

The Participation of Children and Adults with Disability in Participatory and Emancipatory Research

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This paper focuses on the conditions of participatory and emancipatory research with people with disability. In the first part of the article, similarities and differences among various inclusive research approaches are described. Methods of action research, participatory research, and emancipatory research are compared and contrasted, with a special focus on participation and empowerment. The second part of the paper includes a discussion of the benefits and challenges of participatory research with typically developing children and with children with special needs. Children and young people, regardless of their disability, like to be involved in decisions about questions and issues of their own life. If research is well planned and strategies are individualized, then participatory research can be successfully used with children with and without special needs. Results from previous research show that children are able to contribute new ideas and creative thoughts to research projects on healthcare, education, technology, and childhood.

Keywords: emancipatory and participatory research, participation, children with special needs

Introduction

Inclusive research has been in the focus of disability studies for decades but there is still a debate in the literature about the most effective approaches to studying disability related questions (McColl, Adair, Davey, & Kates, 2013). The idea of including affected groups into research targeting questions about their own lives is not a new one. Sociologists, ethnographers, and policy makers have been studying societal issues of different minority groups using various inclusive approaches for a long time (Fine, 2013). Inclusive research is a synthetic term of inquiry that consists of various forms of involvement. There is no consensus in the literature whether the different approaches of inclusive research should be considered as different research styles, research strategies, or research methodologies (Bergold & Thomas, 2012). From a disability point of view, inclusive research approaches provide us with flexible research frameworks that can easily be combined with different qualitative, as well as quantitative methods. The focus of this paper is on the level and quality of participation across different inclusive approaches. First, I am going to review the similarities and differences among action research, participatory research, and emancipatory research with a focus on participation and empowerment. Then, I will discuss how these approaches can be used in research with typically developing children and young people, as well as, with children with special needs.

The rapid advancement of technology in the past few decades resulted in major changes in scientific research. A number of these changes facilitated the development of inclusive research. New technologies enabled people with disability to access the most recent professional literature, web-based education processes and databases. Newly developed online communication systems promoted collaborations among researchers including individuals with disability across the world. Inclusive research, whether it is participatory or emancipatory, always involves groups of people and concentrates on cooperation. Recent scientific research

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trends show us that we passed the era of lonely researchers. Major federal funding agencies are interested in research projects that examine the ways in which collaborative research is conducted and information is transferred. Our current worldview emphasizes participation. This participatory view may be regarded as an integration of positivism and constructivism, as it argues for a "real" reality and acknowledges our contribution to this reality (*Reason and Bradbury, 2001*).

Similarities and differences among action research, participatory research, and emancipatory research

Action research, participatory research, and emancipatory research focus on open-ended questions and require a high-level of participation, commitment, as well as self-reflection. They rely on a strong partnership among disability researchers, policy makers, and disability advocates (*McCull et al., 2013*). Unlike scientific research conducted by dominant groups (i.e. non-disabled researchers in academia), inclusive research is representative of the issues of people with disability because it involves people with disability not only as participants but also as researchers. The findings from inclusive research are directly translated into practice (*Kitchin, 2000*). Inclusive research approaches are process-driven, they focus on societal issues, facilitate change through ongoing learning processes, and involve critical reflection (*Bell et al., 2004; Bergold & Thomas, 2012; Glassman, Bartholomew, & Hur, 2013*).

Participation

Despite the many similarities among inclusive research approaches, there are some essential differences as well. One key component is the level of involvement of individuals with disability. In action research, the researchers, who are not necessarily individuals with disability, act as facilitators to their clients. The researchers lead the process of identifying the problem and action, and they analyze the data. The clients are mainly involved in the interpretation of the findings and in the implementation of the results into practice (*Bell et al., 2004*). Thus, individuals with disability participate only in certain phases of the research process. Participatory research shows a higher level of involvement of individuals with disability than action research. In participatory research, the research team consists of individuals with and without disability and everyone participates in each phase of the research. Research questions and objectives are typically initiated by people and organizations that are affected by the problem. The highest level of involvement is achieved in emancipatory research where all members of the team are individuals with disability. In this form of research, participants assume full control of their research projects (*Barnes, 2008*).

One concern about emancipatory research, even among people with disability, is that individuals with specific disability may concentrate on their own issues and may shape their recommendations based on their own perception of the problem. Researchers often choose topics that are important to them. This personal interest may be rooted at such a deep level that the person may not even be aware of it (*Brown & Heshosius, 2004*). Although most individuals with disability see personal involvement in research as a positive trait, some are concerned about objectivity and generalization. This latter group fears that researchers in emancipatory research may make recommendations to organizations and policy makers that favor their own well-being. Even though some people express concerns about emancipatory research, they all support participation and collaboration between researchers and policy makers with and without disability. The assumption is that not every researcher has to live with disability to perform disability research. As long as they focus on disability and

show a true partnership with other team members, the findings will serve the disability community (*Kitchin, 2000*). This view also supports the notion that disability is not an isolated phenomenon but is part of everyday life. One does not need to be disabled to encounter various issues related to disability. Partnership may broaden everyone's perspectives and may lead to a better understanding of each other.

