

Self-presentations and intellectual disability

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The aim of this article is to demonstrate how some young individuals who are labelled as having intellectual disabilities present themselves and how they understand and relate to the fact that they are included in the category of intellectual disability. The article draws on findings from a study based on participant observation and semi-structured interviews with seven young adults about their self-understanding and daily life experiences. During the data gathering period, which lasted for two years, the participants were followed in their daily activities, at home, at work, and in their leisure time. The study shows that the participants were well aware of their impairments. However, they resisted the notion that intellectual disability should be central to defining who they are.

Keywords: intellectual disability; self-presentation; identity; daily life

Introduction

In recent years an increasing number of studies have given attention to people who are labelled as having intellectual disabilities and how they present themselves and their circumstances (Baron, Riddell, and Wilson 1999; Barron 2002; Goodley 2000a; Gustavsson 1998; Jahoda, Cattermole, and Markova 1990; Knox and Hickson 2001; Löfgren-Mårtensson 2003; Olin 2003; Olsen 2003; Ringsby Jansson 2002; Sundet 1997). These studies show that intellectually disabled people are able to speak for themselves, and that the label intellectual disability conceals great variety of human experiences (Sundet 1997).

Whether the self-presentations of the participants in such studies are trustworthy is a matter about who has the power to define the situation (Barron 2002). Intellectual disability is defined in medical manuals and by people in powerful positions (Gillman, Heyman, and Swain 2000; Goodley and Rapley 2001). In addition, folk tales and anecdotes contain assumptions about intellectually disabled people, including, for instance, ‘eternal children’ or people who are strange or weird (Gustavsson 1999; Sundet 1997; Sætersdal 1998). Intellectual disability is also defined in professional education and practice, and is materialised in segregated services and buildings. Thus, public opinions, professional practice and settings may speak far louder about who people with intellectual disabilities are than their own self-presentations do.

People in the Nordic countries who are defined as having intellectual disabilities are secured rights according to law and conventions to participate in society. In addition, public services are organised in order to give disabled people necessary

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support, access to mainstream society and to prevent exclusion and discrimination. However, during school years an increasing number of intellectually disabled pupils are removed from the mainstream education system and placed in special groups or schools (Wendelborg and Tøssebro 2010). As adults, most individuals who are labelled as having intellectual disabilities lead lives that differ from the lives of people in general. Living conditions surveys show that most intellectually disabled people are offered special housing, special work places and special leisure activities (Kittelsaa and Tøssebro 2011; Söderström and Tøssebro 2011; Tideman 2000; Tøssebro 1996; Tøssebro and Lundebj 2002b; Umb-Carlsson 2005).

While the civic rights of intellectually disabled people are secured in official documents the above mentioned surveys demonstrate that the service system exclude them from mainstream society. In addition, in order to attain necessary assistance, people who are labelled as having intellectual disabilities have to accept that they are treated as a category (Taylor 1998). Thus, society gives intellectually disabled people a mixed message about how they are perceived; they are both individual citizens and belong to a category of service recipients. Intellectually disabled people can be said to live their daily lives at the intersection between categorically based services and public goals of self-determination and participation in social life.

This article draws on findings from a study about self-understanding and daily life experiences of young adults who are labelled as having a mild intellectual disability. Aims of the study were how the participants experienced life with a disability, and whether or not the label intellectual disability influenced their self-understandings and daily life experiences. The aim of the article is to reveal how participants in the study presented themselves, and whether or not intellectual disability was a significant component of their self-presentations. In addition, the article seeks to elaborate whether or not being defined as intellectually disabled prevented the participants from negotiating other identities.

Chosen and ascribed identities

In modern thinking about identity there is agreement that we have a plurality of identities, and these are seen as strategic and fluctuating (Hall 1992). Therefore, if we think that we have a stable and coherent self it is because we construct our identities as a continuous history (Giddens 1991). Castells (1997) describes identities as sources of meaning and experience, and adds that people have different identities on both individual and collective level. Identities only become identities on a personal level when they are internalised, and when one constructs meaning around them. Most people will organise meaning around a primary identity, and this identity will endure across time and space (Castells 1997). To Jenkins (2008) identification is a process; something that individuals do. He claims that our sense of selfhood and, for instance, gender or ethnicity, may be experienced as primary identities. Primary identities may be more resistant to change than other identities but they are not firm or unchangeable (Jenkins 2008).

