Reflections on collaborative research: to what extent and on whose terms?

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Collaborative research, for instance, emancipatory and participatory disability research, arose from critique against the lack of active disabled people’s participation in research, which failed to emphasize their personal experiences. By referring to power positions in a qualitative sociological study with young women with an intellectual impairment, and inspired by collaborative research, I discuss the possible methodological and ethical dilemmas found in different research phases, and in relation to the participants. I argue that collaborative research can benefit from being problematized and discussed further regarding the categorization of disability, as well as participation.

Keywords: collaborative research; categorization; involvement; insider/outsider; methodological and ethical dilemmas

Introduction

‘Really!? Do we know what it’s like? I thought it was the other way around, that you’d tell us how it is!’

This comment was made by a young woman, a participant in an ongoing study; her voice expressed great surprise. This scenario occurred when I was presenting ‘my’ study and explaining to the young women that I was interested in the experience of being a young woman today, in relation to body and womanliness. It is appropriate to use methods such as those used in collaborative research to illustrate the different personal experiences found among the young women. This article does not however focus on the empirical study as such, but rather aims to contribute to a methodological and ethical discussion. The study, on which the present article is based, is inspired by collaborative research in the form of participatory research, because it makes visible young women’s voices and their own experiences. It concerns conceptions of the body and gender among young Swedish women labelled with an intellectual impairment. I am inspired by participatory research, in that the participants in my study take part in constructing the interview themes.

In the present article, I define collaborative research as including the so-called emancipatory, participatory and inclusive research with people with (an intellectual) impairment. Collaborative research is one starting point for an important methodological approach that may have many advantages; it is supposed to make participants’ voices audible and engage them, so that knowledge production is grounded in their lived experiences (for instance,

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Oliver 1990; Zarb 1992). However, the need to develop methods for collaboration, such as in participatory research, has been highlighted (Erdtman et al. 2012). The present article is a reflection on some of the collaborative research in the field of disability. The focus is on how collaborative research can be problematized, and on its usability in light of a number of methodological and ethical dilemmas.

The opening statement, made by one of the participants, indicates surprise at being the one who knows and has the answers, even when the topic is her own experience. The importance of focusing on participants’ experiences led to the development of collaborative research.

**Collaborative research**

Disability research has taken different directions regarding collaborative research; this has resulted in different approaches that are influenced by each other and may be somewhat overlapping. The approaches that will be discussed are the following: emancipatory research, participatory research and inclusive research.

**Emancipatory research**

The emancipatory approach has its roots in the disability movement and the social model (Oliver 1990), the aim of which is to change the interpretation of disability. Oliver (1992) has criticized knowledge production that is grounded in a medical paradigm, which understands disability as a ‘personal tragedy’, and research on alienating:

> The social relations of research production provides the structure within which research is undertaken. These social relations are built upon a firm distinction between the researcher and the researched; upon the belief that it is the researchers who have specialist knowledge and skills; and that it is they who should decide what topics should be researched and be in control of the whole process of research production. (102)

Zarb argues that some research oppresses disabled people and claims that ‘research is still part of the problem and not the solution’ (1992, 127). Emancipatory research is supposed to lead to empowerment (Oliver 1992), which is a much-discussed concept (for instance, Gibbs 2004). Barnes (1990) discusses emancipatory research as a method to make disability research more relevant to the life situations of disabled people. It has been argued that emancipatory research is not a research methodology as such, but rather part of the struggle of disabled people and a way to control the decision-making processes that shape their lives (French and Swain 1997).

