

# WHO AM I? WOMEN WITH LEARNING DIFFICULTIES (RE)CONSTRUCTING THEIR SELF-IDENTITY

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*Abstract: The issue of (re)constructing one's self-identity is an important, sociologically relevant issue of today. Qualitative interviews with women with learning difficulties have been done in order to further the understanding of the meaning of gender and disability, and what this means with regard to one's sense of self. Based on the lives realities of the participants, the analysis concludes that the social background and present situation of the elderly women make it difficult for these to have some control in their everyday lives. Among the participants, there are those who have an ambivalent approach to, and indeed oppose, the ascribed identity as learning disabled. This way of striving to reconstruct one's identity can be understood as a means of rejecting the oppressive situation of being rendered invisible and at the same time marked out as different, i.e. as a means of empowerment.*

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## Introduction

There has during the last decade been an increasing interest in the social meaning of gender and disability, and some studies have consequently focused on the subordinate social position of disabled women (e.g. Morris, 1991; Hillyer, 1993; Barron, 1997; Traustadóttir, 1999; Kristiansen, 2000). Generally, however, it can be argued that a gender neutral approach; i.e. also with regard to the situation of men and the social meaning of manhood, still is relatively common in social research on disability.

Disabled women are not merely an invisible group in the sense of not being

heard, in society generally, but also in research. A gender-neutral approach in research thus risks re-enforcing the invisibility of disabled women, as indeed of disabled men.

A group of women which can be described as particularly invisible are women with learning difficulties. These women are not acknowledged (nor are women with other kinds of impairments) when issues concerning women are discussed in media or in public debate, nor indeed in feminist research generally. This invisibility serves to strengthen the understanding, or reinforce the myth, of women with learning difficulties as helpless and weak which is an ideo-

logical foil for women's oppression and for paternalism (see Charlton, 1998). The little interest in listening to the voices of women with learning difficulties; i.e. their silence in research and society at large, risks being misinterpreted as the women having nothing to say. This is of course not the case.

Women with learning difficulties can, paradoxically enough, also be described as being marked out in the sense of being seen and noticed as different and marked out by stereotypes (see Young, 1990). There is a lot of time and effort spent on training women with learning difficulties to behave in ways defined by others as proper and right for them to behave, which portrays an understanding of them not being "up to scratch" (Barron, 1997).

This paper focuses on the forming or (re)constructing of an identity of those labelled as women with learning difficulties. Some learning disabled women's lived experiences serve as a basis for the analysis.

In line with Manuel Castells (1997), I define identity as involving a process of self-construction and individuation. Identity is here distinguished from social role. Identities are stronger sources of meaning than roles due to the process of self-construction and individuation which they involve. Castells makes the fruitful distinction of identities organising the meaning while roles organise the functions. An identity can then be understood as relating to who I am in a different and deeper sense than a social role.

Castells (*ibid.*, p. 8) argues that the (re)construction of identity always takes place in a context of power relationships. He suggests the following distinction between three forms of identity construction:

- Legitimatising identity, which is introduced by the dominant institutions of society to rationalise and extend their domination with regard to social actors.

- Resistance identity, which is generated by those actors that are in devalued and/or stigmatised social positions by the logic of domination. The actors build trenches of resistance on different or opposing principles from those permeating the institutions of society.

- Project identity, which involves social actors constructing a new identity that redefines their position in society. An example of this is when feminism challenges patriarchy; i.e. the patriarchal family, the structure of production, reproduction, sexuality and personality on which societies have been historically based.

Castells (*ibid.*) brings our attention to an interesting paradox at this time of an increasing globalisation. He argues that our lives are being shaped by, what can be described as, conflicting trends; i.e. that of an increasing importance on identity, and globalisation. A widespread surge of powerful expressions of collective identity, linked to people wanting control over their own lives, has taken place in the last quarter of the century, which indeed serves to challenge globalisation (*ibid.*). Prevailing normative

conceptions of womanhood, as well as of disability, are of importance in furthering the understanding of the everyday lives and self-identity of women with learning difficulties. Acquiring knowledge of what it can entail being women with learning difficulties is not merely of theoretical interest. The implicit and explicit messages of what is expected of women with learning difficulties; i.e. how they should be to live up to the expectations of others (and of themselves) affect their everyday lives in a number of ways.

The two intertwined social roles, which this study explores, are thus the one of being a woman and of being disabled. The way gender and learning disability is understood, or put differently; the social status of gender and learning disability affects the opportunities for education, employment, friendship, sexuality, self-determination etc. (Traustadóttir, 1999), and indeed the self-identity of women with learning difficulties.

The women lead their lives within a certain social context which is important to take into account. Their experiences and lived realities affect, and are affected by, the way they view themselves. While structural (power)relations have a substantial impact on the living conditions and self-identity of women with learning difficulties, the women are not passive recipients of social norms and values. Disabled women are active parties in how gender and disability is understood. The relationship between structural conditions and individuals' approaches and ways of acting can be seen as a dynamic interplay (e.g.

Giddens, 1979). Or put in another way, people are both determined and determining (Thomas, 1999).

### **The study**

The study, of which this paper is one part, seeks, by way of the personal experiences and views of the everyday life situation of women with learning difficulties, to further the understanding of how womanhood and disability are constructed.

