

CHAPTER: 07

Ethical Measures in Inclusive Research Practices

Dr. Angel Selvaraj*

Assistant Professor

Jindal Institute of Behavioural Sciences

O.P. Jindal Global University, Sonipat, Haryana

Dr. Soumya T. Varghese**

Assistant Professor

Jindal Institute of Behavioural Sciences

O.P. Jindal Global University, Sonipat, Haryana

***Abstract:** Inclusive research aims to embrace diversity by involving people with disabilities throughout the research process, from formulating research questions to disseminating findings. Despite increased attention to inclusive practices since the 1994 Salamanca statement, progress remains limited. One challenge is the lack of supportive theories in this area. Ethical measures play a crucial role in ensuring the safety and well-being of participants. Research ethics committees guide researchers by scrutinizing study plans. For inclusive education research, these committees focus on addressing disability-related issues and safeguarding participants. They assess research nature, participation modes, and data collection tools' sensitivity. For instance, alternative communication methods (such as gestures or written messages) are essential for participants who cannot express themselves verbally. Lack of disability knowledge can hinder ethical measures. Researchers should accumulate relevant information before starting their studies. Ethical committees may request stories, videos, or audio recordings from individuals*

with the disability of interest to enhance familiarity. Creating a list of ethical measures helps address individual participant needs. Complex accessibility requirements should be accommodated, ensuring participants feel comfortable throughout the research process. Researchers must consider accessibility and accommodation opportunities, maintaining open communication with participants and their legal guardians.

Keywords: *Ethics, Disability, Inclusivity, Research.*

Introduction:

Inclusive research is a form of equity based approach where the dynamics of human behavior is recognized from the lived experiences of the vulnerable population by the direct participation of the individuals throughout the process of research. In special education, inclusive research has a significant role as most of the research focuses on understanding and promoting wellbeing of the differently abled population. Most research studies and researchers overlook the actual needs of persons with disability in the lens of existing knowledge, experience, applicability of practices, resources available, statistically accurate results and outcomes rather than focusing on empathetically analyzing and ethically sound approaches. “Often, the people who carry the greatest burden of exclusion also have the greatest insight into how to shift design toward inclusion” (McConnell, 2017). Inclusive research approaches highly emphasize the accessibility, representation and involvement of the actual population studied regardless of the potentials, knowledge, social background and Circumstances. This approach ultimately leads to authentic results leading to quality decision making and policy frameworks. Persons with Disabilities are diverse in their nature and type of disability, strength and weaknesses, challenges faced and opportunities provided. Inorder to make the research studies with this special population more inclusive, it is essential to approach them with more respect, dignity and ethically appropriate strategies. This chapter deals with the nuances of undertaking inclusive research projects in special education with special reference to the ethical measures to be focused on different stages of the research process.

Definition of Inclusive Research:

“Inclusive research is research that includes people who are often excluded, such as those with disabilities, as active participants rather than just subjects of the research. It involves them in the planning, execution, and dissemination of the research (Walmsley and Johnson (2003).”

The National Institute for Health Research (NIHR) defines inclusive research as ensuring that the voices of all stakeholders, including patients and the public, are heard and considered throughout the research process. It emphasizes co-production and collaboration with those who have lived experience of the issues being studied.

Inclusive research is a methodological approach that integrates the principles of equity, diversity, and inclusion in research design, data collection, analysis, and dissemination. It ensures that all population groups, especially marginalized communities, are represented and benefit from the research outcomes (United Nations Educational, Scientific and Cultural Organization (UNESCO), 2022).

"Inclusive research describes experience research that actively engages populations that have been historically excluded and underrepresented" (Read, Parfitt, & Bush, 2020).

Principles of Inclusive Research:

There are seven key principles on which inclusive research is grounded. They are as follows

1. **Representation:** The research study should highly involve, reflect and represent the insights, concerns, experiences and expected outcomes of the target population as core content of the study rather than any other existing sources. It is also essential to ensure that the intersectionality within the chosen target group is represented holistically in the chosen study.
2. **Equal Participation and Collaboration:** The representatives or target people should be provided equal opportunity to participate in each and every step of the research process right from choosing the research problem, developing objectives, methodology, data collections, analysis and dissemination of results. This also means not only to use the people from the target population as object of the study but to involve them as a co-researcher and author of the study.
3. **Informed Consent:** It is crucial to confirm that each participant is thoroughly informed about the purpose, nature, method and expected outcomes of the study and to obtain their free will and consent for participating in the study.
4. **Accessibility:** The participants should be provided with necessary accommodations that results in complete accessibility to various contents and processes of the research study. Some of the common barriers to be

kept in consideration while planning accessibility measures include structural, communication, social, attitudinal, political barriers etc.

5. **Decorous language:** It is vital to establish the use of dignified language to address the people of the study. Allow them to self-identify themselves and ask their preferences on how to address them throughout the study. This helps to ascertain that no unintentional harm is caused due to the language used.
6. **Dissemination of results and outcomes:** Inclusion does not stop in carrying out the study with the involvement of the specific population but should guarantee that the results and outcomes of the study are communicated to them. Recommendations and insights of the target audience regarding the outcome measures and policy changes should also be incorporated.
7. **Confidentiality:** Maintaining confidentiality and privacy is one of the fundamental aspects of inclusive research. Any data collected in the process of research should be preserved confidentiality and the modality of the maintenance of confidentiality must be spelled out and documented in the initial phase of the study itself.