**Participatory research**

Participatory research has developed from qualitative methodological research with philosophical roots, its aim being to change the hierarchical power relations between researcher and research participants, for instance, by speaking of participants rather than research subjects (French and Swain 1997). ‘Participatory research thus aims to reflect, explore and disseminate the views, feelings and experiences of research participants from their own perspectives’ (26). Studies that are initiated by others, but involve disabled people, are regarded as participatory research (Zarb 1992). Participatory research is described as a method that equalizes the power balance between the researcher and the researched in the interview situation. This approach has been criticized from a feminist
perspective, which argues that the power balance is not static (and not only based on gender), but rather depends on several power dimensions, for example, gender, age, social class, etc. (for instance, Cotterill 1992). The debate in disability research concerning the complexity of the relationship between the non-disabled researcher and the disabled participants in relation to power positions has been further problematized by, for instance, Barron (1999) and Traustadóttir (2001).

**Inclusive research with people with an intellectual impairment**

There is a specific collaborative research method, so-called inclusive research, which is intended for people with intellectual impairment (for instance, Walmsley and Johnsson 2003). Inclusive research is influenced by a critique of traditional research relationships (Walmsley 2001). The following three principles are embodied in inclusive research: ‘that research must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them, that it must access and represent their views and experiences, that people with learning disabilities need to be treated with respect by the research community’ (Walmsley and Johnsson 2003, 16).

Specific criteria to be met are thus sometimes specified when conducting inclusive research. The participants are expected to take part in the study from its initial phase, as well as creating the interviews, analysing the material and evaluating the study (Walmsley and Johnsson 2003). Accessibility is of primary importance. If the disabled people cannot understand the study, they cannot meaningfully participate in it (Walmsley 2001). Inclusive research also implies a pre-conception that the people who are going to be included in the research process, are generally socially excluded (Walmsley 2004). Shakespeare (2006) has problematized this categorical binary of ‘disabled’ and ‘non-disabled’ people. He also argues for a shift in perspective, in which the focus is on partnership rather than oppression in activism and disability studies:

> Given the difficulties of separating, practically or conceptually, the lives of disabled people from non-disabled people, it seems striking that disability studies and disability activism has failed adequately to conceptualize or understand the roles of disabled people. There is considerable focus on oppression, but less focus on partnership or alliance (187).

**Some examples of dilemmas**

Emancipatory research, participatory research and inclusive research with people with an intellectual impairment vary in their historical and social backgrounds. They also have several similarities, for instance, the issue of ‘choosing sides’ as a researcher, which is implied in collaborative research. As Zarb (1992) argues, it is up to the researchers ‘to prove whose side we are on’ (138). This approach may be of value regarding the history of research based on a medical paradigm, in which collaborative research has been developed to provide resistance. But the issue may also risk not making visible the complexity involved in ‘choosing sides’. This is also a problem with respect to power positions. These two issues will be discussed and problematized below.

Another example of similarities among these approaches, which risk homogenizing heterogeneous groups, is the principle of focusing on ‘issues which really matter’ for disabled people. However, the question remains whether this principle may risk reproducing people with different impairments as homogenous groups, i.e. assuming that ‘they’ share the same interests, and want the same things in life. This approach may
lead to the reproduction of an understanding whereby girls, women, boys and men with different impairments are homogenized. And even if we, as researchers, do not have such intentions, our research may be understood in this way if we fail to specify who is included in the term ‘them’. I wonder whether these approaches risk promoting the assumption that impairment or disability is essential to people’s lived experiences and goals in life, independent of other power dimensions, such as impairment, gender, age, ethnicity, social class, etc. This generalized attitude towards difference may also have other consequences, as articulated by Barnes: ‘A generalized attitude towards a specific category of people, disabled or black, for example, applied indiscriminately to individuals in that category is a major feature of prejudice’ (Barnes 1990, 59).

The dilemma of making certain categorizations will be discussed further below, together with the notion of the insider/outsider dilemma and other dilemmas.

Collaborative research has inspired me because of the knowledge it creates, and the opportunities it provides to focus on participants’ lived experiences and to do inclusive research. However, during my fieldwork, some questions occurred to me regarding different dilemmas, which are embedded in the very premises of collaborative research and which have inspired me to discuss them further. These topics are: categorizations as a possible paradox, insider/outsider positions, the dilemma of inclusion and exclusion and the dilemma of knowledge and interests. These four topics will be discussed in the following sections.

