

AKSHAR WANGMAY

International Peer Reviewed Journal

UGC CARE LISTED JOURNAL

October – 2021

Issue-IV, Volume-III

Chief Editor

Dr. Nanasaheb Suryawanshi

PRATIK PRAKASHAN, 'PRANAV, RUKMENAGAR, THODGA ROAD AHMEDPUR,
DIST. LATUR, -433515, MAHARASHTRA

Editorial Board

Dr. Mahendra S. Kadam

Dr. Netaji B. Kokate

Dr. Balasaheb V. Das

Mr. Zakirhusen B. Mulani

The Editors shall not be responsible for originality and thought expressed in the papers. The author shall be solely held responsible for the originality and thoughts expressed in their papers.

© All rights reserved with the Editors

Price: Rs.1000

'Akshar Wangmay' UGC Care Listed, International Journal of Special Education, Issue-IV, Volume-11, 2021

Living Life to the Fullest: Towards an Understanding of Disabled Children's Childhood Studies

Ms. Noble A. Paliath

Assistant Professor, Department of English, Sacred Heart College, Chalakudy
phd2020kreupasanam@gmail.com

"We live in a world of norms. Each of us endeavours to be normal or else deliberately tries to avoid that state. We consider what the average person does, thinks, earns or consumes... There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated... To understand the disabled body, one must return to the concept of the norm, the normal body. So much of writing about disability has focused on the disabled person as the object of study... I would like to focus not so much on the construction of disability as on the construction of normalcy. I do this because the "problem" is not the person with disabilities; the problem is the way that normalcy is constructed to create the "problem" of the disabled person."

Lennard J. Davis' *the Disability Studies Reader*

Disability Studies being a burgeoning and developing field of academic inquiry, has received worldwide attention across associations of disabled people and their associates. It has now become an action-orientated praxis. Research reveals that more attention is paid to disabled children's everyday interests and their concerns. Contemporaneously, this statement reveals that disabled children's everyday desires, wishes, interests and their concerns are taken into serious consideration. More lively and collective constructions of childhood, movements and campaigns around children's rights have gained much speed and momentum. The daily lives of disabled children are monitored by a galaxy of adults and a host of professionals which include teachers, social workers, doctors and other allied health professionals. The lives of disabled children are in a way surveilled by this team of competent workforce. In fact, the worlds of disabled children are scrutinized by grown-ups more than any other group of children. Despite the heed being paid to the problems of the disabled children and their upliftment, the disabling society is replete with negative practices and stereotypes concerning them. The idea of normal development and the associated services disabled children receive always surfaces when the focus of the critical inquiry is targeted onto disabled children. Hence, a rights discourse also tends to be normative. This paper is an exploratory endeavour to dispel the unconstructive practices and typecasts that persist in the lives of disabled children and in doing so, ventures forth to embrace their lives and to focus on the hopes, needs, dreams, wishes and aspirations of disabled children, young people, their families and other allies and associates.

The current study aims to bring together theories of disability and childhood and how the disabled children are in need of professional intervention to make their life more meaningful and productive. The theories of disability and childhood have always projected a deficit view of disabled children in need of specialized interference. Disabled children's lives have been marginalized within childhood studies. Childhood Studies an adult-centric area of study, has always under-theorised the lives of disabled children. Disabled children are often depicted as being dependent, inactive, and their rights are interpreted as being totally absent and affixed. The highlight is always on their impairments, vulnerabilities and deformities. The focus on disabled children as people with childhood in a social context has been preoccupied with negative images. Disabled children are often defined against the norms of child development. Their voices have often been excluded and the emphasis is placed on the perspectives of parents, young people and professionals.

The study of disabled children's lives is often made from the perspective of a medical or individual model of disability. The medical model approach, widely critiqued in it, conceptualizes disability as a medical problem for individuals. With the initiation of social oppression models of disability, a shift in focus away from the individuals' bodies and minds to viewing disability as a form of social oppression has become increasingly evident. The social oppression models of disability are concerned with disability as social oppression. It sparsely and rarely provides an adequate and sufficient illustrative framework for the experiences of the disabled children. It looks at the ways in which disabled people are subjected to everyday exclusion and discrimination because of disablism.

In fact, disabled people are not disabled by their bodily impairments and limitations but by the attitudes and outlooks of a disabling society. However, in certain parts of the world, the disabled people are expected to live culturally normative lives. With concepts like inclusion, assimilation, acceptance, accommodation and tolerance gaining momentum in today's contemporary global scenario, the systemic cultural and attitudinal barriers that ostracize disabled people are annulled and negated and how these crippling practices might be exposed and removed are also taken into serious consideration. The need for

inclusion and an attention to the voices of disabled children continue to dominate in today's floor of intellectual discussions. Thinking from the standpoint of the disabled children, more focus should be given to their perspectives, their roles in contesting their day by day lives, and to examine the environments, affiliations, and structures which formed their understandings and experiences.

