NOTIONS OF CARE: ANALYZING DISABILITY, GENDER AND SEXUALITY IN SELECTED BRCs IN KERALA

A thesis submitted during 2025 to the University of Hyderabad in partial fulfillment for the award of a Ph.D. degree in Gender Studies

by
SONIYA A. M.
15CWPG02

Centre for Women's Studies
School of Social Sciences

University of Hyderabad,
(P.O.) Central University,
Gachibowli, Hyderabad – 500 046
Telangana, India

July 2025

CERTIFICATE

This is to certify that the thesis entitled **“Notions of Care: Analyzing Disability, Gender and Sexuality in Selected BRCs in Kerala”** submitted by **Soniya A.M.** bearing Registration Number **15CWPG02** in partial fulfillment of the requirements for the award of Doctor of Philosophy in the School of Social Sciences is a bonafide work carried out by her under my supervision and guidance.

This thesis is free from Plagiarism and has not been submitted previously in part or in full to this or any other University or Institution for the award of any degree or diploma.

Further, the student has the following publication(s) before submission of the thesis for adjudication and has produced evidence for the same in the form of acceptance letter or the reprint in the relevant area of her research:

1. Soniya A. M. (2022) “Notions of sexuality: An analysis of the interplays of gender and care among adults with intellectual disabilities in Kerala”, Journal of Gender Studies, 31:7, 863-873, DOI: 10.1080/09589236.2022.2039102, (ISSN: 0958-9236 (Print) 1465-3869 (Online)), Chapter of dissertation where this publication appears “chapter 5, The Domain of Sexual lives of Persons with Intellectual Disabilities in the BRCs”.

and

has made presentations in the following conferences:

1. “Negotiating Sexual Identity; A Case Study from BUDS Rehabilitation Centre, Kerala”, IAWS Southern Regional Conference on *Intersectional Approaches to Addressing Gender, Religion, Culture: South India Focus,* 30-31 January 2019 at University of Calicut, Kerala. (National).

2. "Local Self Government (LSGs) and Disability in Kerala: Experience of Kudumbashree BUDS", National Seminar on *Two Decades of Decentralisation Reforms in Kerala: Lessons Learnt and Tasks Ahead,* 25th-26th July 2018 at Department of International Relations & Politic, Central University of Kerala. (National).

Further, the student was exempted from doing coursework during Ph.D. (recommended by the Doctoral Committee) on the basis of the following courses passed during her M.Phil. Program and the M.Phil. Degree was awarded:

Course Code	**Course Title**	**Credits**	**Pass/Fail**
GS 701	Introduction to Gender Studies	4	Pass
GS 702	Feminist Theories	4	Pass
GS 703	Gender Science, Technology and Health	4	Pass
GS 704	Research Methods and Dissertation Writing	4	Pass

01/07/2025

Prof. Sowmya Dechamma C.C
Research Supervisor

Dr. SOWMYA DECHAMMA C.C.
Professor
Centre for Comparative Literature
School of Humanities
University of Hyderabad
Hyderabad-500 046.

Deepa Sreenivas 1/07/2025

Prof. Deepa Sreenivas
Head
Centre for Women's Studies

अध्यक्ष / Head
महिला अध्ययन केन्द्र /Centre for Women's Studies
समाजिक विज्ञान संकाय /School of Social Sciences
हैदराबाद विश्वविद्यालय/University of Hyderabad
हैदराबाद-४६ / Hyderabad-46., T.S.

K. Suneetha Rani 1/7/25

Prof. K. Suneetha Rani
Dean
School of Social Sciences

अध्यक्ष / DEAN
समाज विज्ञान संकाय
School of Social Sciences
हैदराबाद विश्वविद्यालय
University of Hyderabad
हैदराबाद-500 046., भारत
Hyderabad-500 046. INDIA.

DECLARATION

I, **Soniya A.M., Regd. No: 15CWPG02**, hereby declare that this thesis entitled **"Notions of Care: Analyzing Disability, Gender and Sexuality in Selected BRCs in Kerala"** submitted by me under the guidance and supervision of **Professor Sowmya Dechamma C. C.** is a bonafide research work. I also declare that it has not been submitted previously in part or in full to this University or any other University or Institution for the award of any degree or diploma. I hereby agree that my thesis can be deposited in Shodhganga/INFLIBNET. A report on plagiarism statistics from the University Librarian is enclosed.

Date : 01-07-2025

Soniya A. M.
15CWPG02

SDG Information

Title	Notions of Care: Analyzing Disability, Gender and Sexuality in Selected BRCs in Kerala
Name and Regd. No.	Soniya A.M., Regd. No. 15CWPG02
Supervisor	Prof. Sowmya Dechamma C. C.
Dept/Centre	Centre for Women's Studies
School	School of Social Sciences

Among 17 goals (https://sdgs.un.org/goals), under which SDG the work incorporated in the thesis will be addressed **SGD 5 (Gender Equality), and SGD 10 (Reduce Inequalities)**.The findings of the thesis contribute towards the understanding of certain social issues in the state of Kerala, thereby aiming to create a larger awareness of the same and influence policies. This study has incorporated both disability and gender in the context of sustainable development. The study is carried out in BUDS Rehabilitation centres in Kerala which are established for the upliftment of adults with intellectual disabilities through vocational training, life skill development and rehabilitation. The key strategy of these institutions is based on community based participatory rehabilitation, and women play a major role in this regard. These institutions function under the supervision of the Kudumbashree Mision, a poverty alleviation programme of the state that hopes to achieve its goal through women empowerment. The local government bodies oversee the functioning and manage the funds of these centres. The thesis analyses the role of women in providing the care for persons with intellectual disabilities. A second objective is to understand the status of the intellectually disabled persons in these centres and society at large, and what measures could be taken to reduce the inequality and discrimination faced by such individuals in the society. The findings of the study indicate that persons with intellectual disabilities were not getting adequate vocational training or rehabilitation facilities in these institutions, even though there were many positive steps undertaken to make the participants confident and self-reliant by engaging them in 'work' within these centres. The main factor which restricted quality vocational training for these individuals, thereby creating hurdles for them in attaining their full potential was primarily the lack of funds. It was also found that the persons with intellectual disabilities were not acknowledged as sexual citizens, thus denying them one of their fundamental rights. The study therefore recommends compulsory sex education for persons with intellectual disabilities through BUDS institutions. Another key finding of the thesis is that the strategy adopted by the BUDS model entirely depended on women's labour. Although the overall structure and functioning of the BRCs have created a collective that offered extended care for persons with intellectual disabilities, it has also reinforced the traditional carer roles associated with women. The findings of the study help us understand the ground realities of both persons with intellectual disabilities and women as their carers, which serve as the first step in addressing these issues.

Dedicated to my little brother….

Your presence and absence changed us forever in ways that we could not have imagined…

The world would have been more colourful, with you in it...

Acknowledgements

At this juncture, all I can say to the people around me is a big thank you!

To the participants of Unnikulam and Balussery BUDS Rehabilitation Centres and Perambra BUDS school, for their love and friendship.

To Bindu teacher, Aswathi teacher, and Sarala teacher, for allowing access to their institutions for a prolonged period and sharing their stories with me. These interactions made a profound impact in the way I understand the social world around me. To Sarala *chechi*, Amina *ithaatha* and Shobha *chechi* (helpers), for the compassionate and dedicated conversations we had.

To all the mothers who shared their lives with me on numerous occasions, for waking me up to the realities, and helping me learn and unlearn!

To my supervisor Prof. Sowmya Dechamma C. C., for the countless discussions and suggestions, for pushing me to improve, and most importantly for the patience and faith she had in me. Starting from the MPhil days, she supported me in every decision and backed me in every possible way. She showed me the significance of balancing academic life and non-academic activities, and the importance of healthy relationships, family and friendship.

To my Doctoral Committee members, Dr. Shilpaa Anand for our numerous discussions and brainstorming of ideas, for sharing countless resources and for the constantly encouraging my ideas that guided my readings and shaped my theoretical framework. Prof. Suneetha Rani for her suggestions and consistent encouragement to sharpen my ideas that started from my MPhil days onwards, which helped me to rediscover and challenge myself.

To Head of the Department, Dr. Deepa Sreenivas, for helping me think diversely and critically, right from the period I joined CWS for my MPhil. To Prasad, for being there to assist with every administrative and procedural hurdle. To Jasna, for all the help with library issues. To Shraddha, for providing constant support, guidance and even a good amount of pressure that pushed me to submit and publish in JGS. To Ram, Malay, Ashish, Vineetha chechi and Manju for their companionship in the Centre for Women's Studies. To the office staff of the Centre for Comparative Literature, for all their help in critical phases.

The decade long life in the university shaped me in numerous ways – to think, engage and associate. Thanks to Vinita, Vaikhari, Suchi, Shubi, Alif, Abdu, and Anaswara for our endless discussions, late night debates, the countless jokes and food experiments. That was the most vibrant phase of my student life and I owe you guys for that.

Anu, our discussions and phone calls during the pandemic was one of the reasons how I thrived that phase. I cannot express my gratitude for taking your time, effort and patience to check and correct the draft on a short notice. Your suggestions and critical opinions were most helpful in the finishing phase. Thank you!

To Sandeep, Irfan, Minu, Shibi, Jiji, for their friendship and all the help in difficult situations.

The journey to complete the field work and thesis writing was long, with unexpected obstacles like the Nipah virus outbreak in my area and a global pandemic. I thank KSSP Balussery Area Committee for their support and for including me in their activities during the pandemic. To Girija Parvati who helped me navigate those difficult times by providing me with an opportunity to conduct my research work.

To Prof. Mini Sukumar for the numerous suggestions and opportunities, and for being there always. To the Department of Women's Studies, University of Calicut, for all their help throughout the years. To Shuhaib for his friendship, suggestions, and criticisms.

To the members and officials of the Unnikulam Panchayath, Balussery Panchayath, and Perambra Block Panchayat for their help. To Kunjhammad Master, for his faith and all the help. To the Kozhikode District Kudumbasree Mission, for their generous co-operation.

To Sijith Ettan, Sajin Raj, and Uma, for helping me access the regional libraries during my struggling phase. To Kuttayi for everything a brother does. To Maman and Ammamma, for their love and care. To Shyamalechi, who held me closely when I was in one of the most difficult phases of my life. To Chummamma, for helping with the household duties during the final stages of work.

To A.M. Balan and Vineetha N., my parents, for their unconditional love and support in every phase. All my life they have trusted me and respected my decisions. Without their rock-solid support, I would not have been able to finish this work. To Sathya Nathan, my father-in-law for understanding and support throughout the writing phase. To Anju, thank you for instantly becoming my sister and lending all the support during the pandemic and the writing phase.

To Ajay, who came into my life in the middle of my Ph.D. journey -- for his faith in my abilities and unwavering support throughout my difficulties, and for the infinite patience and warmth he showered during my struggles, thank you! To Thennal, for all the love, joy and hope, love you!

Contents

Chapter 1

Introduction & Methodology

“Don’t ask him to come with us. *Sukham illatha kutti aanu*[1]”, a senior student from my primary school said to me years ago. She was eleven or twelve years old, and I was only six at that time. The person she was referring to was my brother. He had a history of meningitis, and as a result, his head was more prominent than the rest of his body, and bigger than most of the other kids. This remark was made on an occasion when my brother tried to come along with us to school. I complained to my mother about this remark and wondered why he was identified as such. This situation was my first-ever memory of labelling someone as ‘different’.

Years later, when I was brainstorming the idea of a possible research topic for my master’s dissertation, my mother made a suggestion to consider a topic concerning the lives of persons with disabilities. Her suggestion triggered that early childhood memory of my departed brother, which I had not thought about in many years since his passing. Even in his absence, I was left with many such statements, remarks and discriminations to reflect on. My introduction to feminist research methodology during that period through my master’s (women’s studies) curriculum, also made me see the subject in a new light. I found myself gravitating towards the issues concerning the lives of mothers of persons with intellectual disabilities, which I felt was more of a ‘natural’ interest, academically and otherwise, for me. I pondered on the absence of the mothers of persons with intellectual disabilities in local public spaces, almost leading to their complete disappearance or invisibility in my locality.

---

[1] *Sukam illatha kutti* means child with ill health. In this context, ill health implies intellectual disabilities. In the locality, issues related to head/cerebral area usually implied that there was something wrong with the person’s intellect, and is treated as a disease alone.

My engagement with this topic in my local setting was the starting point of my academic interest in the areas of gender and disability.

In this introductory chapter, I discuss the methodology employed, details regarding my fieldwork and my reflections as a feminist researcher and a non-disabled person on the topic of my thesis. Followed by a discussion of my methodology in the next section, I delve into the details regarding the history and nature (of the functioning) of the institutions relevant in my area of fieldwork. A short description of my field ensues, preceding the section narrating the research questions and the framework of this study. The chapter concludes by discussing some of the hindrances encountered during my fieldwork and a description on the limitations of the study.

While working on my master's dissertation, I learnt that there were many persons with various forms of disabilities in my region. My work then also made me become aware of the lack of visibility and mobility of persons with disabilities and their families in the locality. During the fieldwork carried out for my MA dissertation in 2013, I was told by my respondents that most of them were not entitled to any sort of financial assistance from both the State and the Central governments. I was conducting my study among mothers of young children (under the age of fourteen years) with intellectual disabilities then. The mothers described to me their struggles of raising their kids, without adequate family or State support. With no option of having a day-care for their children, they felt that they could not leave their homes at all. Close and extended families would not be a helpful substitute in the long run. They were mostly confined within the domestic space and struggled to get integrated into the world outside their homes.

My interest in this topic continued after the competition of my MA dissertation as well. While preparing a proposal for my doctoral study, the area at the crossroads of gender and disability seemed to be my only logical choice. However, by the time I started my doctoral work, many things had changed. Many day-care centres for adults with intellectual disabilities were established in Kerala, providing a solution to the concerns that were expressed by the mothers in my earlier study. As a result, I wanted to look at the way care operated around persons with intellectual disabilities in the state of Kerala in these institutions. I focused on two things about the topic which I wanted to study: persons with intellectual disability, and the systems of care. Though family is the primary unit in providing care for persons with intellectual disability, I wanted to look at a more outside-the-family way of providing care. In other words, I wanted to understand the role of the community[2] and state in providing care for persons with intellectual disabilities, rooted in a gender perspective.

Around that time, I came to know about a chain of institutions called BUDS (This is not an acronym but the actual name of the institutions) schools functioning under the State Kudumbashree Mission[3] to provide day-care for persons with intellectual disabilities. During my Masters' fieldwork, I had come to know about the hardships endured by each family member, particularly, the mothers of children with intellectual disabilities, without proper care or support from anyone. According to the official website of the BUDS institutions, it was formed precisely to meet this objective: to free mothers from their daytime care duties! This statement struck a chord with me, and as I read more about the institution on its official website, it only

---

[2] In this study, community means like-minded people who are in some way connected to the BUDS Rehabilitation Centres (BRCs). Thus, the community primarily includes the staff, parents, and participants. Those who regularly engaged with the affairs of the BRCs are also included as part of the community here.

[3] The State Kudumbashree Mission is the poverty eradication and women empowerment programme implemented by the Kerala government.

convinced me more that this was the direction my fieldwork and thesis should take. This was the major factor that motivated me to study the system of care provided by the BUDS Rehabilitation Centres in Kerala for persons with intellectual disabilities.

1.1 BUDS/BRC model – A Background

The conceptualisation of BUDS schools can be traced back to the family surveys conducted among Neighbourhood Groups (NHGs) during 2000-2001 by the state Kudumbashree Mission to identify destitute families for the planned *Ashraya* project. Interestingly, disability was not a listed theme in the questionnaire. However, some of the enumerators noted down the intense and excruciating conditions of some families which had a member with intellectual disability. The survey estimated that around 0.5% of the families in Kerala had persons with intellectual disabilities. Many forms of disabilities were listed in the study conducted by the Kudumbashree, which recorded that, on an average, there was about one disabled person per every 60-100 families in a Grampanchayat, (kudumbashreestory.org, 2022). The website further stated:

> The first Gramapanchayats to firm up the idea of care centres for the intellectually challenged were Venganur in Thiruvananthapuram and Mangattidam in Kannur. These initiatives depended on the voluntary service of a few women in the locality who came up with the willingness to work for such centres. What Gramapanchayats could pay them was a mere Rs 1500 for three months a year, allowed to be spent from Plan Funds. (kudumbashreestory.org, 2022)

It must be noted here that this particular website is defunct as of May 2025, and was replaced by the kudumbashree.org website, which has taken away any mention of the women volunteers, the initial survey done by the Kudumbashree workers, and the goal of the institution that centred around reducing the hardships faced by ‘mothers’ has also been replaced with the gender-neutral term, ‘family’ (kudumbashree.org).

By 2007, the Kudumbashree mission decided to formulate effective strategies to constitute a chain of institutions state-wide. Its approach problematized the special school system that existed then and addressed the lack of accessibility of persons belonging to economically weaker sections with intellectual disabilities in these institutions due to their inability to remit fees. Another problem raised by the Kudumbashree was the reading-writing-math approach that was adopted by these institutions. It pointed out the inefficiency of the Integrated Education for the Disabled (IED)/Sarva Siksha Abhiyan (SSA) scheme for making people pass examinations without functional literacy and essential skills. Another vital problem identified by the Kudumbashree was the inability of vocational training in the state at that time, as persons with intellectual disabilities found it impossible to secure employment. Persons residing in rural localities were unable to reach commercial institutions that did not operate in rural regions. Most importantly, the existing institutions in 2007 did not provide care service after 18 years of age (kudumbashreestory.org, 2022).

The proposed institutional system for the BUDS schools was to be owned by the local self-governments and guided by the state Kudumbashree Mission, through Community Development Societies[4] (CDS) and community organisations providing field-level support. By 2009, seven local bodies had established BUDS institutions.

---

[4] CDS is the apex body of the Kudumbashree’s three tier community structure at the local government structure.

Currently, a total of 131 BUDS schools have been established in the state, out of which, 72 are new institutions which have initiated functioning.

1.2 BUDS Rehabilitation Centres (BRCs)

The BRCs were established as part of the Kudumbashree mission and these are the next level of BUDS schools. There are 151 BRCs in the state. These are day-care centres established in 2015 for adults with intellectual disabilities. Unlike BUDS schools, BRCs are the centres for facilitating vocational training and life skill lessons for persons with intellectual disabilities. “BRCs are meant to train and support persons with special needs for equipping them with skills that make them employable” (kudumbashreestory.org). Out of 2840 enrolled persons in the BRCs, 236 persons are from Kozhikode district (Kudumbashree Mission, 2019). In order to achieve the objectives of the programme, they adopted a Community-Based Participatory Rehabilitation (CBPR) strategy. This rehabilitation strategy adopted partnerships with local bodies to achieve sustainable community participation. The CBPR strategy is further discussed in Chapter 4. Adult life skills, vocational training, and adoptive skills are the focus of the training programmes implemented in these BRCs. The CBPR strategy is ensured by the involvement of local self-government institutions (LSGS).

While no two BRCs remain the same in terms of their functioning, the core structure of all the BRCs remain the same. The teacher, the helper and the participants are the key persons in any BRC. The characteristic features that define any BRC are dependent on them. Parents, especially mothers, also play an important role as they visit the institution very often. One of the mothers of the participants was appointed as the helper in most BRCs. One of the main reasons for the establishment of the BRCs was catering to the motto of women empowerment of the Kudumbashree Mission itself. Through the opening of the BRCs, Kudumbashree which is also the poverty eradication programme of the state, helped the mothers to participate in income-generating activities. Thus, while formally acknowledging the role of unpaid care work performed by women in the households, it also helped the carers to be more financially independent.

1.3 Method of Study

There are more than 300 BUDS institutions (both BUDS schools and BUDS Rehabilitaion Centres (BRC)) in the state, and their functioning are based on the objectives described by the state government/Kudumbashree Mission. However, I wanted to specifically look at how care operates in the institutions and the role of gender in the discourse of the BUDS institutions. In order to understand the dynamics of gender, care, and intellectual disability, it was then essential for me to conduct a qualitative study at the grassroots level. Being a female researcher trained in feminist research methodologies, I adopted specific ethnographic techniques to conduct the study.

Feminist ethnography is a distinct way to understand the subjective realities of a society at the micro level. Skeggs (2001, p. 426) describes the similarities between feminist research and ethnography to argue that feminist “ethnography is about understanding a process”.

She explains,

> They both have experience, participants, definitions, meanings and sometimes subjectivity as a focus, and they do not lose sight of context. Just like any feminist research, the ethnographer maps out the physical, cultural and economic possibilities for social action and meaning. (Skeggs, 2014)

Visweswaran (1997, p. 593) defined "feminist ethnography as the ethnography that foregrounds the question of social inequality vis-à-vis the lives of men, women and children". She explained that the peculiarity of feminist ethnography is not in complementing the existing ethnographic works done from an 'objective' point of view; rather, it facilitates knowledge production from diverse perspectives.

Feminist ethnography is a way to exercise reflectivity on the subjective positions of the researcher and research on the basis of power and production of knowledge. Immersion[5] is one of the critical outcomes of any ethnographic study, as feminist research on a whole, and feminist ethnography in particular, help in enhancing the researcher's self-reflexivity. In my study, I incorporate feminist methodology with disability studies. Feminist research itself is a political intervention; thus, opting for feminist ethnographic methods for research was also a conscious political decision. For example, Bailey & Mobley (2019) discussed how the black feminist disability framework centres on race, gender and disability theories, and how they integrate to challenge the notion of 'normal,' i.e., white, ableist men. They argued that this framework would necessitate a shift from the dominant paradigm.

Recently, there have been a number of feminist ethnographic studies conducted in the area of disability studies in India. Mehrotra (2012) discussed methodological issues in disability research in India and observed that sub-disciplinary studies such as Women's Studies and Dalit Studies challenge popular notions. Disability Studies is considered as an interdisciplinary and open discipline because it holds "qualitative, emancipatory, reflexive, and emancipatory knowledge

---

[5] Immersion in ethnography allows the researcher to get accepted and become part of the field in which they study.

production for bringing change in the daily lives of PWDs[6]" (Mehrotra, 2012, p. 6). She also stated that "the gap between rhetoric, policies and experimental realities should be revealed through ethnographic studies" (Mehrotra, 2012, p. 7).

> Both ethnography and feminism thus have experience, participants, definitions, meanings, and subjectivity, as a focus and always take the context into account. The aim is to map out the physical, cultural and economic possibilities for social action and meaning, understand the interaction between structure and agency, and enable women participants to have some say in how they are studied. (Ghosh, 2012, p. 12)

I place my study in the feminist disability framework, as it employed ethnographic methods to collect data. I took conscious positioning/bias in understanding disability. Since I lacked a fully insider perspective, it was important for me to avoid pre-conceived notions regarding disability and its experiences. Therefore, it took some time for me to approach the field and understand it. As I mentioned earlier, I have had training in feminist methods and methodology. Here, I operationalised a feminist disability framework to understand the mechanisms of care in the BRCs. Every methodology is unique, as it involves various frameworks and distinct methods of data collection. In my study, the methodological framework evolved with the unique subjectivities of the field, and my time and experiences in the field were reflected in the shaping of my thesis. I started the study with a vague idea of care and intellectual disabilities, but as I progressed further, it became apparent that care was the foundational idea that weaved through my framework, as it weaved through the activities of the BRCs.

---

[6] Person with disability (PWD).

1.4 Formulating the Framework

Since I look at disability and care through the analytical framework of gender, a feminist research methodology framework is best suited to address my research questions:

1. How is intellectual disability understood and addressed in the BRCs?
2. What is the nature of care in the BRCs? How is ‘care’ provided and practiced in the BRCs?
3. How does gender relate to the practice of care in the BRCs?
4. Is there a relation between care and the sexuality of persons with intellectual disabilities?

Here, in order to understand these research questions, I need to address specific methodological issues. From the beginning, I was worried about my subject position as a non-disabled person working in the area of disability studies, which could cause concerns about my standpoint. There were times during the fieldwork when the insider/outsider question was evoked. For example, during my last phase of fieldwork, there were women who asked me why I was doing research in the area of disability as I was not a person apparently associated with any form of disabilities during that period of time. Though it seems like a natural enquiry from the participants, it alludes to one of the most fundamental questions in feminist disability studies. “Insiders are the members of specified groups and collectivities or occupants of specified social statuses; outsiders are the non-members” (Merton, 1972, p. 21). “Researchers’ insider status entails that they share common characteristics, such as impairment status, race and sexual orientation, with the marginal group they are studying, whilst outsiders stand at a distance from the marginal group and therefore are considered as non-members" (Chhabra, 2020, p. 307). Vaidya (2010) described the complexities of conducting 'insider research' as it evokes ethical questions about how the data is being used, and the utilisation of the relationships with others as they all belong to the same community. Chhabra (2020) and Bridges (2017, 2001) discussed the problem of the monopoly of insider research and the same.

"Nothing about us without us" (Charlton, 2004) is a rhetorical question faced by non-disabled persons (outsiders) doing disability research. It is discussed that "There is no distance between the experiencer and experience" (Sarukkai, 2017, p. 47). In disability research, it is argued that outsider research lacks the personal experiences of persons with disabilities, which might result in frameworks with inherent oppressions or biases (Bridges, 2017). To have a critical awareness about one's own standpoint and positionality, it is essential to conduct outsider research amongst marginalised groups. However, Bridges (2001) explained that insider/outsider debate should be extended to the kind of relationship the researcher and researched should obtain rather than becoming the basis for the exclusion of outsider researchers.

Chhabra (2020) discussed how he was considered an outsider and insider in the same research at times. He highlighted the importance of the diverse identities of the researcher to create different subjective positions during his field work. Even though Chhabra (2020) being a person with visual impairment, who conducted comparative research among visually impaired youths in Delhi and Norway, he was considered as an outsider at times due to his socioeconomic background, and geo-political locations. This portrays the complexities of the insider status. There is not a homogenous group of persons with disabilities as they belong to diverse socio, cultural, economic, geographic locations, religion, gender, etc. Hence, I wanted to bring out the nuances in the insider/outsider dichotomy.

While doing feminist ethnography, I identified myself as a feminist woman. At some point, that identity equipped me to relate with the participants of the study. According to Ghosh (2012), “feminist ethnography emphasised (that) knowledge is interpersonal and contextual based on women’s experience in the realm of everyday experiences and human agency” (p. 12). She further stated that it involves the immersion of researcher in the field and the relation between the researcher and the researched (2012). Hence, being an outsider, there was all the more reason for me to establish a good rapport with my respondents during my fieldwork.

Although during my fieldwork, I started as an outsider, gradually, I was considered as a partial insider within the institution. This partial insider status was not an easy position to achieve, and it was conferred only after a while. It was difficult as I was not related to the BRCs in any manner. Even though I began this with memories of a personal experience, I was not a parent, family member of a participant, a staff, an official in charge of the institution, or a representative of the local body – I was initially seen as an outsider. However, with prolonged interactions and increased familiarity, I was considered as a person the various respondents of my study could freely communicate. For the participants of the BRCs, I was considered as a semi teacher. I often tried to clear this misconception, but still some of them addressed me as ‘teacher’. With the days passing, I was invited to participate in their study tour. This was an invitation for an insider. I was expected to participate in various programmes conducted at the BRCs. Participation required my help and involvement, such as helping them put make-up on, assisting while dressing, etc., for their various programmes. I was also asked to accompany the teacher to resolve an issue once[7]. Thus, despite my initial status an outsider, I was treated as a partial insider in the field. My dialect of Malayalam which was commonly used in the region where the BRCs were located also helped me get closer to them. My gender identity and the proximity of the location of my residence were also factors that helped me achieve this status. Partial insider status is a fluid status between an insider and outsider. Chhabra (2020) argued that this status helps us to maintain the objectivity of the research as well as a subjective understanding of the lived realities.