Categorizations as a possible paradox

The importance of ‘choosing sides’ in collaborative research has been discussed above as both fruitful and problematic. Emphasis on ‘choosing sides’ is easy to understand in relation to the history of research production in disability studies, which was grounded in a medical model and entailed studies that asked irrelevant questions (Oliver 1990). However, the importance of ‘choosing sides’ may also be problematic, in the sense of reproducing a homogenous understanding of the living conditions of girls and boys, women and men, with different impairments. One example of this is inclusive research, a methodological approach that involves a categorization of a non-disabled researcher, who includes disabled people in the research process (for instance, Walmsley and Johnsson 2003), while at the same time the approach explicitly argues for the importance of the non-disabled researcher taking the side of people with an intellectual impairment (Walmsley and Johnsson 2003, 64). Perhaps this is the paradox of inclusive research: i.e. distinguishing the non-disabled researcher from the disabled participant and thereby risking the construction of the ‘Other’? To make this paradox clearer, I will relate it to another discussion about the paradox of normalization and rehabilitation. The following discussion is not related to collaborative research, but the premises of inclusion which implies first being categorized as ‘excluded’:

I want to demonstrate that normalization is an attempt to include by means of an exclusive manoeuvre. First you are marginalised and excluded, so that in the next turn you have to be included and rehabilitated. At the same time, you are doomed to fail. In this kind of situation, no amount of goodwill and desire for equality will help; you will constantly be countered by processes that continue to produce inequality and exclude you – ad infinitum (Moser 2000, 210).

What can the consequences be if, in the so-called inclusive research with people with an intellectual impairment, the focus is solely on the impairment? What about gender, age and social class, for example, or why not individual interests? What if impairment can be
seen as something more flexible, i.e. having an impairment that may be more disabling in some situations and contexts than in others? This problematizing on one categorization is not unique for disability research. Similar discussions have taken place in feminist research, for instance, with a critique that questions whether women should be considered an oppressed group regardless of sexuality, ‘race’ and etc. The unspecified talk about women as oppressed does not clarify, but rather distorts women’s different experiences/realties. This critique mainly comes from black feminism, lesbian feminism and third-world feminism (Wendt Höjer and Åse 1996, 32). Postmodern feminism has a similar critique, i.e. that the classification of people as women and men is just another way of exercising power, where the postmodern project is about deconstructing, questioning and dissolving current identity constructions and thereby enabling new identities (Wendt Höjer and Åse 1996, 33). Wendell (1996) argues that disability is not something universal. It depends on what is categorized as normal, in a specific time and place, and in relation to what.

One example that illustrates this dilemma is provided by a participant discussing the experience of being looked at; an experience which changes depending on place and situation:

People who know we’re studying here [in the special class] they think it’s abnormal. But if they should meet me in town, they can say that’s surely a normal person, but if they then see me here in school, they would say ‘that wasn’t normal’, they would think it’s so strange… But if they didn’t know I was studying here [in the special class] they would think I’m like anybody else. Some people ask me why I’m studying here and then I tell them… But then kind of ‘You seem so normal’… well Yes, Yes.