Identities are negotiated in interactions and as such always ascribed by others. Therefore, it is impossible not to relate to how one is interpreted by others. Some identities can be seen as more or less stable; for instance identities which are displayed through visual information: gender, age, skin colour. Such identities are given distinct meanings in given cultural contexts, and to claim identities that differ

from the expectations of others can be complicated (Prieur 2004). To some, however, it is not easy to choose among different identities because they are heavily burdened with ascribed identities which are negatively valued. One such identity is intellectual disability; which in modern times is defined by the testing of intellectual (in)competence on the basis of what is defined as statistical normality (Jenkins 1998). Based on arguments from Hacking (1990) that ‘normality,’ which was originally developed by statisticians in the nineteenth century, is one of the most powerful ideas in modernity, Jenkins (1998, 17) suggests that the concept of normality does two separate things simultaneously. First, it describes as normal what is seen as typical or usual, and then, it assures that this is the way things ought to be. From such a perspective the average becomes a moral imperative, and intellectually disabled people who intellectually function below the average are defined as neither normal nor average.

An identity as intellectually disabled

Taylor (1998) describes a categorical identity as the ways in which a self-identification is related to others; for instance as belonging to the same group or social category. In some ways a categorical identity can be seen as positive, owing to the fact that it is possible to choose or embrace it and use it as a tool in struggles for empowerment and equal rights. One may, for instance, turn a negatively valued identity into a positive one by opposing its negative characteristics, and by focusing on exclusion and discrimination (Shakespeare 1996). However, the identity or label intellectual disability is not chosen, but always imposed by others (Beart, Hardy, and Buchan 2005). It is even actively resisted, for instance by People First, which is an organisation of intellectually disabled people (Goodley 2000a). Additionally, several studies show that intellectually disabled people do not want to identify with the label (Beart 2005; Cunningham, Glenn, and Fitzpatrick 2000; Aull Davies and Jenkins 1997; Jahoda, Markova, and Cattermole 1988).

An identity as intellectually disabled has been described as both comprehensive and ‘toxic,’ and as an identity that excludes people from many social roles and places them in marginal positions in society (Todd and Shearn 1997). It has also been described as a stigma (Goffman 1963, 11) or a master status that obscures all other identities (Becker 1973). Such negatively valued identities are not what people would ask for (Gillman, Heyman, and Swain 2000). Moreover, some researchers claim that identity development among people with intellectual disabilities cannot be described by modern understandings of floating and negotiable identities because the consequences of the categorised identity as intellectually disabled acts to exclude individuals from participating in society (Baron et al. 1999). Others claim that the borders between the categorised identity as intellectually disabled, and other possible identities, are too firm and difficult to cross (Harris 1995). These points of view are contested by Rapley (2004) who denies definitions of a fixed and stable identity as advanced in much of the literature on intellectual disability, and writes that identities exist only in our expressions and are always negotiable.

Empirical studies show that intellectually disabled people are aware of their impairments and also about the stigma associated with intellectual disability. Edgerton (1967/1993) described how people struggled against being understood as intellectually disabled by trying to pass as competent. Jahoda and Markova (2004) showed that participants in their study presented themselves in a variety of ways in

relation to stigma; for instance as belonging to a minority group. The study also showed that people had to cope with stigma in their daily lives, and that they were concerned about lack of social acceptance. To some, moving to independent living might lead to a more positive sense of self (Jahoda and Markova 2004). This is supported by Riddell, Wilson, and Baron (1999) who emphasise that more inclusion, as for instance in working life, may lead to better mental health.