The aim of the study is thus twofold. The personal accounts bring about a kind of knowledge of the everyday lives of women with learning difficulties in Sweden with particular emphasis on how they themselves view these. This approach can be seen as one way of confronting the silence of these women in research and in society generally. By way of these personal accounts, the aim of the study is also to further our understanding of the meaning of womanhood and disability, which affects the everyday lives of women with learning difficulties.

By way of acquiring knowledge about the everyday lives of women with learning difficulties, societal values and norms, with regard to womanhood and normality, become visible. The way in which the women "present themselves" thus mirrors prevailing conceptions about gender and disability, which in turn affect their self-identity.

The aim is thus to gain theoretical as well as empirical knowledge. The

knowledge that the participating women brings about can be a contribution to the area of gender as well as disability studies, and further our understanding of different forms of subordination, and indeed opposition. One of the key aims of feminist research is to make visible women's experiences and to seek to bring these experiences to the public realm (see Munford, 1995). Learning of the personal experiences, with regard to different kinds of situations and relationships, of women with learning difficulties, can serve to deepen and problematise our understanding of the interconnection between gender and disability. For those working with, and indeed generally associating with, women with learning difficulties, having some understanding of the complex inter-connection between how we understand and interpret gender and disability is of importance. This can serve to deepen the understanding of how this inter-connection can affect the everyday living and self-identity of the women in question. It can, for instance, serve to better understand the interplay between the women and others; e.g. those who assist the women in various ways, and consequently assist in working towards avoiding situations which may be experienced as traumatic and demeaning for the former. This kind of knowledge is thus not merely interesting per se in a theoretical sense, but can serve to making the voices of women with learning difficulties heard in a way which may challenge prejudicial notions of who they are and, more importantly,

notions stemming from others defining who they ought to be, and consequently ought to conduct their lives.

### **Methodology**

Qualitative interviews have been conducted with 10 women with learning difficulties of the ages 21-71 in their homes. I intentionally chose a considerable difference in ages in order to investigate any possible differences with regard to the meaning of womanhood and learning disability linked to phase of life and different social backgrounds. Alongside the interviews, observations have been done as a complementary form of gaining information. I have observed how the women have reacted to different topics discussed and at times adjusted the questions to these reactions. Since some of the women express themselves verbally in a way that requires a certain competence to understand correctly, I have attached importance to being particularly observant in order to avoid misunderstandings. Also I have taken into account the possible tendency among persons with learning difficulties to agree with the interviewer; i.e. be inclined to answer in the affirmative.

An interview guide has served as a means of assistance. The interview guide consists of two different types of questions. The first type of questions deals with areas such as the childhood and time of growing up, school/education, work, leisure, relationships with relatives,

friends, boyfriends/partners and staff, as well as future ambitions etc.

The other type of questions, which are those mostly focused on in this particular paper, deals with what it is/means to be a woman and learning disabled with regard to identity. These issues were dealt with in two different ways. They were posed as direct questions to the participants and also to the transcribed interviews, i.e. used as an analytical tool. The participants have, however, had a considerable impact on which issues were discussed (and thus relevant) with regard to their everyday lives and self-identity.

Discussing these latter kinds of issues with the participants has been most interesting, not least since there appears to be an understanding that (all) those with learning disabilities can only understand simple issues in a concrete manner. While this indeed applies to some people, this is not always the case. The participants in this study welcomed the possibility to talk about a complex issue, which they and I have in common; i.e. being women.

While I have had an interview guide as a means of assistance, the participating women have also identified which particular issues are of relevance and importance to them in everyday life and consequently are to be included in the study.

The contact with the participants was reached with the help of staff; e.g. in group-homes and those in charge of communal services. These persons were asked to briefly introduce the study and

inquire if there were any women which I could contact for possible participation. I then received the names and telephone numbers of those who had said that they were interested, and after further explanation from me of what the participation would involve, they all decided to participate. All of them chose their own homes as a venue for the interview.

The interviews have been recorded, as the participants have not objected to this, with two exceptions. I would not later have heard what two of the participating women said if recorded and thus chose to take notes during these particular interviews. The interviews have been transcribed literally and I have identified similarities and differences in the everyday lives of the participants, and in their different identifications. Some of the participants express themselves by way of short sentences and others in single words. In the reporting of the findings, I make a point of including also the voices of those (although not necessarily in direct citations) in the latter category.

The findings cannot be generalised in the sense of claiming to portray a picture of the social identities and everyday lives of women with learning difficulties in Sweden generally. But the acquired knowledge can contribute with a sociological understanding of the social meaning of womanhood and disability, and how this affects the self-identity; i.e. prevailing conceptions that are not only of relevance with regard to the actual participants in the study.

### *Ethical considerations*

By way of an initiating talk with the prospective participants, the aim of the study was introduced in a clear and concise way. I emphasised that participation was voluntary and that it was possible to withdraw from participation at any time. Attention was also paid to the issue of confidentiality and on an ethically correct approach generally. By participating in a study such as this one, the women do not only give of their time, but also of their personal experiences and thoughts. These have to be dealt with and documented in a respectful way that serves to safeguard the integrity of the participants. I mean that it is the utmost importance to be wary of raising issues that may be demeaning or upsetting in any way. As researcher/interviewer I have to be aware of my superior position of power in relation to the participating women with learning difficulties.

