

Empowering People with Disabilities in Disability Research

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Abstract: A disability is a continuous condition that prevents people from engaging in some daily activities. People with disabilities often feel separated because they are unable to do things in the same way as those in mainstream society. Many researchers have addressed disability research and how it should be conducted; some of the arguments are concerned about the level of involvement of people with disability in disability research and who should be in control of the research and decision-making processes. This paper will review several methodological approaches to involving people with disabilities in disability research. The methods offer varying levels of involvement, depending on the type and level of disability. The methods addressed here are participatory action research (PAR), collaborative research, consultation, and steering and advisory groups. Each method features unique ways of empowering people with disabilities.

Keywords: Disability research, people with disabilities, collaborative research, participatory action research (PAR), steering and advisory groups, consultation method.

I. INTRODUCTION

It is extremely important to understand people's disabilities and the barriers they face in their daily life. Engaging people with disabilities in disability research will improve the quality of research related to these issues. Involving people with disabilities in disability research in an inclusive way means that participants from different groups are included in the research process according to the research subject, either fully or partially, depending on the research objectives. Participants might participate by helping to formulate the research questions, recruit other participants, assisting with the development of an accessible research environment, and improving the accessibility of the field.

Several main considerations should be applied in disability research, such as planning to include the group of people with a disability who represent the main population under study. Accessibility is a second inclusion consideration, as are concerns about the research location, transportation, and building accessibility. Research centres should be located near public transportation and have a convenient and accessible parking area. Buildings should be accessible for all different disabilities in terms of entrances, floor access, and all building services. Communication accessibility, in terms of languages and communication techniques, should be provided for the different impairments and include accessibility to information and the provision of all documents in different formats, in order to suit the different needs of the participants. Disability and equality awareness is another term of inclusion; it is important to ensure that research staff are aware of the rights of the disabled, their social model, and that they use appropriate language that is acceptable to the participants (National Disability Authority, 2002).

II. PURPOSE OF THE STUDY

The purpose of the study is to improve the quality of disability research by empowering people with disabilities and including them and their organizations in the research process. Empowering people with disabilities in research will help deepen our understanding and change the world around them. People with disabilities can be involved in research in various ways, and the main objective of studies of people with disabilities should be to ensure that the group of participants represents the main population under consideration in the research.

III. METHODS OF INVOLVEMENT

There are different ways in which people with disabilities can be involved in disability research in an inclusive way. Each method varies on the level of involvement depending on the type of disability; some of these methods are participatory action research (PAR), collaborative research, consultation, and steering and advisory groups (Farmer & Macleod, 2011).

Participatory action research (PAR):

PAR is an inclusive type of research that can be used in disability research, or any other type of research. One of the main principles to qualify as an inclusive method is for an approach to intend to include the full range of participants in the research and not exclude any. PAR seeks to empower people with disabilities in the research by including them in all aspects of the research process. This method is empowering because people with disabilities participate as co-researchers and work in partnership with the investigators, thus changing the relationship between the researchers and the researched. People with disabilities and their organizations have some control in the research process and are involved in several aspects, such as recruiting participants, conducting surveys, data collection, data analysis, and the design process. The objective of PAR is to gain a deeper understanding and improve the world by changing it. Researchers should share all of their knowledge and skills with disabled participants, in order to reduce the barriers and to improve the quality of life for all people with disabilities (Kitchin, 1999, 2000, 2001).

Collaborative action research:

Collaborative action research is another type of research that can be considered for this or any other research discipline. In this approach, people with disabilities have an open dialogue with the researchers, and may work with or advise them through all stages or specific stages of the project (Farmer & Macleod, 2011). In collaborative research, the research team collaborates with people with disabilities, their organizations, and any associations involved in the research, and invites participants to talk and interact with one another. All participants are treated equally in the research process and collaborate as equal partners in the decision-making processes at all stages. The collaborative research method is a flexible one, in that it creates opportunities for new thinking, new ideas, and has the ability to solve new problems.

The steps of collaborative action research are: choosing a co-researcher, establishing a working relationship, conducting the collaborative action research process (planning, acting, observing, and reflecting), data collection, and data analysis.

The co-researchers in this process are people with disabilities and their organizations, and they must agree voluntarily to participate in the study. In order for the research to be inclusive, researchers should be sure to include different groups of participants in it, in terms of age, sex, language, background, and disability. In turn, participants should affirm their commitment to the research in order to reach the goals of the study. Finally, establishing a positive working relationship is essential for any successful research project. In order to achieve this, members need to feel that they are valued and that their contribution is important and considered in all research phases (Bryant, 1995).

Consultation:

Consultation is another method of including people with disabilities in the research process. In this method, people with disabilities and their organizations work as consultants, but are not involved in all aspects of the process. The researcher may need to consult with the people with disabilities about specific problems and may provide toolkits for them (Emerson, Baines, & Hatton, 2007). The researcher may also arrange a consultation event with the disabled people or their organization to collect all the necessary data (National Disability Authority, 2002). The consultation process helps with getting opinions directly from the people with disabilities, and many types of participants can be included, including children, youths, older persons, and people of different genders, ethnicities, and beliefs.

Consultation events can be planned depending on the research needs. Some studies may need one consultation event; others may need two or more. People with disabilities can be involved in all of the consultation processes, can help plan the event, and assist in the discussion.

Steering and advisory groups:

Steering and advisory groups provide advice and feedback and influence the research process. Advisory group participants provide advice according to their own experiences about the study, while steering group participants also provide ideas and feedback, but have more influence on the way the research is planned. Steering and advisory groups

consist of people with disabilities, and they are consulted to cover the main research ideas, plan the research agenda, and provide feedback for every task that has been done by the researcher. For each task in the research process, the steering and advisory groups evaluate the task and give their feedback after the task is completed.

The steering committee may participate in all the research stages until the final report, the researcher and the group may decide to work on only one or two stages, or the group might only work on the main planning stage (National Disability Authority, 2002).

III. CONCLUSION

Including people with disabilities in disability research will narrow the gap between theory and practice, because the relationship between the researcher and the participant is changed from that of the traditional approach to research. There are several different ways in which people with disabilities can participate in the research process, and researchers can select between these different models depending on their project's objectives. Possible approaches include PAR, collaborative action, the consultation model, and the use of steering and advisory groups. People with disabilities may have full partnership and control in all research processes, as in PAR, or may only participate in some stages. Some essential principles and procedures should be applied to the different types of models, in order to ensure inclusiveness. Further, researchers should plan for inclusion in terms of participants, accessibility, and disability awareness.

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