Todd and Shearn (1997) describe intellectually disabled people as invisible to themselves because they are protected from the ascribed identities by their parents. Furthermore, Craig et al. (2002) describe how individuals struggle to come to terms with an identity of intellectual disability. However, a negatively ascribed identity is not something that people should strive to accept or confess about (Rapley, Kiernan, and Antaki 1998). People are aware of how they are labelled, not least as a result of other people's prejudice and attitudes towards them. With reference to Sacks (1984) the authors state that in the same way as people in general, intellectually disabled people are doing 'being ordinary.' This is a common trait inasmuch as most people do not want to be perceived as strange, mad or different. What is a problem, however, is that people, who, in advance, are defined as different or 'other,' will have to struggle harder than people in general in their efforts to pass as ordinary.

One problem about intellectual disability is that it is often seen as 'naturalized impairment' or biology instead of as a social construct (Goodley 2001). Goodley and Rapley (2001) argue that understanding intellectual disability as biology implies that the way intellectually disabled people behave or interact is interpreted as caused by their impairments. While biology can be understood as more or less unchangeable, intellectual disability understood as a socially produced phenomenon will imply that changes are possible both with regards to common understandings, to responses from other people and society in general (Goodley and Rapley 2001). In this article, intellectual disability is seen as a social construct, and as an identity which is negotiable in social relations. In line with the relational model of disability the concept intellectually disabled people is applied individuals who have to face social barriers because of their cognitive impairments (NOU [Public Report] 2001, 22).

Method

In studies with intellectually disabled people, short and repeated conversations or interviews combined with participant observations are recommended as suitable (Tøssebro 1992). Therefore, along term qualitative ethnographic approach was chosen; participant observation, field conversations, and interviews. The data gathering took place over a period of two years, and the participants were visited in their homes, at work and during leisure time activities.

Participants were recruited through the sheltered workshops in one municipality. Invitations were sent to young adults between 18 and 30 years of age. Potential participants were asked to sign a declaration of consent, and because some of them might have limited ability to give consent (Forskningsetiske komiteer 2000), their parents or guardians were also invited to sign the declaration. In so doing, they confirmed that the participant had understood what participation would mean to them. The final selection of participants consisted of seven people; four women and three men.

Participant observations and interviews

Participant observations give access to real life experiences in natural settings and open up for studying verbal and non-verbal communication, body language, actions, relations, atmosphere, material resources and equipment (Fangen 2004). To this author, it was an advantage that it was possible to include people who did not talk much or had problems expressing themselves verbally. Some intellectually disabled people use gestures and bodily expressions to compensate for fluent verbal language, and by studying them in their natural settings it was easier to understand their expressions. Field conversations can take place during practical tasks, and in this study, such conversations were carried out while sorting cards, sawing firewood or having lunch. Thus, it was possible for the participants to show what they were doing, and speak about what they were thinking about what was going on.

In order to gain a more profound understanding about the experiences and perceptions of the participants, semi-structured interviews were chosen as a supplement to the observations. During the interviews, it was possible to pose questions which demanded reflections and discussions; as for instance what it is to be an adult and the meaning of the concept intellectual disability. It was also possible to reflect about joint experiences from the arenas where the observations took place. Thus, the observations provided an overview of the daily lives of the individuals, while the interviews added depth and reflection.

Kvale (2001) recommends that the researcher should be qualified as an interviewer, and familiar with the field where the interviews take place. It was an advantage that the researcher had experience from speaking with intellectually disabled people, and was familiar with how they live and work. Moreover, the long period of data gathering made it possible for the participants and the researcher to get to know each other. This reduced the problems related to the so called 'interviewer effect'; that the informants tend to answer what they think that the researcher wants them to (Tøssebro 1989). Simultaneously, it was important that the researcher did not get involved in the lives of the participants on a personal level or to give false hopes about friendship (Löfgren-Mårtensson 2003). This demanded clarity about the roles of the researcher and the aims of the study.

Data and analysis

Observation data were written down immediately after leaving the setting by 'jotting down' notes about settings, people, conversations and actions (Emerson, Fretz, and Shaw 1995). As soon as possible afterwards, the full text about the observations was typed, with the addition of the researcher's reactions and reflections. The semi-structured interviews were taped and transcribed verbatim. Finally, notes from the observations and transcriptions from the interviews constituted the data material.