A related question is whether researchers with disability may be negatively affected by the research. To what extent does the research related to a person's everyday problems impact the investigator's self-image and identity (*Tregaskis, 2004*)? For example, when researchers with disability publish a paper on their own problems, they share parts of their self with the world. They share their inner feelings, views, and experiences with a world that may have a very different perspective about the target questions. The differences in worldview may result in substantial confrontation (*Broun & Heshosius, 2004*). This question has not received much attention in the literature but it is an important aspect of emancipatory research. Furthermore, the personal involvement of the researcher may stop him from asking the heard questions, the questions that might hurt. Researchers with disability may unconsciously design their studies in ways that enable them to avoid asking the painful questions (*Broun & Heshosius, 2004*). It is important that researchers with disability prepare themselves to face unexpected emotional and previously unconscious processes and that they honestly explore their own motives (*Tregaskis, 2014*). Moreover, when researchers with disability investigate emotionally demanding questions, they should have a back-up support group and/or counselor. In collaborative projects, these problems may be solved by the team, particularly if the planning process is thoughtful and well-paced.

Empowerment

Another differentiating factor among inclusive research approaches is the level of empowerment; moving from the lowest level in action research to the highest level in emancipatory research. Although action research is primarily researcher lead, the collaborative interpretation of outcomes and the implementation of results provide a certain level of empowerment for people with disability. Although one may think that this is not a high level of empowerment, it is definitely higher than that in traditional research conducted by dominant groups. In comparison to action research, participatory research offers stronger empowerment. In participatory research, all members are equal and the collaborative process itself facilitates empowerment. Empowerment is further enhanced by several guiding principles, such as the appreciation of diverse skills (*Minkler, Vasquez, Tajik, & Petersen, 2008*), the conscious effort to raise awareness (*Reason & Bradbury, 2001*), and the context sensitive framework (*Bell et al., 2004*).

The highest level of empowerment is associated with emancipatory research and it refers to constructing and using one's own knowledge for one's own benefit (*Reason & Bradbury, 2001*). It is assumed in the disability literature that it is the emancipatory research in which the investigators empower their clients most efficiently because all researchers, as well as all participants, are individuals with disability. Researchers with a feminist perspective have criticized the empowerment philosophy for showing a certain level of arrogance. If someone needs to be empowered, then that person needs to be transformed. Even if the researchers themselves have a disability, the empowerment of participants means that one person knows better what the other person needs (*Broun & Heshosius, 2004*). This view may imply that some people with disability do not understand their own issues. As *Tregaskis (2004)* pointed it out, however, the emancipatory research approach should focus on self-empowerment. The researcher should not empower the participants but work with them collaboratively on issues that they are interested in. Reciprocity may be the key to this problem. In reciprocal partnerships no one is

empowering the other person, empowerment occurs as the result of a collaborative effort. Barnes (2008) also suggests that emancipatory research should be evaluated based on whether it facilitates the self-empowerment of people with disability but he also reminds us, that just because someone has a certain disability, that person is not necessarily an expert on issues related to the problem.

Participation in research: children and young people as co-researchers

There is an increasing interest in involving children and young people in inclusive research. The United Nations Convention on the Rights of the Child (UNCRC) gives children a number of substantive rights including the right to “participate in achieving their rights in an accessible and active manner” (*Department of Education, 2014, 1*). Participatory and action researchers value children’s contributions to research on childhood and education and they acknowledge the importance of hearing children’s voices and knowing their perspectives (*Kellett, 2005*). Research *by children* is substantially different from adults’ research *about children*. Children ask different questions and make different observations than adults. Children react and respond differently to their peers than to adults. Young people want to see that their work is having an impact on practices (*McLaughlin, 2005*). Children’s involvement in research is an empowering process and it helps them develop their critical thinking skills, self-reflection, and self-esteem (*Zsolnai, 2004*).

The healthcare system is an area where children have the right to participate in the decision-making process but their views are rarely considered. They are hardly ever consulted as partners in planning their own health service procedures. Moreover, children’s wishes are typically overruled by healthcare professionals (*Coyne, 2008; Moore & Kirk, 2010; Trollvik, Eriksson, Ringsberg, & Hummellvoll, 2013*). A review of the literature suggests that most children wish to be involved in the decision-making process and if they are, they feel respected. Transparent and open dialogues are key components of successful collaborations between young people and adults. Modeling power-sharing to children and young people facilitates their participation (*Flickeret al., 2008*).