The rise and emergence of Disabled Children's Childhood Studies, as a new area of study, is a vital step taken in the right direction to tackle this grave problem of stigmatization. Disabled Children's Childhood Studies, of international origin with its roots at UK, is a developing field. It draws heavily upon both disability studies and childhood studies. It challenges all sorts of everyday exclusionary practices because of disablism and opens with a positive view of disabled children's childhood. This branch of study seeks to re-orientate research inquiry, moving away from 'deficits and lacks,' to focus, instead, on their 'hopes, dreams and aspirations' of disabled children. Disabled Children's Childhood Studies seeks to do something different. It ventures to look at the standpoints of disabled children themselves. The focus is on the positive contributions of disabled children in their everyday worlds. Its attempt is to erase the negative images of disabled children as promoted by the dominant forces of the social world.

Disabled Children's Childhood Studies places the stress on revisiting and revamping off-putting assumptions and pre-suppositions on the lives of disabled children and so to promote all children's potential. It also offers exciting opportunities to re-orientate, reshape and refashion norms that dominate children's lives. It values the contributions of disability studies and childhood studies to disabled children and young people's lives. It is an attempt to re-energise and revitalize deliberations and discourses and destabilizes professionalization, medicalization and pathologization which continue to regulate disabled children's everyday lives. It puts forth an ethical research design that prioritizes the voices and experiences of disabled children at the heart of the inquiry. Thus, Disabled Children's Childhood Studies, as a field of inquiry, argues for a reorientation of research with disabled children. Re-orientating research to the voices and concerns of disabled children, is a shift away from generic claims related to disabled children and professionals' concerns about issues of impairment and vulnerability to inclusion of disabled children's and young people's experiences. The branch also questions the ethicality of research by foregrounding nonspecific claims about the lives of all children and yet excluding disabled children.

Disabled Children's Childhood Studies reflects disabled children's concerns and instead of posing questions like 'What is wrong with you?' it foregrounds, fundamentally ethical questions like 'What is wrong with society?' and all the more, it hits at 'What needs to change?' The relevance of this field of inquiry lies in the fact that apart from involving disabled children in research, the basic query is inevitably linked with what is constructed as the 'problem' to be researched upon. It places a special emphasis on the expertise and insights of the disabled children and their families. It completely negates pejorative practices of objectifying disabled children and nullifies all sorts of exercises in exploitation. It refutes many a deliberate attempt to invalidate their existence. The distinctness of this field of study lies in the fact that it reflects the centrality of disabled children's voices in disability studies.

Disabled Children's Childhood Studies with its focus on the experiences of the disabled children aims to challenge, recognize, investigate and change ableism. It comes down as a gentle reminder to the othering practices enabled by ableism. It identifies and changes a negative culture generated as part of ableism and targets to develop a positive all-inclusive culture. It advocates undertaking social action, participation and recreation in bringing about a positive change in the way societal forces look forward to disabled children. In essence, the voices and concerns of the child are at the heart of Disabled Children's Childhood Studies. At the same time, the voices of the family members and others who care for disabled children also play an instrumental role in Disabled Children's Childhood Studies. This paradigm shift promoted by Disabled Children's Childhood Studies is in the re-positioning of emotion in research. The historic preoccupation with normalization is challenged to the core. Alteration of this imposing paradigm of emotion begins with an aspiration for disabled children and young people and rages against normalcy. This kind of transformative research reimagines possible future for disabled children and young people. The lived experiences of disabled children and parents, when given due stress, serve to dispel the notion of the norm and disapprove the tragedy dynamic of disablism. Disabled Children's Childhood Studies' shift away from the life-limiting, alienating, normalizing, life-threatening and segregating practices represented by medicalised and psychologised accounts of disabled children's lives, involves re-orientation of research so that disabled children and their associates can live life to the fullest. Living life to the fullest, a recently conceived and developed research project within the burgeoning field of Disabled Children's Childhood Studies, envisions new understandings of the hopes, dreams, desires and aspirations of disabled children and young people with short lives. In living life to the fullest, rather than an aporetic situation, disability becomes esteemed, lively and future facing through shared responsibility, collectivity and co-productive

research which aim to stimulate social change. The hitherto unattended lives, concerns and experiences of disabled children and their families acquire an enhanced and added significance in the political, intellectual, emotional and institutional domains of knowledge made possible through the newly emerging and surfacing field of epistemology so called as Disabled Children's Childhood Studies.

Works Cited

1. Barker, Clare et. al. eds. *The Cambridge Companion to Literature and Disability*. Cambridge UP, 2018.
2. Barnes, C. et. al. *Disability: Key Concepts*. Polity Press, 2003.
3. Barton, L. ed. *Disability, Politics and the Struggle for Change*. David Fulton, 2001.
4. Davis, Lennard J. ed. *The Disability Studies Reader*. Routledge, 2017.
5. Foss, Chris et. al. eds. *Disability in Comic Books and Graphic Narratives*. Palgrave Macmillan, 2016.
6. Goodley, Dan. *Disability Studies: An Interdisciplinary Introduction*. Sage, 2011.
7. ---. *Disability Studies: Theorising Disablism and Ableism*. Routledge, 2014.
8. Shakespeare, T. *Disability, Rights and Wrongs*. Routledge, 2013.
9. Stiker, Henri Jacques. *A History of Disability*. University of Michigan P, 2000.
10. Thomas, Gareth M. et al. eds. *Disability, Normalcy and the Everyday*. Routledge, 2018.