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## **Integrating Participatory Approaches in Research: Power, Dilemmas and Potentials**

### *Abstract:*

This article introduces and discusses participatory approaches in research as an epistemological and methodological contribution to research in general and more specifically to diaconal research. I outline characteristics of inclusive research and delve into the opportunities that participatory research offers interdisciplinary research. Next, I introduce and discuss ethical dilemmas that may arise with these inclusive approaches. Finally, I highlight how integrating participatory research approaches can transform diaconal research. I show how this transformation can take place through the codevelopment of new knowledge by citizens who are recognized as subjects of knowledge. The discussion is informed by an example from my own research, a historical study of the Christian diaconal practice for deaf persons with disabilities in a Norwegian context. Drawing on experiences from collaboration in this project, I discuss the spaces of action that researchers have when aiming at inclusion in their research. The article is a contribution to the development of methodological and epistemological issues in participatory research discourses.

### *Keywords:*

participatory research, knowledge production, research ethics, citizenship, disability

## **1. Introduction**

“Participatory research” is an umbrella term, covering different participatory approaches and methodologies. Empirical research is generally practiced by researchers conducting research on, rather than with, persons and groups. For example, in health and social science research, researchers study topics and problems defined from a medical or social-science perspective, wherein persons with situated personal knowledge are involved as interview objects rather than as subjects of knowledge. However, such research practices have been challenged, both methodologically and epistemologically (Spivak: 2016; Siebers: 2008). These practices are critiqued as being objectifying, evoking the civil rights movement’s slogan, “Noth-

ing about us without us” (Pelka, 2012). In other words, stakeholders argue for the right to participate in research that is important to them or their group (Bridges: 2001; Beresford: 2013). In Norway, the Norwegian Research Council has called for researchers to explore opportunities for including users and citizens in research projects (The Research Council of Norway: 2020).

Diaconal research comprises interdisciplinary studies of faith-based institutions and church-related social practices focusing on persons in vulnerable life situations, social justice, and human rights, and phenomena related to diakonia. Diaconal practice both provides social services and contributes to the welfare state as value-based actors (Leis: 2004). As a research practice, diaconal research is characterized by interdisciplinarity, methodological pluralism, and normativity. Empirical studies include studies of practices and contribute to establishing links between theory and practice (Stifoss-Hanssen: 2014, 64). Although often theoretical, diaconal studies have become increasingly empirical (Gynnes: 2020; Lid: 2019; Rønsdal: 2016; Eurich: 2012; Wyller: 2009).

Normative and critical dimensions in empirical studies are elements of diaconal research. One normative principle underpinning participatory research approaches is the principle of equal status. Through research it has been demonstrated that even if the intention of diaconal practices is good, over time there have been wrongs and misdeeds in such practices (Foss, 2011; Lid, 2019). Diaconal research therefore needs to consider the experiences of those persons who have been the objects of diaconal care practices. This ethical motivation for participatory research is valuable as a research approach. Diaconal research must include the situated knowledge from these perspectives if it is to create new knowledge to develop further diaconal practices. Persons should not be reduced to simple care receivers in diaconal settings but always be recognized as subjects of their own life (Dietrich: 2014, 14).

In this article, I present participatory research as an approach in diaconal empirical research. I discuss participatory approaches in the different phases of a research project. I then identify and examine specific ethical dilemmas faced by researchers and research institutions when working collaboratively with researchers who are not trained as such. By using a case from my own research, I examine the participatory aspects of a diaconal research project – of which I was the lead researcher (Lid: 2019). I then discuss the spaces action researchers have when aiming at inclusion in research, and what dilemmas they must handle. Lastly, I discuss the opportunities that emerge when engaging in participatory research, including recognizing new subjects of knowledge in research practices.