During the first stage of the analysis the individual narratives of each of the seven participants were created by combining various experiences and statements into coherent stories that could be understood as meaningful wholes (Ahlberg 2004; Szönyi and Gustavsson 2003). The aim of creating the narratives was to interpret how the participants perceived their environment, relations and themselves in their daily lives. The narratives were then examined in order to look for patterns and variations, and also to look for the unexpected (Miles and Huberman 1994). This stage of the analysis is called historic interpretation (Gustavsson 2000). This is an

interpretation which is ‘experience near’ (Geertz 1973); close to the empirical realities of the lives of the participants, and uses the same kind of concepts as they do when they tell about how things are and what they think or imagine.

However, as both Geertz’ (1973) and Gustavsson (2000) point out: actions or statements from participants can have significance beyond what they know or see. It is therefore important to bring in ‘experience distant perspectives’; to see the participants’ experiences as an outsider, and to lift their experiences onto a theoretical level or framework. Therefore, the second stage of the analysis was to look for more general patterns and categories in the material by using theoretical concepts. Finally, the information from each of the participants was tested against the whole material, and the whole material was evaluated against the interpretations of the parts: the narratives and the categories. This means that the interpretation was a dialectic process; moving between the empirical and the theoretical and between parts and totality in order to link them together and thus to be able to get a new and deeper understanding of the phenomena under study.

Ethical considerations

In research on human beings, Kvale (2001) mentions three considerations that one has to face; informed consent, confidentiality and consequences. In this study, informed consent was seen as a process (Smythe and Murray 2000). This means that the participants were not only asked to give their consent during the recruitment process, but during the data gathering period they were asked now and then whether they still wanted to take part, in order to ensure that their participation was voluntary.

To guarantee total confidentiality in a project like this one is almost impossible. The services for intellectually disabled people are rather limited; professionals know each other and some of them were fully aware of where the observations took place. The participants are given fictitious names, and there is no information in the written text about names or localisation of services and places, but still, at least some professionals might know who the persons are. This is a dilemma that could be potentially harmful to the participants. Further, it is important that people who are perceived as belonging to marginalised groups should not be described in ways that increase their burdens, or position them in an unfavourable light; for instance as always weak or vulnerable. In order to try to handle these dilemmas, the written text has been thoroughly examined for utterings that could harm the people involved by stereotyping them as ‘different’ or ‘special’ in a negative way. In addition, the participants and their guardians were given an opportunity to read what was written about each of the individuals and about the conclusions from the project, and to give their feedback.

Presenting a positive image

People in general present themselves to others in many ways; by talking about job, family or interests or by speaking about social relations or status positions. One may take people home to show how one lives; the standard or equipment of the apartment and other personal possessions of value (Dittmar 1992). Wearing a special outfit or clothing signals belonging to a special workplace or group of people. Some aspects of people’s identities may be obvious without speaking or showing, such as gender, skin

colour or age. Self-presentations display how people want others to perceive who they are, and can be seen as the front-stage of personal identities (Goffman 1969). Because self-presentations must be trustworthy it is necessary to adjust them to the expectations of others in order to prevent the interaction from breaking down (Goffman 1969). However, it is impossible to control all the responses one is met with (Jenkins 2008) and this is especially difficult for people who are seen as different from others, or as belonging to a special group of people. This applies to people who are labelled as having intellectual disabilities because their behaviour is often interpreted as part of their diagnosis or syndrome (Goodley and Rapley 2001).

The following are examples of how the participants constructed and presented their identities. In line with people in general they presented a positive image of who they are (Goffman 1969). This involved for instance being competent, self-sufficient and active; virtues that are seen as essential in the society that they live in. In their self-presentations the young adults talked about having their own homes, and about work and leisure time activities. The self-presentations emphasized that they were living ordinary lives but also revealed that they might need some extra assistance, or that they spent some of their time in special environments.