When a participant appeared to view an issue raised as difficult to handle, such as for instance happened with the one dealing with sexual relationships, I chose to abandon this particular issue. After asking if I had interpreted her reaction correctly and if she preferred that we talked about something else, and this particular participant confirmed this, I thus did not pursue the issue. This choice that I made can be seen as me reinforcing taboos and thus being complicit in silencing women. In the conflict of exploring further something of interest to my research, and indeed the risk of reinforcing taboos, and the

real possibility of offending or upsetting a participant, I thus view the latter aspect as of primary interest and importance (see McCarthy, 1998).

The issue of consent is problematic when staff, who are in a superior position of power, as in this study are used as "links" to prospective participants. I explained to the former that they should not talk the prospective participants into participating, but make sure that they felt free to decline.

The issue of confidentiality is also problematic in a study such as this, an ethical problem which strangely enough has received little attention among disability researchers. The fact that I asked staff to inquire about possible interest to participate among women with learning difficulties means that (at least one of) the staff was/were not only aware of the study (which I nonetheless gave minimal information about), but more seriously also aware of who the participants were. I discussed this problematic issue with the participants. They were all, however, still keen to participate and did not consider this a serious problem. In fact, some of them told everyone in the group-home, as well as parents and other relatives, of their participation. It is, however, important to take into account and openly discuss the difficulty to ensure confidentiality in studies such as this one. Also, it is worth noting that the participants may well have felt more "free" to speak about staff and indeed other issues if complete confidentiality could have been assured. Interviewing women (and

men) with learning difficulties requires, on behalf of the interviewer, a readiness for flexibility and adjustment to different kinds of unexpected situations. My understanding is that this has more to do with the little experience of some persons with learning difficulties of being subject to such interest; i.e. interest in their own thoughts and experiences, than the impairment as such (see Barron, 2001). The elderly (over 70) women in this study appeared embarrassed about my interest in their views and experiences, and repeatedly protested against us only talking about them. These interviews, to a greater extent than the others, also consisted of the women asking me questions about my life which I of course answered. This way of reaction; i.e. being troubled by being “the centre of attention” for a relatively short time also tells us something of these older women’s lives. It can be understood as them having little experience of others being interested in their views and opinions and thus not being accustomed to “being heard” in this sense. An alternative interpretation is that the women in question simply were reluctant to answer my particular questions.

One of these elderly women gave me flowers to thank me for coming to her home and “allowing” her to participate in the study. My initial reaction was to explain to her that if anyone should have flowers, it should be her, and not me, for giving of her time to see me. The situation was difficult at first to handle for me, but I chose to gratefully

accept the flowers. I thus chose not to instruct her as to what is generally understood as normal and consequently the right social conduct with regard to who gives/receives flowers, and who feels gratitude. I mean that this would not only have been impolite, but more importantly that I would have taken on a self-appointed, constricting role of “normality educator”.

### **Social constructionism**

Disability and gender are socially constructed phenomena. The interest in the study here referred to is on the meaning of gender (or womanhood) and disability and how this affects the social identity and lived realities of women with learning difficulties. Having said that, a relevant question is as to what kind of constructionism I am referring to. The social constructionist approach to social problems theory has been provocative and controversial since the 1970s (Miller & Holstein, 1993). There have been objections from those with a more “realist” orientation that there is an objective reality to social problems and that this reality should be the topic of sociological studies. Within the field of constructionism, there is also a kind of division where some adhere to a more “strict” constructionism and others to a “contextual” one which focuses on the claims-making process, but acknowledges assumptions about objective conditions (ibid.). My approach is in line with the

latter. Interest is on the social conditions and experiences of the participants, in the study here referred to, construct as meaningful and/or problematic (see McCall, 1993). Importance is on taking the lived experiences of the participants seriously which has been particularly emphasised by feminist constructionists.

My stance is, however, less in line with feminist constructionism, as described by Michal McCall, when it comes to whom I am doing research for. While I strongly adhere to the stance of the responsibility of the interviewer/researcher including not raising issues or asking questions which can be used to further exploit or marginalise the participants, I cannot claim to be doing research for women with learning difficulties (see *ibid.*), but rather together with them. The goal to help people under study “to understand their lives structurally and locate productive sites for struggle against their oppression” (*ibid.*, p. 185) is most honourable indeed, but one which I cannot be bold enough to claim having reached. It is important to acknowledge that the women participating in the study here referred to have not requested my assistance with regard to oppressive practices nor given me the permission to be their spokesperson, in the sense of speaking for them. Also researchers, who can be described as taking an emancipatory standpoint with regard to marginalised groups, need to be aware of their superior position of power and be self-critical (see Barnes, Mercer & Shakespeare, 1999).

### *The social construction of identity*

A distinction which is fruitful in this study is the one between self-identity and ascribed identity (Thomas, 1999). The issue of self-identity has been neglected in disability studies, which has meant that a key area of disabled women’s and men’s experiences has been ignored (Shakespeare, 1996).