## 2. Knowledge Production in Research

In the context of this article, the term “research” refers to “interdisciplinary research.” As a form of knowledge production, research takes place in social contexts and is contextual. Both theoretical and empirical research aim at the systematic collection and analysis of data. Here, by using the word “production,” I underscore the manufacturing aspect of research. Research is produced by human beings and thus fallible, much like the intended product of research, knowledge is vulnerable. This vulnerability is inherent in the practice of research, regardless of whether the research is mono- or interdisciplinary. My own field of research, disability research, is by necessity interdisciplinary, since disability – both a phenomenon and an experience – comprises individual and contextual factors. These factors include gender, socioeconomic status, the individual embodiment of biopsychosocial health, society, culture, religion, politics, and legislation – all of which are important for understanding disability (Shakespeare: 2018; Garland-Thomson: 2003). Disability, as a site of situated knowledge represents subjects of knowledge, while it is itself an object of knowledge (Harding: 1991).

Knowledge is a complex phenomenon involving knowers, ways of knowing, and the objects of knowledge – including the process of justifying knowledge claims (Stern: 2008). In *Theaetetus*, Plato refers to Socrates’ dialogue on knowledge and its complexities (Stern: 2008). A workable definition of “knowledge” in this dialogue indicates that it can be true, needs to be justified, and concerns belief. In other words, the person who knows something believes that what they know is the truth about that specific subject.

Even today we still struggle with understanding knowledge. The Norwegian philosopher Knut Erik Tranøy understands scientific activity as “the systematic and socially organized a) search for, b) appropriation and production of, and c) administration and communication of knowledge and insight” (Tranøy: 1986, 59). Research as knowledge production is systematic, socially organized, and encompasses both the production and communication of both knowledge and insight. Tranøy’s definition is helpful, but insufficient for knowledge production as a social process aimed at developing knowledge in a social context. Knowledge is contextual. When working on an interdisciplinary and transdisciplinary basis with knowledge production, a shared understanding is helpful, while also acknowledging the complexity of knowledge.

A “knowledge production mode” refers to how scientific knowledge is produced. According to Nowotny, Scott, and Gibbons (2001), basic research, mode 1, is knowledge produced as fundamental, basic knowledge with less focus on applicability, whereas mode 2 research refers to research carried out as collaborative social enterprise. These research practices have a direct focus on implementation and usability, are closely related to contexts, and are carried out in collaborative processes, often

characterized by interdisciplinarity. Because this mode of research is guided by its applicability and usability, the public and the users of research are relevant as actors contributing to the research processes (Nowotny et al.: 2001). Knowledge production in empirical research may therefore include both trained researchers and the users of the research, such as professionals and service users, patients, and clients.

According to the general guidelines for research ethics in Norway, knowledge production in research is guided by four principles: respect, good outcomes, fairness, and integrity (The Norwegian National Research Ethics Committees: 2019). All empirical research builds upon some form of participation: Participants respond to a questionnaire or an interview, or they are observed in specific situations. Each participant consents to the participation, but the researcher does most of the actual decision-making at all phases of the research process. As such, the relationship between the researcher and the researched is largely a subject-object relation, exemplified by a medical doctor researching patients to find a cure for their condition, or a social scientist researching poverty in urban areas to inform future interventions.

In addition to being dependent on participation, empirical research also depends on cooperation. Because it has an inductive dimension, empirical research seeks to develop knowledge from contexts, people, and experiences – in contrast to theoretical studies, where a scholar generally reads and discusses texts with other scholars. However, empirical research is not exclusively inductive: Popper (1979) argues that all data rely on theory for their interpretation and understanding. Empirical material is intentionally generated by a researcher to answer or shed light on the research questions defined by the researcher.

The empirical research process generally follows a specific trajectory. First, there is the planning phase, in which the researchers develop the project and often apply for external funding (even if a research institution has already provided funds). In this phase, the researchers use their own working hours to develop the project and secure (additional) funding. Typically, there is no funding for coresearchers to participate in this phase of the process. However, a successful participatory research project should include participation from the start: This therefore represents a potential dilemma.

The next phase of the research process begins when the research project is fully funded and can thus be carried out. This is an important phase of the project, as many decisions are made early on. Cooperation in this phase is therefore important for establishing symmetric relationships between the researchers and coresearchers – or at least as symmetric as possible, given the distribution of resources in the project. The third phase of the process comprises the analysis of the empirical material. Here, the participatory dimension of the research project may be diminished, or it may play an important role. The process of analysis may be quite productive

in participatory approaches, as coresearchers often see other aspects of and topics in the material the trained researcher might miss.