In the initial stage, I was really focused on studying/understanding the discourse surrounding care and intellectual disabilities in BUDS institutions. At that point, I was determined to achieve this through the analytical category of gender. While preparing for the pilot study, I faced a dearth of such studies in this area in Kerala or South India, in general. The ethnographic/feminist studies of disability were primarily focused on the North and East India. In Kerala, the feminist field studies/ qualitative studies in the area of intellectual disabilities were limited. This situation required a pilot study to understand the field, to locate possible focus areas for the study, and to formulate a proper plan for data collection. For this purpose, I visited three BUDS institutions in Kerala. The first two schools were located in Kozhikode district, one was located in a very remote region near a reserved forest and another one was in the middle of Perambra town. The third institution was called a Model BUDS School, located in Kasaragod district. As the name suggested, they are a complex of BUDS institutions. It has a school and a BRC, where persons after 18 years are enrolled for vocations\al training and life skill development.

---

[7] Please refer to chapter 4 for a detailed narration of this incident.

I did a pilot study which lasted for more than two months in these institutions. After the pilot study, I decided to focus on BRCs instead of BUDS schools. BRCs were comparatively new institutions and were meant for a long duration of training of the participants to achieve life-skills and self-sufficiency, employability etc. Moreover, the institutions were meant for adults with intellectual disabilities. While doing the pilot study, it was comfortable for me to establish a rapport with the respondents Perambra BUDS school. Perambra is located near my maternal home. I had the same local Malayalam as the other respondents. It paved the way to easily establish a good relationship with the participants and the faculty there. At first, it was difficult to break the ice as I identified as a research scholar from a faraway university. When I switched to my local Malayalam there was a significant change in the field relationships. Although I lacked an insider's perspective, somehow my dialect and the identity of a 'local' enabled me to receive a certain level of acceptance in the school. I also understood that being a female researcher, it was easier for them to connect with me. While this was the case from an institution in my locality, it was not easy to establish a comfortable, non-formal relationship in other institutions. I could only use my female identity to establish a rapport with the respondents in the other two institutions. In every way, I was acutely aware of my outsider status. The lack of rapport between the researcher and the researched negatively impacts ethnographic studies. Oakley (2003) observed rapport as "the acceptance by the interviewee of the interviewer's research goals and the interviewee's active search to help the interviewer in providing the relevant information" (p. 246).

Bruskin (2019) charts out the dynamics of insider/outsider status in organizational ethnography. The study observed the researcher's relation with various stakeholders in the field decide a whether a person is an insider or an outsider.

Brukin's study shows that the role of insider/outsider is fluid and it shifts on the basis of "situation, relations and interactions" (Bruskin, 2019, pp. 167–168). From the experiences of the pilot study and later field work, I can attest that over the course of field work, the identity of both researcher and researched shifts based on various relations and as mentioned, is never fixed.

From the insights from my pilot study, I decided to conduct the study in the two BRCs near my hometown for the fieldwork. Ethnographic methods such as participant observation and unstructured interviews were adopted in the fieldwork. Although I did not plan to conduct an interview initially, at some point, mothers of the participants in the institutions expected me to conduct an interview. In reality, they were asking me when I would conduct their interview. This question was repeated several times, and so I conducted several unstructured group interviews. Here, I was sitting with a proper notepad in my hand. Questions were asked with a tone of formality. They answered formally. Here, questions were asked and I received answers that they wanted to reply in a formal interview. This was more of a mechanical process. Before the interview and after the interview, our interactions remained the same, being more informal. However, the tone was formal and mechanical during the time of the interview. For instance, when I asked a mother how they managed to bathe her daughter at home, she answered a 'perfect reply' that all family members helped her. However, the next day she told me it was challenging to take her daughter for a bath as she is all grown-up and her father can no longer help her in the process. Oakley (2003) had used the term 'pseudo conversations' to describe formal, uneventful interviews as they had to keep the etiquette of formal interviews (p. 245). Chase (2003) described the importance of framing questions in the everyday language. She emphasised the importance of a constructed relationship between interviewer and interviewee as it directly affects the quality of their responses to the researcher's questions (p. 275).

Narratives were a major part of my fieldwork. I felt that listening to their life stories or oral narratives shed light to the complex socio-cultural relationship they had. In other words, narratives are the life experiences loaded by their subjective realities. I think listening to life stories/oral narratives play an important part in filling the gap in feminist disability studies. Cortazzy (2014) explains that narratives are the interpretation of events by the teller; it is a process to understand themselves and the event itself. Mere listening itself is an important activity in my fieldwork. Participant listening (Forsey, 2010) was a major tool I adopted in the field. I felt that the mothers of persons with intellectual disabilities were not able to express their feelings or thoughts in an unrestricted way in society. They were often not heard or carefully listened to by the mainstream society. In majority of the cases, they were not part of the mainstream/public spaces. As a result, when I started listening to them, they liked it and they actively talked and shared things they wished to share.

While doing feminist ethnography, it is important to listen to the other women. Listening is also a reflexive process. Forsey (2010) argued that engaged listening is as important as participant observation in ethnographic study. He argued that while writing field notes, engaged listening provides more information than participant observation. Forsey noted that the preference for participant observation also underlined the prominence of sensory methods of data collection, especially the visual methods in ethnography. I think the subjectivity of the participants are better understood while conducting 'participant listening'. Engaged listening strengthens feminist ethnography as feminist ethnographers consider the silence of the participants as political. "I would argue that feminist anthropologists stand to learn not only from women’s speech, but women’s silence as well” (Visweswaran, 1994, p. 31). Therefore, it should be considered as a significant contribution of feminist ethnography to social science research.

One of the most important contributions of my study to the feminist research methodology is my positioning as a partial insider status. Subjective positioning and conscious bias are two most distinct features of feminist research methodology. By accepting my outsider identity and partial acceptance as an insider by the BRC community was important in the research methodology’s frame work. The immersion in the field made it possible for me to get accepted as a partial insider.

1.5 Visiting the BRCs

The two BRCs that I visited, and conducted my fieldwork at, are located in Kozhikode district, in the state of Kerala. The first BRC is located in Unnikulam village. It was a small building situated near the Panchayat office itself, with one study/activity room, one dining room, a small veranda, and a kitchen. The amenities of the BRC were very low. They only had some plastic/fibre chairs and two tables. There were several activity gadgets stacked in the corners of the activity room. The kitchen had plates, glasses, one gas stove, and several cooking utensils. Water was drawn from a well located in a house nearby. They did not have a play area or space outside the building. Their bathroom lacked basic facilities. There were no specific amenities here, as this institution was designed for the rehabilitation of persons with intellectual disabilities.

The BRC had two staff members -- one teacher and a helper. Although there were 22 persons enrolled in the institution, only 7-10 were present on a daily basis. I was told that the absentees were either chronically ill or they lacked proper transportation facilities. There was, however, an auto rickshaw to pick up and drop off the participants daily.

The other BRC functions under the Balusserry Village Panchayat. The activity room, washroom, and kitchen were more spacious here than in the former. However, the location of the BRC was very remote. They did not have any proper transportation facility. There was only one minibus running in the village. The participants were expected to travel by this bus to reach the institution. Therefore, only 6-7 persons came to the BRC on a daily basis, and only one female participant attended regularly, even though there were more than 20 participants who were enrolled in the institution. Both institutions had one teacher and one helper each. In order to protect the privacy of the participants, mothers and staff, I used pseudo names throughout the study. All the field narratives in the study were translated from Malayalam to English. All the translations, including the translation of some of the quotations from the BRC handbook, were done by me.

1.6 Unpredicted Hindrances

I had never previously thought of how much a natural calamity or the spread of infectious diseases could affect fieldwork. Unfortunately, the outbreak of NIPAH virus happened in Kozhikode district in 2018. This outbreak happened in Perambra and Balussery, (near my village) and the high infection risks forced the government to announce a travel ban in Kozhikode district. For more than two weeks, a medical emergency was declared. All offices, schools, and even the district taluk courts had to close for a period of time. Among the 14 people who died, 3 of them were from near my native place, and we had to stay home for two weeks. The BRCs were also closed following this virus outbreak. The travel ban imposed severe restrictions on coming into and going from Kozhikode triggered mass panic, anxiety, despair and fright.

There was a time when we were isolated as a community or as a region from the rest of Kerala. After the isolation period, another case was reported, and seven more days were gone. For almost a month, Kozhikode was isolated from the rest of Kerala. A public medical emergency was something I had never experienced before. Along with the directions from the Health Ministry, people were very concerned about the situation, and we were taking precautions by ourselves. The resistance and survival efforts displayed a collective feeling that was as rare as it was remarkable.

During the following semester, when I was about to go back for fieldwork, Kerala was hit by the worst flood in its history. For months, it was impossible to conduct fieldwork or any activity there. As I was out of Kerala at the time of the heavy rains, it became impossible to go back home. Only once the rains stopped and transportation options were restored was I able to reach home. Even after the flood, it took months to get back to a ‘normal’ life. The socio-cultural as well as disaster economic impacts had the potential to turn my field upside down. This was apart from my own obligations to participate in rehabilitation and relief work. I had to completely set aside other duties and personal issues, as my community’s recovery was the only thing that mattered to me at the time. Until the outbreak of these two disasters, I did not recognize how a good climate or an overall well-being of one’s community could be such crucial, enabling factors for one to be able to finish fieldwork in peace.

This study was, thus, a personal journey for me in many ways. It tested my limits in every manner. I believe I have been growing with these experiences. As I reach the end of this particular journey, I have a feeling that I have changed in many ways. I learned and unlearned many things, I learned about my vulnerabilities. The field made me realise the limitations of the knowledge I possessed regarding disability. It made me reflect on the ableist and heteronormative notions that I had previously inculcated about intellectual disability, and sexuality of persons with intellectual disabilities. Often, in the field, I stood alone as a person who could not or did not understand the dynamics of the centre. I recognised my own inability to understand the dynamic nature of the BRCs. It was my own ableist notions that prevented me to acknowledge their way of communication as normal. I witnessed how they (the BRCs) negotiated their odds and established channels for survival. Their resilience and agency to assert day-to-day activities challenged my prejudicial mindset.

My interactions with the participants, their parents, teachers, helpers, Panchayat officials, and other people who visited these BRCs shaped the methodological aspects of this study. As I mentioned earlier, the method of participant listening was a game-changer for me. This technique helped me understand the field better. I now strongly believe in feminist research methodology and disability studies. Also, participant listening is crucial to hear and understand the participant’s point of view. Unlike participant observation, where the ‘observer’ perceived things from their own point of view, participant listening puts focus on the interlocutor or participant’s point of view, of their own experiences, and lived realities. This better equips the researcher for emersion in the field, to become more reflexive of the field. For a feminist disability framework or any identity-based study, participant listening is, thus, a significant method.

Over time, we came to form endearing relationships in the BRC. One of the most important issues with a long-time engagement in the field is that it becomes quite difficult to set boundaries between the researcher and the researched. Therefore, sometimes, I displayed a notepad or a recorder to remind myself and others of the purpose of my visits in the centre. Over time, there was an overlap in the roles and boundaries between us. Once, I was asked to accompany a mother and teacher to obtain several official documents from a participant's father's home. The participant and his mother were staying separately, and were not in good terms with the family members. When the teacher requested me to accompany her, I did not think twice about the intervention that I would be participating in. However, after the retrieval of the official documents, while analysing the events of the day, I could only think of such interventions as defining my field experiences and the research methodology itself.

The everyday lives in the centre impacted the whole research process. Once I became partially accepted and got integrated into the field, through listening and observation, the research and its focus were gradually modified. At first, the staff and mothers simply expected me to conduct surveys, as they were more familiar with the methods of filling questionnaires or interview schedules, and attending interviews. It took some time for us to find a rapport. Although I conducted several interviews to satisfy the parents and staff, over time, they understood that I preferred to listen and converse casually with them. Sometime in the beginning of the fieldwork, in all the institutions I visited, they expected me to conduct awareness classes regarding disabilities and coping mechanisms. I suppose they expected either a medical explanation of things, or legal and rights-based classes. However, I told them that I was not knowledgeable in the area, and that I was there to just learn their experiences and share their knowledge. Nevertheless, during our conversations, we still discussed the existing laws, rights of persons with disabilities, and also the schemes and programmes under the state government. In that way, I was learning from them and they also gained some perspective from me as an outsider. In a multitude of ways, the interactions and the relations formed in the field, illuminates the fluidity of insider/outsider categorisation. Methodologically, this study complicates the insider/outsider binary discussed in feminist/disability studies. Immersion and reflexivity of the researcher shakes these definite categorisations and shed light on the centrality of ‘fluidity’ in the relations between the researcher and their field. Mohler & Rudman (2022), argued that reflexivity is the most important aspect of qualitative research. They illustrate how critical reflections of one’s positionality and subjectivities help deconstruct the hierarchical assumptions in research. The study argued that, the approach strengthens the intersubjective reflex in research. Therefore, considering the dynamics of the field I engaged in, I can say that the journey was a learning and maturing process that ultimately shaped me as a person and also the researcher in me.

1.7 Limitations of the study

There are a lot of limitations in the present study. I opted for ethnographic methods to study the dynamics of care in the BRCs. Although an in-depth fieldwork and analysis of the data provided me a micro-level understanding of the situations of the BRCs, it was insufficient to draw generalisations in the study. The BUDS-BRC model comprises a chain of institutions scattered throughout the state. Each centre is situated in its own distinct cultural and social environment. Therefore, an in-depth study of two centres cannot provide generalisations about the nature and exercise of the model across the whole state. In order to understand the BUDS-BRC model and its effectiveness, large-scale surveys and mixed methods might be required in any future study in this area.

Chapter 2

Review of Literature

Disability is a large and complex term that encompasses a multitude of experiences, ideologies, policies, discourses, cultures, and so on. Disability or discussions on disabilities can be traced back to antiquity. The term arouses notions about an individual's limitation to participate in the socio-cultural, political, and economic spheres of life. Disability is not a homogenous category. It is a combination of heterogeneous views and subjectivities. These discourses evolved over the course of decades and transformed the lives of persons with disability and our understanding of the term itself. Discussions about deficiency or limitation of physical/ intellectual/ developmental issues are done using medical terms in our society. At the same time, their existence and experience are explained through sociocultural understandings. This divergence, in a nutshell, shows the evolution of disability studies through or various models of disability.

Disability is discussed from various perspectives by numerous scholars throughout the world. For the purpose of this study, I intend to limit the discussions to the themes that emerge from the objectives of this thesis. I discuss the medical, social, and cultural models of disability, along with feminist disability studies. Disability studies in India and the evolution of the discourse of intellectual disability will also be discussed in different sections of this chapter. The concluding section of this chapter maps the gap in literature review and how this study helps fill the existing gaps.

2.1 Medical Model of Disability

The growth of disability studies can be traced back to the development of various models of disability. The term 'medical model' was first introduced by Dr.

Szasz, a psychiatrist, to discuss the trends in psychiatric treatment during the 1950s. He identified the practice of pathologizing natural human behaviours and emotions to maintain social order. He argued that the prevalent treatments during that period did not help in ending stigma associated with mental illness, poverty, and cultural attitudes towards people with mental illness (Zaks, 2024). The term was then used as an umbrella term to discuss anything associated with disability and medical support/medical intervention. The biomedical model emphasised ‘impairment’ as the root cause of disability. All the interventions developed under this model focused on correction, prevention, and elimination of individual problems. According to Haegele & Hodge (2016), disabled persons are expected be part of the ‘normal’ society by fixing their disability. While individuals are said to be at fault, society remains the same under this model. As its name indicates, the authority to identify a person’s disability are medical professionals (Haegele & Hodge, 2016).

Persons with disabilities violate the ‘sick roles’ by neither withdrawing fully from social activities nor functioning as part of ‘normal’ society (Marks, 1997). Murphy (2001) used the concept of liminality to explain the transitional stage of disabled people. He described it as an undefined state which is neither here nor there. This in-between state can be understood using the concept of medical model of disability. This theory complicates the strict categorisation of the medical model/ individual model of disability as individual failure. Mark (1997) explains, “impairment relates to the organic level; disability relates to the consequences of organic impairment; and handicap to the social consequences of deficient ability” (p. 84).

Care and rehabilitation principles also heavily depend on this model as they primarily relied on the principles of cure/elimination of individual problems. Chander

(2013) observed that the medical model of disability focused on prevention or cure in physical, sensory, and cognitive impairments. If this cannot be achieved, then the appropriate social response to disability under this model is to undergo rehabilitation. Therefore, “disability under the medical model is considered to be a ‘loss’ to be compensated rather than a ‘difference’ to be accommodated” (2013, p. 68). Even after recognising the social disadvantages of disabilities, the core of the rehabilitative worldview is its attachment to the idea that, it is impairment that leads to “social difficulties and exclusions”; not the other way around (Thomas, 2002, p. 41). The medical model presupposes the idea of a ‘normal’ body free from challenges. “The bio-sociality notion that guided the medical paradigm objectified and categorised people as sick or healthy, mad, or sane and justified the hierarchical standard for treating some bodies as abnormal and inferior”(Reddy, 2011, p. 290). “[The] notion of loss is underlined by the response to disability, *rehabilitation*, which implies restoration to a previous condition. There is an underlying ideal of equality lost and restored, and of the *right* to be able to participate equally” (Ingstad & Whyte, 1995, p. 8).

It is essential to look at the evolution of the United Nations’ concept of disability which has moulded the global perception of the concept, that is, in turn, used to develop frameworks, policies and programmes by nation-states and other national/international agencies. In 1975, the declaration on the Rights of Disabled Persons defined “a disabled person as any person who is unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/ or social life as a result of a deficiency, either congenital or acquired, in his/her physical or mental capabilities”(Sundaresan, 2013, p. 82). This definition was based on the biological /biomedical model of disability. Following the Declaration on the Rights of the

Disabled, World Health Organization (WHO) proposed a three-fold classification called International Classification of Impairment Disability Handicap (ICIDH) for a universally acceptable definition.

> […] impairments, concerned with abnormalities of body structure and appearance and with organ or system function resulting from any cause; in principle, impairments represent disturbances at the organ level. Disabilities, reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person. Handicaps, concerned with the disadvantages experienced by the individual as a result of impairment and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings. (World Health Organization, 1980, p. 14)

According to this definition, 'impairment' refers to the biological conditions of the person and it depends on the possibility of correction through medical interventions. Disability, on the other hand, is reflected in the performance level of the impaired person. Handicap is the discrimination and disadvantages faced by persons with impairments. This effort tried to differentiate biological and social implications of disability. The year 1981 was declared as the International Year of the Disabled. It was the year that witnessed a surge in the number of research projects in this area, along with conferences and symposiums on this topic, which were followed by policy recommendations[8]. A World Programme of Action (WPA) was adopted in 1982 by the United Nations General Assembly, which was mainly aimed to 'enhance disability prevention, rehabilitation and equalisation of opportunities' (Sundaresan, 2013, p. 83). Sundaresan (2013) observed that one of the underlying themes of WPA was to avoid

---

[8] See Sundaresan, 2013 for a more detailed discussion on the same.

treating persons with disabilities in isolation, but as part of ‘normal’ community services. He also highlighted that this must be the foundation for a Community-Based Rehabilitation (CBR) model and an integrated education of children with disabilities. Watson (2012) discussed the problems of this approach. He pointed three major issues in the ICIDH definition. Firstly, he argued that it focussed on medical definitions and bio-physical belief on ‘normality’. Secondly, according to him, it defined impairment as the reason for both disability and handicap. He further explained that “what is and what is not impairment is historically and culturally variable” (Watson, 2012, p. 16). Thirdly, the definition put “people with actual or accredited impairment in a dependant position” (Watson, 2012, p. 16). According to Watson, based on this approach, impairment is the individualised medical condition which required cure or eradiation. It is the root cause behind disability.

From the above discussions, it is evident that the initial definition of the term by the United Nations and the subsequent formulation and adoption of disability policies by many countries were largely influenced by the bio-medical model of disability. While it created a starting point for discussions for the policy makers, it was severely limited in scope. However, there were course-corrections in the direction of the policies later on, in light of better understandings of the concept of disability itself. One of the theoretical models that paved the way for this change was the social model of disability, discussed in the next section.

2.2 Social Model of Disability

The idea of the social model of disability was influenced by the Union of the Physically Impaired Against Segregation (UPIAS) document in 1976 in the United Kingdom (UK). The document argued that disability was the result of social barriers and not because of the impairment of a person (Oliver, 2013). Mike Oliver, in 1980, coined the term ‘social model of disability’ (Watson, 2012, p. 18). He introduced the social and individual models of disability (Oliver, 2013) thus: ‘The social interpretation of disability argues that people with accredited or perceived impairments, regardless of cause, are disabled by society's failure to accommodate their needs’ (Barnes et al., 2002, p. 4) . This approach does not deny the significance of impairment in a disabled person's life, but it focuses on the social, economic and political barriers along with impairment (p. 5). “The social model of disability is a tool with which to provide insights into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication” (Watson, 2012, p. 18). The social model argues the case for the agency of persons with disabilities- the right to choose their lives, the right to make choices by themselves. Shakespeare (2004) identified “barrier removal, citizenship rights, anti-discrimination legislations” (p. 11) as the areas of action under this model. This model was instrumental in forming a collective disability consciousness over the years (Oliver, 2013).

The following table is an attempt by Chander (2013) to distinguish the medical/individual model of disability from the social model.

Individual Model	**Social Model**
Personal tragedy theory	Social oppression theory
Personal problem	Social problem
Individual treatment	Social action
Medicalisation	Self-help
Professional dominance	Individual and collective responsibility
Expertise	Experience
Adjustment	Affirmation
Individual identity	Collective identity

Prejudice	Discrimination
Attitudes	Behaviour
Care	Rights
Control	Choice
Policy	Politics
Individual adaptation	Social change

Source: Chander (2013)

Goodley (2011) observed that the social model scholars have turned their attention away from people's impairments to social, economic, relational, political, and cultural barriers as the reason for the exclusions of persons with disabilities (p. 11). The social model of disability rejected the institutionalisation of persons with disabilities (Marks, 1997); it rejected corrective techniques and rehabilitation strategies (which are based on the medical model's correction and normalisation philosophy) as well. The social model of disability was widely received in the UK and became a part of the global discourse of disability within a short period of time. The model structured national and international policies and laws on disability. As the popularity of the model grew, the critiques pointed out that the model excluded impairment and bodily experiences in its narratives.

The model's heavy reliance on non-inclusive social structure as the reason for disablement was critiqued by feminist scholars like Morris (1993) and Wendell (1996). Shakespeare and Watson (2001) discussed the evolution of the social model of disability and acknowledged the criticisms of this model. Wendell (1996) critiqued the model by pointing to its rejection of bodily experiences of impairment, body pain, etc. There was a growing literature on the sociology of body at the time. Like

Wendell, many other scholars also criticised the ‘disappearance’ (Hughes & Paterson, 1997) of the body in the social model discourse.

The social model was prominent in the UK, while the minority model of disability was being developed in the US simultaneously.

> By illuminating the common marginalised experiences of disabled people, African, Native and Hispanic American groups, the minority model addresses the importance of race and ethnicity in North American politics and the emergence of new activism from minority bodies, behaviours and abilities. (McRuer & Wilkerson, 2003, cited by Goodley, 2011)

Mitchell & Snydar:

> The minority model gives primary position to disability as being located in the environment rather than the person. It also solidifies a rights-based argument about the ability of people with disabilities to actively participate alongside able-bodied people as full citizens on the basis of equal access. (Mitchell & Snydar, 2012, p. 42)

These are the two dominant models of disability that originated in the UK and the US. There are other models that focus on the regional and cultural differences in experiencing and defining disability globally which are discussed in the subsequent sections of the chapter.

2.3 Human Rights Model of Disability

This model of disability was developed after the prominence of British social model of disability faded. The human rights model of disability focused on the rights of persons with disabilities. In the majority of cases, basic human rights like shelter, education, employment, or cultural participation were, and have been, denied to persons with disabilities (Degener, 2017). Therefore, a model focused on social justice and the rights of persons with disabilities was required to ensure the dignity and quality of opportunities for persons with disabilities. This model was developed to act as a compliment to the social model of disability (Berghs et al., 2019).

2.4 Cultural Model of Disability

After the United Nations decade for disabled persons, the meaning of disability in different cultures and societies became a point to be taken seriously. Terms such as handicap, disability and rehabilitation are based on the assumptions of individual/medical model of disability. For example, rehabilitation is the restoration of a past condition (Ingstad & Whyte, 1995). The nature of the local economy and many other regional factors also determine the status of disability in each culture.

The cultural model emphasised on the potential of disability as a state of being (P. J. Devlieger, 2005). It focused on "emphasising the social, cultural, political aspects of disability to address the wholeness, historical depths and cross-cultural comparisons" (2005, p. 12). Based on this argument, he proposed a sameness-difference focus on disability as, he argued, people are different and the same at the same time (P. Devlieger et al., 2003, p. 12). He argued for an examination into "inclusive modes of thought that confirm the complexity of disability as both an existential, technical, and social phenomenon, in other words defined and reflected by culture" (P. J. Devlieger, 2005, p. 8). He further argued that, "the location of disability is situated in meaning itself, information, and communication. From the social model of disability, the lack of access, inadequacy or misrepresentation of information presents the core of understanding disability as cultural" (P. J. Devlieger, 2005, p. 8).

Twardowski (2022) differentiated the cultural model of disability from other dominant models of disabilities.

> Generally speaking, without any in-depth analysis of the manifestations of the functioning of culture, it is impossible to determine how the phenomenon of disability is understood in a given culture and why people with disabilities are treated in this culture in this and no other way…Thus, there is no one universal definition of disability, as it changes over time and may have a different meaning for anyone. Consequently, disability may not only be understood differently in different cultures but also differently by members of the same culture. (pp. 54-55)

In this manner, Twardowski (2022) argues for “the need to reverse the current epistemological perspective in the approach to disability issues. Namely,the commonly unquestionable “efficiency” usually referred to as “normality” should be questioned” (p. 56). The cultural model of disability takes into account, the interdependence between ‘able-bodied and disabled persons’ in day-to-day lives and seek the consequences of interdependence for the autonomy of both (Twardowski, 2022, p. 57).