Many similarities in both benefits and challenges can be identified across participatory studies involving minors. One general outcome was that the success of participatory research with children and young people is highly influenced by the *preparatory phase*. Researches need to invest time and resources in training children for research. Children need research method trainings that are engaging and that focus on issues of their interest. The methods should be interactive and may include hands on experiences, brainstorming, role-playing, as well as creative forms of expressions, such as photography (*Chen, Weiss, Nicholson, & Girls Incorporated, 2010*). Children with more information and knowledge can participate with more weight in the decision making process (*Kellett, 2005; Moore & Kirk, 2010*). Research with young social service users identified language as a key factor in participative research. Children and young researchers use the same language as their peers; therefore they build rapport more easily with them than the adults. The questionnaires, flyers, and consent forms developed by young researchers have been shown to be more accessible to young clients than the ones developed by adults (*McLaughlin, 2005*).

The benefits of participation for children and young people include strong connections with other team members and the feeling of being part of a community. Socially supportive and reciprocal bonds gave participants the feeling of being respected and cared for (*Duckett, Kagan, & Sixsmith, 2010*). Children valued the opportunity of becoming part of a community. The positive feelings of connectedness are closely tied to questions about children’s safety. Child/youth protection is an important aspect of participatory research with

minors. Support has to occur at various levels, from providing the necessary resources to having an adult available to discuss questions and concerns during each phase of the research. Adults need to be available to drive children from one place to another, to secure the financial resources, to provide emotional support, and to serve as intellectual partners (McLaughlin, 2005; Chen et al., 2010).

Another common theme across studies was the importance of technology in keeping children and young people engaged in research. Technology is an essential part of children's everyday life. They use it for information, as well as for communication and self-expression. An increasing number of young people use technology for social network purposes (Chen et al., 2010). An example of a successful innovative participatory research program that engages young people in health promotion activities through intensive use of technology is TeenNet (Flicker et al., 2008). Within this research project, participants created a number of health education websites and developed manuals for their peers. The researchers have not only engaged young people in each phase of research but they also focused on issues that were identified by young co-researchers. Their programs can be accessed globally and they serve as bridges across cultures and nations. One of their projects that was integrated into classrooms is *Smoking Zine*. It has been used in different schools with evidence of being effective in preventing smoking in specific groups (Norman & Skinner, 2007). The TeenNet program has been successful for over 20 years and teens express pride and a sense of ownership when they talk about their research.

On the negative side, the most common claim of sceptics against participation of children and young people as co-researchers was that children are incompetent and not reliable (Kellett, 2005; Duckett et al., 2010). This accusation was often linked to their young age. Kellett (2005) argued, however, that besides age, social experience also has a great impact on children's maturity level. Thus, providing children with more opportunities of participation may have a positive effect on the development of their decision-making skills. A related complaint was children's lack of knowledge. This view was particularly strongly emphasized by doctors, who did not support children's participation in decisions about their health and by teachers, who did not want children to participate in research about their schools (Kellett, 2005; Coyne, 2008; Duckett et al., 2010). As evidenced by numerous studies, if the research project is well-designed and if there is time and opportunity for research training, then children and young people can become invaluable co-researchers. Although children's research differs from adults' research, it is still as rigorous and ethical as research by the dominant groups.

Participation of children and youth with special needs

The main philosophy and the major questions of participatory research with children with special needs do not differ from that of typically developing children. There are many similarities in general principles, such as child protection and safety, participation, power-sharing, and transparent and open communication. The differences between research with typically developing children and children with special needs are mainly related to methodological questions. Researchers may need to use more individualized strategies, modify traditional methods, and combine them with non-traditional ones when children with special needs serve as co-investigators (Gray & Winter, 2011). Children with special needs are not a homogeneous group, so research questions and methods need to be tailored toward their individual experiences. One method that has been efficiently used across participatory research studies is the "*Mosaic approach*" (Moss, Clark, & Kjørholt, 2005). It combines verbal and visual methods with one-on-one activities and different hands-on exercises. It may also incorporate the newest technology.

As in participatory research with typically developing children, innovative interactive technology plays a key role in research with children with special needs. Over the years, technology has become a major component of special education. Technology provides children with freedom and full participation (*Alper, Hourcade, & Gilutz, 2012*). An increasing number of researchers of participatory studies have recognized both the need and the opportunity for involving children with special needs into designing new technology (*Benton & Johnson, 2014*). Children may serve as users, testers, informants and design partners (*Druin, 2002*). Although it has been reported in the literature that co-designing technology with children with special needs is particularly challenging, it is also known that often these children are the ones, who benefit the most from the design process (*Frauenberger, Good, & Keay-Bright, 2011*).