When Frida presented herself to others, she showed that she had a number of identities. She was a woman, an adult who manages well on her own, a good friend, a daughter and a sister, a worker, a football player, and a dancer. To be a woman, to be of a certain age, and to be a family member are stable identities, but nevertheless their significance in different situations is open to negotiation. The remaining identities can be seen as chosen, and are as such, fluid and always open for negotiation. Frida's primary identity seemed to be that of an 'ordinary person.' At home she made a gesture and said:

As you can see, I live a normal life, just like people who are not intellectually disabled. . . . I can take the bus, and I do everything by myself . . .

In her self-presentation, it seemed important to Frida to use her apartment as a setting in which she could be perceived as ordinary (Goffman 1969), and she spoke about her competence by highlighting what she was able to do without assistance. Frida was not concealing the fact that she needs a little help to clean her apartment, but she was more eager to tell about what she achieves; such as cooking, doing the laundry and shopping for what she needs. She concluded: 'I am intellectually disabled, but not much . . .'

To Henrik an important identity was that of a hardworking man. He presented himself as a skilled and self-sufficient worker, and emphasized this by showing that he was wearing the outfit of a blue collar worker with coverall and safety boots. As a worker, he stood out in a masculine role always willing to demonstrate how well he was coping with the challenges of the workplace. By showing his abilities and eagerness at work Henrik showed that he lives up to ethical standards of working life. Several of the other participants also highlighted the importance of doing a good job. Lars was working with sawing firewood and claimed that it was important to be as strong as he was in order to be able to do the job properly. Grete and Kjersti were working in a sheltered workshop where they were counting and sorting cards and packing them into boxes. Both were fast workers who tried their best to get the job done. However, they knew that they were working in a special workplace. When Grete was asked if she was paid, she answered: 'I get my salary, but it is not much.'

She knew that her pension was her real income and that the salary from work was not more than just pocket money. In spite of this, Grete was content with her job. This is in line with some participants in a study by Olsen (2003) who placed little weight on being paid, but highlighted other aspects about the workplace such as the relations with their co-workers. By de-emphasizing the question about payment and highlighting her competence Grete presented an image of herself as an ordinary worker who was doing a job that is useful for others, but she also showed that she was aware that the job is not regarded by others as an ordinary job.

Grete was also presenting her competence in her leisure time activities. She was dancing in a semi-professional dance group, and the identity as dancer was very important to her. Some of the dancers were professionals, some were amateurs, some were disabled and some were not. The leader of the group was clear about the fact that this group had nothing to do with special education or special services. All the participants were dancers, and the group made use of the variations among members to explore possibilities and to create good shows. Grete shared that she was the first person with a disability to be included in the group, and she was proud about having broken a few barriers. To Grete, it was of great significance that she was a part of the dance group, not in spite of or because of her disability, but with her qualifications as a dancer on equal terms with all the other members of the group.

Inger was also proud about what she was achieving in her leisure time. She was playing in a marching band and was eager to demonstrate how she plays her cornet and to talk about concerts and other events. She informed that the name of the marching band had recently been changed. Previously, it was named like a school band, and now the name of the band sounded like the name of an ordinary marching band for adult amateurs. By talking about the name change Inger was simultaneously presenting herself as an adult, and that she did not like to be associated with school children. She may have experienced that adult status is hard to achieve for people who are labelled as having intellectual disabilities (Baron et al. 1999). However, even if Inger demonstrated that it was important to be perceived as an adult, she did not try to hide the fact that she needs someone to accompany her when she attends the band rehearsals. Inger seemed to take the help she got for granted in the same way as Grete regarded the wheelchair that she was using as a natural fact; a helping device that allowed her to lead an active life.

These extracts from the self-presentations of participants in this study shows that what was most important for them to tell others about were that they wanted to pass as typical people (Edgerton 1967/1993; Goffman 1963). They seemed to have taken seriously the message from society that they are ordinary citizens. Even if some of them, for instance Grete in her wheelchair and Henrik with Down's syndrome, were visibly marked out as impaired, they seemed to feel that they had the right to be accepted as the same as others. Thus, none of them seemed to be willing to be identified by their impairments or let the label intellectual disability influence the way that they were presenting themselves (Beart 2005). By showing their competence and the way that they lead active lives, the participants demonstrated that they have characteristics and abilities that are valued in society.