The final phase of the project involves discussing and then disseminating the findings. If the research is to be characterized by participatory approaches in all phases of the project, methods facilitating cooperation in the dissemination phase must be employed as well (Chalachanova et al.: 2019; Chalachanova et al. :2020). Below, I refer to all phases, more generally, and to more specific phases when discussing participatory research approaches.

Persons who are involved in research without being educated as researchers are referred to as “coresearchers.” They work together with the trained researchers on research projects. As Cook (2012) explains it, participatory research means conducting research *with* people rather than *on* people. Moreover, according to MacTaggart (1997), this participation must be authentic rather than merely symbolic. The research practices must therefore be guided by an inherent recognition of the new research participants as equal subjects of knowledge. As such, participatory research is characterized by systematic cooperation and relations between the researcher and persons in the field, such as coresearchers.

Inherent to participatory approaches, then, is a shift from subject–object relations to subject–subject relations. Here, new subjects of knowledge are recognized. For example, in disability research, disability as a phenomenon should not be reduced to a medical issue, but instead recognized as an existential and human rights issue. In this understanding, the person with the disability is not approached as a source of scientific data (i.e., as an object of knowledge) but as a subject of knowledge. Such a shift is motivated by a desire to include lived experiences and situated knowledge in knowledge production. New knowledge becomes the product of collaborative work. Access to knowledge production, however, is limited in empirical research. For instance, patients’ knowledge is often marginalized, as is that of undocumented migrants and homeless and low-income individuals (Beresford: 2013; Stålsett, Taksdal & Hilden: 2018).

Participatory research has been employed in theology, perhaps most prominently in contextual theology, where laypersons with differently situated knowledge interpret biblical texts together with trained theologians (Green: 2014; Bevans & Tahaafe-Williams: 2012; Pears: 2010). The participants bring with them their situated knowledge – i.e., user knowledge or lay knowledge – and participate in developing new knowledge in cooperation with researchers. Their participation brings with it the potential of providing new ways of seeing (Cook: 2012). It is important to note, however, that scientific knowledge and situated knowledge may differ or be described with varying words and concepts.

Participatory research methods have also been applied for decades in disability studies. In these two fields (disability studies and theology), participants in inclusive approaches may be patients, nurses, persons with disabilities, service users,

members of a congregation, deacons, ministers, and more. Indeed, participatory research in general involves many different actors, including researchers, (professional) practitioners, research funders, ethical committees, and the academy (Seale, Nind, Tilley & Chapman: 2015). Researchers may also choose a participatory approach for many reasons, to democratize research, to emancipate the researched, to obtain stronger knowledge claims (justification), and for ethical considerations (Askheim, Lid & Østensjø: 2019). Motivations for participatory approaches can be traced back to Paolo Freire and his liberation pedagogy and theology (Kindon, Pain & Kesby: 2010).

The strength and breadth of the element of participation in research range from user-led research, at one end of the scale, to consultation of users, at the other end. The “ladder of participation,” a model developed by Sherry R. Arnstein (1969), describes the steps from the lowest level to the highest level of participation. However, this model has been criticized for being static (Tritter & McCallum; 2006). The practice of participation is often more complex, and the lines between strong and weak participation may blur and change throughout a project.

An analytical differentiation of participation in research was proposed by Peter Beresford (2013), who himself is both a researcher and a service user and has participated in research as a coresearcher. Beresford proposes an analytical distinction between three levels of participation. At the first level, input from service users to the researchers defines how participation in research is organized; this can mean answering a questionnaire or responding to interview questions. The next level is collaborative or partnership research, where service users and/or their organizations and researchers and/or their organizations jointly develop and undertake projects. The third level has the highest degree of user participation, namely, user-controlled research, where the users also initiate and control the research (Beresford: 2013, 142, referring to Sweeny et al.: 2009). The user-led research level prioritizes the interests and perspectives of user organizations. For this article, we consider the second level, collaborative approaches between researchers and organizations and individuals, to be most relevant.