The way identity has been used has been criticised; for instance by Lois MacNay (2000), who is critical to feminist work on gender identity, which she claims has tended to focus on identity as a lived set of embodied potentialities instead of externally imposed constraining norms. We learn who we are in a number of different ways. Included in socialisation processes are expectations and beliefs about who we are, and who we should be (Kristiansen, 2000). Social identities can be understood as achieved social statuses or entitlement to which requires negotiation and maintenance (see Rapley et al, 1998). This is a different way of understanding identity than as immutable properties of persons. Anthony Giddens (1991) adheres to a similar definition in describing identity as, not something just given, but as something which has to be created and sustained in the reflexive activities of an individual. Giddens argues that individuals only feel secure in their self-identities in so far as others recognise their behaviour as appropriate.

While there may be a plurality of identities for a given actor, for most people, meaning is organised around a primary identity; i.e. an identity that



frames the others (Castells, 1997). Castells focuses primarily on collective identity and means that an essential sociological issue is how, from what, by whom, and for what a certain identity is constructed.

The interviews show that the primary identity ascribed women with learning difficulties is the one of learning disabled. Taking into account the above mentioned essential issue of by whom this ascribed identity is constructed, it is not primarily by the women themselves. Instead, those (decision-makers) who are in a superior position of power have decided which label is appropriate for these women, which has a considerable impact on their sense of self. Dominant groups construct the differences of some groups, such as women with learning difficulties, as negation and lack (Young, 1990). This status of Otherness creates certain experiences not shared (nor always understood) by the dominant groups.

The participating women are not used to talking nor thinking in terms of them being women; i.e. in terms of gender. They can be described as being seen primarily as disabled. This can be understood as a positive aspect indeed if it would mean that these women are not discriminated against because of them being women; i.e. being subject to discrimination related to gender. But this is not a fruitful nor, more importantly, a relevant interpretation. (Any more than assuming that gender-neutral research means that disabled women are not discriminated against!)

The interrelationship of gender, or womanhood, and learning disability can instead be understood as these women being particularly vulnerable to discrimination. Not being seen as, what is understood as, a normal or an ideal woman in the sense of living up to prevailing societal ideals and stereotypes of womanhood does not mean not being subjected to discrimination or oppression linked to gender. The experience of disability, like other kinds of experiences, is gendered. The impacts and forms of disablism is interwoven with sexism (Thomas, 1999).

### **To be(come) a woman**

Feminist studies have been criticised for not having taken into account the fact that women constitute a heterogeneous group. Some of this critique has been focusing on that the issues discussed in feminist research tend to, or run the risk of being most relevant for middle-class, white, heterosexual, non-disabled women. This line of critique makes visible the paradox that also research which has as an articulated aim to assist in empowering a marginalised group such as women at the same time runs the risk of marginalising certain groups of women.

Disabled women are sometimes referred to as if constituting a homogeneous group. This is not entirely misleading as women with different kinds of impairments have in common an underprivileged social position in societal life generally. But having said this, it is nonetheless

important to acknowledge the obvious fact that disabled women have different experiences and approaches to life generally.

One question that I asked the participants was what it is to be a woman. One interesting aspect, was how much some of the women clearly liked talking about this complex issue. Some of them, after pondering about it, came back to this issue after we had left it and were talking about other things. The question was clearly understood as difficult to give a direct answer to (which of course is not surprising), but nonetheless most interesting to think and talk about. It is clear that the participants are far more used to speaking of themselves as learning impaired and that some are tired of this one-sided perspective, than in terms of what it involves being women. The impairment in the sense of individualised problems and difficulties has taken over and other aspects are less emphasised.

The most common kind of answer to what a woman is referred to, what can be described as, biological aspects as the following account by Anna, a young woman can exemplify:

*K: What is a woman?*

*A: It's this with the girl-illness.*

*K: Girl-illness, what is that?*

*A: It's the period.*

*K: I see. I'm much older than you so I'm not familiar with that word.*

*Girl-illness is the period, is it?*

*A: Yes, that women get that is.*

*K: What is it like having the period?*

*A: Well, it's really awful because my stomach hurts.*

*K: Yes, that's no fun.*

*A: No.*

There are some interesting aspects of Anna's immediate answer to the question as to what a woman is. One is that she associates it to, what can be referred to as, biological aspects and to negative ones; i.e. pain. Another interesting aspect is that she, as do some of the other participants, does not appear to link menstruation primarily to pregnancy, but rather to a general inconvenience. One way of understanding this approach is that the participants (with one exception) in this study do not wish to have children. Menstruating is thus not seen as a prerequisite for having children, i.e. something important which one wishes to experience, but rather exclusively as a general nuisance and discomfort. Anna is aware of the link between menstruation and pregnancy, but this is not of any concrete importance or relevance to her own living situation, as she has ruled out having children of her own.