At the same time, the self-presentations also included disclosures that they need some assistance in their daily lives. By receiving public help, they seemed to accept that they were defined as belonging to a category of service recipients (Taylor 1998). Thus, they also showed that they have received the message from society that disabled people are entitled to assistance in order for them to be able to lead active

lives and to participate in working life and social life. Like participants in Gustavsson's study (1998), the participants seemed to think that the services were supporting them in order for them to fulfil their roles as citizens. They also insisted that their impairments were a part of the lives they were living and not something that decisively separated them from other people. Thus, the participants seemed to have merged the two messages from society into one; they have civic rights, and society secures these by offering necessary services.

Self-presentations and the label intellectual disability

To be given a diagnosis usually influences people's lives. A diagnosis can be experienced as a medical category, as a stigma, as a gate opener to services and benefits, or as a factor that influences identity development and experiences of self (Tøssebro and Lundeby 2002a). A diagnosis can, moreover, be experienced as traumatic or threatening, especially if it signalises future reduction in function or serious illness. On the other hand, to some, a diagnosis may be experienced as a relief because it finally explains the source of their problems. This has been found to be the case for instance when teenagers or adults are diagnosed as having Asperger syndrome (Kittelsaa 2000). Such a diagnosis can act as self-defence, because behaviour, which may seem odd to others, can be explained as the result of having Asperger's syndrome, not because people are stupid or bad.

However, some diagnoses are experienced as stigmatising labels (Gillman, Heyman, and Swain 2000). This is the case when people's individualities are ignored, and the diagnosis or label becomes the most prominent aspect of the person, as for instance when a person is labelled as having intellectual disabilities or serious mental illness (Shakespeare 2006). Such an identity is not something that one actively chooses, and it is not an identity that one has to come to terms with because that would imply that others have the right to define who an individual first and foremost is (Gillman, Heyman, and Swain 2000). Therefore, it is not strange that people who are defined by such a diagnosis or label do not use it when they present themselves to others because that might mean that they accept that the label applies to them. Another way of understanding this is that people who are labelled as having intellectual disabilities may try to control the impressions they give by reducing the significance of stigma in order to be perceived as the same as others (Goffman 1963).

Frida was the only one among the participants who used the label intellectual disability about herself, but she insisted that she was 'not very intellectually disabled.' In her opinion, the label did not reveal much about her, and therefore, she presented other identities that were more essential to her. Besides, she claimed that other people were more intellectually disabled than she was, and that this applied to people who she defined as 'people who are living in group homes and needs a lot of help.' Several authors suggest that some intellectually disabled people tend to describe themselves by comparing their abilities to others who need more support (Dagnan and Sandhu 2001; Finlay and Lyons 2000). It seemed that Frida was using the same kind of comparison in order to be seen as 'almost ordinary.'

Henrik was rejecting the label in the same way as people in the self-advocacy movement (Goodley 2000a). When he was asked about what disability means, he answered: 'I don't like it.' And when he was introduced to the word intellectual disability, he said: 'It's derogatory.' When he was asked what he prefers instead, he answered that he accepts the term 'people who need some help.' Henrik knew

perfectly well the significance of the label intellectual disability, and knew the negative attitudes attached to it. But it seems he understood that people would know that he was not able to manage totally on his own, and therefore, he was willing to admit that he needs a little assistance. Seemingly, Jens shared the same opinion. At the lunch table one day the discussion was about disability. He leaned over and said: 'I am not... (disabled).' Thus, he stated that he was not willing to include (intellectual) disability in his identity. By rejecting the label, Henrik and Jens behaved like some of the participants with physical disabilities in a study about disabled people's self-identity (Watson 2002). In this study, some of the informants challenged the notion of normality by not regarding themselves as different from typical people, but presented themselves in terms of what they were able to do.