Seen from a researcher’s perspective, the participatory aspect requires preparation and accommodation. Limited resources (time and money) may hinder participation in research. For instance, coresearchers are often representatives of nongovernmental, religious, disability, or human-rights organizations. While some of these organizations may pay for their participatory work, it is usually seen as volunteer work. And while research institutions allocate time for research for professors and sometimes teachers, this is often not the case for researchers from outside the academy. Paying interviewees can be seen as potentially problematic, as it may unduly influence the empirical material. Clarifying the difference between asking someone to participate as an interviewee or as a coresearcher therefore has financial consequences for a research project. Furthermore, as participatory research meth-

ods become increasingly popular, participation fatigue may be a result, as different researchers may ask the same persons to participate.

### 3. Participatory Approaches in Diaconal Research

Diaconal institutions are faith-based organizations whose work is value-based. However, diaconal research should not be reduced to the study of institutional practices. Social work, health, and welfare studies are also relevant to diaconal research. Furthermore, one must examine what lies at the core of the diaconal research: Is it the church, the institution, or the person? In a Scandinavian context, diaconal research is anchored in the interdisciplinary studies of theology, practical theology, and welfare practice, which include social work and interdisciplinary health and welfare studies. The Norwegian diaconal scholar Sturla Stålsett and his colleagues (Stålsett, Taksdal & Hilden: 2018) argue for a rethinking of knowledge production in diaconia and for understanding the process of researching a diaconal practice. Their argument is anchored in liberation theology, alongside a participatory action research paradigm (PAR) as a methodology and research program. Stålsett et al. argue that research, when carried out correctly, can itself become a diaconal practice and argue that specific criteria must be present, for example, the research must be morally committed to social justice, expressed as (diaconal) action, and participatory and dialogical in nature (Stålsett et al.: 2018, 176).

I agree with Stålsett et al.'s argument that research as a practice has the potential to create and establish political and sociocultural changes. To do so, however, the researchers must focus on the aim of the research and strive to take a heterotopic position. In other words, the center of the practice – in this case, the research practice – must lie outside the research institution (Wyller: 2009; Gunnes: 2017). The person involved in research, as a subject of knowledge, is at the center of knowledge production. I am, however, reluctant to describe research as diaconal practice, because of the ambivalences inherent in the power relations in research (discussed below). I am also not confident that a PAR research method can guarantee specific results, as research conducted in social contexts is difficult in so many ways (Dedding, Goedhart, Broerse, & Abma: 2020).

To further the discussion on participatory diaconal research, I now turn to a research project I have headed and been involved in as a researcher. The project was a commissioned research project to examine Christian social practice in the evolving Norwegian welfare state, a historical study conducted between 2015 to 2018 on a diaconal foundation in Norway called the Home of the Deaf (*Hjemmet for døve*) (Lid: 2019). The foundation has offered education, a home, and welfare services to deaf persons with disabilities since 1898. According to Beresford's analytical distinction presented above, the project was not characterized by strong participatory aspects.

The participation was mostly reduced to input to inform the study. My role, as the main researcher, was to lead an interdisciplinary group of researchers which included researchers from sign language, rehabilitation, theology, pedagogy, and disability studies. As such, the project focused on topics across many disciplines – pedagogy, history, theology, sign language, deaf studies, and disability studies. I present and discuss the character of participation in this project below.

The Home of the Deaf was initiated in 1898 by Conrad Svendsen, the first minister for deaf persons in the Church of Norway. It was owned by the Lutheran Home Mission Foundation (Det norske lutherske Indremisjonsselskapet) and was funded through local governments and private gifts. The foundation identified deaf and deafblind persons with disabilities as their target group for diaconal practice; most of the persons living at the Home of the Deaf had learning disabilities. This was one of the few diaconal institutions providing services to persons with disabilities in Norway.

The research project on the social and diaconal historical practice included theoretical resources from diaconal research and disability research. The foundation itself was engaged in the research, as it both commissioned and funded the project. Moreover, throughout the research process, the methods, approaches, and results were all discussed with the foundation. There was, however, less involvement with the service providers and the service users, i.e., the deaf persons with disabilities.