Motherhood is closely linked to a conventional and stereotypical understanding of what a "real" woman is. Barbara Brook (1999) refers to the critique of such essentialising definitions and poses the rhetorical question as to whether a woman who is unable or unwilling to bear children then is less of a woman. Most of the participants were clear about them not wanting, or having wanted, children of their own. This approach is one which I have come across also in earlier studies with

women with learning difficulties (Barron, 2000). When asked why she doesn't want any children, a young woman whom I call Lisa explains:

*They carry on and cry all night when they want milk, and hard work.*

This understanding of motherhood as demanding and tiresome is not unusual among the participants. Possible positive aspects of motherhood are usually not referred to and firmly rejected when I ask about these.

One reasonable interpretation of this view is that it mirrors the oppression that women with learning difficulties are subjected to; i.e. them having been given the message (implicitly or explicitly) that they are not fit for motherhood. Oppression is here understood in a structural sense and refers to systematic constraints on groups with causes that are embedded in societal norms and values (Young, 1990). The participants have thus internalised a view on themselves as unsuitable and incompetent as mothers. This one-sided view of incompetence is not supported by current research, which in fact has shown that when women with learning difficulties have adequate support and assistance, they can usually cope well with the task of motherhood (Sigurjónsdóttir & Traustadóttir, 2000).

But the negative approach to having children of one's own, among the participants in this study, can also be interpreted as them having realised the hard work involved in having children and that this would involve having a great deal more assistance in everyday

living. It is thus also the added assistance required that they reject (which in turns means less privacy) and not just the idea of motherhood as such. This latter interpretation corresponds well with the critical approach to some of the staff (in the group-homes) among some of the participants, who they mean control their lives too much.

Having sexual relations with one's partner(s) is something which we associate with womanhood and indeed adulthood generally. It is one of those things we view as "natural" with regard to these kinds of relationships. Some of the participants had (at the time of the interview), or have had, partners or boyfriends. With the exception of one, none of them had experienced sexual relations. This issue was just briefly referred to with some of the participants and then left as some clearly indicated that they did not wish to discuss it. Vera is a young woman who has had eight different boyfriends. She tells that a nurse at a habilitation centre has explained about sexual relations. When asked if this information was good, Vera replies:

*V: Yes, but if a guy should spend the night. And has brought his pyjamas and me too. And they want to do sex, but I didn't want to, I have to say no.*

*K: You should decide yourself?*

*V: Yes.*

*K: Did she say that, the nurse?*

*V: Yes, I should decide myself and say what I want.*

*K: I see. Do you agree with that?*

*V: I don't know.*

*K: Have you ever had sex?*

*V: No, never.*

*K: I see. Has anybody wanted to have sex with you and you have said no or?*

*V: Yes, they are interested, but they aren't interested in talking about sex, oh no.*

*K. I see.*

*V: But they want to.*

*K: Do they want to do it, but not talk about it? Is that what you mean?*

*V: They do sex and you say no, and I said no, I don't want to. I want to wait.*

*K: I see, What does the guy say when you say "No, I want to wait"?*

*V: Yes, it's okay, but they struggle against me.*

*K: Struggle against you?*

*V: Yes, they do, but I can get pregnant.*

*K: But you have never done sex?*

*V: No.*

Vera is clear about, as are most of the other participants, that she does not want any children nor does she want to have sexual relations at present. She emphasises, as we can see above, that it is her that should decide whether she has sexual relations and that it is important to say no, which she indeed does, despite young men trying to talk her into it. I later tried to figure out, and discuss with Vera, what she meant with guys "struggling against her" and reached the understanding that she meant verbally.

Saying no to unwanted invitations to sexual relations may seem an obvious and unproblematic thing for young women to do. Studies show, however, that young women tend to find it difficult rejecting unwanted sexual invitations (e.g. Kitzinger & Frith, 2000). This difficulty among young women of asserting themselves with regard to sexual relations can be understood as part of internalising conventional ideals of subservience with regard to womanhood.

According to this way of reasoning, Vera and the other participants in the study at hand, who have declined sexual invitations, can thus be described as opposing and confronting traditional norms and ideals linked to womanhood. In other words, constructing themselves as women in a way that does not coincide with traditional norms and values with regard to sexual availability.

This particular interpretation may appear to conflict with the understanding of women with learning difficulties as victims of oppression. My understanding, not least based on the personal accounts of the participants in the study here referred to, is that women with learning difficulties indeed can be defined as an oppressed group in society generally, but that they at the same time, in a number of different ways, oppose and confront these oppressive practices. Saying no to unwanted sexual invitations can be understood as an example of not adhering uncritically to the wishes and demands of others; i.e. to those men who want sexual intercourse with them.

When discussing motherhood with the participating women, it became evident that some of them are uncertain about the issue of contraception. There are those who appear to avoid sexual relations because of the fear of getting pregnant. Some of the participants tell of the pleasure of kissing and fondling their partner whom they love, but make it clear that sexual intercourse is a different matter in that it is, as referred to by Anna, "not nice and makes you pregnant". Eva is a woman in her fifties who has had the same partner for eleven years and who stays at his place in the weekends. She explains that they have never had sexual intercourse and do not intend to in the future either:

*No, that is nothing to do. Oh, no.*

Interestingly enough, this view does not seem to stem from lack of information with regard to contraception and sexual intercourse. Some of the participants mention that they have received this kind of information from habilitation personnel, such as nurses. Instead, I understand it as that the women in question having been given this image or understanding of sexual intercourse (by others in their surroundings, whom they have great faith in) as something which involves some elements of risk and have consequently internalised this understanding. This shows that being informed about an issue does not necessarily mean acquiring adequate knowledge about the same. The information about contraception hindering pregnancy has thus been given, but not in a way which has meant the women

acquiring adequate knowledge about this issue. We can thus see that there are several different factors to take into account when trying to understand the reasons behind the women in question taking a stand against having sexual intercourse.