Not all of the participants were familiar with the concept intellectual disability. Inger said that she had heard the word, but she was not sure what it meant. To Grete it might be the same as cerebral palsy; the impairment which was the reason why she needed a wheelchair. According to Todd and Shearn (1997) this would mean that Inger and Grete were invisible to themselves because they did not know that they were intellectually disabled. However, Inger knew that she needed help on a daily basis, and Grete was aware that she learns more slowly than others, and they both knew that people they worked with and spent time with in leisure activities had learning difficulties. One of Grete's saddest memories was from secondary school where she did not make any friends. According to Grete, the reason for this was that the assistant who was supposed to help her did not make any effort to assist her when she wanted to get to know her classmates. Thus, Grete might not know what intellectual disability means on a cognitive level, but because of her experiences she was emotionally living what intellectual disability means (Beart, Hardy, and Buchan 2005).

It is not obvious whether Kjersti was familiar with the concept intellectual disability, but she was eager to show that she differed from her co-workers at the sheltered workshop by her clothing and her interests. She dressed in black and red and had her hair coloured dark red. In addition, she shared that she worked out in a gym, liked motorbikes and rock music, and that she wanted to learn to play the drums. Her clothing and interests challenged the idea that intellectually disabled women are passive and dependent (Barron 2002). The impression was that Kjersti used her appearance consciously in order to emphasize that she was special because of her interests and not because of her impairment, and thus she visualised an embodied identity (Giddens 1991). She was simultaneously resisting the ascribed identity of intellectual disability by choosing an identity of resistance (Castells 1997). Castells uses the concept identity of resistance in relation to resistance to suppression on a collective level while Barron (2002) has used the same concept on an individual level to refer to intellectually disabled women who resist exclusion from life chances and possibilities.

These empirical examples indicate that the participants were aware of the consequences of the label intellectual disability even if some of them did not understand the meaning of it. To Frida intellectual disability was one of her identities but not essential to her self-understanding. Others, like Henrik and Jens, were rejecting the label, and Kjersti seemed to resist it by choosing an identity that made her stand out as special in a way that challenges stereotypes of intellectually disabled women (Barron 2002). Conclusively, none of the participants self-identified primarily as intellectually disabled even if they were aware of their impairments (Beart 2005,

Cunningham, Glenn, and Fitzpatrick 2000, Aull Davies and Jenkins 1997, Jahoda, Markova, and Cattermole 1988). By presenting themselves through their preferred identities as ‘ordinary,’ competent and active they remained aloof from the category intellectual disability and stood out as individual human beings. With Castells (1997) it is possible to say that they simultaneously were choosing identities of resistance.

Discussion

Participants in this study were negotiating their identities in the same way people in general do, and like most people, they presented a positive image of who they are (Goffman 1969). This may be the reason why an identity as intellectually disabled was not included in most of the self-presentations. Both Henrik and Jens were, for instance, aware of the negative impact of the label and did not want to describe themselves in such negative terms. They were in line with participants in Watson’s study (2002) when they refused to let others define who they are. Several authors have described how intellectually disabled people reject being identified by the label intellectual disability (Cunningham, Glenn, and Fitzpatrick 2000; Aull Davies and Jenkins 1997; Jahoda, Markova, and Cattermole 1988). Frida seemed to accept the label, but she insisted that it did not say much about who she is. According to Goffman (1963) stigmatized individuals have the same opinions about themselves as others, and therefore they try to reduce the significance of stigma and highlight a positive image about themselves. When Frida chose ‘ordinary’ as her primary identity (Castells 1997) she de-emphasised the significance of the label and highlighted her abilities. Several of the other participants as for instance Lars and Henrik, were doing the same when they self-identified as workers and did not place weight on the fact that they were working in sheltered employment.

Inger and Grete did not know the concept intellectual disability even if they were familiar with their impairments and thus demonstrated that they were not invisible to themselves (Todd and Shearn 1997). However, in their self-presentations they spoke little about the significance of being impaired. This may be described as a way of ‘passing’ (Edgerton 1967/1993; Goffman 1963) or ways of protecting themselves against the categorical identity (Bauman 2004). However, it is also possible to see the self-presentations as resistance against the negative labelling and an understanding of intellectually disabled people as immature children or individuals in eternal transition between childhood and adulthood (Baron et al. 1999). Kjersti was actively demonstrating resistance by choosing to stand out as visible and opposed to stereotypes about intellectually disabled women. Thus, she refused to be excluded from opportunities that other people have (Barron 2002).