Ingstad and Whyte (1995) discussed the nature of the personhood of disabled persons. The concept of personhood and social relations are considered important in the cultural model of disability. Unlike the social model/independent model, where individual autonomy and competency are prioritised, the cultural model discusses personhood, dependency, and the social lives of persons with disabilities (P. Devlieger et al., 2003; Ingstad & Whyte, 1995). The cultural model of disability discussed the cultural variations in the perceptions of disability. Ingstad and Whyte (1995) observed that the dominant perception of disability was based on its biomedical understanding and the concept of medicalisation; it is based on individual autonomy and dependence. On the other hand, disability is perceived on the basis of personhood and community life in developing countries. “One of the basic questions for cross-cultural research on disability is that of how biological impairments relate to personhood and to culturally defined differences among persons” (Ingstad & Whyte, 1995, p. 10). Lived experiences of Asian (Ghosh, 2010; Kohrman, 2005), African (Ingstad & Whyte, 1995; Kohrman, 2005), and Australian (King et al., 2014) persons with disabilities have been discussed by various scholars. These non-Western perspectives of disability, experience and knowledge have enriched the discourse of disability studies globally.

Primarily, the UK and the US manufactured and disseminated the social model/medical model of disability discourses to different parts of the globe. However, with an increased attention spent on Disability studies around the world, diverse topics of discussion have been incorporated into the same. The efforts of the United Nations received global attention, and then, disability studies became an important topic of discussion and discourse. However, the upsurge in the sheer number disability studies also meant a widespread critical engagement with the existing models of disability (Meekosha, 2008).

Meekosha (2008) discussed the need for a disability theory that directly addresses and place non-Western subjectivities in the forefront of disability studies. She argued that the existing disability theories and models do not address the lived realities of the ‘Global South’, which has had long colonialist histories to reflect on in their discourses on disability. According to her, post-colonial societies have had long histories of oppression that impacted the socio-cultural and economic aspects of their post-colonial societies. She remarked that the concept of social suffering helps to understand the subjective realities of post-colonial societies better than the Western imports. The major themes in the area of disability in these societies are poverty, lack of access to drinking water, sanitation, illiteracy, lack of medical facilities etc. According to her, it is vital to acknowledge the difference in the realities between the Western and non-Western societies. The prominent frameworks and models of disability, however, do not address these issues. They formulated frameworks that directly address the realities of the UK/US models; therefore, Meekosha (2008) argued for a framework that challenges the traditional medical/social models of disabilities.

2.5 Feminist Disability studies

Another significant development in the trajectory of disability studies was the development of feminist disability studies (Hall, 2011; Thompson, 2002). Feminist disability studies problematised the very experiences of disability against the backdrop of gender and sexuality (Hall, 2011). The existing sexism and androcentrism in disability studies accelerated the need for the development of feminist disability theories. Nasa Begum (1992) explained how mainstream feminist movements did not acknowledge the needs and rights of disabled women. She elaborated that both the feminist and disability movements had neglected the subjectivities of disabled women. Hence, she proposed a feminist perspective to address the issues of disabled women’s self-image, sexuality, gender roles and so on. “Now the feminist movement needs to engage in an open dialogue with disabled women to learn from our experiences and develop a movement which reflects the diversity of the sisterhood”. (Begum, 1992, p. 82). Morris (1993, p. 59) pointed out that “The fact that disability has not been integrated into feminist theory arises from one of the most significant problems with feminism's premise that ‘the personal is political’”. She further problematised the category of women and identified the plurality of experiences of diverse women that could potentially enrich feminism and disability studies.

Ghai (2002) notes that the manner in which Indian feminist movement excludes disabled women in its discourses. She highlighted the lack of inclusivity of feminist movements to integrate disabled women’s experiences in its movements in India. Thompson proposed the integration of feminism and disability studies to create a solid framework that would directly address gendered subjectivities. She identified both feminism and disability rooted in identity studies, to integrate both to ensure the enrichment of each disciplines.

> A feminist disability theory introduces the ability/disability system as a category of analysis into this diverse and diffuse enterprise. It aims to extend current notions of cultural diversity and to more fully integrate the academy and the larger world it helps shape. (Thompson, 2002, p. 4)

2.6 Disability Studies in India

In this section, I refrain from discussing all the developments in disability studies in India, and mostly showcase the development of feminist disability studies in India. Disability studies as a discipline sprouted tremendously in India over time. Anand (2013) has discussed the problems of historicising disability in India. She showcases the trend of applying Western approaches directly to the Indian context and its inability to produce historical validity. “Contemporary trends in historicising disability cross-culturally reflect a paucity of historical methods. Scholarly naïveté is apparent in uncritically adopting Western histories of disablement as the blueprint for histories of disability in different cultures” (Anand, 2013, p. 34).

Chander (2013) discusses the evolution of blind persons’ movements in India. He asserted their role in the expansion of a rights-based approach in India. He tried to blend activism and academia to trace the development of discourse.

One of the earliest works in the area of disability studies was by Anita Ghai (2003). She considered a variety of topics including the ‘structural amnesia’ (p. 16) of women’s movements to incorporate disability in its movements, the explanation of then-unfamiliar terms such as medical/social models, and discussions on the definitions of disability. Ghai also discussed the life of a woman with disability in the Indian cultural space, where women are devalued inherently. She exposed the exclusion of mainstream feminist movements in addressing the lives of disabled women (Ghai, 2002). Ghai also focused on poverty in the lives of disabled persons. She addressed the diverse cultural backgrounds of India, poverty and its effect in the lives of persons with disabilities in India, how the lack of access to health, education, and technology impacts and makes persons with disabilities vulnerable throughout their lives (Ghai, 2001).

Addlakha (2013), in her edited volume attempts to incorporate various aspects such as the evolution of the disciple, gender and disability, family relations and care, the concept of marginality, and the representations in the area of arts in her volume. She incorporated an inter-disciplinary approach rooted in the feminist disability framework in the volume.

Another important figure in the area of disability and Anthropology in India is Nilika Mehrotra (2013, 2020). Her studies marked the cultural understanding of disability from an anthropological perspective. She has done extensive work on the cultural conceptions of disability in rural Haryana. Her work challenges the biomedical model of disabilities. She also discussed the role of the state in shaping the lives of persons with disabilities. Mehrotra discussed the complexities of methodology in disability studies as well. Nandini Ghosh (2010, 2012, 2016) focuses on the nuances of feminist disability studies. Her notable works addressed the methodological complexities of feminist ethnography, disability and female subjectivities, disability and sexuality etc.

Another significant figure in the area of disability studies with a solid feminist standpoint is Shubhangi Vaidya. She is one of the pioneers in studying autism in India. Her studies articulated the complexities of urban families of children with autism. She elaborated on the lived experiences of parents of children with autism. She, thus, complicated the socio-cultural understandings of autism.

2.7 Intellectual Disability – A Western Concept

Within the domain of disability studies, intellectual disability is underrepresented. Studies and scholarly engagements have been taking place very slowly in this area. Intellectual disability had been overlooked by various other disciplines such as psychiatry, psychology and even policy analysis in sociology (Atkinson & Walmsley, 2010). There have been various terms used in the place of intellectual disability over the course of time and regions. The concept of persons with intellectual disability considered them as ‘incompetent, sub-human’. Jenkins argued:

> A general definition of intellectual disability might stress social and cognitive incompetence: difficulties experienced by an individual in doing things as well as most other people in the appropriate cultural context. In use, however, the concept clearly means more than this. (Jenkins, 1998, p. 9)

In the US, the intellectually disabled were addressed as imbecile, moron, retarded and so on in the dominant culture. The evolution of the American society in addressing intellectual disabilities mirrors (Jenkins, 2019) the evolution of the global outlook towards eugenics, institutionalisation etc. American policy and ‘developments’ in the state have been heavily influenced by the principles of eugenics. As a result, persons with intellectual disabilities are treated as ‘moral imbeciles’, a terminology that depicts disabled persons as unworthy and morally corrupt. They were considered to be a dangerous population that degenerated society. As a result, in the US, the institutionalisation of persons with intellectual disabilities was initiated. Ferguson (2019) explained how a new category was constructed by creating a new category of persons with ‘mild intellectual disability (morons)’. He narrated how various theorists of that age propagated pseudo-science/defective science to cultivate eugenicist ideology in the national policies and development agendas by promoting confinement, institutionalisation, and the elimination of certain sections of the population to create a ‘superior society’ in future.

At some point, all the discussions of intellectual disability in the Western context have had to address eugenics politics and its implication on the policies of national states. The word eugenics was coined by Francis Galton in 1883. It was promoted as the new science of improving the human race through selective breeding.

> The aim of modern eugenics was to rid society of the characteristics that dominant groups consider to be disabilities in the broadest sense and, often by extension, people with disabilities. What counts as disability and who count as disabled change over time and across cultures, as do the social or governmental initiatives mustered to eliminate them. (Thompson, 2015, p. 75)

Eugenics was considered as a progressive science for the creation of advanced populations in nation-states. After its wide reception in the US, the ideology advanced to the global stage. Experiments were conducted and policies were shaped according to these new eugenics across the globe. By the ‘purification’ of human beings through the means of sterilisation, elimination, isolation, and confinement, this ideology rejected the very existence of the intellectually disabled population. By emphasising the supposed physical and mental superiority of some sections of the population, it reinforced racial, religious, ideological, ableist, and gendered hierarchies (Ferguson, 2019; Thompson, 2015). Thompson, cited the screening of prenatal Down syndrome as an example of new 'velvet eugenics' (Thompson, 2015, p. 78).

In the UK, the term intellectual disability "has involved progressive shifts of nomenclature: from 'idiocy', to 'feeble-mindedness', to 'mental sub-normality', to 'mental handicap', to 'learning difficulties', and finally, on the part of the Department of Health, to 'learning disabilities" (Jenkins, 1998a, p. 8). In the UK, in the 1870s, idiot asylums were established to house the 'idiot' offsprings of the London poor. This marked the introduction of institutionalisation of care in the UK; the family was also part of this nexus. With the introduction of eugenics politics, the institutionalisation of 'feeble-minded' population started. The First and Second World Wars profoundly impacted the implementation of these policy changes. Even the participation and capability of asylum inmates in the productive sectors during the prolonged war were never acknowledged, and they were deemed as unworthy. However, the Holocaust influenced the policymakers to critically engage with the eugenicist ideology of cleansing of 'feeble minded' population (Jarrett & Walmsley, 2019).

In Iceland, segregation in institutions was the norm for persons with intellectual disabilities. However, it has now shifted to a **'**Normalization Ideology'**.** It notes the increasing criticism of institutions for individuals with intellectual disabilities in the 1950s, as research studies and official investigations revealed abusive and dehumanising conditions within these facilities. During the 1960s and

1970s, there was a shift towards the ideology of normalisation, which advocated for integrating individuals with intellectual disabilities into mainstream community life and providing them with a ‘normal life’ experience (Stefánsdóttir, 2019).

The understanding of intellectual disability in these countries is linked with rapid industrialisation and high competence expectations. Therefore, individuals are expected to perform independently and rapidly to succeed in such a competitive world. The deep-rootedness of the eugenics principle can be tied to the advancements in technology and competence levels. The history and process by which the biomedical concept of intellectual disability was internalised by nation-states, international agencies and the general population is well-researched and documented (Jenkins, 1998a). This framework defined the socio, cultural and biological definitions of persons with intellectual disabilities.

2.8 Intellectual Disability in Different Societies

Intellectual disability is perceived by different cultures in different ways. There are multiple factors that influence the categorisation/acknowledgement of intellectual disability in diverse cultural spaces (P. J. Devlieger, 2005; Ingstad & Whyte, 1995). Social, cultural, economic and geographical factors determine the status and personhood of a person with intellectual disability. Unlike the biomedical approach rooted in the ideology of eugenics propagated by the mainstream Western discourse, intellectual disability in the global south is acknowledged differently (Jenkins, 1998a). With the advancement of the social/cultural model (Ingstad & Whyte, 1995; Oliver, 2013) multiple subjectivities of disability (intellectual disability) have been acknowledged.

Ingstand and Whyte (1995) observed that one of the major themes in the Western concept of personhood is autonomy and dependency. Each individual, at some point, has to deal with this expectation. They articulated that sociality is valued over autonomy and individuality in some societies, and highlighted the Barbados case to emphasise how a socio-cultural society shapes the personhood of persons with disabilities (1995).

Aud Talle (1995), in his study of Masai of Kenya, explained the Masai concept of disability rooted in practical incompetence. Their ability to perform daily activities in the society determines the status of the person with a disability. Persons with intellectual disability are not regarded as disabled in the physical sense; they are simply regarded as ‘abnormal’ or fools (59). Devlieger (1995) argued that the idea of personhood is based on the ability to interact with others in the social context. The case study of South Africa challenges the Western bio-medical model. Abraham and Odoom (2019) argued that mild intellectual disability is not secluded or confined in the family home in Ghana. Being an agrarian society, rural Ghanan society values physical health and participation in labour. With a high rate of illiteracy, education is not very significant in rural Ghana and hence, persons with intellectual disabilities are not discriminated on this basis. They believe disability is caused by the wrongdoings of grandparents and family. Therefore, individuals are not blamed for their disability. However, this reinforces stigma and negativity within the family. Employment/ vocational opportunities for persons with intellectual disabilities in Ghana are lesser due to higher unemployment rates. Since many non-disabled persons are available in the job market, the vendors/ shop owners do not opt to employ disabled persons. They also believe that buying from the intellectually disabled brings bad luck in life (Abraham & Odoom, 2019).

2.9 Intellectual disability: An Overview from India

The majority of the studies based on the Indian context on disability start with the beliefs in Hindu mythology on disability. The Hindu view of disability is based on the *karma* theory (Melhotra (2013), which argues that the sins from past lives are responsible for the disability of a person in the current life. Unlike the mainstream Western discourse, this approach does not account for disability as an individual tragedy. Staples (2007) pointed out that, in coastal Andhra Pradesh, local people believe in certain deities and spirits that cause disability.

Nilika Mehrotra (2013) describe the cultural constructions of intellectual disability in rural Haryana. She narrated the socio-cultural and family lives of persons with intellectual disability. People are not recognised as disabled if their deficiencies are not visible. They are addressed as *bawla or bhola* (simple and innocent), not *asrit* (dependent). This is because of the prevalence of manual labour in the area, where physical deformity is devalued (p. 147). Mehrotra shows the complexity of the masculine status of intellectually disabled males. As marriage and employment are the defining characteristics of masculinity, intellectually disabled men are kind of ‘elusive’ in the situation. On the other hand, disabled women are married off to men belonging to lower economic status, widowers, and disabled men with a heavy dowry:

> After marriage, disabled women perform usual household chores: fetching water from the well, cutting fodder, cooking, cleaning, etc. Domestic violence is a routine occurrence, and disability gives another excuse for wife beating since the negotiating power of women with disabilities is even less than that of their non-disabled counterparts. (p. 147)

Upali Chakravarty (2018) delves into the complex system of caregiving for persons with Down syndrome in urban Delhi. She discussed the nuances in caregiving in the family as well as by the state. She critically discussed the state policy in providing care for persons with Down syndrome. The feminist disability standpoint engages with state policy in a critical light, as the study recognises the role of state as paternalistic.

Shubhangi Vaidya (2016), in her book, *Autism and Family in Urban India,* discussed the lives of the parents of children with autism in urban India. Being a mother of a child with autism, she has an insider perspective to discuss the subjective realities of families of persons with autism. She engages with the complexities of parents of children with autism. In her book, she notes the resilience, resistance and empowerment of these parents, especially the mothers of children with autism. She highlighted the role played by certain institutions in providing caregiving for the children with autism in urban India. The study incorporated the perspectives of feminism, disability studies and sociology.

2.10 Studies on BUDS Institutions

There are few studies on BUDS institutions published in the past couple of years. These studies primarily focused on the effectiveness of rehabilitation strategies (Vincent, 2024), the impact of local government institutions in the rehabilitation process of BUDS institutions (P. Jose et al., 2023), and the effectiveness of assistive technology in BUDS institutions (Rajeevan & C, 2022). These studies unanimously observed that due to the limited financial resources, BUDS institutions are unable to provide the necessary rehabilitation facilities for the enrolled participants. These studies highlight that, the BUDS institutions provide accessibility to persons with intellectual disabilities from rural and lower income households. Studies on other aspects of BUDS institutions are yet to get published.

2.11 Conclusion

The above discussion is a short analysis of the prominent theories and concepts in the areas of disability and intellectual disability. The discussion also intended to give a short analysis of Disability Studies in the Indian context. The above discussions traced the origins of the medical model of disability, and the formulation and growth of the social model disability. The discussion also included a portion on the shortcomings of the social model of disability in its reluctance to engage with the discussions on impairment, individual experiences of impairment, the relevance of body, and its lack of confidence in rehabilitation or medical treatments.

The cultural model developed later as a response to the social model of disability, and it focused on the diverse socio-cultural experiences of persons with disabilities. This model accepts the bodily experiences of individuals, as well as the barriers of the socio-cultural world in the construction of disability in a given society.

The next section discussed intellectual disability at length and delved into how the mainstream models of disability were reluctant to address its lived situations. This section also discussed how the politics of eugenics helped in the elimination of persons with intellectual disability in policies. The discussion also showed the way in which intellectual disability was addressed in different societies. This discussion depicted the development of disability studies in India and how feminist disability studies became a critical factor in complementing disability studies.

Although there are various discussions in disability studies that happened in the country, most of the above-mentioned studies do not provide much engagement with intellectual disability and care through the prism of gender. Although Vaidya, Chakravorty, Mehrotra discussed intellectual disability, this thesis is distinct in that manner. The field work for my thesis was conducted in a chain of institutions called the BUDS Rehabilitation Centres. These institutions function under the supervision of the state government and local self-government mechanisms. As a result, it was analysed as a space provided by the state for the rehabilitation/daycare of persons with intellectual disabilities. My study engaged and grew with the analytical category of gender, as the institution chosen for my field work was founded under the wings of the State Kudumbashree Mission, which aimed to achieve the goal of poverty eradication through women's empowerment. Therefore, the role of gender becomes foregrounded in this study. There are only a limited number of studies that directly discuss the meaning of living with an intellectual disability in India. While Mehrotra discussed intellectual disability in the context of rural Haryana, there are not many studies conducted in the context of the southern states to compare the involvement of the state mechanisms.

This thesis takes on a distinct approach in the discussion of intellectual disability, as it looks into how intellectual disability is constructed and treated in the BRCs. The thesis also discusses the importance of inclusive spaces for persons and families of persons with intellectual disabilities. With the feminist disability take of the thesis, it explores the role of gender in the construction, and caring process for persons with intellectual disabilities. In that sense, this thesis attempts to contribute to a hopefully growing wealth of knowledge and future studies on intellectual disability, care, and sexuality in the context of Kerala.

Chapter 3

The Construction of Normalcy: An Analysis of Daily Lives in the BRCs

3.1 Intellectual Disability in the BRCs

BRCs are the institutions specifically established in Kerala for the day-care and rehabilitation of adults with intellectual disabilities by the State Kudumbashree Mission. As institutions established for the training and rehabilitation of adults with intellectual disabilities, it is essential to see how BRCs, as a physical and emotional space, perceive and enact notions of intellectual disabilities. Apart from the participants, the significant stakeholders in the BRCs are teachers, helpers (aayah), mothers, Panchayat representatives (occasional official visits), and villagers (who come to donate food, money, and clothes). Therefore, it is important to understand how these agents enact the idea of intellectual disability and how the participants conceive their identity in the BRC. The interaction pattern between these agents provides an idea regarding the domain of intellectual disability in and around BRC. The official discourse in Kerala uses the term *bhinnasheshi* (differently abled) to address disability.

In BRCs, they mostly use the word *bhinnasheshi* to discuss disability in formal situations. *Bhinnasheshikkaar* (plural) was used when discussing official matters like scholarships or any such concerns. Within the institution, in the everyday context, they use this term with visitors. In general, everyone, except the participants, commonly use this word. Participants in the BRCs are adults with intellectual disabilities. They are aged between 17-38 and included both men and women. Whereas, the participants use the term *njangal* (us). Here, they use the term *njangal* (us) to discuss something about themselves. It is used as a collective identity in day-to-day conversations. Here it has multiple meanings as the term project the identity of person with intellectual disabilities as well as participant of that BRC. During my interaction with the public, they also used the word *bhinnasheshi* to address the disability of the participants. This word is almost like an acceptable and respectable term for persons with intellectual disabilities in formal situations. However, in order to specify the category of disability, people often use terms like *manasika velluvili ullavar* (mentally-challenged people) during the official/formal dialogues and *budhi illatha makkal* (kids without intelligence), informally. The usage of the term *mandabudhi* (intellectually disabled) was common some years back, however currently the term is regarded as a derogatory even by mainstream. In spite of that, I noticed while in heated arguments people still use the term as a slang! During my visits to the BRCs, the helper and teacher used the term *ivar*/*ingane ulla* (them/these kind of people) with me; between themselves, they used the name of the participants to address. While describing the participants they sometimes also included the disability with its condition – for instance, "Sreejith has seizures often", "Sreya is autistic and has mental retardation as well", "Shahanath has Cerebral Palsy (CP), so she needs assistance to enter the dining room[9]".

Within the BRC, when discussing the general situation concerning participants, mothers mostly used words such as '*ivaru'*, '*ee kuttikal'* (meaning these kids) collectively. Within the BRC, daily functioning was considered 'normal' unless some unforeseen incidents happened. Mostly, an upset stomach or illness like fever were the deviant factors that disrupt the constructed normativity of the BRCs. Sreejith was a 17-year-old boy with severe intellectual disability in Unnikulam BRC. He often had epileptic attacks in the classroom and when he suffered from seizures, the staff

---

[9] During 2018-2019 teachers and helpers of both BRCs commented like this.

and other participants took care of him. What I observed was that these kinds of situations were typical occurrences inside the BRC. As for the staff and the mothers, the BRC was considered as their ‘own space’ which was built for them. These mothers and their children were accepted and respected as individuals in the institution and they could engage freely within the institution, without any hindrances. Those who were outside the constructed normality of the BRC were considered ‘other’ in the institution. Within the BRC, there is an unspoken agreement about what is considered ‘normal’ and what is not. By that agreement, there were gestures and attitudes expected within the institution. Providing care was considered the fundamental duty of the BRC, and by doing so, they defined a normative structure for the BRC. I will discuss the constructed normalcy of BRCs in detail, later in this chapter.

3.2 “If God gives me a child, I will give food to these children.”[10]

As I mentioned earlier, there was a constructed normality in each of the BRCs. The mainstream expectations were not the benchmark for the ‘constructed normality’ of BRC. Instead, it functioned as a space that accepted adults with intellectual disability, and allowed the participants’ gestures and interactions to decide and establish the ‘normal’ state of the institution. This normalcy in the BRCs was disrupted in the presence of the ‘outsiders’. Their arrivals reinstated the able/disabled binary, during the times when they were present. The purpose of their visits was mostly to sponsor lunch or donate money for the well-being of the participants. The notion of donation/sponsored food evoked the otherness of the participants in relation to that of the staff and outsiders. “I decided that if I have a child, I will give food to these children. This will give us more happiness”– these were the words of a mother

---

[10] This is a quote from the visit of a sponsor in a BRC.

of a newborn who sponsored lunch to the BRC in 2019. There was another woman who used to give food to the BRC on her husband's death anniversary. She said, "What else can I do for him? Feeding these children in his name gives me peace" (Pers. Comm., 2019).

The attitudes of the persons who came to sponsor food were mostly the same. Every sponsor who came to the BRC when I was present, kept their distance from the participants. They stood outside the classroom and dining room. They watched the participants having the food they sponsored. A few of them interacted with one or two of the participants. Usually, they just observed the participants having food and their other mannerisms with a keen interest, without trying to interact with them. They usually had conversations with the teacher, helper, and me. Sponsoring food was different from the camps conducted by some organisations.

Donating or sponsoring food has connections to religious beliefs. When I asked a family why they wanted to donate food to the institution, they said that it was their *nercha* (offering to the God). "I prayed to lord *Guruvayoorappan*[11] and made an offering that if I have a child, I will give these kids a meal before his (the baby's) first birthday" (Pers. Comm., Mother of a Newborn. 2019). This is an example of the direct connection between the notion of charity and disability. Staples (2018) has discussed the role of religion in the charity model of disability. He mentions that philanthropy is an integral part of Indian ways of being in the world (p. 2). He further stated that the donors accumulated their spiritual capital and fulfilled their 'dharma' "without subordinating themselves to the recipients of their gifts" (p. 11). He explained that the disabled were considered as a distinctive category of the needy and offering them food/money paved the way for the salvation of the donors (p. 12). In

---

[11] The deity of Guruvayoor temple is known as Guruvayoorappan. Guruvayoorappan is Vishnu

the study, he observed that the institutions for the blind were more likely to be selected for philanthropy by donors. The situation of the blind persons was often seen as a case of ‘tragedy’. The donors perceived that they could make a real impact on the lives of blind people by making them ready for the job market with training at the specialised institutions, the very ones they had chosen to donate in the first place. However, a sponsor in the BRC told me they opted for this particular institution because,

> These children lacked ‘intellect’ (*budhi illatha*). When we think about it, this is the most unfortunate kind of condition a person is in. They cannot ‘think rationally’ (*chinthikkan kazhiyilla*.)[12]. So, who else would we give (food) to? Whenever I think about these children, I feel very sorry (*paavam kuttikal).* (Pers. Comm., Sponsor, 2019)

Osella (2018) has discussed in detail the context of charity and philanthropy in India. He elaborated on the soteriological dimensions of charity in the Indian context. According to him, the act of *daana (*donation) was done after careful consideration by the donors as it reciprocated a give-and-receive ideal. The same mentality was observed amongst the donors as well. First, this offering or promise of donation of food to the disabled in the institution was made to a deity by the donor in the hope of getting into the good graces of the deity. This good grace was equated to material gain/ inner peace. If the donor distributed food to honour the memory of a person, it also evoked the memory of the deceased and helped the donors achieve inner peace by knowing that the act of donation must have helped the deceased in the afterlife.

---

[12] *Chintha* means thinking. In this situation lack of ability to think also means lack of ability to think rationally.

From this, it is clear that the biomedical notion of intellectual disability and the sense of charity are combined here. Although the category of intellectual disability is referred to as a form of disability, the cultural ableist notions associated with intellectual disability perpetuate the dependent image (Staples, 2018, p. 18). The distance they kept from the participants in the institution also signifies their difference from the participants and the binary of ability and disability. There is a stigma associated with intellectual disabilities.

Coleman (2017) stated that fear is one of the most significant components of stigma. There are detailed studies about the nature of fear generated by the image of intellectual disability. It is a threat towards ‘normality’. Carlson (2010) discussed how intellectual disability is considered feeble-mindedness in the earlier Western philosophical discourses, and later, it enacted fear and the image of monstrosity accompanying intellectual disability. However, in India, intellectual disability is considered the other of ‘normality’, which hiked the fear element. Keeping distance and lack of interaction with participants, in a sense, assert the dominance of ‘ableism’. The very act of sponsorship was from a dominant position; the recipients are regarded as dependant and helpless. This situation acts as in the case of caste hierarchy in India. There is a patronizing nature in food charity. And, at the same time they maintain a moral distance between the dominant and vulnerable sections. The lack of interaction further perpetuates this hierarchy.