Another question which I posed to the participants was what it involves being a "good woman"; i.e. whether there are any special ways one should be(have) to be a good woman? Nora, a woman in her thirties, explains her view on this issue:

*N: A good woman, it is independent and thinks good things.*

*K: Yes, independent. You shouldn't just do what others tell you to or?*

*N: Oh yes, you should.*

*K: You should?*

*N: You should, different things. Good way, what's it called, mature woman.*

*K: Yes, you should be mature?*

*N: Yes.*

*K: Are you mature?*

*N: Yes.*

*K: You said that a good woman should be independent. Do you mean managing certain things by yourself?*

*N: Yes.*

*K: You seem to manage certain things yourself?*

*N: Yes, I do actually.*

*K: You make coffee and?*

*N: Yes.*

When I asked if there is any special way a woman should look, Nora replies:

*N: Yes, it should be a good-looking girl.*

*K: You should be good-looking?*

*N: Yes.*

*K: So it's important to be good-looking. Why is it important to be good-looking?*

*N: Yes, to be good-looking, to go out and meet guys and dance and that.*

*K: You can dance then?*

*N: Yes, and take part and that.*

### ***The body***

There is a dilemma in asking questions or raising issues which risk reinforcing a stereotyped or prejudiced view and understanding of womanhood. I mean that questions dealing with appearances or notions of how a "real" woman should look run such a risk, but nevertheless are of relevance in a study such as this. These assist in understanding the meaning of womanhood; i.e. what is understood as important criteria for being seen as an ideal(ised) woman. We are confronted with normative messages and images not least by way of media of how a "real" woman not only should behave, but also look in order to live up to prevailing ideals. Iris Marion Young has aptly expressed this situation as follows:

*Judgements of beauty and ugliness, attraction and aversion, cleverness or stupidity, competence or ineptness, and so on are made unconsciously*

*in interactive contexts and in generalised media culture, and these judgements often mark, stereotype, devalue, or degrade some groups (1990, p. 133).*

Within the context of how gender is constructed and understood, and linked to physical appearances, are sociological relevant aspects which deal with the biological and social (i.e. a site of meaning) body. This is an issue which has attracted attention in feminist studies (e.g. Butler, 1996). It has, however, not been of interest generally in social research nor with regard to disabled women in feminist studies (Fawcett, 2000). The body has been described as the first and most important arena for social norms and social control: i.e. socialisation (Widerberg, 1995). Women's bodies (as indeed have men's to a certain extent) have become "a project" in modern society. In an earlier conducted study (Barron, 1997) dealing with the situation of mobility disabled young women, the participants, when asked about what they think of their own bodies, all replied in terms of looks; i.e. that their bodies were inadequate as far as "ideal appearances" for women. Interesting enough, when exactly the same question was posed in the here referred to study, the participants replied in terms of health and strength and thus not in terms of appearances. Sara, a young woman in her twenties, tells me her view on her body:

*My heart is beating. My body is strong and good.*

How then can we understand this different approach to this question formulated in exactly the same way among young physically disabled women and that of the participants in this study? I intentionally asked it in a somewhat unclear way in the sense that I was interested in what the participants first thought of with regard to their own bodies. One reasonable interpretation is that women with learning difficulties from an early age have been subjected to the views, or critique, of others with regard to their behaviour. The focus has been on intellectual or behavioural training and correction rather than on, as with mobility disabled women, physical and bodily training and correction. This does not mean, however, that women with learning difficulties are not aware of and affected by the focus on perceptions of "the perfect or ideal body" for women in our society (see McCarthy, 1998). When I later asked what they thought of the appearances of their bodies, some answered that their bodies look fine while others had a more critical view on that which they perceived as inadequacies with regard to "ideal appearances".

The different reaction and reply to the question as to what one thinks of one's body referred to above is interesting also from a methodological standpoint. It can serve to remind us that different frames of reference, or different lives realities, mean that an identical question can be understood in different ways.

## **To be(come) disabled**

### ***The social model of disability***

The so called social model of disability focuses on the oppressive society which disables people with impairments. Any meaningful solution must thus be directed towards societal change rather than individual adjustments (Barnes, Mercer & Shakespeare, 1999). The social model can be seen as a reaction to the individual medical model of disability which focuses on the disabling effects of the impairment as such.

While the social model has had some impact on social research on disability by way of researchers focusing on the effects of a disablist society for people with impairments, this model has nevertheless been subjected to some critique, particularly by feminist writers. In the same way that early feminists have been criticised for reducing the experience of women to the experience of white, middle-class, Western women, social model theorists can be criticised for understanding disability in terms of the way in which physical obstacles are confronted by white, Western, male wheelchair users (Marks, 1999). There has been critique forthcoming of the lack of work from a social model perspective which examines the disabling obstacles to those who have learning difficulties (ibid.), as well as the social model neglecting to include aspects such as bodily pain and weakness (Wendell, 1996). The social model has also been criticised for prioritising work

and independence and thus adopting values of capitalist society.

