might threaten their desired social identity. Health and social welfare professionals may thus be seen as opponents instead of helpers. This fact may cause misunderstandings and jeopardize the young person’s possibilities to get adequate and supportive help. To help young individuals with disabilities to find their way and place in society, the health and social welfare professionals need to listen to each individual story, in order to get knowledge about how young persons experiences themselves and their everyday life. In that way the young persons is viewed as active and reflecting subjects with the ability to make their own choices to acquire more control and self-determination.

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