From the sponsor's perspective, by distributing food to the participants, they would get inner peace and happiness. Food charity or *anna-daana* is very much associated with religion. Food charity is an important means of ensuring food security in India. *Anna-daana* in temples provides food to a large section of people. Sikh *gurudwaras* offer large amounts of food. *Zakat,* or food distribution, is very important in Islam. In Hinduism, *daana*[13] is meant for worthy persons who never expect anything in return (Raju & Manasi, 2024, p. 5). As for *anna-daana,* giving food is considered a supreme act because it is considered that food nourishes life. Therefore, providing food helps to sustain life. As a result, person's well-being in this world and beyond is ensured through *anna-daana* (Raju & Manasi, 2024). This philosophy in Hinduism guides food charity or *anna-daana* in all forms. Whether celebrating a child's birth or honouring an individual's memory, nourishing life through food distribution (*daana*) is understood to provide welfare in this world and beyond for that person. From my interactions with the food donors, this philosophy strongly emerged as their motive for donation. However, the distance and lack of communication with the participants of the BRC reiterated notions of 'purity'. Most often than not, when someone donated food in the institution, they kept their distance from the participants and ate separately from the participants. According to the staff of the institution, the lack of space in the BRC led to this barrier. However, the lack of communication between the donors and the participants before, during, or after the food indicated the prevalence of a hierarchy between them. I think impurity associated with the disabled bodies was a significant reason for maintaining the distance. Like gendered bodies or Dalit bodies, the disabled bodies are also labelled as impure, leaking, fragile bodies.

Though food charity helps ensure food security and maintain the nutritional value of people in impoverished areas, the religious food charity reinforces the dominance of the elite/upper caste while the receiving-end is usually the vulnerable/ lowered section of society. Although *anna-daana* provides temporary relief, in the larger context, food distribution hinders meaningful engagement/confrontation of

---

[13] *Daana* has been defined in traditional texts as any action of relinquishing the ownership of what one considers or identifies as one's own and investing the same in a recipient without expecting anything in return (Raju & Manasi, 2024, p. 5).

structural inequalities. I will discuss the shortcomings or structural issues faced by the BRCs in the coming chapter in detail.

Why do these sponsors specifically choose BRCs is an important question to analyse. Intellectual disability is regarded as the worst form of disability by the sponsors. The level of vulnerability associated with lack of ‘intellect’ is a significant concern for the sponsors. Although the medical diagnosis of intellectual disability provides a set of understanding about the participants’ condition, cultural labelling of them as ‘children’ evokes a set of ableist notions about vulnerability. Goodley talks about (2014) how ableist normativity constructed an independent human image as an ideal. In a neoliberal[14] society, care and assistance are provided for people who are not fit to participate in the production process. Those who cannot fit in the ableist normative society are vulnerable and are in need of care. The infantilisation of persons with intellectual disabilities is a continuation of the vulnerability discourse propagated by ableism. The idea of infantilisation of persons with intellectual disabilities will be discussed in the following chapter.

In Unnikulam BRC, they received donations very often. Participants loved to have sponsored food. Usually, they made requests to the sponsor on what they would like to eat, and it was always Biriyani. In a way, they also were aware that they get this food because they were ‘different’, and they also utilised the opportunity by demanding their favourite food. For example, since I was a regular at the institution, the participants asked me to buy lunch sometimes. When I received my fellowship, I told them that I would buy them lunch the following week. They got excited and told

---

[14] In this study, neoliberalism explains the construction of ableism in relation to the concepts of work in its relationship to the capital market, workability, competence/ incompetence.

me they all wanted Biriyani. They told me they didn't want *sadhya*[15] or any other food. The teacher jokingly told us that the participants valued Biriyani alone as a 'treat' or sponsored food. From my experience, they also seem to bargain for their favourite food from the sponsors, which was also a way to underscore their needs in the given situation. Another time, a person came there to offer lunch. Initially, he planned to bring *sadhya*, however, the participants told him to change that into Biriyani. They told him they wanted Biriyani and instead of *sadhya*, he bought Biriyani for all. The participants had the power to demand what food they wished to have in situations like these. This was another instant where they decided what they wanted to eat. The teacher, however, pointed out that since many participants faced health issues such as high cholesterol, and as the BRC received food donations frequently, their demands for Biriyani raised health risks. After a while, she took the initiate to intervene and arranged regular meals with chicken curry for the participants from the donors.

From the perspective of participants and staff, the act of food sponsorship was considered positive. There was an acknowledgement of their 'disability' as the reason for this sponsorship, and they all considered it as a reason to receive donations. In the case of Unnikulam BRC and Perambra BUDS, they frequently received sponsorship of lunch. In a way, they negotiated this 'special status' of the institution to receive donations and make better use of it to survive. In the case of food donations, there were diverse perspectives within the BRC. From the helper's perspective, she was free from cooking on those days; instead, she only had to distribute food. For the teacher, the scarcity of Panchayat funds had a lesser impact on the food rations this way. From

---

[15] *Sadhya* is the traditional meals served in a banana leaf in Kerala. It is the meal of special occasions such as weddings, festivals such as *Onam, Vishu*. *Sadhya* is mostly regarded as Kerala Hindu cuisine although regional, religious and caste vice variations are seen throughout the state.

the participants' perspective, they received 'special' food that they may not get from their homes. So, there were different versions of perceiving the sponsorship of lunch within the BRC. As fund allocation for food become scarce in some months, staff even requested nearby shops to give them vegetables and other groceries. Like I discussed earlier, this was a temporary way to solve their crisis, while the structural issue remained unattended. The staff and participants depended on various donations and food charities as a means to survive within the system. Staples (2018) observed that they have internalised charity as a means to attain resources for the disabled. He cited examples of persons with leprosy and their decision to engage in begging to make money and means by displaying their disability/condition as a leper. Though this was not such a situation, participants and staff considered that they were entitled to receive such sponsorship due to their special status.

The above-mentioned sponsorships were done by individuals and families, and the donations were made primarily to cover the cost for lunch. However, certain organisations also made other donations and their nature was different. When I was doing a pilot study in Perambra BUDS school, an organisation[16] came from Kozhikode city to conduct a day camp. On that day, the volunteers actively interacted with the participants, parents, and teachers in the institution. It was a pleasant experience as they engaged in singing folk songs and other activities. However, they started to feed some children with their hands during lunchtime. Usually, the children ate by themselves, a stage they reached after putting in a lot of effort by the mothers and the teachers alike. This group of volunteers made things worse even after the teachers urged them to leave the children alone and they continued to mouth-feed the

---

[16] This is a youth forum based in Kozhikode city intended for social services. They focused on charity-oriented work like conducting camps and volunteer visits in various institutions. They also organised blood donation drives, conducted motivation classes, volunteered in emergencies etc.

children. They also posted pictures of feeding the children online on the spot. Although some mothers found it burdensome, they agreed that such publicity would make the public aware of the conditions of children with intellectual disabilities. Unlike the former situations involving individual charity, this was a charity programme of an organisation, supported by funding from various people.

Individuals or family sponsorship to BRCs have a common nature as it is part of their offering to God or in the memory of loved ones. So, there were some personal/emotional factors behind these sponsorships. Institutional charity had another dimension such as mass funding or financial aid from other organisations involved. Exhibition of their charity and highlighting the ‘disability’ of the participants were both part of the process. Market interests and the notion of charity were intertwined in that instance. In both instances, I noticed that even before interacting with the participants or visiting the BRC, a concrete image of intellectual disability was already created amongst the laypeople. This view was formulated on the basis of medical diagnosis and was perceived as either a tragedy or something to get treated. The influence of the Medical Model of Disability was evident in such situations. Instead of understanding and acting according to the needs and circumstances of the institutions, laypeople either distanced themselves or exhibited the ‘dependency’ image rooted in ableist politics.

3.3 Lives in the BRCs – The Construction of an Identity

Vocational training is the most important activity that the participants undergo in every BRC. It was introduced in the BRCs to enhance the employability of persons with intellectual disabilities. However, with the limited resources available to them, the BRCs I visited were not able to achieve this objective. Other than the paper bags-making in the Unnikulam BRC and duster/eraser-making in the Balussery BRC, the participants did not receive any other vocational training.

Goodley (2014) has studied the role of neoliberal policies and the social structure in constructing the ‘abled’ persons. The mainstream market-oriented society accepts independent, competitive individuals who can meet the demands of the state and market. This is the labour force that helps in the production process of the state. The limitations of an ideal person is also defined by the neoliberal economy and its policies. Hence, persons with intellectual disabilities are excluded from this workforce. This ableist norm of global politics has also influenced Kerala’s market. The participants are people who are considered normal within the special institution meant for the rehabilitation of adults with intellectual disabilities. These individuals were struggling to find suitable employment outside the BRC. Within the BRC, the works done by the participants were again not valued as “work” in the neoliberal society.[17]

The teacher shared her experiences when she tried to get some of the jobs outside of the BRC for the participants:

> I tried to recruit Anshad in a shop nearby. The owners told me they could not employ him. They had their reasons. Anshad could not count or efficiently communicate with the staff and customers. Actually, they told me if he had any other forms of disability, like speaking impairment or such, they would have employed him. For them, employing this kind of persons (ones with intellectual disability) was considered as next to impossible. (Pers. Comm., Teacher, Unnikulam BRC, 2019)

---

[17] Detailed descriptions about their day today works are described in the fourth chapter.

Teachers from Balussery, Chakkittapara, Kanjanghad expressed the same concerns. A teacher from Chakkittapara BRC told me:

> My biggest dream is to get at least one of these children employed outside the BRC. I have tried my best… I have asked around … But nobody is willing to employ these kids. They are willing to give all the treats and aids to the BRC. However, nobody wants to employ them. (Pers. Comm., Teacher, Chakkittapara BRC, 2019)

The ableist social structure explained by Campbell (2008) and later by Goodley (2014) is relevant in this situation. The employers were not ready to even try to give a temporary job to any of the participants. In other words, the ableist normativity excludes differences or plurality. Ableism is the underlying reason behind the rejection of the participants in considering them for employment opportunities. The notion of ableism creates a divisive strategy -those who are able and those who are not able, and the latter category broadly falls within the realm of disability. This division decides who really ‘fits’ in the production process. Singh (2018) has shown from her personal experiences the significance of creative ideas and the participation of others for the inclusion of persons with intellectual disabilities in the mainstream society. The experiences I shared earlier by various teachers on the other hand shows the reductionist view of the larger ableist political society.

Swaraj is a 26-year-old male participant in the Balussery BRC. He had a learning disability and speech impairment due to a condition in his nose. He was enrolled in the BRC since its inception. He was brilliant at repairing electronic items and machines and he was very handy with vehicle repairs too. The teacher, Ashwathi, told me he was employed in a workshop before. Later, his parents stopped it and enrolled him in the BRC. The teacher and helper tried to convince the parents to let him work and earn money. However, the parents told them that the shop owners exploited him. They reasoned that he was very naïve and could not understand when someone tried to exploit him. They said he had received significantly less payment compared to others, despite forcing him to work overtime. They did not want their son to get exploited this way as the situation could create numerous other problems as well.

The fundamental problem was workplace exploitation of the person with intellectual disability and the parents' deliberate opposition against Swaraj's employment. They refused to accept his ambition and passion for working outside the BRC, despite the lower-income status of the family. While I acknowledge their struggle to make Swaraj acceptable in the society, their opposition to outside employment indirectly denies his right to work. This denial of the right to work is not just the problem of the particular family, but it is part of a larger problem concerning the workplaces as well as our society. This however has also made it impossible for him to integrate outside the BRC. Campbell (2018) explaining the concept of internalised ableism mentions that disability is tolerated rather than celebrated as human diversity. Internalised ableism utilizes two strategies: the distancing of disabled people from each other and the emulation by disabled people of ableist norms. Ability was determined by the ableist normative, and it denies diversity of people. The idea of normate (Thompson, 2002) marginalises the differences and plurality.

> Ableist normativity results in compulsive passing, wherein there is a failure to ask about difference, to imagine human beingness differently. 'An abled

> imaginary' relies upon the existence of an unacknowledged imagined shared community of abled bodied/minded people, held together by a common ableist homosocial worldview that asserts the 'preferability' of the norms of ableism. (Campbell, 2018b, p. 40)

The exploitation by the workshop owners is another crucial matter. They made him work overtime and also paid him a lower salary. As discussed earlier, the job prospects for the participants outside BRCs were limited. Swaraj's case was different, as he was hired in a workplace outside the institution. His proficiency in work and skills were acknowledged and accepted, yet his learning disability and speech impairment were the key reasons that were used against him to justify paying him less. Although the teacher from the Balussery BRC mentioned about workplace exploitations, and familial disagreement over Swaraj's employment, it was evident that the BRC did not have any means to address work place exploitation of the participants. Though the employees of the institution talked with the shopkeepers, they could not make any difference to this situation as this was a systematic exploitation of the disabled. Other scholars have also narrated the same kind of experience from other parts of the world. The common trend observed in all these cases was low payment.

Based on the ableist normativity, disabled persons are labelled as incompetent (Jenkins, 1998a) and not productive. Their work is not recognised on the same basis as the non-disabled.[18] This is very discriminatory and is based on divisive policy and politics. Intellectual disability or learning disability essentialises the notions of 'innocence' and 'naivety'. This makes them lesser adults and denies their agency in

---

[18] Here, upper caste, hetero sexual men belongs to this 'non-disabled' category. Caste/ gender/ disability plays vital role to create this disparity.

society. While discussing the gendered nature of care work, Palriwala (2021) pointed out that women,

> Due to their unpaid work, lack of property, and lack of income, they were economically dependent and socially devalued for supposedly not making an economic contribution to the family and to the national economy, thus uncounted in social relations and state policy. (p. 61)

Similarly, persons with intellectual disabilities are also devalued and uncounted as economically productive citizens of the country—the incompetent and unproductive tag provide high barriers to persons with intellectual disabilities to join the workforce effectively. From Swaraj’s narrative, it is evident that he had been devalued and not accounted as economically productive in the ableist patriarchal society.

Here it is important to complicate the idea of ‘work’. The above examples show different forms or dimensions of work. Although BUDS institutions are established as day-care centres for children with intellectual disabilities, BRCs are primarily aimed at the rehabilitation and vocational training of persons with intellectual disabilities. However, deep down, they hold the nature of being a day-care instead of nurturing vocational training/employability. There are several terms used interchangeably -- such as job, employment, vocation, work and so on to describe an activity that is economically productive for the individual and economy. In Malayalam, *pani* (work), *joli* (job), and *thozhil* (vocation) are the words that describe this. As an umbrella term *pani* (work) is used in the BRC as well as outside to describe any activity people engage in. This term is very fluid as it can incorporate almost anything ranging from non-productive work to economic, productive work.

The term was also used to mention informal activities as well as formal jobs. That way, *pani* is an umbrella term that can be used in almost every aspect of daily life. For example, '*Vere pani onnum ille*?' – is a question that can be loosely translated as 'don't you have any other job?' '*Pani aayo?'* is an enquiry translated as 'did you get any job?' '*Nalla pani undu'* means heavy workload. '*Adukkala pani' means* kitchen work and '*Vaarkka pani*' means concreting work in construction. In the BRCs, work was an important aspect that dictated the whole chore. And since the aspect of vocational training was one of the fundamental objectives of the BRCs, concerns or discussions around work/job were always happening amongst teachers, helper, parents and participants.

In each of the BRCs, they engaged in some form of economically productive activity. Though the activities in these BRCs were for namesake only, it helped to build some self-esteem among the participants. Here, I want to examine the concept of work (*pani*) itself. Who are the people engaged in 'work' is an important question to ponder. The eligibility of engagement in 'job' or work is determined by various sets of beliefs or cultural understandings. Work-ability or employability is an important criterion for achieving adulthood status. Employment is the formal segment that ensures social adulthood (Davies, 1998) in mainstream society. Employment is very official as it indirectly underlines the dynamics between the employer and the employee. Both production and distribution are important in a neoliberal economy, where competitions are already very high. Achieving the maximum production has therefore become a norm. This norm limits the opportunities for persons with intellectual disabilities to enter the workforce. Maastricht (1998) discussed the cultural patterns that constructed and defined work. "'Work' is not a straightforward category. What is understood by work and how it is valued is not self-evident, but culturally and historically constructed” (p. 136).

A comparative study of Greece and Wales explained the importance of culture in creating the notions of employment and work (Maastricht 1998, p. 134). The study explained the nuances in acknowledging work. How can informal or any kind of activity be considered work for persons with intellectual disabilities? The study underscores the social aspect of day centres for persons with intellectual disabilities by recognising its uniqueness as a place to nurture their social relations and structuring their days (Maastricht, 1998, p. 134).

Like the case highlighted by Maastricht, the BRCs also provide a place for the participants to structure their days. Rehabilitation or vocational training ensures various kinds of opportunities for the participants to look forward to. In the Unnikulam BRC, they make paper bags daily. The participants were not a homogenous group. Some required more assistance than others. Some could not participate in any kind of activity or training. For instance, Anshad used to go to the shop in the local town to get the materials to make paper cover by public transport. On the other hand, Sreejith could not complete any activity without assistance. Other participants made the paper bags for him. This bag making was however considered the centre of all daily activities. This activity gave them the satisfaction of ‘working’. However, outside the BRC, this might not be considered as work. The lack of economic benefit is the main reason. Participants on the other hand considered this activity to be the most significant one in the centre.

In Balussery BRC, they made cloth carpets. This required more skills than making paper bags. Only a few participants were able to participate in the core part of this activity. The teacher and the helper contributed heavily to finishing the products while undertaking this activity. Another work done in almost all the BRCs I visited was the cultivation of various crops. In higher altitude areas, they planted tapioca, turmeric, etc. In the centres that were located near the local towns, vegetables were planted for daily use. It varied according to the availability of various seeds. They also made pickles in small batches.

During Christmas season in one of the years, the participants from Unnikulam BRC made a number of greeting cards for the Christmas market. This was a one-time activity as the lead artist was not present in the following season. Here I want to highlight the versatility of the works undertaken in each BRCs. It is closely associated with the cultural background of each BRC. The normative understanding of ‘work’ or employment’ is not designed to accommodate persons with intellectual disabilities in its category. However, I want to reiterate the need to recognise the work done by persons with intellectual disabilities. The participants were engaged in various works in the BRCs, including paper bag making, carpet making, gardening, small-scale farming, artwork, etc. They also received training for day-to-day activities that helped structure their daily lives. These activities helped provide and improve the self-confidence of the participants. One of the most important dimensions of any form of work or employment in the society is the idea of fulfilment (mostly in the form of self-confidence) it provides for people who undertake them, which ultimately leads to their self-reliance. For persons with intellectual disabilities, the BRCs are not only places to work and to meet people, it is also a space that helps them to develop self-confidence. For example, Ajmal a 23-year-old participant with intellectual disability told me that he liked to come to the BRC to meet his friends. He also told me that at home, his parents and siblings would not allow him to do the things he would normally do in the BRC. Bindu teacher from Unnikulam BRC also told me he was not allowed to eat alone at home and only once he started to attend the BRC, the teacher and helper let him eat by himself and even guided him to eat properly. The helper told me that Ajmal still would not eat well at home and only ate well when he was present at the BRC. This change attests to the fact that the BRCs help to raise self-confidence of its participants. At the same time, their own agency, relating to matters of employment or otherwise, remained limited outside the BRC. They were aware of this and had told me about it on various occasions – that they were not like the others (*bakki ullavare pole alla*) and therefore were unable to work or participate in work outside (*purath*[19]) of the BRC. They related all these issues with their intellectual disability and somehow accepted their discriminated position. Yet, participants like Ajmal hoped and yearned to be employed outside, in jobs that could include some sort of manual work, to earn their own money. Other participants like Manu and Swaraj also clearly expressed their desire to work outside on various occasions. Applying under various poverty alleviation and self-employment schemes under the State and Central Government schemes again indicated this and their desire to assert an employable and skilled identity, in short being ‘workable’, besides being self-reliant.

The participants also vigorously worked in the centres, sometimes even beyond their limitations. In doing so, they complicate the discourse of ‘workability’ (who are eligible to work and lead a work life). Jenkins used the word incompetence to discuss this status of persons with intellectual disabilities. Jenkins (1998) states that the social model of (in)competence to explain competency and (in)competency are not fixed categories. They are fluid categories that are historically and culturally constructed. There is no uniform category of competent persons as the ideas of work

---

[19] Here, the word *purath* exclusively meant spaces outside of the BRC, which include both domestic and public domains.

and ability to work are varied across cultures. The participants in the BRC challenge this notion of work and assert their participation in the workforce. This also complicates the mainstream understanding of ‘work’. Identifying work beyond the category of economic productivity is important to recognise the efforts of rehabilitation and vocational training activities of BRCs.

3.4 Adulthood and the Question of Acceptance

Even though the BRCs were established for the rehabilitation and vocational training of adults with intellectual disabilities, I try to explore in this section whether the participants were acknowledged as adults. In their study *DisHuman child*, Goodley and Runswik-Cole stated that “failure to play ‘properly’ is a risky business as it raises a red flag for ‘atypical development’, difference, disorder, and monstrosity” (2016, p. 778). According to Capri (2019) “Intellectually impaired adults are morally demoted when referred to as children, yet are easily denied the enforceable rights best owed on those they are liked to” (p. 272). Due to their dependence on caregivers, they are relatively powerless and silent. As a result, they have little opportunity to assert access to resources independently. In their study about identity construction among young people with mild intellectual disabilities, Midjo and Aune (2018) critically examine the role of parents who had a tendency to hamper the independent living, including choices and self-determination, of such young adults.

The participants in the BRC were not considered as ‘adults’ by the staff and mothers. During our daily conversations, most of the time, they were addressed as *Kuttikal* (children), *makkal* (kids) etc. Another common term used is *ivar* (these people). Usage of terms like *mandabudhi* (mentally retarded) is prohibited by the state government. *Bhinnasheshikkar* (differently-abled) is the officially agreed term in Malayalam. Now, all the people I have talked with use this term during formal discussions. Informally, they use *inganathe Kuttikal* (these kinds of children) or *sukham illatha kuttikal* (children with illness). Usage of the term is interesting as primarily it addresses the group than the disability. These terms give a collective identity here. The lack of usage of specific terms such as *mandabudhi* is significant as the denial or reluctance to use these terms also brought out the derogatory political meaning of these words which were used more commonly in the past. During the period of the study, people were aware of the derogatory meaning of these terms. Though there was a collective identity, they were mostly referred to as some kind of *Kutti* (child). This labelling by staff and others indicated their perspective of viewing the participants as immature. Here, immaturity also referred to the dependency state and naivety of the participants. On the contrary, adulthood generally indicated maturity and independence.

Based on the "rehabilitation narratives of the disabled African body", Alfred Ndi (2012) noted that one of the objectives of rehabilitation is to bring the "body of the disabled person…as closely as possible to the condition of normality" (p. 1). One of the central goals of the BRC is to ensure the employability of the participants. Based on this principle, participation in the workforce or securing a job is also taken to be an acceptance as a normative individual in society. However, the concept of work and the ability to perform them were referred to on the basis of their gender roles in the BRCs. The ability of the female participants was measured on the basis of their ability to perform domestic work. For instance, Swapna was regarded as able as she could perform all the domestic work, while Shahanath, a woman with Cerebral Palsy (CP), was not regarded as able as she could not perform such chores at her home. Male participants were evaluated on the basis of their ability to secure any kind of job outside the BRCs. Ajmal was a male participant with a moderate intellectual disability and he had expressed his desire to be financially independent by being a construction labourer and even wished to marry a woman after securing the said work. Marriage and sexuality in relation to adulthood are, indeed extremely complex.[20] In Ajmal's case, he internalized the ableist patriarchal norm that men were considered to be providers and women were dependent on them. So, securing a job outside the BRC was crucial for him, a passage for him to attaining maturity. In Swaraj's case, though the workshop owners were willing to employ him, his parents denied him to work outside the BRC in any shop due to their fear of him being underpaid and exploited. However, despite the poor work conditions and payment, Swaraj really loved to work in the shops. He liked to socialise more and desired to do work outside his home. In the case of men in Kerala, spending time outside of home, heading to market, socialising in public spaces, are considered as important milestones in attaining social adulthood. Therefore, Swaraj, Ajmal and others male participants in both BRCs desired to achieve this social adulthood and masculinity, by stepping outside their homes and working outside the BRCS.

From the above examples, it is evident that the typical gender division of labour influenced the participants' thought processes. Male participants were always linked to economically productive activity. Some of them tried to do various other works such as lottery ticket selling and even worked as helpers in a readymade dress shop. Women, on the other hand, were expected to do household chores. Their ability was measured on the basis of what they can do at home. The efficiency to perform household chores was considered as the benchmark in achieving the adult status for

---

[20] A detailed discussion on the topic is given in chapter 5.

women with intellectual disabilities. Attaining adulthood is important in every person’s life. In the case of persons with intellectual disabilities, attaining this stage is particularly difficult. The above-mentioned narratives show the complexity of recognising participants as adults. The usage of ‘children’ irrespective of their biological age, neutralises any efforts or roles done by persons with intellectual disabilities as adults. The importance given to their condition and tendency to identify them as child/children makes it difficult for them to achieve the status of social adulthood.

The formulation of social identity is essentially constructed on the basis of their intellectual disability. Davies complicated this category on different levels. First,

> learning difficulties as a social identity virtually entirely determined by others; the individuals who receive it neither seek it nor participate in defining it. Second, it is assigned to a child by adults. Thus, the differential in power and authority between those who label and those being labelled is maximised…A third point regarding this labelling is that it initiates a process of socialisation of the individual into a particularly comprehensive social identity. (Davies, 1998, p. 106)

Adulthood is characterised as reaching maturity and it is considered that mature persons are self-reliant. It is believed that mature persons have control of their bodies and mind (Davies, 1998). In other words, social adulthood is achieved when a person can control their biological and psychological urges.

Social adulthood is very important because it ensures a particular status in the community. In failing to achieve this, individuals are not accepted as full members of that society. This complicates every aspect of their social life as well. For example, the participants of the BRC were not able to marry or lead satisfactory family lives. Other than the activity in the centre, most of the participants in the BRCs lead isolated lives. They were not able to build their social lives in any meaningful way. The majority of the participants were not able to participate in family functions or any such social functions. The participants, therefore, were not considered as social adults in this case.

3.5 Arun: The Misfit in the BRC

Drawing from the concept of the cultural construction of disabled identity, I wish to argue that there is a specific way to establish normalcy in the BRC. Unlike in the “abled imaginary” (Campbell, 2018, p. 40), which is led by a standard ableist homosocial worldview that asserts the preferability of ‘the norms of ableism’, this ‘contextually framed normalcy’ in the BRC is based on the identity of the ‘intellectual disability’(Campbell, 2018a). Therefore, normalcy is evaluated on different parameters. The interventions of laypeople evoke ableist normativity in the BRC. That is the disruption point for the contextual normalcy created inside the BRCs.

However, a participant was considered deviant in Balussery BRC. This was a different scenario, compared to the general case where the contextual normalcy existed within the BRCs, at least when there was no interruption from outside. This participant, Arun, had a complex case history. He met with a motorbike accident when he was 28 years old and his skull was severely damaged due to this incident. Arun, who had completed his graduation from a nearby arts college, was working in a private company in the locality during the time of the accident. However, after the accident, he suffered brain damage and developed amnesia. His memory retention was only for a period of 20 minutes. He also expressed all his emotions on the spot.