The challenges may occur at different levels. One of the common problems is a limitation in language. Many children with special needs interpret everything literally (*Benton et al., 2012*). A number of children show difficulty with expressing their ideas, thoughts, and feelings verbally but they may contribute creative ideas to the project non-verbally using photos, drawings, and role-play. Special children's social communication skills may also differ from that of typically developing children therefore, it is crucial that researchers plan more time for team-building activities. Building and maintaining stable and trustful relationships with these children is a key to participatory research (*Frauenberger et al., 2011; Benton et al., 2012*), since it provides the foundation for any collaboration.

One specific method that was developed for participatory research purposes and has extensively been used with minority groups, people with different cultural backgrounds, and with individuals with disability is *Photovoice* (*Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009*). Participants using the *Photovoice* method take photographs to address different issues, such as living with chronic mental illness (*Thompson et al., 2008*), inclusion of children with autism (*Carnahan, 2006*), or definition of self by mothers with learning disability (*Hergenrather et al., 2009*). The photographs reflect participants' personal voices without the need for verbal communication. *Photovoice* can easily be combined with other digital technologies providing children with an array of tools.

Further challenges in research with special populations are related to motivating children and maintaining their engagement. A number of special needs children have short attention spans and are easily distracted. They might think about certain questions in unusual ways and may show difficulty with participation in traditional sessions. Thus, it is crucial that researchers learn about the children with special needs and rely on these children's strengths during their collaboration. For example, researchers were able to increase high functioning autistic children's engagement when they provided opportunities for practicing repetitive activities related to the children's special interests (*Benton et al., 2012*). In another case, to involve children in a computer design process, researchers needed to learn about the objects that children engaged with spontaneously and then, they needed to understand how children approached and interacted with those objects. Having this knowledge helped them develop activities in which children could truly feel their active participation (*Frauenberger et al., 2011*). Similarly to findings with typically developing children, children with special needs felt cared of and valued when the researchers engaged them in different collaborative activities.

In sum, a growing number of researchers involve children with special needs in participatory research, in part, because they recognize that products and interventions are more effective if their designers are familiar with the needs of the users. Outcomes from numerous studies show that children with special needs are able to participate in collaborative research and contribute new ideas and solutions to the research project when

researchers know the children and the research process is well planned and prepared (*Dolan & Hall, 2001; Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012*).

Participatory research initiatives with individuals with disability in Hungary

Participatory research has been used in decision-making processes (*Szántó, 2012*), in futures research (*Nováky, 2010*), and in studies that aimed to introduce different research methods to children (*Zsolnai, 2004*). The first paper in Hungarian on participatory and emancipatory research with people with disability was published in 2009 (*Marton & Könczei, 2009*). During the last 5 years, several new studies were initiated and most of them are still in progress. In a participative research project *Loványi and Piczkó (2013)* examined children's attitudes toward disability with the assistance of service dogs. The researcher herself used a service dog during her daily activities. She and her team visited different schools and shared personal stories with over 250 children. Their interaction was highly enhanced by the presence of the service dog. The results showed that children felt more comfortable asking questions from people with disability when the service dog was present. The data from a questionnaire indicated that following a meeting with individuals who used service dogs, children showed more positive attitudes toward people with disability. Children incorporated more positive attributes in their descriptions of people with disability following these meetings.

Heiszer's project with young individuals with intellectual disability combines participative research with focus group and "Play decide" methods. This project is based on her participative work with young people with Williams-syndrome. The study focused on decision-making and empowerment questions and used the focus group method to take advantage of the good verbal skills of individuals with Williams-syndrome. By the end of the first year, participants with Williams-syndrome showed increased self-reflection, initiated more discussions, and became better listeners (*Heiszer & Marton, submitted*). In an emancipatory project, *Flamich and Hoffman* examine how disability memoirs can be incorporated into the music education of visually impaired young people. Their goal is to raise awareness about musicians with disability and to facilitate the development and use of more individualized strategies in music education (unpublished, personal information). These studies are examples of participative projects with people with disability in Hungary. Until the recent years, individuals with disability served only as subjects but not as researchers in different projects. The new initiatives clearly show that there is a growing interest in using different inclusive research methods and in working with diverse populations among junior researchers.

Summary and conclusions

In recent years, inclusive research has been in the center of attention across a variety of disciplines. This paper focused on research with children and young people with and without disability. The different forms of inclusive research – action, participatory, and emancipatory – show many similarities in their questions and methods. Two key elements, along which these approaches differ, are participation and empowerment. All three approaches have been used successfully with individuals with disability. Depending on the situation, the question, and the population, one approach may be favored over the other. The review of the literature and our own work suggest that children and young people, regardless of their disability, like to be involved in decisions about questions and issues of their own life. Children may contribute new ideas and creative thoughts to research projects about healthcare, education, technology, and childhood. There is evidence that any of the above approaches can be used successfully if the research is well-planned and the strategies are individualized.

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