The above quotation from one of the young women in the study on which the present article is based shows the importance of not only focusing on the impairment, but also highlighting that, in relation to identity, the experience of impairment is individual and may vary in different places and contexts (for instance, Watson 2002). The conception of a static dichotomy between disabled people and non-disabled people is also problematic: ‘The boundary between disabled people and non-disabled people is permeable in a way that gender boundaries or ethnic boundaries usually are not’ (Shakespeare 2006, 186). The young woman’s account also illustrates the importance of emphasizing the meaning of place and context in relation to impairment and disability. The school system in Sweden makes the intellectual impairment clearly visible because of the fact that there are special classes for people who have been diagnosed as having an intellectual impairment. These special classes are usually located in the same main building as the so-called regular school. However, the special classes are sometimes in a separate part of the school building, or in separate classrooms. The Swedish school system thus contributes to the categorization of intellectual impairment. However, it is important to bear in mind that the young women referred to here do not necessarily identify with their impairment in all places, situations and contexts. The intellectual impairment is not necessarily experienced as disabling in all places, for instance, outside the school. Shakespeare (2006) highlights how important it is that people have ‘multiple affiliations’, i.e. that they can identify with categories other than impairment, for example, gender or ethnicity (2006, 186). Kristiansen (2004) defines this as ‘multiple jeopardy’ and focuses on the multiple intersections of categories, defining them as a ‘broad zone of risk and vulnerability’ (Kristiansen 2004, 377). In Kristiansen’s example, the ‘multiple jeopardy’ implies being a woman, a disabled person and a person seeking help. This implies multiple risk and
vulnerability, which is not identical to discrimination, but where being subject to discrimination may be one consequence. ‘Having a position of multiple jeopardy is not a sign of individual weakness or personal deficit, but is rather something that is created and maintained in a complex social, political, cultural, and historical context’ (377).

Shakespeare (2006) also highlights the importance of realizing that having the same diagnosis does not automatically mean having the same impairment experience: ‘Rather than allowing impairment/disability to dominate their lives, they adopt a ‘really normal’ persona, disavowing their difference and seeking what connects them to non-disabled people, not what separates them’ (186).

The categorization in some collaborative research (for instance, so-called inclusive research with people with intellectual impairment), which focuses on the non-disabled researcher including the disabled participant, may be problematized from an intersectional perspective, in line with Shakespeare’s (2006) and Kristiansen’s (2004) arguments. An intersectional perspective is based on a multidimensional understanding of identities, rather than on one based on impairment, the aim of which is to avoid the risk of reproducing people with specific impairments as a homogenous group. It is relevant here to highlight that other discussions are also evident, for instance, the importance of giving disabled people the chance to be in the position of the researcher (Oliver and Barnes 1997).

The importance of ‘choosing sides’ that was discussed above as a possible dilemma, within some collaborative research, is related to insider/outsider positions, which will be discussed in the next section.

**Insider/outsider positions**

Barron (1999) exemplifies some ethical dilemmas when it comes to the relationship between the non-disabled researcher and disabled participants. Barron (1999) argues that ‘siding with’ the participants can create ethical problems; for instance, masking the superior power position of the researcher makes visible the insider/outsider dilemma. What if I, as a researcher, identify at different times and in different situations, with both the position of being an insider and an outsider in relation to the participants? What if I can be an insider and an outsider at the same time? Or, go back and forth between the two positions? In the present study, I could possibly position myself as part insider and part outsider. I can see myself as an insider regarding gender. I am/have and construct a gendered so-called ‘female body’ in a consumer-gendered culture, as do the participants. I also have the experience of having been a young woman in a Swedish school (even if I do not share the experience of attending a special class). At the same time, I have the preconception that these young women are labelled with an intellectual impairment and I, being older than them and having earned university credits, can be understood as an outsider. Also, how I position myself in the study may not be identical to the ways in which the participants position me.

It is also of relevance to discuss the insider/outsider positions in relation to place and context. During my fieldwork, which was done in the young women’s school, I strategically avoided being associated with an authoritative teacher position by, for instance, not interfering if the participants spoke at the same time during the group interviews, and not following the time constraints meticulously (this illustrates my experience and preconceptions of a teacher’s position). I clearly described what my aim and position were for the participants, but despite my strategic attempts to not be associated with an authoritative teacher position, the participants noted in the evaluation at the end of the study that I had been a ‘really good teacher’ – the one thing I had hoped they
would not say. This illustrates that the meaning of place and context, in this case the school, is of great importance, i.e. the expectations placed on the researcher and on the categorization process and how the participants positioned me were not what I expected/wanted. Among the teachers at the school, on the other hand, I was seen and treated like one of the students. For example, one of the teachers once commented on my appearance and adjusted my sweatshirt which was somewhat untidy in appearance. Another teacher once took me kindly but firmly aside to inform me about the importance of being punctual (it is important here to mention that the participants did not have an issue with my time keeping). These examples may be understood as indicating that, in the school arena, the two positions of teacher and student are most prominent. What that means for the research process and, for instance, the conclusion and analysis is important to reflect on.