And additionally, as his urinary bladder was also damaged during the accident, he had to be taken to the washroom every half an hour. These peculiar conditions made him different in the community and even within the BRC. During my visits, all the other participants showed a dislike towards him. Some of them like Swaraj mimicked Arun from behind. According to the helper, Arun uses *cheetha vaakkukal* (foul words) when he gets angry. Apparently, he had a tendency to lose his temper very often. The helper also had a form of dislike for him. During our conversations, the staff emphasized his difference from the rest of the class. They said:

> He is normal in every sense. Unlike these kids, he has *buddhi* (intellect). He had learnt everything like us… he was like us. After the accident, something got wrong with his brain. Mostly, some nuts and bolts got loose during that time. You can speak to him like any normal person. He was normal like us. That's the problem. He also has bad habits. If we talk to him in a very friendly way, then he may physically approach you. You know it's terrifying. So, we keep our distance from him. Other kids know that he is different. None of them like him. Mainly because he uses foul language and also because of his different (different than the common norms of the centre) ways. (Pers. Comm., Teacher and Helper, BRC Balussery, 2019)

Arun's case was distinct. The most important point the staff emphasised was his acquired disability. He talks like the staff and laypeople. Another vital point behind his deviant image was the use of 'bad' words and his approach towards women. The combination of acquired intellectual disability and usage of 'vulgar language', along with unpredictable physical approach made him the deviant of the BRC. The helper said that. "After his arrival, nothing was like before. We had to monitor him all the time. I also feel insecure at times" (Pers. Comm., Helper, BRC

Balussery, 2019). From this narrative, it was evident that there was a contextual normalcy in the institution, which was laden with tense moral elements. Arun's foul language and unanswered questions disrupted the said 'normalcy'.

Garland-Thompson (2011) introduced the concept of 'misfit' to describe disability from a materialist feminist disability point of view. According to her, "the concept of misfitting as a shifting spatial and perpetually temporal relationship confers agency and value on disabled subjects at risk of social devaluation by highlighting adaptability, resourcefulness, and subjugated knowledge as potential effects of misfitting" (Garland-Thompson, 2011, p. 592). She pointed that 'fit' "suggests a generally positive way of being and positioning based on an absence of conflict and a state of correct synchronization with one's circumstances" (Garland-Thompson, 2011, p. 593).

> Fitting occurs when a generic body enters a generic world, a world conceptualized, designed, and built in anticipation of bodies considered in the dominant perspective as uniform, standard, majority bodies. In contrast, misfitting emphasizes particularity by focusing on the specific singularities of shape, size, and function of the person in question. (Garland-Thompson, 2011, p. 595)

I want to analyse Arun's case using the concept of misfit. Arun's deviant status in the BRC can be understood in terms of the process of misfitting. As discussed earlier, Arun's disability and his behaviour patterns were somehow seen as different by the participants and staff. Whenever he spoke, the other participants made some gestures which essentially mocked him from behind. Other participants who communicated with each other in friendly terms, did not allow him be a part of their ‘group’. In another way, Arun also considered himself different from other folks. He said, “I am not like these guys. I can understand everything. I am here because of that accident. It damaged my head.” (Pers. Comm., Participant Arun, BRC Balussery, 2019). Another commonality I noticed among the participants in this specific BRC was that all of them had speech impairments. Arun, on the other hand, did not have any speech impairment. From my observations, this was also a significant difference. Others who spoke like Arun were either staff or parents. Along with his acquired disability, his ways of speaking also differentiated him from the ‘normal’ identity of the BRC.

Manu, a 27-year-old participant in Unnikulam BRC, also ended up being a participant in the BRC as he had also met with an accident when he was eight years old. His head and legs were severely affected. He had a limp on his left leg, and he also has speech impairment after the accident. His cognitive capacity was also affected by this accident. In Unnikulam BRC, all the participants had speech impairments. Manu was not treated as ‘different’ or a deviant there. The teacher once told me, “He looks really handsome. You won’t be to say that he has a disability when he sits down. He has a white shirt (gifted by the teacher), and when he wears that shirt, he looks dashing. I think girls notice him when he wore that shirt” (Pers. Comm., Teacher, Unnikulam BRC, 2019). Manu was able to blend into the constructed normality of the BRC. Hence, this was not seen as misfitting, and hence, there was no deviancy.

Comparing these two instances explain how Arun had become the ‘different one’ in Balussery BRC. This process can be considered as ‘misfitting’, and he became the deviant of the contextual normality of the BRC. Garland-Thompson formulated ‘misfit’ on the basis of the concept of ‘visible identities’[21] (Alcoff, 2006). I applied the process of ‘misfitting’ to understand the subjectivity of Arun in the BRC. Although the concept of misfitting[22] (2011) encompasses complex meaning, I want to point out that, the nuances of a space, it’s “visible identity” is intellectual disability. Here, the misfit Arun subverted the constructed normality of the BRC. This disruption complicated the idea of ‘normality’ within the BRC.

3.6 Interrogating Normalcy

The concept of normalcy has been extensively discussed in disability research throughout the years. The construction of normalcy and the labelling of disability are part of a historical and political process. The critical engagement of the medical and the social models have paved the way to understand the socio-cultural constructions of disability (Shakespear and Watson (2001), Watson (2012), Devlieger (2005), Ingstad & Whyte (1995)). The definition of what is considered ‘normal’ varies according to space and time. Mehrotra (2013) observes the importance of the culturally sensitive approach in understanding the layered socially and culturally constructed identity of the disabled. The interplay between socio-cultural factors like gender, class, caste, religion, locality, family, kinship, community produce the disability identity. In this study, it is evident that the above-mentioned factors played a crucial role in shaping the ‘normal’ of the intellectual disability within the specific BRCs.

Gender-specific roles were expected to be fulfilled by persons with intellectual disabilities. Male participants were expected to work and be connected to economic/

---

[21] Alcoff argued that identities of gender, race are embodied and visible. They are ‘situations’ which we understand, came to know the world.

[22] Misfitting is a complex concept that includes the process of misfitting, the formulation of an identity that is based on misfits of that particular situation. Although the term predominantly used in feminist disability studies, misfitting varies on space, time and subjectivities.

production narratives, while discussion around female participants were always about their efficiency in performing household chores and reproductive duties. Women were more prone to moral scrutiny while men were less scrutinised for the same. Locality was another key to defining ability/disability. Since the locations of both BRCs were in rural areas, various factors/features were unique to those areas. For example, participants were trained to plant small-scale vegetables. These plantations were location-specific and were closely connected to the local market as well as the local food habits. In other words, way, their activities were unique to their locality. The proficiency to do these works defined their ability, which in-turn decided the ‘normal’ of that BRC.

From the patterns mentioned earlier, I would like to highlight the fluidity of the concept of disability. Even though neoliberal policies have an ableist agenda in creating the disablement of persons on the basis of their impairment or cognitive disability, the distinctive cultural definitions are also very significant in formulating disabled identities in a specific space. Therefore, the discussions of normalcy in BRCs have to be understood on the basis of the socio-cultural context of that specific BRC. As I have discussed earlier, there are specific ways of defining disability in each BRC – what is considered as normal in one BRC may not be the treated the same way in another BRC. Therefore, in each BRC, intellectual disability is perceived and normalcy is constructed through the diverse socio-cultural background of that BRC. Nevertheless, the constructed normalcy in these institutions, challenges the ableist construction of normalcy. In that sense these institutions, with their distinctive ways of addressing intellectual disability, challenge the dominant discourses of normalcy and ability.

The disability and differences of the participants are understood on the basis of comparison with those outside the BRC. Though there were anxieties and other crises in the lives of the participants, there was a kind of counter-narration on normalcy happening inside the BRCs. Words such as ‘abled’ and ‘disabled’ are not used inside the BRC. Speech impairment was a crucial factor that labelled participants as intellectually disabled. Anshad had a mild intellectual disability and severe speech problems. The teacher in the BRC said if he had been given speech therapy on time, he would have been considered a ‘normal yet not bright’ kind of person by society. In the BRC everyone was aware of what was going on around them and what others were talking about. When outsiders were present in the BRCs, the issue of inability to speak arises. This was used as an indicator to show the distinct ways of evoking the able/disabled divide in the BRC.

One of the most frequent concepts that kept on repeating through various instances in the BRC was the complex definition of normalcy. It was interesting to note that what was considered ‘normal’ for the participants and staff in BRC and how they related the participants within and outside, on the basis of the same concept. When trying to understand the way normal/normalcy defined within the BRC, various other concepts also have to be highlighted. A derogatory Malayalam term word *manthabudhi* (mentally retard) was never used by anyone inside the institution. Even the laypeople never used that word, when I interacted with them. At the same time, Manas (a 24-year-old male participant with Down Syndrome) told me that none of the participants in the BRC had *Budhi* (intellect). Manu and Akhil also agreed with him.

These various perspectives contributed to the formation of the identity of the person with intellectual disabilities in the BRCs. The observations I made earlier point to the construction of ‘normality’ within the institution. Without the comparison with others or anyone outside the institution, they were normal and their common, daily routine was created based on it. Sreejith was a 17-year-old participant in Unnikulam BRC at the beginning of the fieldwork. He had a severe intellectual disability and often had seizures. This occurred very often, and all the other participants, staff, the mothers who regularly visited the BRC and even the staff of the Panchayat office were accustomed to these episodes. As a result, they perceived this occurrence as normal in the BRC. According to the teacher:

> He has had this condition from the beginning itself. Earlier, it was much worse, as it happened twice or thrice in a day. Even though we had received training on how to handle such situations and participants, it wasn't easy to witness this. Other children (participants) also became upset with the episode. Now that we have already witnessed this many times, everybody finds it normal. If this happens when I am not in the class, someone will come and inform me. Manas and Anshad used to help him. They make space for Sreejith and wait beside him. Earlier, we used to call his mother. Now we manage this on our own. We allow him to rest afterwards in the class. There is nothing more his mother can do. If she were doing some work, we found it better not to disturb her. And she also trusts us. The only problem that remains is that he might get injured when he falls without any warning. So now we help him to sit in places where there won't be injury even after the fall. (Pers. Comm., Teacher, Unnikulam BRC, 2018)

This account shows how the staff and students ‘normalised’ the seizure episodes in the BRC. These kinds of interventions and interpretation of incidents as normal were the key features that contributed to a ‘constructed normalcy’ in the BRC. There were discussions about the ability of the participants every day, but they were not judgemental about the participants. The dialogues were mainly focused on the daily activities and everyday lives.

When laypeople visited the institution, the ableist normativity generally determined activities and lives in the BRC. There was always an ableist gaze during the visits. A person with intellectual disabilities remained one of the most stigmatized persons. Their every gesture and communication came under the radar of the ableist gaze. Coleman (2017, p. 146) identifies the false superiority of stigmatizers over stigmatized, and it is based on the notion that stigmatized persons are inferior. As I mentioned earlier, donating food specifically for the person with intellectually disabled reinstated the notions of both superiority and inferiority. This stigmatized status of the intellectual disability and the superiority-inferiority binary are rooted in the ablest normativity; hence the gaze is an ableist gaze over the participants. Campbell (2018), describes ableism as “a trajectory of perfection, a deep thinking about bodies, wholeness and permeability” (p. 40).

The constructed normalcy in the BRC disrupts when the ability of the participants were compared to outsiders. The activities done by the participants in the institution, for example, making paper bags or erasers/dusters was normal in the institution. Whether they were all able to engage in such activities was not a concern, as it was the norm there. However, the question about their employability, whether the same set of people could find a job outside, disrupted the normalcy of the institution. The constructed normalcy in the institutions was context-specific and not based on the ableist normativity. Any relation with the outside disrupted this constructed normalcy.

Ingstad and Whyte (1995) discuss the differences in defining disability among different countries in Africa. Vaidya (2018) discusses the peculiarities of different cultural contexts that determine a person as disabled. Mehrotra (2013) shows the cultural construction of intellectual disability in Haryana India from a different perspective. The study demonstrates that, in the particular context of Haryana, the importance was given to physical fitness rather than intellectual capacity as the nature of work in that area was very different as well. The author also discusses the significance of collectivity and community participation, which is backed by other authors like Srivastava and Baipai (2005) who also discuss the importance of community participation in the identity and rehabilitation of persons with intellectual disability in India. Rao (2006) discusses the case of the mothers of children with intellectual disability and how they negotiate the definition of intellectual disability through their daily lives.

Here in the BRCs, they also negotiate their normalcy and disability within the context of the BRCs. Community-based rehabilitation encourages collectivity. So, the collective activity that includes the participants, along with the staff and the mothers redefined the normalcy in the institution.

3.7 Ableism

Concepts such as ability/disability are important domains to explain the societal norms in a given space and time. The way a person is conceived as disabled is a complex political construction. Campell (2008) discusses the role of ableist politics in making divisive political strategy and marginalising persons with disabilities. Wolbring (2008) extends this concept by explaining different forms of ableism. He extended ableism to include biological structure-based ableism, cognition-based ableism, social structure–-based ableism in a given economic system (p. 253). Campbell (2008) describes that the “formulation of ableism not only problematized the signifier disability but points to the fact that the essential core of ableism is the formation of naturalised understanding of being fully human…” (para. 6). Goodley (2014) defines ableism as the “System from which forms of disablism, hetero/sexism and racism emanate and has in mind a ‘species-typical human being. This system promotes scientific, therapeutic and medicalised interventions that maintain the ableist prerogative”(p. 22). Goodley, Runswick and Licddiard (2016), observes that “Failure to play ‘properly’ is a risky business as it raises a red flag for ‘atypical development’, different disorder and monstrosity” (p. 778). In the context of the Global North, traditional approaches on *DisFamily*[23] focuses on normative family ideals, and the failure to match up to the normative have been described as ‘corrective’ approaches. Capri states that,

> …[I]ntellectually impaired individuals are often enormously recognised as a member of a homogenous group, ‘unfit’ for citizenship or economic viability for neither suiting the liberal political model of being independent and autonomous, nor a materialist model of being economic instrument that makes financially measurable contributions. (2019, p. 271)

Campbell states that ‘disableism’ is a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities” (2018b, p. 39). Goodley (2014) explains the role of the medicalization of disability, and that the neoliberal capitalist agenda, based on ableism, constructs the very category of disability. Caretaking and the policies related

---

[23] Dan Goodley (2014) introduced the concept ‘Dis/Ability’ to explain the normative sociopolitical structure that is driven on the basis of ableist norms that create the ‘Disablity’. He also introduced terms such as DisHuman, DisFamily etc to explain the complexity of disability/ ability social structure.

to caring are based on ableist normativity. The notion of the normate gets prominence, and people who do not ‘fit’ (Garland-Thomson, 2011) or are labelled thus (Shakespeare, 2014) in the ableist normative social structure fall into the category of being disabled.

3.8 Conclusion

This chapter is an attempt to disrupt the idea of normal/normativity based on the core idea of ableism. I narrate the complexity of the constructed term ‘disability’ by complicating the construction of ‘normal’ in BRC and outside. This chapter is structured around the concept of intellectual disability and how the BRCs constructed and interpreted this. Ableism, as explained earlier, is the category that determines what disability is and how it is reproduced in the everyday discourse. This chapter is an attempt to redefine the ableist understanding of the intellectual disability. I want to conclude this chapter by connecting the construction of the category of intellectual disability to the larger framework of ableism. Gender, class, caste and locality are prominent elements that influence the identity of the person with intellectual disability.

This chapter attempts to complicate the category of ‘normal’ in the BRCs. The narrative accounts, observation, and participant listening illuminate the different kinds of ‘normal’ constructed in these BRCs. The first category is the outsider/insider normal. As I narrated earlier in this chapter, the BRCs maintained a constructed normality and when laypeople visited the BRC, they were treated as outsiders to BRC. There was this invisible barrier that dictated the outsiders as the ‘other’. This notion challenges the ableist normativity by asserting their unique ways to perceive what is natural and social in the given space.

The second category is the staff's/participants' normal. Interestingly, the staff belonged to a fluctuating category. They belonged to the insider category for the most part and they also acted as outsiders. Situations decided their positionality as an insider or outsider. If the situation demanded advocacy for the disabled, they were considered as part of the community and were identified as the participants' ally. On the contrary, if the situation was based on the participant's deviance from certain societal norms, the staff might stand as outsiders. Especially if the situation involved the sexuality or sexual identity of the participants, the staff positioned themselves as detached and stayed as outsiders. Since the participants belonged to different caste, class, religion, locality, and possessed different ability, their status in the BRC was also based on these factors. Majority of the participants belonged to the lower middle class or lower class category. Caste-wise, most of them belonged to Dalit and OBC categories. There was only one participant from a dominant caste group. Although there was no direct/ visible discrimination on the basis of caste or religion, the staff members were aware of each other's caste. The various conversations with parents and teachers from different BRCs and BUDS schools revealed that the upper class participants preferred schools or rehabilitation centres with more facilities and training options. Private or charity-based institutions provided more rehabilitation and training possibilities. With years of repeated tasks in the BUDS institutions, with limited to no facilities, forced many parents to shift their children to other institutions with more facilities for therapies and rehabilitation.[24]

The third category is the 'normal' between the participants. In the BRC, the participants were a heterogeneous group based on their ability to perform. Some participants were completely dependent on the staff and other participants, while

---

[24] Discussed in detail in chapter 4.

others were not that depended on the staff or the other participants. Among the participants, they treated everyone alike. They told me they were not well and that they lacked the ‘intellect’ (*budhi illa*). They cared for other participants who required assistance from others. I felt that they had a collective feeling of being in a group and were aware of each other’s physical and intellectual conditions. Although some of them required more attention than the others, the participants considered themselves as a group and that group was regarded as ‘normal’ within the BRC. They were aware of their differentiated status in the society, but considered themselves as normal in the BRC. Illnesses, according to them, wee other physical illnesses such as fever or cold. At the same time, they told me they were *sukham illatha kuttikal* (children with some kind of illness).

This contradictory identity leads to the fourth category: the normalcy of the researcher, participants and staff. Here, I wish to address my identity. I was an outsider and not ‘normal’ in the BRC. I was not able to comprehend their talk and I was not familiar with epilepsy episodes in the centre. I was an outsider who was not aware of their routine and was not able to participate in their paper bag-making activity. They taught me to fold paper and paste gum in the proper spots. I think that as an outsider and as someone who did not have any official duty or insider knowledge, I was the ‘abnormal’ in the BRC, and eventually, I learnt to become a part of the group. When they told me that they were ‘*sukham illatha kuttikal’* they conveyed the ableist notion of normal. However, I felt out of place in the BRC for a long time.

Here, I would like to challenge the ableist normative constructed by the neoliberal and medical regimes. I want to emphasise the centrality of each locality in the construction of intellectual disability. Although in the BRC, intellectual disability was diagnosed and verified on the basis of various medical tests, it was exercised differently according to the cultural contexts. There were various socio-cultural layers that practically constructed and integrated persons with intellectual disabilities in the BRCs. Their lives are more than the ableist construction of the category of intellectual disability. Therefore, this chapter is an attempt to understand intellectual disability from the feminist disability studies framework.

Chapter 4

Care and Female Subjectivities in BUDS Rehabilitation Centres (BRCs)

While the previous chapter discussed the way intellectual disability is constructed and normalised in the BRCs, the present chapter explores the concept of care from a feminist disability perspective. The chapter delves into the complex networks of caregiving and care-receiving. There are various socio-cultural factors that are constituted in the care network, which are interrelated and connected at various degrees of social lives. The agents that provide and receive care also operate on the basis of the social dynamics constructed by these socio-cultural factors. Over the years, the BRCs have outgrown the concept of being day-care centres for persons with intellectual disabilities. They have evolved from their official description of a space constructed for rehabilitation and day-care to a space that embodied deep emotional connections. The intense network of relations among its various agents has transformed the BRCs to a very space that defines their social citizenship– a space that allows them to 'teach and learn' and 'live and grow'[25].

4.1 Care, Disability, and Gender

'Care' is a broad spectrum to address. Over the years, disability studies and gender/feminist studies have extensively discussed the concept of care. Who receives care, who provides care, and how the state addresses the issues of care are some of the areas discussed widely in scholarship. While discussing care, disability studies focused more on the 'cared for', while feminist studies stuck to the 'carer'. The difference in focus is the fundamental difference between both the disciplines.

---

[25] "Care encompasses the intimate, fleshy and mundane exchange between bodies engaged in everyday affects and acts of giving and receiving, of living and growing, of teaching and learning –that are fraught with ethical complexity"(Douglas et al., 2017, p. 400).

Over the years, scholars in disability studies have discussed the concept of care comprehensively, identifying care as disempowering and dependency as vulnerability (Kröger, 2009). These earlier studies, in particular, were critical of the concept of care-providing and caretaking. The origin of the independent living movement (ILM) in the United States marks a significant point in the discussions of care. The movement argued for independence for the disabled population from the controlling regiments of care. The ILM emphasised that disabled persons should have control and choice over their lives (Morris, 2004). The movement has its origin in the British social model of disability. The social model of disability identifies disability or disablement as the result of society's discriminatory stand against disabled people. Hence, the model distances disability from the 'private' and makes caregiving a public matter (Watson et al., 2004).

The social model and ILM argued that caring leads to dependency for the disabled people. They envisaged independence as the ability to make their own life choices. The social model argues for the term 'personal assistant' (PA), instead of the term 'carer' (Watson et al., 2004). They argued that the term 'carer' gave authority to the caretaker while disabled persons were identified as persons in need of care, marginalised on the basis of these 'needs'. Here, the social model of disability introduced the term PA to ensure that the relations between the 'carer' and 'cared for' are purely contract-based and not personal (Watson et al., 2004). This approach neglected emotional or subjective relations between the carer and the cared for. For disability studies, care has always been a sensitive topic as, historically, in the US and Britain, providing care was a way of disciplining and controlling people with disabilities (Watson et al., 2004). Therefore, any discussion on care in disability studies marked the carer as a person who controls people with disabilities. The slogan, “nothing about us, without us” (Charlton, 2004) emphasised the centrality of persons with disability as the authority to make decisions about their lives. These movements in disability studies argued for the term ‘assistance’ instead of the term ‘care’ (Watson et al., 2004), as the former implied formal relations, which neutralises the nuances of the ‘needs’ of persons with disabilities. Therefore, the usage of the term PA by the social model of disabilities argued for maintaining formal relations with carers.

The debates and discussions in disability studies depicted how the disability movement critically engaged with the concerns of caring practices and emphasised on the importance of independence and agency of persons with disabilities. Feminism, on the other hand, discussed care extensively, primarily focusing on the exploitation of women as carers. Feminists questioned the fundamental notion of women as ‘natural’ carers, expected to fulfil caring as an extension of their natural duties. They emphasised that women, as a category, are exploited to meet the care needs of the family and society. They also articulated how the category of women is automatically assigned to care duties and how policies are constructed on the basis of the gendered assumption of the ‘natural duties’ of women.

Morris (1991) discussed how the conservative welfare state policies in the UK in the 1980s displaced care from the setting of the institution to that of the community, transferring the responsibilities of care duties from the state to families. The institution of family relies on women as carers, while being dependent on the financial resources of male members. This pattern practically entrenched the position of women as ‘unpaid carers’ for the sick, persons with disabilities and seniors. Morris (1991), on the other hand, also highlighted the mainstream feminist discussions of that time which rejected the disabled women’s perspectives on community care. She noted that the feminist discussions of community care undermined the disabled women’s subjective experiences as carers. The mainstream feminist discourses of that time distinguished disabled women from the category of women as carers. These discussions eliminated the choices and agency of disabled women in the process of caring (Morris, 1993, 2004). In short, the ableist notions of these mainstream feminist discussions on care failed to accommodate disabled women/disabled feminist perspective on community care (Morris, 1991, 1993, 2004).

I reiterate here that both these approaches failed to accommodate the subjective experiences of the persons with intellectual disability. Kittay (1999) emphasised the need to address emotional care, along with physical care, in any discussion in the context of care for/of persons with intellectual disabilities. The feminist critique of care classified caring as a profession that is devalued in society, as professional carers were compensated with low wages and lacked formal support systems. In the case of informal carers, mothers are expected to take on that role in the family as caring is perceived as an extension of female duties -- their duties never being recognised as ‘labour’ or in financial terms. This situation makes them devoid of physical, financial, and emotional support from anyone. The social model also never recognised the emotional labour of carers. They focused on autonomy and independence so much that they failed to acknowledge or accommodate the situation of informal carers.

The feminist ethics of care, on the other hand, recognised this aspect of care. Feminist ethics emphasises on the interdependence, mutual relations, and emotional reciprocation between the carer and the cared for (Ghosh & Banerjee, 2017). The shifting understanding and valuation of the notion of ‘interdependence’ in the discussions on the ethics of care becomes significant in this context. Interdependence was negatively addressed earlier by the social model of disability. However, the

British social model later addressed ‘interdependence’ (Watson et al., 2004) as a way to discuss the complex relations between the different agents in a caring relationship.

The social model and Independent Living Movement failed to account for the differences in disability and caring experiences in different regional/national contexts, like India. Ghosh & Banerjee (2017) argued that these models are not flexible enough to accommodate care practices of the diverse cultural contexts in India, underscoring the existence of multiple systems of care networks here. They discussed ‘cripping care[26]’, as a strategy to address the complexities of care in the Indian context, and as a way to understand the empowerment, agency, emotional reciprocations, mutual sharing, aid and interests of the ‘carer’ and the ‘cared for’, or persons with intellectual disabilities, within a patriarchal and ableist social structure. Although this study primarily focused on familial or informal care work, this framework helps us understand the diverse experiences of care work. .

From the above discussion, it is evident that there are conflicting perspectives on the concept of care between feminism and disability studies. Upali Chakravarti (2008, 2018) argued that, even as a welfare state, the government’s involvement in disability care seems distant and withdrawn. She observed the prevalence of community-based rehabilitation (CBR) in the Indian care system. By leaning on NGOs for disability-based care and support, the state skips its duties to disabled people. Chakravarti made crucial interventions in the studies of disability care. She bridged the gap between the feminist and disability discourses on care by highlighting the role of the state in providing care. She accepted the disabled critique of care and accommodated feminist care ethics. These studies critically engaged with the

---

[26] Cripping care “foregrounds the agency,experience and value of disabled persons, and has implications for remaking social policy, support and services in ways that do not foreclose disabled persons’ access to life or eschew all those in caring relationships”(Douglas et al., 2017, pp. no).

dominant social model of disability in care work. With its peculiar socio-cultural and economic conditions, disability care in India cannot be understood within the contexts of the social model and ILM. These studies gave a cultural-specific acknowledgement to disability care in India. This chapter is purposefully situated in this paradigm, and takes on a feminist disability perspective.

Although family becomes the ultimate care-providing unit in India, the BUDS institutions in Kerala are an attempt by the state to share the responsibility of care for persons with intellectual disabilities. In this chapter, I wanted to acknowledge the ableist social and bureaucratic structures that construct a disabling environment for persons with disabilities. As the majority of the studies and discussions on care are on physical disabilities, I attempt to contextualise the situations of persons with intellectual disabilities in this study by analysing the everyday functions of the BRCs. How does each stakeholder influence the other mutually? What are the limitations faced by these institutions with regard to care? This chapter also takes a feminist analysis of care by discussing the gendered nature of care, and the gendered interventions of the state in the discourse of care. Along with these perspectives, the chapter narrates how interdependence, community care and collective care create a care web that weaves through the lives of the various stakeholders of these selected BRCs in this context.