Of particular relevance to the study referred to in this paper, is the arguing inherent in the social model of disability that a criterion for the inclusion in the disabled people's movement is having a positive self-identity as disabled (see Thomas, 1999). Carol Thomas makes the important point, that the accounts of some of the participants in this study verify, that people may be most critical of disablism and yet only partially, or indeed not at all, identify as disabled.

### *Double consciousness*

I asked the participants about their understanding of learning disability and whether they identify themselves as disabled. While there were those who said that they are learning disabled and clearly identified themselves as that, there are others who have a more ambivalent approach to this ascribed identity. There are also those who firmly reject a self-identity as disabled, such as Debbie, a woman in her forties. She replies to the question as to what learning disabled means:

*That's those with Down's syndrome.  
Not me. I'm an animal lover. That's me.*

Debbie explains that she is not learning disabled, or put differently; learning disabled is not who she is. She does not identify with other women with learning difficulties and identifies herself as an animal lover. When asked about the reason for living in a group-home with available staff, Debbie told

me that this living arrangement suits her as she requires a considerable amount of assistance in everyday life. Debbie does thus not "deny" her requirement of various kinds of assistance, but takes a stand against the ascribed identity as disabled. Debbie does not identify with other women either, but with those (irrespective of gender) who, like her, view animals as the most important aspect of life and consequently an essential part of their selves.

A somewhat different answer to the question as to what learning disability is, is the one by Hanna, a woman in her thirties:

*Those who can't read or write. But I can, a bit.*

Hanna has an ambivalent approach as to identifying with other learning disabled people. While she says that she is not really learning disabled as she can read and write a little, she nevertheless says that she is "called learning disabled and perhaps is one of them then".

The ambivalence and rejection with regard to the ascribed identity as disabled is not surprising. The participants are aware that they require assistance with tasks that women their age usually manage without help. They are also aware of being categorised as learning disabled and that this can involve stigmatisation and oppression. My understanding of the personal accounts referred to here with regard to this issue is that these participants take a stand against them being seen exclusively as disabled and not as, for instance, women or animal-lovers. This is something which



some of the participants express discontent with and thus *negotiate for alternative* identities, such as those linked to other aspects than the impairment.

The approaches shown above with regard to identity can be understood in terms of “double consciousness” (Young, 1990). Double consciousness comes about when an oppressed individual refuses to coincide with the devalued and stereotyped view on her/himself. Young here refers to the situation when an individual wants recognition as capable and full of possibility and receives from, that which Young calls, “the dominant culture” (page 60) the judgement that s/he is marked and inferior.

### **Paradoxical oppression**

Women with learning difficulties can thus be described as being subjected to a paradoxical oppression (see Young, 1990). They are rendered invisible and at the same time marked out by stereotypes. The study here referred to shows that women with learning difficulties may be expected to live up to stereotypical, traditional notions of subservience linked to the meaning of learning disability and to womanhood. Some of the participants tell of being treated by staff in a manner, which we usually associate with that of treating children or youngsters. A recurring theme is that of keeping one’s apartment tidy in a way which staff accept. Debbie, who is 30 years old, gets upset when she tells of

these occasions, when she, or rather her own wish, is rendered invisible:

D: I don’t want to always clean my room.

K: And do you have to?

D: Yes, I said this time: “No, no”.

K: And what happened then?

D: I had to stay in my apartment.

K: Why?

D: Because I got angry and I had to quiet down.

K: And then, what happened?

D: I quietened down and could come out.

K: Did you clean your apartment?

D: Yes.

As Debbie’s account shows, she initially objects to having to abide by the staff’s rules and regulations with regard to how she keeps her apartment. She thus at first challenges the stereotypical view and expectation of herself, linked to subordination and obedience. But later Debbie, after being punished for her behaviour, adheres to the demands by the staff and tidies her apartment in the way they approve of and presumably see as a normal way to keep one’s apartment.

Mike Oliver (1996) refers to normality as a construct imposed on reality where there is only difference. This “imposition on reality” is most powerful and indeed an important part of the everyday living of women with learning difficulties. The philosophy of normalisation, or the important aim of making available so called normal living conditions for women and men with learning difficulties (as a reaction to earlier institutional

living), can, as the example with Debbie shows, have disciplinary aspects (see Sandvin et al, 1998). Staff making women with learning difficulties keep their own apartment in a way which has been defined as a normal (and thus an ideal) way is indeed a form of disciplinary action. These kinds of incidents make visible the superior position of power of the staff in question. Despite Debbie challenging and opposing the subservient ascribed role of being obedient, she finally gave in and abided to the rules of the staff.

Lena, a young participant, tells of the importance of saying "no" to that which she does not wish to do. When asked if she in fact does this, she replies:

*Yes, I have learnt that from "the soap operas" on TV. The women there say no when they don't want to.*

The actresses in these TV-programs, or rather the characters they portray, have thus become role- models for Lena with regard to how to be a woman. Again, we can see that the meaning, and construction, of womanhood also contains elements of resistance and opposition.