The deaf persons were not treated as equal citizens (neither in life nor in death), from the foundation's start in 1898 until the welfare reform in 1991.<sup>1</sup> Two empirical examples illustrate this. The first example is an illustration of inequality in life. The foundation owned two institutions, one in Nordstrand, on the outskirts of Oslo (now part of Oslo), and the other on the outskirts of Andebu, a small village 120 kilometers south of Oslo. In Nordstrand, the institution consisted of two three-story houses. In the census of 1939, 77 persons lived in the two houses, 11 of whom were members of the Svendsen family, who headed the foundation: one was Conrad Bonnevie-Svendsen, at the time the minister for the deaf in the Church of Norway and the Head of the Home of the Deaf Foundation. In addition, 40 people were listed as inhabitants, being cared for by the foundation. These inhabitants lived under less beneficial living conditions than the Svendsen family, both in terms of physical space and nutrition. The situation was similar at Andebu, where the foundation owned a farm. Here, members of the Svendsen family lived in a large and beautiful farmhouse, while the deaf inhabitants lived in a dormitory – two in each room and without access to hot water. The foundation did in the decades

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1 The welfare reform (in Norwegian: *HVPU-reformen*) transferred the responsibility of providing services to persons with learning disabilities from the state level to the local level. The aim of the reform was to improve living conditions and support inclusion in local communities.



before the welfare reform not prioritize improving the living conditions for the deaf inhabitants, deciding instead to renew the farm buildings (Lid: 2018).

The second example illustrates the deaf persons' unequal treatment in death. Not until 1970 did the foundation board decide that upon death the deaf inhabitants should be given individual gravestones (Lid: 2018, 31–32). In other words, before that time the service users were not treated as individuals in death and in the context of the diaconal practice not considered as equal to other citizens in society at that time.

When conducting this historical study, I found it difficult to understand why a diaconal foundation did not work harder to treat the inhabitants as equal citizens in life and in death. The family in charge of the foundation were ministers in the Lutheran State Church and lived in very close proximity to the inhabitants. In other words, they could see the differences in living conditions very clearly. Moreover, the deaf inhabitants were providing the family with the opportunity to live in what in the census of 1939 could be seen as affluence. Indeed, family members lived in nice homes with a cook, driver, and maidservant (Lid: 2018, 45–46). I wondered how this was possible and how to understand the asymmetry in privilege and power in the inner space of this institution, which was led by representatives of the Svendsen family for more than 80 years.

I have been reflecting on the impact a broader involvement might have had on the study. An interview I conducted with Lasse Seder – a service user and on and off resident of the institution since the 1950s – offers some insight into what might have been achieved through an inclusive design. Seder reflected an interesting ambivalence toward the diaconal institution: a balance between critique and recognition. The recognition centered on accepting that perhaps the Home of the Deaf did the best they could, given the era and financial and professional conditions. There were few professionals employed, and little time was available to care for the needs of the individual.

According to Lisa Hall, participatory research includes different spaces and has the potential to create a new third space of understanding (Hall: 2014; Seale et al.: 2015). Participatory research can be understood as a space that is shared between different actors, researchers, the institution, and the users of the institutions' services (Seale et al: 2015, 485). In the study of the historical practice of the Home of the Deaf, I represented the academic interdisciplinary space – as did the other researchers involved in the project. The involvement of the diaconal institution in the project (i.e., via the administrative head and the board) represented a management space. The practitioner space and the service users space were only partly represented through the interview with Lasse Seder and a few other persons.

Participatory research as a research design may influence knowledge production on the microlevel, the institutional level, and the macrolevel. An additional way of understanding this is that two perspectives – both at the microlevel of knowledge

production – were weakly represented. Consequently, the models, theoretical perspectives, and conceptual approaches may not have addressed issues of relevance to the individuals involved. In this case, the interplay between service users and service providers at the microlevel is of specific interest, as both groups knew each other quite well. Some of the service providers were children of former service providers or had grown up near the institution: They knew the inhabitants and service users over a long time and from different perspectives and in different situations. In this kind of context, an inclusive approach could have been promising; a third space for new understandings could have been added to the specific and concrete situations historical studies normally focus on (Hall: 2014). According to Annette Leis (2004), values are of importance for the motivation of independent welfare organizations such as diaconal institutions. When studying the institutions then, the microlevel is crucial to exploring how the institutions' values work in practices involving the lives of persons in vulnerable life situations.