The Role of Ethical Measures in Inclusive Research:

Inclusive research ensures to adopt strategies that accept the diversity of people with disabilities respecting their views and involve them throughout the research process right from the formulation of the research question till the propagation of the findings to the wider audience. Since the Salamanca statement introduced in 1994 a great amount of research practices are happening in this area (Ainscow, M., Slee, R., & Best, M., 2019). However, the lack of progress in the area of inclusive research practices is of various reasons. Reviews on inclusive education practices are arguing that there is a consistent lack of supportive theories in this area (Mitchell, D., & Sutherland, D., 2020).. Consequently, an effect is determined on the ethical measures in inclusive educational practices.

Researchers across the globe follow rules and policies to make sure the research is authentic and valid. The research ethical committee constitution is the usual practice of beginning a research journey. They act as a guiding star in the whole process to scrutinize each and every plan of the researchers to make sure the process is safe and ethical. In terms of research in inclusive education, the research ethical committees always express their concern over dealing with

issues of disabilities and the ways to protect people with disabilities while they participate actively in the process (Walsh, M., Stead, V., Sawyer, S. M., O'Shea, A., Watson, J. M., & Anderson, K. L., 2024). The way the committee asks for ethical measures can start with reviewing the nature of research, the mode of participation and the sensitivity of tools or procedures for data collection etc. For example, if a researcher is working among people who can't express their views through verbal means, then there should be alternative methods for communication like gestures, devices or even through writing the messages in a book or diary. It is a significant turn in research to make the participants comfortable during the entire process. Ethical measures should be followed to make sure that the participants are feeling good and comfortable (Lindsay, S., & McPherson, A. C., 2012). Sometimes lack of knowledge about the disabilities involved in the research may create barriers to a researcher. This in turn may affect the ethical measures, for that accumulating enough knowledge or information about the disability should have been done prior to the commencement of research. The ethical committee can ask for similar stories, videos or audio recordings of people with the disability in focus can be collected for familiarizing.

The ethical measures that need to be followed can be prepared as a list to see different risks and needs of the participants. This will help the research ethical committee to see the individual needs of each participant as there may be chances of having more than one accessibility need for an individual. If there are multiple needs which are complex in nature then the participants must be ensured that will be taken care of and will provide a pace to get them familiarized with the research process. The research ethical measures are nothing but to protect people with disabilities to feel good about the research process they are involved with a broader inclusive framework. The researcher will be having specific information in hand with respect to the nature of impairment, degree of impairment and the vulnerabilities they are having.

Inclusive research practices are mostly aimed at accessibility and accommodation opportunities and the researcher has to consider the accessibility throughout the research. This communication regarding the research should happen between the participant and their legal guardian. Many times, participants may find it difficult to communicate the sensitive information and a support system through family or guardian should be permitted to ease the process. The ethical measures will help the researcher to overcome barriers and obstacles in the research.

Conclusion:

Ethical measures are to make the research to be safe and more inclusive. Everyone has their right to participate in any research they are interested in doing. The disabilities shouldn't limit them or cause tension. Dynamic and broader ethical measures will assure fullest participation with assured confidentiality. Participants being in a comfort zone are crucial to conduct research in a smoother way. The practices from the beginning of the research processes can be prioritized with the necessary measures and can be communicated to the participant or their guardian to safeguard their rights.

References:

- Ainscow, M., Slee, R., & Best, M. (2019). The Salamanca statement: 25 years on. *International Journal of inclusive education*, 23(7-8), 671-676.
- Cluley, V. (2017). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British journal of learning disabilities*, 45(1), 39-46.
- Commons Library. (n.d.). What is inclusive research? Commons Library. Retrieved July 5, 2024, from <https://commonslibrary.org/what-is-inclusive-research/>
- Dark, J. (2024). Eight principles of neuro-inclusion: An autistic perspective on innovating inclusive research methods. *Frontiers in Psychology*, 15, Article 1326536. <https://doi.org/10.3389/fpsyg.2024.1326536>
- Kramer-Roy, D. (2020, May 13). Preparing for inclusive research with people with disabilities. *Medium*. Retrieved from <https://medium.com/inclusive-research/preparing-for-inclusive-research-with-people-with-disabilities-228ce2f8cb2e>
- La Vigne, N. (2023, August 21). The importance of inclusive research. *National Institute of Justice*. Retrieved from <https://nij.ojp.gov/topics/articles/importance-inclusive-research>
- Lindsay, S., & McPherson, A. C. (2012). Strategies for improving disability awareness and social inclusion of children and young people with cerebral palsy. *Child: care, health and development*, 38(6), 809-816.
- McConnell, I. (2017, April 20). Exclusionary design: Asking a new question. *Design Observer*. Retrieved from [Design Observer](#).

- Mitchell, D., & Sutherland, D. (2020). *What really works in special and inclusive education: Using evidence-based teaching strategies*. Routledge.
- National Institute for Health Research. (2022). NIHR's commitment to equality, diversity and inclusion. *NIHR*. Retrieved from <https://www.nihr.ac.uk/documents/equality-diversity-and-inclusion-strategy-2022-2027/31295>
- Read, S., Parfitt, A., & Bush, T. (2020, October 27). How do we know that our research is inclusive? *LSE Impact Blog*. London School of Economics and Political Science. <https://blogs.lse.ac.uk/impactofsocialsciences/2020/10/27/how-do-we-know-that-our-research-is-inclusive/>
- UNESCO. (2022). Inclusive research. *UNESCO*. Retrieved from <https://www.unesco.org>
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.
- Walsh, M., Stead, V., Sawyer, S. M., O'Shea, A., Watson, J. M., & Anderson, K. L. (2024). In pursuit of ethical and inclusive research: What ethics committees and disability researchers can learn from each other. *International Journal of Qualitative Methods*, 23, 16094069241237549.