#### **"One mustn't complain" approach**

Participating in the study in question are, as having been mentioned, also a couple of elderly (over 70 years old) women. Their accounts and actions differ from the other participants in that the former give no examples of challenging the opinions and demands of others; e.g. staff. This is another form of

subservience that the one we could see characterising Debbie's situation. These two women's situation can best be described in terms of a resigned kind of gratitude or a "one mustn't complain" approach. Important to take into account is here the different frames of reference of these older women to that of the younger participants. The former have a background of institutional living, which they did not wish to talk about other than to say that it was "bad". They thus compare their present living situation with their former one and consequently think that everything, which is an improvement on their earlier living conditions, is satisfactory. Also, it is likely that these participants have little opportunity to express their own requirements but have had to abide to the wishes and demands of others. However, it is important to acknowledge that also these women should be seen as active agents. They act in a way which most likely is rewarding in the sense of not having conflicts with the staff, and consequently being well liked by the same. One of these women, whom I call Ella, hardly ever goes "to town" despite longing to do so. She requires assistance in order to go, and doesn't wish to bother the staff with this requirement; i.e. ask them about it. She explains:

*The staff here much to do so don't think they the time. The girls work so hard.*

*Not want to make trouble.*

Ella's situation can serve to exemplify the importance of taking other factors than gender and disability, such as, for

instance, age or phase of life into account when examining and analysing the everyday lives of disabled people.

These elderly women's situation can also serve as an example of a life in accordance with a stereotyped, traditional one of subservience. When asked about the staff at the group-home where they lived; i.e. if there were those they got on better with than others, these women clearly got nervous. They looked behind themselves as if the staff were present in the room and did not want to talk about this issue other than saying that everyone they had to do with was "good and kind". The way these women reacted thus shows their subservient position in relation to the staff. The superior position of power of the staff thus was "in the walls": i.e. felt and taken notice of despite them not being in the room at the time of the interview. This demonstrates the close link between dependence (of assistance and support) and control. Those who provide assistance are often in a position to exercise some control over those having it, particularly when the latter are learning disabled.

### **Reconstructing one's self-identity as a means of empowerment**

#### ***Different forms of identity construction***

I have been referring to the paradox of women with learning difficulties being rendered invisible and at the same time marked out as different (see Young, 1990). The elderly women referred to above can be described as having

internalised this invisibility; i.e. as rendering themselves as invisible.

One aspect of being marked out, linked to the understanding of women with learning difficulties as different and not normal, is the various kinds of provided specialised services, i.e. with regard to school, housing, work, leisure etc. While these can be described as, and indeed are, a means of supporting women with learning differences in different ways, they are also part of constructing difference in the sense of deviating from the norm. Difference is thus constructed by way of an understanding that women with learning difficulties cannot or should not, with adequate assistance, attend a regular class in school (but a special one), work at a regular place of work (but a day-centre, often unpaid), participate in regular leisure activities, together also with non-disabled peers (but exclusively in those organised for those with learning difficulties) etc.

But these specialised services which are physically segregated from regular classes, places of work and leisure activities also have the effect of rendering women with learning disabilities invisible. They are not seen or noticed in regular classes in school, at regular places of work, where regular leisure activities take place etc.

Some may argue that opposing the ascribed identity as learning disabled, as we have seen examples of among the participating women, can be understood as "false consciousness". This is, however, an interpretation which implies some

kind of essentialism with regard to self-identity; i.e. that there is one "true" or "natural" way (as determined by others) of seeing one's sense of self. I mean that understanding those who have an ambivalent approach to, or indeed oppose the ascribed identity as disabled, in this way has disciplinary overtones, and does not serve to further our understanding of the issue in question.

Instead, I mean that the earlier referred to forms of identity construction, particularly those named "resistance identity" and "project identity" serve as a useful analytical tool in understanding the situation of those rejecting a self-identity as disabled. Castells (1997, p. 9) refers to "resistance identity" as involving expressions of "the exclusion of the excluders by the excluded". In line with this reasoning, we can understand the approach of the women in question as actively taking a stand against being excluded from various activities and opportunities.

The third form of identity construction "project identity" can involve (re)constructing an identity on the basis of an oppressed identity (ibid.). The (re)construction of an identity is here a project of a different life. With regard to women with learning difficulties, this can involve striving for a living situation with increased control and self-determination, or as Castells (ibid., p. 200) has formulated it: "Claiming identity is power-making".

Castells means that power in the Information Age is both diffused and identifiable, as power is part of an endless battle around the cultural codes of

society. Identities are important in the sense of them building interests, projects and values around experience, and anchor power in some areas of the social structure (ibid.).

Insisting on determining one's sense of self, which does not necessarily coincide with one's ascribed identity (as disabled), can thus be understood as a means of empowerment of women with learning difficulties. It can be seen as a reaction to being rendered invisible and at the same time marked out as different, and indeed as forwarding the message of "Don't tell me who I am. Instead, I will tell you"!

Opposing an ascribed identity with a devalued status and attempt to (re)construct one's self-identity thus redefines one's position in society, or put differently, serves to construct a meaningful interpretation of the self.

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