4.2 A Brief History of the Beginnings of the BRCs

Grech (Grech, 2016, 2019) studied how the caring roles of lower-economic families impact the overall family income, escalating their economic hardships. Mothers, or any female family member who acts as a caregiver, cannot effectively engage in any income-generating job. This resulted in the loss of income for more than one member of the family -- for both the disabled person and their carers:

> (…) impacts on time and labour were more severe for those women providing care to a disabled family member requiring substantial and sustained care during the day (e.g., toileting and feeding), who had limited or no mobility and could no longer contribute any labour power, and when there were no other family members (especially daughters, sisters or women in the extended family) to support with these tasks. The key analytical point here is that labouring power and the capacity to earn an income by these women is impacted just when direct and indirect costs (notably health care of disabled member) are at their highest. (Grech, 2019, p. 8)

When we look at the history of the establishment of the BRC/BUDS schools, the fundamental reason for the conceptualization of the BUDS model was the demand to form a day-care facility for children with intellectual disabilities from their mothers. A survey was conducted by the Kudumbashree Mission to gauge the conditions of children with intellectual disabilities. From the survey, it became clear that the mothers of children with intellectual disabilities were not able to participate in any of the activities conducted by the Kudumbashree Mission. It also reflected the isolation endured by the mothers of children with intellectual disabilities.

The Kudumbashree Mission acknowledged the mothers' caring role and the need for financial stability for the mothers of persons with intellectual disabilities. "Care imposes costs in the form of financial obligations, lost opportunities, and foregone wages…" (Folbre, 2006, p. 184). There was no scholarship scheme for persons with disabilities and carers at that time. Therefore, these mothers did not have any income. The lower income of the family also impacted the rehabilitation and medical care for the persons with intellectual disabilities. Followed by the survey, the Kudumbashree Mission recommended the establishment of day-care centres for children with intellectual disabilities. Finally, with a number requests from various groups, the state government approved the formation of day-care centres known as BUDS schools for children with intellectual disabilities. Later on, its success paved way for the establishment of the BRCs for adults with intellectual disabilities (kudumbashreestory.org). The Kudumbashree Mission, in a way, helped in attaining a formal acknowledgement of the caring roles played by the mothers by the State.

There are many points to look at more closely in this brief note on the history of the establishment of the BRCs, the first being the Kudumbashree Mission itself. The Kudumbashree mission is a poverty eradication mission of the Kerala state, which plays a crucial role in the empowerment (arguably, as its motto suggests) and financial independence of women across the state. The Kudumbashree has since become a strong presence at the grassroots level in Kerala. The mission established for the “empowerment” of women in the state contributes to an extensive network of institutions meant for the care and rehabilitation of persons with intellectual disability. Kudumbashree extended their support to ensure the participation of mothers in income-generating and community activities. This programme by the state can be read as an acknowledgement of women’s unpaid care work at home. With the BUDS institutions, the mothers could participate in income-generating activities like the National Rural Employment Guarantee scheme

There are three categories of people present in the BRC on a daily basis -- the teacher, the helper, and the participants. Parents, especially mothers, came to the institution very often. Someone or the other would come to the BRC every day.

Outsiders like lay people came to donate food or something else. The Panchayat officials, ICDS supervisor, medical staff for rehabilitation, the physiotherapist, vocational trainer, arts teacher, and so on seldom visited these institutions. Though all these persons are regarded as allies of the community by the staff and participants alike, other than the donations and charity activities conducted by individuals, groups and, organisations, official visits are very rare. The most important specification of the BRCs is that they predominantly relied on women for their functioning at almost all operation levels -- from helpers to ICDS supervisors, all the agents are women only and this stipulation can probably be linked to the history of the establishment of the BRCs in Kerala, as laid out in the paragraphs above.

The ideal BUDS/BRC model proposed in the Kudumbashree website describes a “complex of institutions starting from the kinder garden, BUDS schools, BRCs and a self-employment scheme for mothers of the participants in the same complex” (kudumbashree.org). Though this proposal was officially given in the Kudumbashree website, most of the Village Panchayats still cannot fulfil these goals due to lack of finances and other constraints like the unavailability of land.

However, initially, there were several BRCs constructed according to the ‘ideal’ model of BUDS institutions. The Mahatma BUDS school in Periya, Kasaragod district, is an example of one such institution. This BUDS school is among the eleven BUDS schools that were proposed by the state government for the rehabilitation of the victims of Endosulfan poisoning in Kasaragod district. Although some of these institutions' construction had started earlier, only the Mahatma BUDS School in Periya got inaugurated and began functioning in 2016. By the time I visited the school in 2018, a livelihood scheme for the mothers of persons with intellectual disabilities was also started here, where they made cloth bags and umbrellas.

Everybody points at the Mahatma BUDS school as a success story with 84 regular participants and 20 staff members, including six teachers, four helpers and three therapists. According to the head teacher, the cooperation between the parents and teachers is the reason for the success of the school. However, on the other hand, many of the equipment she showed us were unused because of the infrequent availability of specialists, and the staff's inability to operate them. Asianet News, a prominent Malayalam news channel, reported that all the other proposed BUDS schools in the Endosulfan-affected villages in Kasargod still functioned in community halls and rented buildings. The report indicates the negligence and lack of interest on the part of the authorities to cater to the needs of these institutions.

The head teacher of the Mahatma BUDS school informed me that they got a financial assistance of one crore rupees from the NABARD-RIDF (Rural Infrastructure Development Fund) package for purchasing land and the construction of buildings. Malayala Manorama (a leading daily in Kerala) also donated one crore rupees for infrastructure development and purchasing equipment. According to the head teacher, 2.5 crore rupees from various sources was spent on the school's construction and furnishing. Followed by the Periya Mahatma BUDS school, several other smart BUDS schools are under construction in the state.

4.3 An Overview of the Daily Activities of the BRCs.

4.3.1 Transportation

Transportation in both the BRCs that were part of my study operated differently. In the Unnikulam BRC, they picked each participant in an auto-rickshaw in two batches. Since the helper was also the mother of a participant, she accompanied them; this was mandatory if the vehicle had female and male participants together[27]. The Village Panchayat paid for the travel fare. The rikshaw came to the institution twice -- by 9.45-10.00 AM and 3.34-4.00 PM. The auto driver was friendly and helped them settle into the vehicle. Even though his payment had been delayed in some months, he still regularly picked them up. In case the auto was not available for a day, then the majority of the regular participants would not be able to come, as most of them resided within a 5-10 km radius from the BRC. This showed how much they relied on these transportation facilities to remain functional.

The situation in the Balussery BRC was very different from the former. They did not have their own means of transportation. The teacher told me that the Village Panchayat said that they could not pay for the monthly travel expenses of the participants, citing a lack of funds as the reason. The helper and the teacher told me that various persons offered vehicles for the institution. Even then, maintenance and other expenditures could not be met by the Panchayat and the institution here. So, their hopes were in vain. The location of this BRC was very remote. Although it was easily accessible from the road, no other public transport service existed in that area besides a minibus service. Participants came to the institution in that bus. They came in by the 9.30 AM bus and left by the 3.00 PM bus. The teacher told me that the bus service was running on loss. However, since they were the sole means available for the participants, they tried their best to conduct the bus trips regularly. None of the female participants came to the institution in the bus. As a result, the BRC only had a single female participant on a regular basis; she lived near the institution and someone from her home accompanied her on her trip. Unlike the Unnikulam BRC, this institution had 6-7 daily participants.

---

[27] This is discussed in more detail in the coming chapter.

These contrasting situations show the importance of transportation facilities for institutions situated in remote and rural areas. It particularly depicts the importance of transportation facilities for women to access the BRC. The lack of this facility makes this a gendered issue. Women with intellectual disability are constantly under the vigilance/surveillance of the society, as evidenced by the fact that the female participants of the BRCs only accessed the institution with their mothers. The mothers stayed the whole day with the participants and accompanied them in the bus to return home. When I asked the mothers why their children were not allowed to come to the BRC by bus, they told me they could not trust their children with anyone apart from their family and the staff of the institution. They also said they could not afford to hire rickshaws daily. So, here, when the Panchayat, signifying the state, failed to meet their needs, women with intellectual disabilities are unable to access the institution.

The social model of disability argues that disabling barriers are responsible for disability (Oliver, 1995). Here, the female participants of the BRC are unable to access the institution due to the lack of free/affordable transportation facilities to the institution, and as the ableist-patriarchal social structure neglects to provide for the same, it reduces/denies physical mobility for women with disabilities.

4.3.2 Daily Training/Activities

The BRCs were established as day-care centres for persons with intellectual disabilities. The centres were envisaged as vocational training centres as well as centres for imparting daily life skills. In the Unnikulam BRC, these visions of the state are implemented by making the participants produce paper covers daily. The cut pieces are taken from a store in Balussery, a nearby local town, and are returned as finished products. They received significantly less wages for their work. The teacher told me that it was worthless to perform this labour for an economic reason. They were made to do this work as a part of life skill training and not as an occupation. Anshad or Manu get the paper from Balussery town. The money they received from the finished packages was added to buy necessary items for the BRC. Sometimes, the teacher spent her own money on vegetable seeds and plants for the cultivation of beds in the BRC. Not all of participants could fold the covers neatly. Regardless, all of them helped each other to accomplish their targets. If the teacher and helper had free time, they also helped the participants to fold the covers. The mothers who occasionally visited the institute also participated in this activity whenever they came.

They had a small patch in the BRC where they planted pumpkins, ginger, and turmeric. The harvest was used in the BRC itself. Once they bought gooseberries, green chillies, and mangoes to prepare pickles and sell in the local Kudumbashree Onam market. They made some money and spent it on the preparations for the BUDS–BRC youth festivals. They were taught rhymes, songs, and daily tasks like tying shoes, lace, etc. She taught many of the students to read and write their names. Sooraj painted and had won many prizes in youth festivals. They displayed his sketches in the hall. The teacher also made New Year greeting cards out of his paintings and sold them in an expo conducted by the Village Panchayat as part of their New Year celebrations. Other than these activities, no vocational or rehabilitation training took place in this BRC. The lack of funds in the Panchayat was cited as the reason for this.

Compared with the Unnikulam BRC, the participants in the Balussery BRC were capable of more physical mobility, and were able to communicate and engage in various activities. One participant in the Balussery BRC was brilliant in repairing electronic items. He was technically skilful and could repair almost anything. He made a lot of LED bulbs for decoration. He also linked their stereo system with the light circuit. It was brilliant to watch the lights blink to loud music. Unlike the Unnikulam BRC, they made cloth mats and dusters daily. They had also made umbrellas for a while. The high cost of raw materials became a considerable setback for them. The teacher (Aswathi) told me that only one participant could sew and stitch there. When the umbrella-making activity became challenging to manage, they had to halt it temporarily. The products were sold by various shops and in local markets. Their expense was barely met with these sales. The earnings were spent on purchasing daily groceries and vegetables for the BRC. They also maintained a small vegetable garden on the rooftop of the BRC. They grew various leafy vegetables, bitter guard, long beans, cucumber, green chillies etc. The Balussery BRC also complained about the lack of funds from the Panchayat for their training and other activities. The Panchayat kept to their usual rhetoric and claimed that they did not have funds to provide for these ‘extra’ needs.

4.3.3 Food

Food was an important component in each of the BRCs. Social relations were constructed and maintained on the basis of food. The BRCs had a tea break at 11 AM. The helper prepared the tea and some snacks, and some of the participants would bring breakfast items from their homes for the tea break. The mothers used to tell the teachers (and me) that their children did not eat properly at their homes. As a solution, they packed the leftover items from the breakfast for tea-time snacks at the BRCs. The regular tea-time snacks provided at the BRCs included common items bought from the local bakery, or bananas, served along with tea. The lunch break was at 1

PM. The students helped each other to wash their hands and sit in proper chairs. If there was leftover food, the teacher packed the food for the participants' homes.

Thus, food time was also the time to learn daily life skills and foster interdependence among the participants. They helped each other to settle down to have food. Some participants, like Ajmal, learned to eat by himself, without spilling much in the BRCs. Some of them would not eat like this at home. Mothers complained that some participants refused to eat like the way they ate at the BRC, at their own homes.

I have already discussed about food donations in the previous chapter. Other than the common food provided by the BRCs, there would be extra food on those days. However, in the Balussery BRC, due to its remote location, they rarely get any food donation. When they received a food donation offer, they usually preferred to get the money instead of food. The teacher told me that they were low on food funds. During some months it was impossible for them to provide food daily. As a result, they accepted money instead of food as donations. With these occasional donations, they could manage to provide for some more days. Basically, these donations were used as a means of survival in this BRC.

4.4 The Role of Teachers - Interventions and Beyond

The most critical and powerful agent in each BRC are the teachers. They are the mediators between the official discourse and the BRCs' domestic space. They deal with multiple duties and roles in the BRCs. As per the government order (G.O. (P) No: 56/2017/ published on 28/04/2017), the essential qualification for the appointment of teachers are: the Rehabilitation Council of India (RCI) approved

D.Ed. Special Diploma in Early Childhood Special Education (DECSE)[28], Diploma in Community Based Rehabilitation; Diploma in Vocation, Rehabilitation. The same order also mentioned that the already-employed teachers who had a work experience of two years or more would not be terminated. The teachers of Unnikulam BRC and Koorachund Panchayats did not have any of these required diplomas recognised by the RCI. However, they continued working in their posts as they were amongst one of the earliest appointed batch of teachers in Kozhikode district.

The establishment of each BRC depended more or less on the teachers. Deepa Perur, the headmistress of Mahatma BUDS school, Periya said,

> The teachers must approach anyone and utilise all the potential opportunities that come across their paths for the betterment of their respective schools. Without innovative ideas and the willingness to seek help from others, on the part of teachers, it would not be possible to develop and maintain any of the BUDS schools. (Pers. Comm., 2018)

Perur’s statement summarises the crucial role played by the teachers in establishing the BRCs. Aswathi, a teacher of BRC Balussery, narrated her struggles in setting up new buildings and improve the infrastructure of the school. She recalled the process being very long and tedious, that almost resulted in an administrative headlock with the Panchayat. This resulted in a long waiting period for the final approvals for even the basic facilities from the Panchayat’s side. The school was left with just the basic structure of a building, from which they struggled to function. With a lack of sufficient water availability, furniture, and even limited crockery items to feed the participants, it was almost impossible to function as a day-care centre.

---

[28] The special diplomas covered specific areas that trained teachers to deal efficiently with persons with Autism Spectrum Disorder, Cerebral Palsy, hearing impairment, visual impairment etc.

Aswathi and the helper of the BRC had to personally struggle as well with all the extra effort that was required to keep the BRC running during that period. The helper, who was later interviewed, told me it was the teacher's willpower that helped the school run, and through her persistent efforts, the infrastructure of the school improved. The floors of the school were tiled as a result. The teacher also sought help from other institutions and used her personal connections to secure essential furniture like desks, benches, tables and kitchen equipment.

In the case of Unnikulam BRC, the present building was inaugurated only in 2009, after functioning in rented buildings for a long time. Unnikulam was no different than other BRCs, which faced many resignations from the teachers in the past. Lack of proper infrastructure and inadequate funds which delayed or even skipped the monthly salaries of teachers forced them to quit. Bindu teacher was the third teacher appointed in the BRC, after a series of resignations before her. After taking charge as the teacher, with the help from Anganwadi workers, she did a survey to identify persons with intellectual disability within the Panchayat. However, the report was not officially published. It was rather a matter of formality for the establishment of the new BRC building. In the process, the teacher visited all the houses of persons with intellectual disability. She had to visit and pursue the parents of such kids repeatedly to send their child to the BRC. Many of the parents were hesitant about the proposal. Most persons with intellectual disability also had some significant health issues and so it was difficult for them to travel to school. With some encouragement from the teacher and others in the neighbourhood and Panchayth, some families decided to send the children to school. It was the availability of transportation that turned out to be the main deciding factor for the parents[29]. However, the role played by Bindhu teacher in influencing 30 households to send their kids to the BRC was crucial as well.

The narratives show that, other than teaching and vocational training, the teachers have extra duties to perform in each of the BRCs. During the initial period, the teacher's salary was significantly less, forcing many teachers to leave the job. Bindu teacher said that, despite the job's underpayment, she stayed on the job because of the financial difficulties she faced at home. She mentioned that the primary outcome of the role as a teacher did not include much financial gains. However, she also added that since this was one of those jobs that required empathy and compassion in carrying out the tasks, the teacher's role could provide job satisfaction in non-monetary ways. Teachers from Perambra BUDS school, where I did the pilot study, also reported underpayment and requirement of provision of additional care work. All the teachers said that they were having a hard time due to the minimal pay. During the time of the fieldwork, the salary was only ₹7000 for the teachers. The helpers also approved the need for an increase in the payment for teachers. Sudha, a helper, commented,

> They have studied a lot to be in this role! You have no idea the amount of hard work they do over here. These kids are not like the children from 'normal' (*sadhaarana*) school. The effort to look after even one child at home is tremendous. How can they manage these many children at a meagre rate of just ₹7000 paid for their services? (Pers. Comm., 2018)

---

[29] In my personal interactions with the mothers, they have often cited the free transportation as one best features of the BRCs itself.

Until G.O. (M.S) No. 20/2018, BRC teachers were officially termed as BRC workers. With the government order issued in 2018, their status was upgraded to that of BRC teachers, with an increase in salary from ₹7000 to ₹30675 for teachers who had the desired qualification, and ₹23100 for those who did not possess the desired qualification. It is interesting to observe that their salaries increased only with the change in official designation and not the role they carried out as part of it – when the official term was just BRC workers, they received only a minimum pay! The role of the teachers, observed in the each of the BRCs, was not limited to just teaching and training the participants, they played a far more complex role that impact the daily lives of the participants and even the functioning of the BRCs itself.

The teachers perform multiple roles in each institution, besides the role of a trainer/teacher. She is in-charge of the finances, and her responsibilities also include making decisions for the institution in every aspect. She conveys the institution's needs and shortages to the Panchayats and gramasabhas. Apart from the official duties, the teacher also relies on personal network to smoothly run the BRC. For instance, the Unnikulam BRC was located very close to the Panchayat office. As a result, Bindu teacher had good contacts with the Panchayat officials. She mentioned that she had used her personal contact, a contract worker in the Panchayat office named Sreeni, to expedite the approval of many requests from her institution. Through him, the BRCs funds got sanctioned and the application for field trips was approved faster. She credited him for the speedy approvals of these requests. In another instance, Sreeni recommended a newly appointed Junior Panchayat Secretary (JPS) who was having health-related issues to have lunch from the nearby BRC. This lunch arrangement continued for a few months and it paved the way for the BRC to have a good rapport with the official. Bindu teacher again used this connection to expedite the sanctioning of the bills and funds. When the official was transferred to another district, he donated several desks and benches to the BRC.

It is interesting to observe the wide variety of ‘out of the box’ roles performed in the BRC. In the earlier example, it was impossible for the teacher to deny the lunch provision request from Sreeni and the Secretary as they held official positions of power. The gender dimension of this incident is also significant. The request from the male officials of the Panchayat, which could be treated as an order because of the power dynamics, was clearly made to an institution with all-women staff. However, the women, especially the teacher in-charge, converted it into an opportunity for making personal networks and later used the same for the smooth functioning of the institution.

Besides these roles, the teacher also keeps personal bonds with participants and their parents. Most of the mothers reveal their family issues to the teacher. The precarious conditions they face at home, financial difficulties, and even other emotional vulnerabilities. The perception of power they associated with the position of the teacher also played a significant part in trusting her and confiding their issues. Most of the times, the interactions between the teacher and the mothers were conducted for solving some difficulties of the latter. The mothers sought advice and suggestions from the teacher, as they clearly looked up to her as a person who is capable of helping them out. Fineman (2000) used the term ‘inevitable dependencies’ to describe situations beyond physical dependence – “[I]n addition to biological dependence, one may be psychologically or emotionally dependent on others. In fact, these other forms of dependence may even accompany the physiological or biological dependence, which I have labelled inevitable” (p. 6). Along with the institutional care, the two BRCs provided emotional and psychological support to mothers with the teachers’ presence. In doing so, these teachers move above and beyond the normative duties allotted to them.

Apart from fulfilling the formal roles and providing emotional support to various actors in the BRC, the teachers are again involved in many informal interventions that could be seen in many instances. When the ICDS supervisor delayed funds for the purchase of a new LPG connection, Aswathi teacher paid from her salary to expedite the process and claimed the bill amount only much later when the proposal was finally approved by the ICDS supervisor and the funds were released. The story repeated in the Unnikulam, when the Panchayat did not provide the funds to purchase a pressure cooker and some other basic utensils for the preparation of meals in the premises of the BRC and Bindu teacher had to purchase them personally from a nearby shop to ensure the smooth running of the institution. Most BRCs I visited exhibited similar kinds of patterns. These kinds of interventions are beyond the prescribed role of a BRC teacher, and however, are routinely done by the teachers. By deliberately making the institutional structure of the BRC as somewhat of a semi-formal nature, these additional duties fulfilled by the teachers are almost expected of them.

Traustadttir (1991) observed that the mothers of children with disabilities had an 'extended caring role as the boundaries of their care extended beyond their child to the broader community and other societal concerns. He further stated that this provided them with the opportunity to move beyond the traditional caring job of the mothers. I would like to extend this concept to the case of BRC teachers as well. They move beyond their expected duties of just a teacher/trainer in multitude of ways – asserting the needs of the institution in-front of the Panchayat administration, purchasing things without ICDS supervisors’ allotted fund, using personal connections to expedite the sanctions, providing emotional care and support to various actors in the BRCs, including mothers, etc. Their unofficial roles exceed that of their formal ones. The ‘extended caring’ role of the teachers, however, is instrumental to the running of the BRCs.

4.5 The Role of the Helpers – Food and Friendship

Food plays a significant role in the functioning of the BRCs. Everyday activities are highly influenced by the type of food and the preparation required. The helper was responsible for the food and maintaining the good spirits in the BRCs. In all the BRCs I visited, a mother of the participant was officially appointed as the Ayah/ helper. Although each of the BRCs and BUDS has a separate food allowance, from what I have observed, this allocation was usually not sufficient for their monthly food requirements. The BRCs like Unnikulam and Koorachund usually received food sponsorship for at least ten days in a month because of the advantage of their locations, being close to other government and private institutions. During the first phase of my fieldwork in Unnikulam BRC, I was considered their ‘lucky charm for Biryani’. Almost on every day of my visit, they had received donations of biryani. Biryani was considered as the favourite food of the participants in almost all the BRCs.

In some months, when they received fewer days of sponsorship, the teacher of the concerned BRC had to either borrow vegetables and groceries from the nearby vendors or pay out of her pocket. Food donations were also received in the form of vegetables, rice, coconuts, etc. Sometimes, the teacher and the helper brought food ingredients from their homes as well. For instance, they brought fruits like jackfruit and mango during summer from their homes or shared whatever they had received from their neighbours with the BRCs. From March to May, the menu in the BRCs mainly consisted of summer produce that were commonly available in the region like Malabar cucumbers, jackfruit seeds, raw mangoes, locally-grown varieties of spinach, etc. Neighbourhood community of the BRCs also sponsored home-grown produce from their vegetable gardens during this time. The helper played a significant role in the BRCs by bringing the neighbourhood communities together. In most cases, the connections maintained by the helper with the neighbours and other people in the same ward or the Panchayat helped secure additional food resources. The helpers were also instrumental in maintaining good relationship with the other mothers in the BRCs. I had observed that in every BRC, there was always some extra food cooked each time, sufficient to feed at least two more people. Most of the time, at least one of the mothers of the participants would be present during the lunch break and would have their lunch with the staff. Not just the mothers, if anyone else visited the BRC during the lunch hours, the helper (Sarojni) would insist them on not leaving until they had lunch with them. During my fieldwork, I was assured that there was always extra food at the BRC, and I ended up having most of my lunches from there. The sharing of food had created a friendlier atmosphere, where the bonds between the mothers and the BRC staff were strengthened. Sharing of more intimate details of their lives happened during these mealtimes. These mealtime-discussions covered a wide variety of topics, including storylines of TV serials, discussion on political parties, sharing of common problems faced by them with regard to the of Panchayat administration and the issues of funding from the ICDS or other sources, etc. Apart from these general topics, intimate details of the domestic lives emerged during these meal times, where the home and life of mothers of children with intellectual disabilities were discussed in detail. They sought advice from each other as well as from the staff to handle on a wide variety of topics including illness, familial problems and, of course, child care. As Sajitha observed, food paved the way for stronger ties between the mothers and the helpers.

The helpers were also catalysts in maintaining a good relationship between the mothers and teachers. In some cases, like in Perambra BUDS, mothers shared a better relationship with the helper than the teacher. They also had a collective of mothers inside the BUDS, which the teachers did not appreciate due to professional reasons. The helpers being mothers themselves were able to bring people together, on the basis of common grounds. However, in some cases, the helper being a mother of the participant was disliked by other parents. In Unnikulam BRC, the helper Sarala’s daughter, Lachu, was also part of the class. (Lachu, who was thirty-five years old, was a person with intellectual disability and autism, who could not speak and engage in any activity. She mostly played with the toys and loved to sit near the door to gaze outside. She was often seen being looked after by her mother who was also the helper to the entire class. There were many complaints from the other mothers and even the teacher that she paid more attention to her own daughter than others. When the duties and responsibilities of being a helper and being a mother of a disabled person overlapped, some of the helpers ended up being criticised for the partiality towards their own kid, like in the case of Sarala. While these remain exceptions rather than the norm, the helper-mothers were generally found to be liked and appreciated by all.

In Balussery BRC, I could observe that the helper (Ayisha) and the teacher (Aswathi) had a good rapport and worked together as a team. Ayisha’s son Rashad was also a participant there. However, in the beginning, the Panchayat had, appointed another helper. When the officially-appointed helper did not come regularly to the institution, the teacher was in-charge of the classroom as well as the kitchen. During those times, Ayisha often helped the teacher by taking charge of the food preparation. When Ayisha regularly filled in-the place of the helper and had continuously worked for more than a month, the other mothers and the teacher jointly contributed some money for paying Ayisha a small remuneration. However, on the day of receiving the remuneration, the officially-appointed helper went to the Panchayat and collected the same. This created an uproar in the community and the parents and the teacher jointly filed a complaint at the Panchayat against the helper, which eventually led to the termination of her contract. Soon after that, Ayisha was appointed as the new helper.