The above experiences provide some examples of the complexity of researchers viewing ourselves as (static) outsiders or insiders in the research process. The position of insider/outsider is dynamic and affected by impairment, disability, gender, age, social class, place and context.

One aspect of the insider/outsider dilemma is that I enter the field with the preconception that the participants are labelled with an intellectual impairment. How does this affect my role as a researcher? How can I be sure to do my interviews in an acceptable way; for instance, without being patronizing? Barron (1999) reflects on these questions: What if I, as a researcher, cannot explain the aim of the research clearly enough, so that all the participants with an intellectual impairment understand this and their rights? Is it then ethically correct to conduct the study? This is a dilemma which needs careful consideration. I question whether we can ever be absolutely sure that our participants in general, i.e. not only participants with an intellectual impairment, fully understand the aim of our study. It is thus of importance to give information in different ways and regularly at different times throughout the research process. Although I did precisely this, one of the participants once asked me, after the group interview: ‘What is that lying on the table’ and pointed at the dictaphone. This illustrates the importance of self-reflection among researchers (for instance, Traustadóttir 2001; Llewellyn 2009; Petersen 2011), during the study, and of being clearer, following-up and reminding participants about the research process. Consent is of great importance, and it is up to researchers to clearly inform participants about the aim of the study and the procedures when necessary; not only at the beginning of the study.

The dilemma of the insider/outsider position(s) in research is complex and is thus fruitful to problematize further regarding several power dimensions, for instance, gender, age, ethnicity, social class and (dis)ability as well as in relation to the meaning of the place and context where the research is conducted (for instance, Barron 2011). The dilemmas of categorization and the insider/outsider positions are also related to what ‘involvement’ actually entails. Involvement is central in collaborative research. What we mean by involvement, and involvement to what extent and on whose terms, is fruitful to discuss further.

The dilemma of inclusion and exclusion
I argue that it is important that we reflect on our choice of all kinds of collaborative research, in the same way as we think about other methodological and ethical considerations. Collaborative research may involve participants in a time-consuming process. But what do we mean by involvement? And involvement on whose terms?
Barron (2001) discusses the experience of interviewing some elderly women with an intellectual impairment, who were not used to being asked about their own opinions, and not used to being at the centre of attention in this way. The following example from my fieldwork is an example of being uncomfortable about being at the centre of attention, and it also illustrates my bias as to the meaning of inclusion and the dilemma of inclusion and exclusion.

Lisa (fictitious name) really wanted to take part in the study. She was always on time. However, she did not say much in the focus group interviews from the beginning; rather the opposite. She was always among the first to enter the room. Despite this she always sat alongside but not at the table I had arranged so that all participants would have a place to sit. She sat on the side at her own little table. Her desire to sit apart from the rest of the group caused me to experience some stress. I wanted all of the participants to have a feeling of participating, and because of this I had a preconception that physical participation was valuable and that all of the participants would sit together around the table and by doing so bring about a feeling of participation. But for whose benefit was all this participation, and on whose terms? So, how did I handle this situation, when one of the participants loved to be part of the project but at the same time decided to sit alone at another table? Lisa’s choice made me worried. In my effort to correct the situation I asked if she wanted to come and sit with the rest of us. As soon as I asked the question, she got up from the table and walked out the door.

The following Monday she was, as usual, among the first in place. And, as usual, she sat down at her own isolated table, and as usual I pulled up a chair from our table and asked if she wanted to sit at the table with us. She got up and left the room again. This scenario was repeated on three different occasions. I have now realized that it was my intention to include her physically in the group that made her leave the room. The following Monday she was on time as usual. But this Monday I did not ask the question that made her leave the room. She now stayed in the room and in the discussion, still sitting isolated at her own table. As time passed she came closer, and by the end of the empirical work she was sitting at the same table with the other young women and was participating in the discussion, on her own terms.