These new approaches developing from historical analysis can serve as a basis for creating new practices, which in turn can support goals of equal opportunity, participation in society, and access to social and political citizenship. Furthermore, one may then evaluate the social and welfare practices of diaconal foundations regarding the degree to which these services are supportive, and advance everyday citizenship for the service users.

#### **4. Institutional Responsibility for Ethically Sound Research**

One must clarify what characterizes the participatory aspect of a research project and how the participation is facilitated, in terms of time and resources. Here, discussing the research institution's responsibility is also key to strengthening the structural support for participatory methods. Participatory approaches call for a certain kind of sensitivity and skills at the microlevel. Such approaches need to be facilitated at the institutional level regarding training and resources such as time and money. I first discuss the matter of institutional responsibility.

When a research institution – for example, a university – wants to support participatory approaches, there are legal and ethical issues the institution must attend to. For example, research ethics are part of the methodological training for Ph.D. students and for researchers more generally. This is an important element of conducting ethically sound research that centers on the treatment of all those involved in that research. Institutions and researchers alike bear the responsibility for conducting ethically sound research.

However, when including researchers from outside the academy, the institution alone is responsible for training the coresearchers. According to the Norwegian law on research ethics, the academic institution is responsible for teaching them

the “acknowledged norms for research ethics” (*anerkjente forskningsetiske normer*) (Ministry of Education and Research: 2017). In other words, the ethical guidelines and principles must be known and recognized by all individuals involved in the research. The acknowledged norms for research ethics include the two fundamental ethical principles of “do no harm” and the Kantian humanity formula stating that we should never act in such a way that we treat humanity as a means only but always respect the humanity in persons. Taken together, these guidelines and principles provide the basis for practicing ethically sound research; they represent the acknowledged ethical norms that are then expected to guide the research project throughout each phase. The pedagogical and didactical challenge lies in imparting this knowledge effectively to *all* persons involved in the research. The abstract and universal principles must be applied using concrete examples, so that any coresearchers gain experience with identifying potential ethical dilemmas and conflicts of values – in context, of course. This practice is in itself didactical, as one learns from practicing ethics in social contexts.

#### 4.1 Who Can and Who Should Participate in Research?

A participatory research project has different stakeholders. For example, in diaconal research, the stakeholders are the users of a diaconal social practice: the workers, the leaders, the community, and the researcher working on a project. This may be a project seeking to solve some social or political problem. Those involved in the project have different roles and responsibilities, for example, the trained researcher (a professor who is supervising a Ph.D. student), the junior research (a Ph.D. student in the role of learner, who is learning by doing), and the coresearcher from outside the academia (perhaps someone with a disability, a patient, a child, or a person with dementia). This coresearcher works closely with the trained researcher, either alone or in a team with others. In user-led research, the coresearcher may even oversee the project – either alone or together with the trained researcher.

In research projects relating to practice, including service providers and professional practitioners (i.e., ministers and deacons) may also prove valuable. Indeed, persons who work as professionals have experiential knowledge that is valuable in the production of new knowledge. For example, teachers have knowledge on education that is important to research on education, in combination with their students’ knowledge. Moreover, if the topic of the study is the well-being and welfare services for persons with disabilities, both disabilities rights organizations and service providers should be involved as stakeholders. Finally, policymakers deciding what services should be offered would also be important stakeholders in some projects.

## 4.2 Ethical and Epistemological Dilemmas

There are several ethical and epistemological dilemmas in participatory research. In this article, I focus on power (im)balances: language, analytical concepts, and theoretical models, payment as recognition of time spent, education of coresearchers, and time and money as limited resources. These are all relevant in all the phases of the research process.