In Ayisha's opinion,

> Only mothers have the right mentality (*manassu*) to take care of these children. Only I or any mother can do the everyday work here. Mothers are confident to leave them here as they know that I will look after them like my Rashad. You know these kids have other physical issues also. Sometimes, they vomit or salivate on the benches and desks. We cannot yell at them or show any aggression as it is beyond their control. I can easily handle these instances as I have always considered all of them as my own children. Only a fellow mother can perform all these tasks without any hesitation. If somebody from outside gets appointed, they will not be as honest as a mother of a participant. (Pers. Comm, 2018)

Sudha, the helper in Perambra BUDS, also shared the same point of view on this matter as Ayisha. She said,

> only a mother of a disabled child can understand another such mother's feelings. Only we have the courage and strength to do the tasks required for these children. I would say that the mothers should be employed in the BRCs

> under a different scheme, so that we can work and attend to our children at the same time. (Pers. Comm., 2018)

Traustadttir (1991) used the term ‘combining care with a career’ to explain the lived realities of a working mother of a child with a disability. Here in BUDS/BRC’s context, taking care of these children itself has been seen as their ‘career’. Not all BRCs appointed mothers as helpers, but BRCs like Unnikulam and Balussery provide mothers the opportunity to work with their children. There are more than one side to this model. Employing mothers as part of an official body of the BRC is the inclusion and active participation of mothers in this programme. By forming a ‘collective’ for the children's day-care, Kudumbashree and the State government provide an opportunity for the mothers to get outside of the normative pattern of caretaking. Even then, appointing a mother as the helper indirectly encourages the gendered division of care provision. By adopting the Community Based Participatory Rehabilitation (CBPR) strategy for integration and participation of mothers along with the community as one of the main objectives of the BRCs[30], the institution attempts to place/expand the concept of ‘care’ from the domestic sphere to the community, again with the mothers' help. This integration model hinges on the already established channels of provision of care, especially using the mothers’ labour, and has not really been successful in encouraging the other actors in the community to take up a larger role as care givers to persons with intellectual disability.

4.6 Mothers

This section analyses the role of the mothers in the BRCs in detail. In Mahatma BUDS school, Periya, which was also recognised as the ‘ideal BUDS

---

[30] See BRC Hand book, 2013, for a detailed discussion on the same.

model' by the Kudumbashree mission and the State Government, the mothers of the persons with intellectual disabilities were a crucial part of the model itself. They were physically present in the BUDS complex under the livelihood plan. Whenever I had a conversation about any BUDS institutions' effective functioning, all the mothers opined that they wanted to be accommodated in the BUDS school/ BRC compound as part of the livelihood development plan. In their view, that was considered the option for both the children and the mothers. In a village background, where a majority of the participants' families were from a lower-class background, they wanted both income-earning jobs as well as a facility to provide care for their children.

The Perambra BUDS school, where I conducted the pilot study, also incorporated this model to an extent. There were three teachers and one helper (daily wage) as official employees in the institution. In addition, two or three mothers were present daily. All the mothers said that their children needed more attention than others, and they came in as the teachers sometimes could not provide adequate care for them as many students were present. The initial idea behind establishing these institutions with day-care facilities for children with intellectual disabilities was to ensure that their mothers were less burdened with the responsibilities of care and could be part of the workforce, earning an income for their household. However, even after establishing the institutions, mothers devoted their time to take care of their children, not at homes, but within the premises of these very institutions. During the group discussion, these mothers shared their concern that the teachers would not sometimes understand their children's needs as they do. They did not blame the teachers, but only reasoned that the lived experiences they had as being mothers of children with intellectual disabilities (*ith polathe kuttikal*) made them better caregivers who were capable of understanding even the unspoken words of their children.

Mothers who were present at any time in the institution, cooperated with the staff and took care of the children even during difficult situations -- like when some of them had vomited or pooped in class. They helped the teacher to get the child cleaned. They also cleaned the dining area and assisted the helper in the kitchen. As most helpers were also mothers themselves[31], the helpers and the mothers shared a strong bond. Mothers had a good camaraderie amongst themselves within the institutions. This was possible even without the aid of social media and dedicated online communities. They did not even have a dedicated WhatsApp group that could have been really helpful for them as well as for the institutions. But most of these mothers could not even afford a smartphone due to their poor economic status.

The care provision by the mothers could be better understood if we analyse the situation using the concepts of gender and care, and the interplay between them. Feminists have discussed the women's role in care for a long time. Caring is mostly regarded as a female virtue in the society, something which women develop is 'naturally' from a young age onwards. Chakravarty (2018) pointed out that the virtues of women had always included altruism and self-sacrifice, a view that had been perpetuated through literature, art and even social welfare policies of the state. Gillian Dalley (1996), in her study, focused on the underlying beliefs and attitudes which governed the patterns of gendered care provision to dependents in a household. Dalley also observed that the social policies for the provision of care for dependent people were based on familism[32] and collectivism. Chakravarthy (2018) noted that "with women as carers, man becomes provider; the foundation of the nuclear family is laid. It became the ideal model to which all should approximate" (p. 174). To put in another way, these 'natural and feminine' virtues which form the basis of the

---

[31] See Section no 4.5 for a longer discussion on this topic.

[32] Familism, according to Dalley (1996) analysed as the centrality of family in caring and care policies.

domestic sphere was extended to the public sphere as well. Chant (2008), Folbre (2006) and Palriwala (2019) have also discussed the naturalisation of care work as women’s duty.

The mothers who willingly came to Perambra BUDS School, despite the presence of teachers and the helper, perceived the provision of care for their children as their own duty. Soja, a mother who regularly accompanied her son, explained her presence due to her son’s severe condition (she used the term severe MR, that is Mental Retardation) which was difficult to manage. Along with idea of fulfilment of their duties, the mothers of these children also preferred a model of BUDS which also doubled as a jobsite that generated incomes for them. This idea of transforming the BUDS/BRC model into one that generated incomes for the mothers was backed by the institutions themselves, and a formal request had been submitted to the State Government for considering the proposed change. It should also be noted that the proposed model sits comfortably in a zone where the mothers’ duties to their children did not conflict with their economic needs.

The idea of a mother’s duties was not perceived the same across individuals and the patterns varied among the BRCs as well. In Unnikulam BRC, where I had spent a lot of time, I could observe that the mothers did not visit routinely. However, when they visited, the other larger patterns remained the same – they spent a lot of time there including having food. They also maintained a good rapport with the teacher and sought her help to resolve issues related to official/technical matters, like obtaining disability certificate, matters related to scholarship, etc. In Balussery BRC, mothers did not accompany children as a routine. They mostly came to attend PTA arranged by the institution, and attending the special Neighbourhood group meetings (SNHG). In these two BRCs, mothers were not present throughout the day routinely.

After the initial hesitation to send their children to the BRCs, the presence of the institution and the activities related to it became an integral part of the daily routines of the mothers. It was considered alright and acceptable for the mothers to leave their children at the BRC during the day time. This was a positive change in the outlook of the mothers and the community as a whole, and this also created economic opportunities for the mothers. For instance, in the Balussery BRC, Arun’s mother decided to send him there because she wanted to be financially more independent and needed a few hours in a day without child care duties to participate in the NREGA scheme. However, even with the presence of the BRCs, mothers were not completely ‘free’ during the daytime to pursue economic activities. They often had to make time to take their children to the doctors, or participate with their children in free medical camps organised in their area, or go to various government offices (which were sometimes as far as Kozhikode) to obtain disability certificates, etc., as these were all still part of their duties. Mothers were the centres of each of the participant’s lives as they were the primary care providers as well as kept a track of all the activities related to these persons with disabilities.

Aneja & Vaidya (2016) discuss the concept of ‘intensive mothering’ that “requires mothers to focus most of their time and energies on child development, nutrition, education, hobbies and play so that the child gets the best possible start in the life” (p. 112). The mothers in the BUDS wanted to provide as much care as possible to their children. They all believed that their child needed ‘more’ care than the rest, as their own children’s disability was considered more severe than the rest of the children in the school. This perspective, which was prevalent amongst almost all the mothers, reflected the altruistic nature of the female care. During my fieldwork, Sona, a mother, mentioned that her mother-in-law no longer provided care to her son as her parents-in-law firmly believed that it was the duty of the mother to look after her son, and not the grandparents'. Initially, the in-laws helped her out a bit, but as her son grew older, they started withdrawing from their roles of being supportive care providers. Sona also drew the ire of her mother-in-law who wanted her to quit her tailoring job to focus on her son. She was often critiqued for the lack of 'adequate' care provided to her son due to her working hours. This eventually led her to quit her job as the guilt of being a working mother weighed down on her. The altruist nature of a mother's care that involved 'intensive mothering', became a burden on her when she dedicated herself to be a full-time care provider for her son at the expense of quitting her job.

Without the participation and the support of close family members and other relatives, the responsibility of care falls entirely on the mothers. Fineman (2000) observed that there were significant economic costs and career sacrifices associated with caregiving which were borne by the primary caretaker. From the experiences of the BRCs and BUDS schools, the mothers were the primary carers and they were under immense pressure to meet the demands of their children, both economically and otherwise. They were almost entirely responsible for making the routine tasks and arrangements for their children on a daily basis. Even though their husbands sometimes provided a lending hand, their roles were mostly restricted to being the primary earners in each of the families. The fathers concentrated on managing just the finances of the families. Even in those capacities, mothers often played a significant role in bringing down the expenses of the houses. I had met many non-earning mothers who were under a lot of stress as they tried to meet the expenses of the transportation, medicines and other essential requirements of their children on a meagre budget provided to them by their husbands, who were not even aware of the actual costs involved! As McLaughlin et al. (2008) observed, the men participated in only a few of the aspects of care provision, while women were wholly responsible for it.[33] Thompson (1993) acknowledged the problem as "not simply the question of most carers being women, but, more profoundly, that caring is part of the socially constructed self-identity of women. It is an expression of feminine in our society" (p. 656). Hughes et al (2005) observed that "participants in the caring relationship constructed as the vulnerable, the monstrous, and the feminine and therefore, as 'other to the masculine subject of modernity'" (p. 265). In other words, caring turned out to be the duty of only women in the society.

During my entire fieldwork period, I had met only one of the fathers of the participants, who had visited the institution just twice. Unlike the mothers, the fathers were virtually absent from the premises of the BRCs. On the days of the PTA meetings, from what I had observed, only the mothers participated. There was not much of a discussion in the meeting. Rather, the mothers passively listened to whatever the teacher was saying. In Perambra Buds school, Sudha, a mother, told me that there was never any participation from the fathers in any of the daily activities of the school, barring from the occasional presence of some of them during the PTA meetings. She also said that the mothers were quiet as they were mostly shy to ask questions to the teachers or initiate any other discussions in public forums. In Balussery BRC, some of the mothers who came for *bhinnasheshi ayalsabha* (the neighbourhood meeting for the disabled), told me that if the fathers were present for the PTA meetings, they were at the forum for their own agendas, which were more political than to do with the everyday concerns for their children. On most occasions when the fathers were present, political speeches and slogans were raised against the

---

[33] See McLaughlin et al. 2008, p 164, for a more contextualised discussion on the same by the authors.

Panchayat administration. During a group meeting in Balussery BRC, when there was a discussion on delays in the distribution of the scholarships, a mother raised the demand that they wanted Mohen *chettan* (father of a participant) to accompany the group to the Panchayat office to make enquiries regarding the same. According to her, the said person had leadership qualities and could raise his voice, if the situation demanded it, to argue with the Panchayat Secretary and ICDS supervisor. Except in a few situations like these, the mothers in the BRCs never depended on the fathers for any of the day-to-day activities related to their children's welfare in these institutions.

Not just in the case of PTA meetings, the participation of the fathers was less even in the special gramasabhas. The special gramasabhas were conducted especially for all the persons with disabilities residing in the Panchayat. This also provided a forum for the persons with disabilities as well as the caretakers of the disabled to raise their demands in front of the Gramapanchayat during special gramasabha conducted in Unnikulam Panchayat in 2018. While there was a large participation by people with disabilities, only some of the parents of the children in the BRCs participated. Less than five fathers, out of a class of 38 participants, were present at the gramasabha, while. The rest were all mothers. However, during the meeting, only the fathers spoke regarding various issues, apart from the BRC teacher. The helper was also the mother of a participant, and yet she did not speak at the meeting. All the demands for the BRC were proposed by men/fathers. This event reflected the larger patterns observed in the society, where women are not encouraged to speak out or address a large audience. The private and public aspects of care can be observed here. The everyday material and emotional needs of the participants were met by their mothers. These caretaking roles were performed within the 'private' domain, either within their homes or inside the institution, as extra help for the teachers or the Ayah. The fathers catered to the roles performed outside the homes or in the ‘public’ domain, which included providing the funds required for care activities as well as take on the other roles performed on other occasions, like speaking out in a public forum in the interests of their children. These ‘visible’ roles were almost exclusively performed by men. The patriarchal and ableist biases of the society devalued the invisible and hard labour performed by the mothers in the private spheres.

Various authors (Chakravarti (2008, 2018), Vaidya (2016), McLaughlin et al., (2008)) have discussed the devaluation and feminisation of care work in the context of mothers of children with intellectual disabilities. Chakravarti (2018) in her study described the devaluation associated with the care work provided by women. She noted that women’s care work, being invisible in society, received little to no support from the state in India. McLaughlin et al. (2008) also highlighted the case of isolation and heavy work pressure of the mothers of children with intellectual disabilities. The authors also talked about the complexity of the gender division of care work. According to these authors, the actual participation of the fathers could not even be correctly estimated due to the societal biases. The current social structure and the care work support mechanisms offered by the state often fail to even acknowledge the fathers' role as one of the primary carers, along with the mothers, due to the deep-rooted biases. The father is often omitted from the immediate care circles both by the state and the society. The same principle could be extended to the case of the BRCs, which followed a discourse that omitted the importance of the fathers or other men in the society in the provision of care, while formulating the guiding principles of the institution itself. The gendered division of care is implemented at the core of these institutions, which could be seen in the employment of only female staff in in the various roles of care provision as well as relying only on the mothers for the day-to-day activities related to the children within these schools. Instead of ensuring the equal participation of both the parents, only the mothers' integration into the working of the institutions reflects the mainstream view of the roles associated with nurturing and caring as feminine.

4.7 Gendered Division of Care: A BRC experience

While analysing the structure of care offered in the BRC, gender as an analytical category becomes apparent. The vision of the BRCs to help mothers participate in the community or public domain contradicted with the almost exclusive reliance of the model on women for its day-to-day functioning. As mentioned earlier, every position in the hierarchy of the BRC complex -- from the vocational trainers/teachers and helpers, to the ICDS supervisor are all reserved for women. The BUDS/BRC heavily relies upon women and expects collective participation and effort from the community, especially mothers, for its successful functioning. Healthy relations among every single one of them is significant for the smooth functioning of these institutions.

Even though women play the primary role in the collective care offered in the institution, the strategy for caring was designed externally. That means, as per earlier-decided rehabilitation strategies, local authorities and persons who are not identified as ‘insiders’ in the BRC made decisions about the funding and strategies to implement the various plans and activities in these institutions.

The teachers and helpers were not part of any of the decision-making groups. They send requests for the release of funds, amenities, etc., but they did not possess any bureaucratic power to change or redesign the activities of the BRC. As they struggled to survive with their financial constraints and bureaucratic hardships, it was apparent that their role as carers was devalued within the system, evidenced by underpayment and delays in payments.[34] Caring is not only a paid labour, it also constitutes an emotional labour. According to Nancy Folbre,

> (Care) typically conveys a sense of emotional engagement and personal connection that has direct implications for the quality of the services provided. That is, the best care is likely to be motivated by genuine concern for the well-being of the care recipient. (Folbre, 2014, p. 4)

She observed that care work can be unpaid within the family, and paid work in the market. Folbre (2014) observed that care is usually gazed upon ethically than economically and it is largely associated with the discussions on rights and justice than as an economic activity.

The underpayment associated with caring jobs holds wider economic equations. The ones who need care held minimum importance in the production sector of the state. In other words, ‘dependent’ people are considered unproductive in economic terms. In the case of the BRCs, teacher and helpers are paid care workers. Folbre (2014) observed that paid care work also involves an emotional attachment with the dependents. Paid or unpaid, care work is embedded in the notion of altruism. Therefore, when discussing on underpayment, the BRC staff also reflected on the complexities of work and their emotional state. The helper from the Balussery BRC recounted her days without payment. She said that without payment it was difficult to maintain finances at home. However, she said that emotional satisfaction was the key factor which motivated her to continue on the job. Teachers from both the BRCs said almost the same thing -- despite financial hardships at home and in the centres, it was

---

[34] Although the basic pay of teachers and helpers increased by a government order, they still received delayed or reduced payments (P. Jose et al., 2023). The funding constraints of the local government were attributed as the reason.

the self-satisfaction and emotional fulfilment from the job that gave them the courage to continue. It is important to analyse this aspect of underpaid care work. Folbre (2014) and Kittay (1999) discuss the emotional attachment that put care workers in a vulnerable situation for negotiations. The inherent altruist notion surrounding the nature of work prevents their negotiation power for better payment or any moderation for care workers.

Sylvia Chant (2008) in her discussion on dealing with gendered poverty, explained the “feminisation of responsibility and obligation” to ensure household survival. Women diversify their intense unpaid household labour to ensure their survival (2008). The study discussed how women exclusively performed unpaid care work and multiple household duties to evade poverty and ensure their survival. Though placed in different cultural and economic contexts, the multitasking and altruistic notions associated with unpaid care work can be placed in the context of the BRCs also. Despite underpayment and funding constraints, the BRC model thrives on the efforts and negotiations made by its women.

Chant (2008) also analysed the absence of men in poverty eradication programmes. Chant observed that men’s absence in the poverty eradication programmes reduced its effectiveness. It reaffirmed the traditional roles and statuses of men and women. “In relying heavily on mothers, and making little effort to involve fathers in any of the unpaid volunteer work, the programme has ‘built upon, endorsed and entrenched a highly non-egalitarian model of the family’” (Chant, 2008, p. 185). Chant argued that anti-poverty programmes and policies, without the involvement of men, are not helpful in challenging the underlying disparity (Chant, 2008). She observed that the poverty eradication programmes aimed at the empowerment of women, precisely because they were incapable of challenging or negotiating for greater gender equality. In the case of the BUDS-BRC model, all the activities were designed on the basis of women’s (mothers) participation; the participation of men (fathers) were not addressed in the activities in any way. Special neighbourhood groups – meant to build a collective/community -- were also mothers’ focus groups. Hence, the BUDS-BRC model reiterated women’s association with care as natural.

4.8 Conflicting Ideas of Care

Mothers also acknowledged the empathy from teachers as a significant quality. However, there might be a difference in opinion between the teachers and mothers regarding how empathy should be shown to the participants. From the teachers' perspective, ‘care’ means allowing the children/participants to be self-sufficient individuals who can participate in mainstream society. The head teacher from the Perambra BUDS said that she allowed children to play with each other. Bindu teacher told me that she trained them to eat and clean their plates by themselves. Even if the plates were not clean enough, this activity conveyed an idea of self-sufficiency in doing basic chores by themselves. The mothers, sometimes, did not share this vision. In the Perambra BUDS school, a mother came to the head teacher’s class and found one of the classmates sitting on her son’s back. This situation got out of hand when she shouted at the other boy and beat him in front of the teacher. The teacher, however, said that she saw this happening during leisure time, and that they were playing without any physical violence and were laughing. To the teacher, mothers did not understand this dynamic and interrupted classes and activities. Teachers opined that the mothers tended to pamper their children and did not provide enough opportunities to grow into their self-sufficient lives.

The above incident indicates the difference in attitude between the teachers and mothers regarding the nature of 'care' and 'compassion' shown to the participants; the meaning associated with care seems different here. The Handbook designed for the functioning and curriculum for the BRCs mentioned basic skill training as an essential activity in the BRCs/ BUDS schools. Some mothers on the other hand, considered this training as a form of neglect on the part of the teachers. Sometimes mothers complained that the teacher was not properly taking care of their children (*nalllonam nokkunnilla*). The meaning associated with care deepens here—the Malayalam word used here, "*nokkuka*", roughly means "looking/to look after"; this signifies a constant vigilance from carers. Drawing from Carol Thomas (1993), the word "*nokkuka*" sometimes act as "both an activity and feeling state'.

As was mentioned earlier, the teachers acted as mediators between the mothers and the local self-government. In other words, they were the link between official discourse and the domestic sphere of the BRC. In the case of the BRCs, mothers used to share their grievances to the teacher- about the official barriers to receive scholarship or welfare for the child and other related matters. The teachers usually helped them with official matters like filling application forms, understanding government orders, etc. Teachers also raised concerns about the health issues of the mothers as well as the participants. In the Unnikulam BUDS, Bindu teacher had bonds with most of the mothers. She even knew about their domestic issues and other social barriers. In that sense, the teachers are not just trainers or managers in the BRC; they are also the emotional supporters of the mothers. Kari Waerness (1984) used the term 'rationality of caring' to explain certain situations where the carer breaks away from official job instructions to respond better to the needs of care receivers (quoted in Kröger, 2009). Bindu teacher here engaged with the mothers and participants beyond the scope of her role as a trainer and instructor.

There are studies about the limits of a carer in the lives of person with disabilities. The impact of paid carers in the lives of persons with disabilities from various stand points ((Kittay, 1999; Kröger, 2009; Morris, 2004; Watson et al., 2004), and the agency of the carer and the cared for have been discussed in disability studies and care studies. Over the years, concepts like dependence, inter-dependence, and collectivism have also been discussed by many scholars (Dalley, 1996; Kittay, 1999; Watson et al., 2004). Watson et al. (2004, p. 332) who distinguished 'caring about' as the feeling that is part of care, and 'caring for' as the practical work of caring. In the case of Bindu teacher, there is an overlap between 'caring about' and 'caring for', as she maintained professional and personal relations with most of the mothers.

4.9 BRCs as an Emotional Space

The BRCs are not just structure with facilities for the day care of persons with intellectual disabilities. It acted as an emotional and psychological support for the mothers. This is the space where the mothers were not the 'other'. The physical structure is a symbolic representation of a complex, yet inclusive space for the mothers and participants. Overlapping areas and relations turned the physical space of the BRCs into a collective space for solidarity.

Sajitha's son was enrolled in the BRC. Currently, due to financial and familial problems, he was enrolled in a nearby special residential school. She had a troubled relationship with her husband and in-laws. As a result, she was separated from her husband and worked as a residential carer for an older couple. She came to the BRC one day and told the teacher that her husband and in-laws took custody of their ration card. Since it was the last day to apply for the disability certificate, she had to get the card. Her elder daughter had told her that she would hand the card in to the BRC by 11 AM, but she did not. Sunitha had to get the card at least by 12.30 PM, only then would she be able to reach the Kozhikode office on time. Therefore, it was not possible to seek police assistance to retrieve the card. After some thinking, the helper and teacher decided to go to Sajitha's husband's home to retrieve the card. She requested me to accompany them, while the helper stayed at the institution. Both of us, along with Sajitha, reached her husband's home and retrieved the card.

The teacher's mediation in Sajitha's case was a personal one. Sajitha's son was not a participant there at that time in the BRC. I asked Sajitha which institution she preferred for her son. She preferred the other one. She said,

> They have more facilities there -- full-time classes, and more teachers and trainers. The fee is a bit higher there. However, he gets a discount as he sings well and has won many prizes for the residential school. Even then, here in the BRC, I feel at home. The teacher is very understanding and supportive. She does everything she can to help me. It is more transparent and approachable. The staff and the whole structure of this institution itself are very helping (*ithinte motham set-up angane aanu*). (Pers. comm., 2018)

This incident and her narrative told me that the BRCs are not just institutions for the participants, they also serve as the mothers' emotional and psychological space. The teacher and helper were the agents who provided that solidarity for them. Personal interventions like this helped in the configuration of solidarity among the staff and mothers. This solidarity served as a strong foundation for a collective interest amongst them. As mentioned earlier, their relations were nurtured through the sharing of food, help and companionship. There are several other elements that seal the collective efforts of the BRCs, which are addressed below.

4.10 Community, Meaning and Participation in the BRCs

The BUDS institutions heavily rely on the concept of Community-based Participatory Rehabilitation (CBPR) for its effective functioning. As mentioned in the previous chapters, there are four components in the BUDS Kudumbashree (CBPR) model: the family, BRCs, community support mechanisms, and local self-governments (LSGs) (BRC Handbook, 2013). The joint participation and co-operation of these mechanisms mark the success of any BUDS institution. The handbook noted that the participatory approach is a distinguished approach developed by the Kudumbashree and the involvement of the LSGs ensures its success. The official position states that incorporating Panchayati Raj institutions (LSGs) to the BUDS strategy is the distinctive element that ensures the community's effective participation (BRC Handbook, 2013).

It is worth reiterating that the Kudumbashree Mission advocated for the establishment of BUDS institutions. The lack of engagement of the mothers of children with intellectual disabilities in the Kudumbashree Mission programmes was the triggering factor behind this advocacy. Initially, the mission argued for day-care centres for children with intellectual disabilities where these mothers were expected to participate in the Kudumbashree activities there. The motive itself underscored the perceived role of mothers as the primary carers of children with intellectual disabilities.

Unlike the arguments of the social model of disability, the material/economic situation of the persons with disabilities is important here. Loss of work indicates a loss of pay. In the BRCs that I visited, almost all participants belonged to the Below Poverty Line (BPL) category. Others belonged to other economically lower classes. For them, the earning income is of utmost importance, as their earnings make a big difference in the lives of the persons with intellectual disabilities. With the BRCs and BUDS schools, the mothers could then engage in economically productive jobs and contribute to the family's overall income. Even so, most of the participants lacked access to early intervention. Though they received treatments and diagnoses eventually, they still lacked accessibility, assistive techniques, etc.

However, I wanted to focus on the broader concept of care here. The official discourse recognises the family as the most fundamental and integral unit in the rehabilitation of persons with intellectual disabilities. The discourse identifies the isolation and lack of support mechanisms as common lived experience of each family. Hence CBPR was introduced to overcome this lack of support. The community participation envisioned in the Kudumbashree BUDS discourse intended to provide care for persons with intellectual disability in a collective form. With the engagement of the Village Panchayat and other official mechanisms, the burden of care for persons with intellectual disabilities was to be shared. Essentially, the caring duties of mothers should be shared by all the agents. The term community used in the official notes addresses persons with intellectual disabilities and their families. But it was extended to the involvement of elected members, members of the administration, health inspectors, ICDS (Integrated Child Development Scheme) supervisors, parents, BUDS employees (instructor, helper), etc. This whole group is regarded as a community in the official discourse of the BUDS.

However, despite being described in the official discourse, I never witnessed the direct involvement of anybody other than mothers and the staff. There was no facility for medical check-ups, occupational therapy, or other forms of intervention from any expert. The visits of ICDS supervisor, as described by Bindu teacher (Unnikulam BRC), were for official inspections than casual visits, measuring and accounting in an official capacity, rather than co-operation, and participation at a community level. The ICDS supervisor is the direct link in the intervention efforts from the local body. Yet, their lack of compassion and the stiff bureaucratic nature of visits distinguish them from other stakeholders.

Bindu teacher said:

> The ICDS supervisor is biased towards Anganwadis; she spends more time and resources on their welfare. She is not concerned about the BRCs. The previous supervisor was better than the current person. All these women were Anganwadi workers earlier. They got a promotion and became ICDS supervisors. That is the reason for the bias and partiality towards the Anganwadi! There were certain forms to fill for the scholarships of BRC participants. However, the supervisor allotted this form to the Anganwadi teachers to fill. Anganwadi teachers have more than enough work without additional duties like this. They do not know disabled people and their families as well as I do. What else to say? It was a one-of-a kind experience. The Anganwadi teacher sends mothers to me. Some parents came here, and some parents went there. It was hectic! Think about this -- the ICDS supervisor should have allotted that work to us. That is our area to intervene. (Pers. comm., 2019)

This is an example of the nature of the intervention of the ICDS at the ground level. These top-down interventions lack the very essence of the community-based participation of persons with disabilities. Even though both agencies – the BRCs and the Anganwadis function at the grassroots level, the BRCs are the only agencies that directly deal with disabilities, sincerely working towards the mainstreaming and empowerment of persons with intellectual disabilities. Therefore, the omission of the BRCs' participation in these situations like the one narrated above also need to be attributed as an expression of the mainstream society's ableism.