The way that the participants were resisting the label was to present another image of who people who are labelled as having intellectual disabilities are; competent adults who do their best to participate in society. By standing out as individual human beings with their own interests and preferences, they demonstrated that the category intellectual disability masks a variety of individual characteristics (Sundet 1997). Like most people, they wanted to be perceived as normal, or at least they did not want to be placed in categories which are negatively valued (Solvang 2006). Even if the participants knew that they needed a little help, in their opinion, this did not prevent them from seeing themselves as (almost) the same as typical people. They seemed to take seriously the message from society that they are citizens

just like others, and they also took seriously the other message from society that they are entitled to certain rights in order to be able to lead good lives.

However, in their struggle to be accepted as 'ordinary' intellectually disabled people are met with powerful objections. One is the notion of statistical normality which defines intellectually disabled people as those who function below what is seen as normal competence. Thus, to be defined as intellectually disabled is in itself a definition of not being normal. In addition, they are met with deeply rooted ideas of intellectually disabled people as immature, weak and pitiable. Such understandings exist in folk tales, literature and the media (Gustavsson 1999) and are almost impossible to eliminate. Furthermore, these kinds of stereotypes have serious consequences for people who are labelled as having intellectual disabilities because they are offered living conditions which are decisively different from those of people in general, including special housing, sheltered work and specially arranged leisure activities. The specially arranged services add to the stereotypes by signalling that they are for people who are different and special.

Conclusion

According to Rapley (2004) it is not strange that people do not want to identify with the label intellectual disability because it is so negatively loaded. Besides, an ascribed identity as intellectually disabled is embodied and controlled by professionals, and is not an identity that one is searching for (Gillman, Heyman, and Swain 2000). Neither is intellectual disability an identity that one should come to terms with as Craig et al. (2002) discuss, as this would mean that others have the right to define who intellectually disabled people first and foremost are. There is solid evidence in research that neither intellectually disabled people nor disabled people with other impairments want to be identified by their disabilities (Beart 2005; Cunningham, Glenn, and Fitzpatrick 2000; Aull Davies and Jenkins 1997; Jahoda, Markova, and Cattermole 1988; Watson 2002).

When studying identity and intellectual disability it is important to clarify how these two concepts are defined. Some researchers seem to define intellectual disability as 'naturalised impairment' (Goodley and Rapley 2001) and hence, an identity as intellectual disability is stable and does not vacillate between several possible identities. Such an understanding overlooks that even an identity as intellectually disabled is negotiated in social relations (Giddens 1991; Rapley 2004). Beart (2005) criticise Todd and Shearn (1997) for having an overly static perspective of identity, and for failing to distinguish between how intellectual disability is understood on a cognitive level and what it means to have an emotional experience of what the categorization means.

Intellectual disability as 'naturalised' impairment is not negotiable (Goodley and Rapley 2001) but it is possible to negotiate a socially constructed identity as intellectually disabled person. Therefore, how intellectual disability is defined is of great importance. Participants in this study were demonstrating that they had several identities which they were able to choose among according to circumstances and context. In their self-presentations they were showing that they were active, intentional and goal oriented (Goodley 2000b). Moreover, with necessary assistance they were convinced that they would be able to live ordinary lives and contribute to the society they were living in.

Limitations and contribution of the article

The article draws on findings from a study with a limited number of participants and is therefore not representative of intellectually disabled people as such. It is also one-sided as it highlights only how the participants present themselves and not how their identities are negotiated in interaction. More research is needed on how identity negotiations progress when one party is labelled as having intellectual disabilities.

The study on which this article is based has been performed over a period of two years and therefore, it has been possible to study how different identities were constructed according to context and on-going interaction, and to take note of how the participants actively chose outfit and settings to emphasize their self-presentations. By bringing in questions about living conditions, services and environment the article demonstrates that the barriers that intellectually disabled people face when they try to choose identities are complex.

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