The power balance between trained researchers and coresearchers is often asymmetrical. The researchers may be in the most powerful position, through their access to knowledge and important resources while conducting the research. However, there are also situations in which the research users are more powerful than the researcher, for example, when the user represents an institution, such as a state directorate or political office, or a nongovernmental organization (NGO) with formal and informal power (Storeng et al.: 2019). In addition, coresearchers can sometimes have more power than the researcher, for example, when the researcher is a student. One area in which power is exercised is when discussing who should decide which persons are to be involved in a research project: the researcher (academy) or the organization?

Language, concepts, and models may create dilemmas in the research process, for example, if the researcher uses language unfamiliar to the coresearchers. Such language could either be discipline-specific terminology or rooted in epistemological or theoretical concepts. This disconnect occurs because of the difference between the role of language in lay knowledge and in research-based knowledge. Similarly, even academics from different disciplines and contexts sometimes use the same words and concepts for different purposes. For example, from a medical or biological perspective, a word may be neutral yet offensive from a social science perspective. Both gender and disability studies include such terminology dilemmas, as discussed more comprehensively by Judith Butler and Martha C. Nussbaum (Butler: 2006; Nussbaum: 2007).

Recognition through payment of the time spent on research is an important and relevant dilemma in all participatory research projects. Most researchers have a paid position at a university. Consequently, the researchers get paid for their time and have access to a supportive infrastructure, such as libraries, printers, desks, and means of data storage. In research libraries, they can search for literature and receive assistance from a librarian. In addition, researchers often have access to additional support. For example, Ph.D. students have access to supervisors, research courses, and research groups in which they can discuss their research (e.g., choice of methods, theoretical perspectives, and epistemological challenges). The person engaged in research as a coresearcher, however, usually does not have access to any of these resources. One basic question, therefore, is whether the coresearcher should get paid for their work and support throughout the research process.

In nonparticipatory empirical research, the person being interviewed also spends time contributing to the research project. However, in such research projects, payment is often seen as problematic, as it may affect objectivity or create participation bias. But when the interviewee becomes a coresearcher, they engage in a stronger commitment to the research. Thus, paying for coresearchers' time is a way to recognize the work they are doing. Payment for coresearchers should therefore be included in the budget for every research project that uses participatory methods. The head of the research project should also involve the coresearcher in the relevant institution's research infrastructure, including research groups and the use of the library, wherever pertinent.

Diverse research teams that include persons with different types of knowledge and interdisciplinary knowledge bases must establish a common ground for work together and conducting research. Here, I focus on two specific elements: a common understanding of the topic's aim and scope and a common understanding of research ethics, including confidentiality, methods, and research limitations. While Norwegian legislation dictates that the institution bears the responsibility for training coresearchers in research ethics, a good program for such training may be lacking. In these instances, the responsibility rests clearly with the researchers. Continuous interaction between the researcher, supervisors, and institutions may facilitate the development of relevant courses in research ethics for all those involved in a project, which may establish a common ground for – and understanding of – the project.

Can there be *too much* of the participatory dimension? For projects that are not user- or citizen-led, it is the researcher's responsibility to decide what kind of participation is helpful and in which parts of a project. It is also the researcher's responsibility to facilitate equality in the relations between everyone involved. This may be a challenge, as academia is characterized by asymmetrical relations, and as researchers, we may not be conscious enough when identifying asymmetrical relations.

A focus on securing equal and universal citizenship for all has informed the shift from conducting research *on* persons and groups to conducting research *with* them (Beresford: 2013). The persons involved in research are not reduced to simple data for the researcher but instead are recognized as subjects in their own right – subjects who can also develop research topics, questions, models, and concepts (Spivak: 2016). Citizenship agendas prescribe relations between people and larger structures of rules and belonging, which are often but not exclusively the nation-state. A citizenship perspective in research approaches the person as a subject and individual person with rights and duties in line with the UN Human Rights treaties.

At a microlevel, we can employ the concept of everyday lived citizenship, which draws attention to the significance of citizenship as it is experienced and enacted in various real-life contexts. (Kallio, Wood & Häkli: 2020, p. 713). The idea of everyday

and universal citizenship is novel, as citizenship is typically associated with politics or civic life. However, citizenship is important in many arenas and can be described as cultural, religious/existential/spiritual, and social. Citizenship is highly relevant for diaconal research and was an important theoretical perspective in the previously discussed research project on the practice of the Home of the Deaf. However, as noted earlier (and described further below), this study was not characterized by a strong participatory practice.