This example from my fieldwork may not necessarily be methodologically associated with collaborative research, but I see it as relevant to discuss in relation to this type of research. The dilemma was caused by my action and my intention to make sure that Lisa would feel included. However, I directed her to a place where she was not ready to be and because of this she became, for a time, excluded. Inclusion may mean different things depending on who you ask and on the situation. Collaborative research is supposed to have positive effects for the participants (for instance, French and Swain 1997; Walmsley and Johnsson 2003). But how can we make sure this will actually always be the case? (for instance, Hyder and Tissot 2013).

One strict definition of collaborative research claims that the participants should take part in all phases of the research. For instance, when deciding on the aims of the study, constructing the interviews, doing the interviews, writing and analysing (for instance, Starring and Söder 2005). It is, however, important to emphasize again that the aim of the present study was decided before the participants were contacted. A collaborative approach would have been difficult because the study was done in an academic context with its own rules and regulations. The aim was embodied in the research question: ‘What can it be like to be a young woman in Sweden today, with regard to conceptions of the body and womanliness?’ The young women were informed that I was interested in their experiences. This made some interview themes possible, but not others. What is
probable in this case is that what was discussed in the focus group interviews, and the interview themes that were decided by the young women themselves, would not have been the same if the young women had also decided the aim of the study. It has been argued that it is problematic when the participants are not involved in decisions, as this implies a lack of control over the research process on the part of the participants (for instance, Stone and Priestly 1996; French and Swain 1997; Barnes and Sheldon 2007). Perhaps the fact that the participants did not take part in deciding the aim of the study, or in the process of analysis, means that what I was doing was ‘light’ participatory research. The question remains, however, is there automatically ‘more’ participation in practice if the participants are involved in all research phases? Or is it more important that the participants are actively involved in deciding how much, how and when they will (not) participate in the research process?

In the analytical process, the relative power of the non-disabled researcher requires to be problematized. Participatory research has been discussed as an important method because it is more likely to produce results that are representative of the participants’ lived realities, when the participants create the research questions based on their lived experiences (Lunn and Munford 2007). However, Lunn and Munford ask the thought-provoking question: ‘She knows who she is! But can she find herself in the analysis?’ (2007, 65). The question deals with whether or not we, as researchers, illustrate the participants’ voices, or rather create a new story and a new experience: ‘She knows who she is, her reality is her own, but she is handicapped (sic!) by her lack of voice in the research text’ (65). The question we may ask ourselves before starting a research project is, according to Lunn and Munford: ‘What are the discourses that the research is supporting and disrupting? Are we disrupting the dominant discourses and replacing them with new voices of resistance and representation?’ (65). These dilemmas are worth reflecting on, even though the issue of us knowing who we ‘are’ can be further problematized from a social constructivist perspective (Butler 1990). However, including the participants in the analysis – participants who do not necessarily have knowledge of (or an interest in) the consequences from the written material – and including quotations from them may also be a dilemma in need of consideration.

A central aim of collaborative research is to confront oppression and make injustice visible. But what is the role of social disability research? Can this line of research make a difference in the life situation of disabled people, and if so what difference can it make?

**The dilemma of knowledge and interests**

In the initial phase of the research process, when I contacted the school where the fieldwork was conducted to ask for permission to meet the young women (in order to ask them if they were interested in participating in the study), the teachers asked me the important and somewhat tricky question: ‘How will this research benefit the participants?’ How do we, as researchers, answer that question? And can we give a definitive answer? Whether research can make a difference in the life situation of disabled people, for instance, by increasing self-determination, has been important in disability studies. This issue that research must benefit those involved is central to collaborative research. Emancipatory research is described as an approach that is intended to change and improve the life situation of disabled people and lead to their empowerment (see, for instance, Oliver 1992; Zarb 1992). Similarly inclusive research with people with an intellectual impairment is intended to lead ‘ultimately … to improved lives for them’ (Walmsley and Johnsson 2003, 16). However, it may also be fruitful to question these
pre-conceived ideas; the taken-for-granted notion that the participants experience is one of oppression, and that they want a change in their life situation. I argue that this is an empirical question. Shakespeare (1996) problematizes the idea that research can make major changes in the lives of disabled people, even as he appreciates the motives driving researchers who are engaged in emancipatory research:

Shakespeare also argues that research can contribute to an environment that makes change possible:

We must address the different approaches regarding the role of social research, i.e. can it, or should it, change the life situation of disabled people may be understood as different statements of knowledge interests. Habermas (1987) identifies three ‘knowledge interests’ that need to be understood in order of make sense of the practice of social science and its consequences for society. These are: the ‘empiric-analytic’, the ‘historical-hermeneutic’ and the ‘critical sciences’.

The empiric-analytic approach is interested in technical control. Scientific knowledge increases control over the material conditions in which we find ourselves, and thereby increases our physical and spiritual health and our security. The aim is to produce prediction and explanation. ‘Empirical-analytic knowledge is thus potentially predictive knowledge. However, the value of such predictions, that is their technical exploitability, is established only by the rules according to which we apply theories to reality’ (308). The historical-hermeneutic sciences arise through a practical interest to achieve consensus which is necessarily fluid and dynamic. Hermeneutic understanding (Verstehen) aims to restore broken channels of communication: Access to the facts is provided by the understanding of meaning, not observation’ (Habermas 1987, 309). The critical sciences have emancipatory interests and according to Habermas (1987) go further than the creation of nomological knowledge (the empirical–analytical interest) and Verstehen (the ‘historical hermeneutic’ interest). The critical sciences are ‘concerned with going beyond [the] goal to determine when theoretical statements grasp invariant regularities of social action as such when they express ideologically frozen relations of dependence that can in principle be transformed’ (310).

Habermas (1987) highlights the importance of self-reflection within critical science in order to identify conceptions of what is understood as ‘natural’ as well as structures of power that embody ‘systematically distorted communication and thinly legitimised repression’ (371).

According to Habermas (1987) the knowledge interest, and the method used, is not important with regard to emancipatory work. It is crucial that researchers are willing to challenge their own assumptions and interpretations. The way in which the results are
received and by whom are more important than the choice of method regarding the possibilities of emancipatory work.

Critical self-reflection is fruitful if researchers want to avoid, or make visible, the ‘trap of goodwill’ (Barron 1999). Having a research goal to, for instance, improve the life situation of beneficiaries may run the risk of overlooking different individual experiences among disabled people. A question for further reflection is whether or not it is really up to researchers to determine the meaning of emancipation.

Conclusion

In this article, I have highlighted the importance of further reflection on collaborative research, by problematizing on whose terms and to what extent the research is participatory. This is a complex question that is worth analysis and discussion with those who are in fact being actively ‘included’ in the research rather than only the ‘research world’.

Inclusive research with people with intellectual impairment implies a pre-conception that the subjects who are going to be included in the research process are generally excluded from society (for instance, Walmsley 2004). What are the consequences of inclusive research assuming that ‘disabled people’ are excluded? And if they are, what are ‘they’ excluded from? And according to whom? Perhaps an intersectional approach can be of use to ‘so-called’ collaborative research. It may help to avoid homogenizing people with different impairments, interests and experiences. Moreover, an intersectional approach (for instance, Kristiansen 2004; Björnsdóttir and Traustadóttir 2010; Barron 2011) may be of value in the continuation of the discussion of the problem of the researcher ‘choosing sides’, to problematize the idea that the different ‘sides’ are static.

The dilemmas that have been discussed in this article are examples of dilemmas that require further reflection among the research community. The central question is whether it is really up to the research community to determine whether or not so-called collaborative research is emancipatory.

References