To obtain knowledge related to everyday citizenship, we need a participatory, inclusive approach to one's research that is open to diverse perspectives from diverse subjects of knowledge. Furthermore, it is important to acknowledge the inherent potentials in participatory research, not least in terms of human rights and social justice. Care must be taken, however, to attend to the power imbalances between trained researchers and the coresearchers, as these can lead to ethical challenges in the research.

## 5. New Collaborations in Research

Emancipation and democratization in research have led to new collaborations in research between researchers and nonresearchers and involving research-based knowledge and lay knowledge. I discussed what such changes entail for research ethics. Sound research practice, however, is not just a question of research ethics: One must also take the conditions for participatory research into question. How are coresearchers treated? Can they learn and flourish in these collaborative practices, or are they seen as mere deliverers of knowledge, after which the rest of the work is left to the trained researcher? Do they have the opportunity to improve their CVs and get new contacts, to have access to new (paid) job opportunities?

As we saw above, the most powerful people in the diaconal institution in the historical study – the leaders and those in the head office – participated more directly in the study than the service providers, service users, and professionals. Consequently, the leaders also influenced the study more than the other actors, partly because of restrictions and because of research ethics: Service users are citizens in vulnerable life situations, and some need support from persons they know well to understand the research and provide informed consent during the research process (Chalachanova, Lid & Gjermestad: 2019). A systematic effort to include service users and service providers would likely have provided richer material for the study. If research is to come closer to and support social justice, it definitely needs to apply a systematic focus on finding methods for involving both the powerful and the less powerful.

Based on my rethinking of this diaconal study, we may argue that the use of participatory research methods would strengthen the human rights aspects of this

research. Objectifying subjects in, for example, medical or diaconal research may have supported existing systems and structures of power. For example, it was striking how few traces there were of the inhabitants in the archive of the institution. While this may not come as a surprise, as the archives were established by the foundation, it arguably reflects an interest in the development of the institution – and less of an interest in the living conditions and the everyday life of those who occupied the institution.

## 6. Conclusion

Diaconal research has normative foundations and focuses on persons in vulnerable life situations and contexts. Participatory research approaches have the potential to support social justice and human rights by facilitating subject–subject relations in research rather than objectifying persons and groups. Focusing on the research process together with the product of research, and identifying ways to work together throughout the project, are valuable means of knowledge production, not the least in diaconal research projects. Such participatory and inclusive processes should be supported by institutional structures and a research infrastructure that is supportive of new actors in research practices. At an institutional level, this may mean cooperation between research institutions, NGOs, and religious/faith-based organizations.

In diaconal research, participatory processes hold the potential for developing new levels of understandings, for example, of historical practices and of how to support citizenship for persons in vulnerable life situations. These kinds of participatory processes can be developed further by finding new forms of collaboration between research institutions and NGOs. One productive way forward may be to facilitate economic and practical coproduction in diaconal research: The participatory aspects risk being weakened in the absence of institutional and financial support. One might even argue that it is a diaconal responsibility to request that researchers include stakeholders in all their projects – in other words, to conduct research *with* persons and groups rather than *on* them.

At a microlevel, participatory methods enable new insights and fill part of the void resulting from the hermeneutical void in diaconal research. This void refers to the voices of the persons living in the institutions that are missing in the archives (Stuckey: 2014). As noted earlier, in my study on the Home of the Deaf Foundation, I had interview dialogues with Lasse Seder, who had been living in or near the institution for 60 years, from his childhood onward. Speaking with Seder offered new perspectives and opened up a new and productive space for understanding and knowing (Lid: 2018, 210 ff).

As a subject of knowledge, Lasse Seder should have been asked to join us as a coresearcher. Seder's recalling of episodes and practices pointed toward ambivalences that were not accessible to me as an outsider, alone. I could neither have analyzed nor understood them without his perspective. Thus, the promise of participatory research lies in these new shared spaces, in facilitating meetings, which are aimed at developing knowledge and understanding together with new subjects of knowledge.

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