4.11 Special *Ayalkkoottam*[35] Neighbourhood Groups (SNHGs)

Ayalkkoottams are an integral part of the success story of the Kudumbashree Mission in Kerala. The Kudumbashree Mission was also mandated to form and organise Special Kudumbashree Neighbourhood Groups for persons with intellectual disabilities. The BRCs and Special Neighbourhood Groups are an integral part of the Kudumbashree Mission policy to empower people with intellectual disabilities and their families. The Handbook (2013) for the formation of special neighbourhood groups specifically mentioned the different subjective realities of persons with physical disabilities and persons with intellectual disabilities. The Handbook recognised the barriers of communication and articulation faced by persons with intellectual disabilities. As per the government notification dated 09/07/2011 (G.O (P) No.162/2011/DECE), it is mandatory to form common directions and guidelines for the formation of SNHGs. The formation of these SNHGs was meant to facilitate the independent living of persons with intellectual disabilities. Only women were allowed to participate in the SNHGs. Special neighbourhood groups were also based on the microcredit system that existed in other Kudumbashree neighbourhood groups. The thrift and credit system practised in the Kudumbashree mission neighbourhood groups

---

[35] *Ayalkkoottams* are translated as neighbourhood groups.

were followed in SNHGs as well: “The savings of the women are pooled together and redistributed as loans to the deserving members” (Rajagopal, 2020).

Special NHGs took place on Thursdays in Unnikulam and Wednesdays in Balussery. This was an opportunity for the mothers to meet together and discuss matters related to them and the institution. Usually, not all mothers would come for the meetings. They would still give the teachers cash remittances. The teachers gave the money to the SNHG Secretary during the meeting. Though the BUDS/BRCs do not have any official role in the SNHGs’ functioning, in most cases, they provided the physical space for the meeting. Teachers in both BRCs facilitated the meetings by all means possible. While the BRCs do not dictate any official duty for the *ayalkkoottams*, they are the common platform that brings all these mothers together for the meetings. In that sense, the BRCs are a source of the emotional strength of every mother here.

BRCs not only provide shelter for the mothers but also bring a collective identity for the participants and their mothers. These BRCs symbolise solidarity and collective identity, sometimes irrespective of whether the children were formally enrolled there or not.

4.12 The Making of a ‘Community’

The BRCs are primarily rehabilitation/day care centres, where the strategy of Community-based Participatory Rehabilitation (CBPR) is adopted to provide care for persons with intellectual disabilities. It is a revised form of Community-based Rehabilitation (CBR). CBR had emerged as a method to engage with the situations of persons with disabilities in developing countries, especially when the World Health Organisation (WHO) promoted it as an effective strategy to cope with the rehabilitation shortages in the 1970s by transferring the rehabilitation skills to families and other volunteer organisations (Kuipers & Sabuni, 2016; M. Thomas & Thomas, 1999). Over the years, this strategy has evolved greatly shifting from the medical model to the social model of engaging with disability and rehabilitation (M. Thomas & Thomas, 1999, 2002). However, the CBR strategy was criticised by various studies as its rehabilitation plans were mainly formulated as a top-down approach, where programme planning and decision-making were made by ‘professionals’, while persons with disabilities were not an active part or agents in the rehabilitation strategy (M. Thomas & Thomas, 1999). They were simply the ‘beneficiaries’ of the plan’s implementation.

Even though the BUDS-model implemented CBPR, where participatory rehabilitation was the focus, the local government still remained as the most important decision-making body in this model. Efforts to achieve decentralisation through the LSG were still attempted; the *Bhinnaseshi* gramasabha (Gramsabha meant for persons with disabilities) was an important step to achieve this goal. Various studies on rehabilitation underscored the importance of the involvement of persons with disabilities in rehabilitation planning. Needs should be raised by the disabled community and plans should be formulated on the basis of those needs (M. Thomas & Thomas, 2002). The *bhinnaseshi gramsabha* is meant to fulfil this role. In every Panchayat, the requirements and needs of persons with disabilities are presented before the local representatives; the local government should then plan their activities accordingly. This would ensure that the voices of the disabled are heard by the local government through a decentralised process.

In the BUDS model, the *bhinnaseshi* gramasabha and special neighbourhood groups are important components in community making. While attending one session of the *bhinnaseshi* gramasabha, I also became a part of the BUDS institutions. The gramasabha session was lengthy. People from all parts of the Panchayat gathered there. One of the important things I noticed was that many of the attendees did not bother to go to the usual gramasabha. They would only come to this gramasabha. One of the parents of the BRC participants told me,

> The reason most people come for this gramasabha is that this is for us only. This is the platform (*vedi*) where we can assert our voices. Last time, many things were requested for the BRC. We did not get even half of that. Still, we can see like-minded people here. Those who are not enrolled in the BRC also come here. This is an opportunity to meet new *(puthiya*) and similar (*ore polathe*) people. (Pers. comm., 2018)

This platform amassed the participation of people identified as disabled by society in large numbers. Meetings like this strengthened their community bond.

Special Neighbourhood Groups, as mentioned earlier, are another forum to build a community bond. Neighbourhood groups are the primary and most important bodies in Kudumbashree. The BUDS model asked for a special neighbourhood group meeting every month. Both BRCs conduct this meeting monthly. Admittedly, not all mothers of enrolled participants attended these sessions. Most mothers took this opportunity to form emotional and material connections with each other and the staff.

4.12.1 BUDS *Kaloltsavam*[36]

One of the important opportunities for the BUDS/BRC community to come together is the BUDS/BRC youth festival. The competitions included various dance forms (folk, cinematic, and group dances), songs (light music, cinema, group, and

---

[36] Youth festival for BUDS institutions

action songs), painting, mimicry, etc. The list of items changes each year. District-level competitions were the first stage and the winners were then selected for the state-level completion.The 2018 state-level competition was held in Kozhikode district. Prasanth from the Unnikulam BUDS secured the first place in painting. During this festival, the entire BUDS/BRC community came together. The programme was conducted by the Kudumbashree state mission. The District Panchayat also plays a significant role in conducting this youth festival. In the Unnikulam BRC, a dance teacher was appointed to train for the upcoming youth festival. Make-up and costumes were rented. Often, Bindu teacher commented, it was tough to get any place in the competition; some schools maintained the competition level at par with state school youth festivals.

4.12.2 Occasional Outings

Field trips were another opportunity for all the participants, mothers, and teachers to come close. They visited places, or watched movies. Because of funding issues, the BRCs that I visited only conducted small-scale trips and outings. They visited nearby towns, cinemas etc. Some other BRCs with external funding took their participants and families in long distance trips to places like Hyderabad, Goa, etc. These plans also depended on the availability of funding from the local government, external agencies, or from parents. The BRC that took their participants to Hyderabad received funding from several individuals, the local government and also the parents of the participants who could afford more money for the travel. I participated in one such field trip to the Malampuzha Dam with the parents and participants of the Unnikulam BRC. Except three participants, all the others were present with their mothers. Sreeni was the Panchayat’s agent. The mothers enjoyed the trip very much. During the trip, the mothers were very comfortable to discuss their personal matters with each other. I in fact thought that more than the participants, the mothers enjoyed the field trip. These field trips were their opportunity to travel and discover new places. As they were accompanying their children there was no guilt of leaving them behind. All the participants were connected with each other and so, even unfamiliar places became relaxed spaces where they could enjoy. These opportunities were also a basis for the collective feeling for the participants and those who were related to them in many ways.

These are also opportunities for the participants to be a part of the larger society. These occasions provided the participants an experience of the outside social world. Through the BUDS *kalotsavam,* traveling, meeting strangers, making friends with 'outsiders' are opportunities for persons with intellectual disabilities to learn and experience novel or unfamiliar situations. These opportunities are also creative expressions of care envisaged under the BUDS-BRC model in a wider manner. Along with direct and immediate care, these kinds of opportunities are also made to be a part of individuals' lives, which are otherwise missed for persons with intellectual disabilities, especially from disadvantaged social backgrounds. Most of the parents in these BRCs would not be able to raise the funds to take their disabled children on leisure trips on their own. The BRCs provide that opportunity for the participants and their families from diverse backgrounds.

4.13 Collectivism in BRCs

According to Dalley (Dalley, 1996), the practical components of collectivism are responsibility, form and domain. These three components provided the basis for a comprehensive framework for caring (Dalley, 1996, p. 121). Collectivism is also a social responsibility: "Collective responsibility ensures welfare of all members of the collectivity or particular specified categories within it” (Dalley, 1996, p. 52). Collective care deconstructs the public/private divide in care work. Community as the collective takes responsibility for its members.

The BRCs are founded on the basis of community care principles. By establishing a BRC, the Panchayat and Kudumbashree Mission provide for an institution for day-care in the locality. Unlike the institutions based on self-care principles and professional assistance, the BRCs are more transparent in their structure. With the involvement of the Panchayat/decentralised political institutions, transparency can be ensured to an extent. Other than the official staff and authorities, lay people and family members of the members can also actively participate in the Unnikulam and Balussery BRCs. With its transparency and barrier-free structure, they help to create community consciousness. Even though the BRCs are based on institutional care, they are under the local government's direct power. These ensure increased participation at the grassroots level.

This community feeling in turn helps to build a collective feeling in the institution. Though the BRCs are consciously founded for the care of persons with intellectual disabilities, they exhibit many characteristics of collectivism described by Dally (1996). They provide opportunity for group interaction among the parents, teachers and participants outside official meetings as well. The SNHGs and field trips help to foster friendships and togetherness among the mothers and teachers. In situations like Sajitha’s, the teacher transgresses the boundaries of formal/institutional care for the participant’s family. There is a degree of solidarity developed among the mothers who help each other in all occasions. These ‘care webs’ (Piepzna-Samarasinha, 2018), were unintentionally created between the mothers to help each other, including lending a hand in caretaking children in the BRC/BUDS during critical situations. It also helps children during field trips where unfriendly structures may hinder their access/entry. I remember how diligently 2-3 mothers and the teacher allied to take Shamna (a participant with severe CP) to the ropeway station without a wheelchair or any other access mechanism in place.

With their close ties with the Panchayat and the Kudumbashree, the BRCs also provide the mothers with an opportunity to participate in mainstream society. Those mothers who constantly approach the Panchayat and the BRCs for various needs also utilise other mechanisms. They have frequent contacts with Panchayat members, as well as the with the Kudumbashree personin-charge. Thinking through these aspects together, the BRCs provide the mothers who are otherwise isolated in their homes, an opportunity to also access the wider community. In the Unnikulam BUDS, some mothers, including the helper, enrolled in the state literacy mission's 10th standard equivalency exam. These mothers had separate groups. Through the BRCs, they got this opportunity to utilise the *Saksharata Prerak* for completing the exam. This is an example that highlights the benefits of the BRC as a community development programme.

4.14 Conclusion

This chapter analysed how the concept of care is exercised in the two BUDS Rehabilitation Centres in Kerala through the analytical category of gender. The chapter focused on the complex care structure that exists in these BRCs. Various agents of care were identified in the BRC structure along with the participants. Various socio-cultural factors also influenced the construction and distribution of care. These institutions which were established to aid mothers of children with intellectual disabilities in their care duties by the Kerala state government relied heavily on the State Kudumbashree Mission, comprising and aimed at only women, for its proper functioning.

The BRCs, for the same reason, focused on an all-women model for its functioning where the employees and stakeholders are primarily women. As a result, men are not directly involved in the daily activities of the BRCs. This model, in effect, reinforces the traditional patriarchal values associated with caring roles. In this heteronormative patriarchal system, women are regarded as natural carers and the BUDS-BRC model holds on to this principle. Men only came out to mediate with the Village Panchayat or for meetings to articulate their needs. This trend depicted the binary understanding of men as earners and women as carers. However, the sustainability of each BRC depends on the physical and emotional labour performed by its female stakeholders. The “feminisation of responsibilities” (Chant, 2008) is a way to analyse the diverse roles played by women to ensure their survival. The intense work done by the various female stakeholders is the primary reason for the BRCs to thrive. However, in doing so, the BRCs also unintentionally provide a platform for emotional connections and solidarity among the mothers of the participants and staff of the BRCs. The activities and interventions which take place in the BRCs are beyond the official description of the roles dictated for the BRC staff.

Though there are funding constraints and minimal involvement of the fathers in particular and the men in general in the BRC discourse, the BUDS-BRC model is a huge intervention from the state. It being mobilised under the Kudumbashree Mission, the state ensures community participation in the caring of persons with intellectual disabilities. This model ensures its presence in the remotest areas of the state, increasing accessibility for the persons with intellectual disabilities from diverse socio-cultural backgrounds.

Chapter 5

The Domain of Sexual lives of Persons with Intellectual Disabilities in the BRCs

Any discussion on sexuality is a very complex affair as it is multi-faceted and also an intimate personal experience. The subjective experience of each individual is unique, based on their own socio-cultural background. Hence, any discussion on sexuality is a highly political as well as a very sensitive area to begin with. Sexuality is an umbrella term that includes sexual orientation, gender roles, relationships, issues around reproduction, feelings, attitudes, etc. At the same time, social, cultural, moral and ethical values are also attached to individual sexuality.

> In Indian society, sexuality concerns have been publicly addressed primarily, and often reluctantly, in the context of abuse, violence and the unwanted negative consequences of unsafe sex such as infections and unwanted pregnancies. (TARSHI, 2018)

Although these are essential areas of concern, the discussions on sexuality should be carried beyond the scope of these. Along with the sexual rights of individuals, other aspects like sensuality, pleasure, erotism, sexual identity, desire are also areas within the discourse of sexuality. The development of sexuality studies and gender studies help us to enhance our understanding of the relation between disability and sexuality (Addlakha, 2007; Garland-Thomson, 2002; Ghosh, 2013; Gill, 2015; Hall, 2011).

Studies on disability and sexuality have begun to take an upswing in India (Addlakha, 2007; Ghosh, 2013; TARSHI, 2018). Sexual subjectivities, body identity, lived experiences, sexual identity, marriage, and so are studied along with the sexual and reproductive rights of women with disabilities. Addlakha (2007) studies the sexual subjectivities of adolescents with visual impairments and argues that the body image and sexual identities of adolescents with visual impairments are constructed on the basis of their impairment and its subjective experiences. Female and male youths with visual impairments have diverse lived experiences due to different social expectations or the lack of social expectations associated with their disability and gender (Addlakha, 2007). Goyal (2017) discusses the role of culture in shaping the sexuality of women with visual impairments in India. The diverse cultural background in India holds multitude of customs and values throughout the country, and according to Goyal, the cultural elements made women with disabilities more vulnerable and less accessible to sexual rights. She again points out that the socio-cultural perception of women with disabilities is asexual. In other words, they are desexualised and denied their right to sexuality (Goyal, 2017). Ghosh (2010, 2013) has studied in detail the sexual subjectivities of women with physical disabilities in West Bengal. She discusses the way the body image and sexual identities of young women with physical disabilities are perceived and constructed, and how sexual subjectivities of women with disabilities are constructed in specific cultural contexts. Staples (2011) examines the intersections of masculinity and disability through an ethnographic study on men affected with cerebral palsy (CP) and leprosy in India. The study points out that the masculine identities are not only grounded in the body, "but also that those identities are, ultimately, configured and constrained by the particular capacities of individual bodies" (Staples, 2011, p. 558). However, studies related to sexual morality, sexual citizenship, sexual ableism are yet to be explored in detail within local contexts.

Another aspect to explore in detail is the sexuality of persons with intellectual disabilities. Vaidya (2024) in her study has looked into the sexuality of persons with intellectual disabilities in India from a non-normative perspective. The study uses the political/relational model of disability (Kafer, 2013) to analyse the importance of facilitation approach to address the sexuality of persons with intellectual disabilities. The study argues that problematizing[37] sexuality facilitates non-normative possibilities for persons with intellectual disabilities (Vaidya, 2024). The complexity of the identity of persons with intellectual disabilities has to be explored in detail in sexuality studies. In India, diverse social and cultural values prevail in different parts of the country. An intersectional exploration of the cultural constructions of disability and sexuality can bring forth a complex understanding of the sexuality of persons with intellectual disabilities.

5.2 Kerala and the Sexual Morality

Sexuality or sexual morality in the state changed according to the changes in Kerala society. The State has undergone a series of socio-cultural and political changes over the years. Religious agencies, caste systems, and political parties are the principal agencies that formulate and define the dominant ideology of sexuality and sexual morality in the state. The majority of discussions on sexual morality focused on women alone. There are recent attempts to address the experiences of LGBTQ+ people in the State. However, sexual morality and specific sexual codes for different genders prevail. Variations or violations of these codes create discussions in the public. Sexual morality has an elitist heterosexual view and patriarchal roots in Kerala’s socio-cultural and discursive space.

Devika (2011) has mapped the evolution of the discourse on the good woman (*Nalla sthree*) and bad woman (*cheetha sthree*) in Kerala. Sexual morality is fundamental in defining the characteristics of a good woman (*kula sthree*). With the

---

[37] Vaidya (2024) used Foucault’s concept of problematization (Foucault, 1994).

arrival of modernity[38], English education, and select few western ideologies popularised in the state, a new liberal masculine ideology was produced (p. 73).

These socio-political changes were significant to define the dominant feminine ideology. Even before the introduction of modernity, there were strict notions to define who acceptable women were and the spaces such women belonged to. The deep-rooted caste system in the State labelled market space (*chantha*) as the domain of immorality; and hence, the woman associated with the markets was labelled as *chantha pennu*[39]. The domestic space and household work were considered as ideal space for women. Such women were regarded as ideal women (*kula sthree*) in Kerala and these women belonged to upper castes. Nurturing and domestic chores became their primary duties.

Although gradual political changes happened in the society along with economic changes as well as cultural evolutions, the ideological basis for the discourse on morality has remained the same. The public/private divide remains strong and the women who spend a considerable amount of time in public spaces are still accused of immorality (Aswathy & Kalpana, 2019; Devika, 2011). The state has witnessed many instances of moral policing[40] even in recent times almost on a regular

---

[38] Devika (2011) discusses the introduction of English education and other related events also shaped the rapidly changing cultural and political map of Kerala to describe the construction of an ‘immoral woman’ . I have used Devika’s arguments here to show an important aspect of the evolution of the discourse of sexuality in Kerala.

[39] Devika (2010) discusses how historically the categories of *chantha pennu* (market woman) and *kula sthree* (good woman) are constructed. The book critically examines the role of caste and patriarchy in shaping the good/bad, moral/ immoral binary in the state. Devika (2010) highlights how casteism and patriarchy equated the term *chantha pennu* with sexual immorality. It was argued that, women’s access to public space, especially to market instigate sexual immorality. Since the lower caste women had to work and buy from the market, the usage of the term is purely casteist and also patriarchal. In a broad sense, the women’s physical mobility is tied to the sexual immorality, which is directly linked to casteism.

[40] ““Moral police” is a blanket term used to describe vigilante groups which act to enforce a code of morality in India.” (Tharayil, 2014) They are the group of people who act as vigilantes to uphold ‘morality’ set by the dominant ideology. Any act that opposes/threatens/rejects the ‘constructed morality’ is opposed by these groups by various means of violence. Morality upheld by the group usually followed the upper caste/puritanian ideals.

basis. Devika (2011) narrates the act of moral policing and points out the notions of immorality and its ideological tie with the caste system in the state. She describes certain dress codes and acts that violate the morality constructed by the dominant Kerala society. Access to modern education, adoption of new types of clothes, spending time in the public, taking up jobs in distant places, etc., were contested by the dominant masculine authorities during the earlier period. However, for the lowered caste women, all these were massive political conflicts to overcome. Sexuality and casteism were the underlying problems in all these discourses. That is how sexual morality became the most critical discussion point in Kerala's modernity discourse.

Tharayil (2014) discusses the paradigm of gender and sexuality discourse in Kerala. His study shows the evolution of homosexuality discourse in Kerala's discursive space. The study analysed Kozhikode's homosociality and the way it was treated by the public across Kerala. The study shows the ambiguities surrounding of homosocial masculine spaces in and around Kozhikode. Though discursively acknowledged later, there was complex relational and emotional ties around the homosocial masculine spaces of Kozhikode. Tharayil (2014) further discussed the meanings associated with the word 'kundan'[41] in Kozhikode. His study denotes the word's negative stereotype with gay sexuality and its strong association with Muslim community. As a person from Kozhikode region, I could say that we use the word in our day today lives to address any 'boy'. I also acknowledge the complexity of the term as in certain situations, it does ignite homosexual connotations.

---

[41] The word kundan, commonly used to refer to an effeminate or at least "soft looking" young male, who could potentially play a "passive" role in a same-sex encounter/relationship. In some parts of Malabar, the term initially meant "handsome young man" (Tharayil, 2014, p. 72).

One of the most remarkable incidents that challenged the mainstream morality was the Kiss of Love (KoL)[42] protest in 2014. That was a direct interrogation of the moral policing and dominant ideologies regarding sexual morality. It advocated the entry in public spaces by women and all sexual minorities, and the discourse revolved around public display of affection and desire. Although this discourse was inclusive of queer and other sexual minorities, the sexuality of persons with disabilities and their right to sexuality were not discussed, or their access to public spaces.

Alternative narratives of sexual rights of LGBT and queer sexual rights have begun to change the discourse of sexuality in Kerala. With prolonged engagements from the academics and activists, mainstream society has begun to acknowledge the plurality in sexuality and sexual orientation of the individuals. Mokkil (2018) discusses how Kamala Surayya's short story '*Sthree*' was not acknowledged as the first lesbian Malayalam short story during her time. It was published as the first lesbian short story in Malayalam only after her death. However, Mokkil's writing helped throw light on this issue and initiated a discussion on queer sexuality[43]. Over time, homosexuality and other queer identities are beginning to be acknowledged by a section of people in Kerala society. Increasing visibility for transpeople can also be discussed here as the reason for initiating the change. The repression regarding any open discussion on sexuality is steadily changing as there are steady and regular discussions on sexual minorities and queer politics in the State. Movies like

---

[42] Kiss of Love was a mode of protest against vigilantism and moral policing of the conservative groups in Kerala. The protest started when a mob attacked few couple and demolished a coffee shop in Kozhikode on the ground of 'alleged immoral activities' in 2014. The protest later spread all over the country against.

[43] Mokkil (2018) discusses fantasy and queer sexuality in Malayalam cinema and literature by analysing Malayatoor's *Yakshi* and its film adaptations along with Kamala Surayya's *Sthreekal*. The writing discussed the complexity of masculinity and lesbian identity and how fantasy was used to describe women's sexual expressions and displays. The term *Yakshi* denotes supernatural power and the immorality of certain women's sexuality.

Moothon[44] (the elder one) were screened and accepted by a section of people. Though these are positive glimpses of the awakening of an inclusive and diverse sexual culture in the state, patriarchal, homophobic, and trans-phobic communities are dominant in Kerala’s public spaces. Moral policing and vigilantism are the tools that these dominant groups use to control public discussions and the display of sexuality. The suicide of trans-woman *Ananya* is the latest instance that shows the ignorance and insensitivity of the mainstream society and the medical system regarding diverse bodies and sexual identities. These biases form the premise of any discussions on disability and sexuality in the state.

Discussions around sexuality of persons with intellectual disabilities have emerged over the years (Carlson, 2010; Kempton & Kahn, 1991; Kim, 2011). Discussions on institutionalised care and sexuality also indicate concepts such as control and disciplining of persons (Feely, 2016). Feely (2016) has examined how community-based intellectual disability services put restrictions and disciplines over the sexuality of persons with intellectual disabilities. He used a combination of both Foucault and Deleuze's concepts to substantiate his argument regarding the complex systems of disciplinary control that exist in group homes and rehabilitation facilities. His study says that the combinations of technology, policies, and staff create an environment which leads to sexual surveillance on participants with intellectual disability. However, the position of BRCs is not comparable to that narrated in Feely’s (2016) study. For instance, I have already stated that these BRCs did not have surveillance cameras, but staff members took over the role of observation and vigilance instead of the cameras. Service provisions are also different in the BRCs.

---

[44] The movie tells the story of a transgender child from Lakshadweep, travelling to Mumbai to find their elder brother, Akbar (portrayed by Nivin Pauly, one of the most prominent Malayalam actor), who left the island due to his homosexual orientation.

The physical/material difference is striking when it comes to different BRCs as the ones located in the urban areas are far more developed than the rural ones[45].

When we focus on the status of persons with intellectual disabilities, they are either ‘desexualised’ or ‘hyper-sexualised’ by the normative society. Disabled sexuality is considered as deviant sexuality, and therefore, stigmatized by the hetero normative and patriarchal society. Siebers (2012) argued that the sexual rights of persons with disabilities have to be considered along with queer rights as a sexual minority. He argued that it was necessary for persons with disabilities to identify as a sexual minority and assert their sexual identity and to become a part of the political discourse of sexuality. According to Richardson (2000):

> Fundamentally, important are institutionalized (hetero) sexual norms and practices, whereby heterosexuality is established as ‘natural’ and ‘normal’; an ideal form of sexual relations and behaviour by which all forms of sexuality are judged. (p. 111)

Richardson (2000) formulated a framework, which interprets sexual rights through three sub-streams within the sexual rights discourse: conduct-based, identity-based and relationship-based rights claims (p.107). Conduct-based sexual rights includes right to participate and enjoy sexual acts, right to sexual pleasure, right to bodily control or sexual and reproductive self-determination. Under the identity stream, right to self-definition, right to expression, and, right to self-realisation are identified. Relationship category includes right of consent in relationships, right to publicly recognised sexual relationships. This framework helps to place the ‘private’ discourse into the ‘public’ realm of citizenship. The sexual lives of persons with intellectual

---

[45] I visited several BRCs throughout the state. Most of the BRCs in the urban areas I visited were receiving donations and other forms of financial/ material help from various sources. Generally speaking BRCs located near urban centres had more infrastructural facilities.

disabilities can also be recognised under this framework. The framework provides the private and subjective experiences of persons with intellectual disabilities with a public discursive strength.

5.3 BRCs - The Experience of Sexual life of Participants

There are discussions about the strategies adopted by rehabilitation centres and institutions employed to 'normalise' persons with intellectual disabilities. One of the objectives for the manifestation of BUDS institutions was to provide 'day-care' to children with intellectual disabilities. Providing 'care' includes a vast network of activities and a wide variety of interventions from the institution. I understood from the various interactions and casual talks with the parents that they were expecting necessary interventions from the staff members to ensure the safety of their son/daughter. From the parents' perspectives, the BRC was a safe space where they can leave their son/daughter without worrying.

The word 'safe' is complicated in many ways. When I talked to the teachers or parents, or officials from the Panchayat, they use the word safe/safety (*surakshitham, urappulla*) in different contexts. For the teachers: "they leave children here, with us, in the belief that they are safe here and we will watch over [them]. That is a huge responsibility. That is why I would not take my eyes away from them" (Pers. Comm., Teacher, Unnikulam BRC, 2019).

In the words of the helper:

> Since she is not able to think (*oru ormayum illatha*) at all, I have to watch her constantly and her interaction with the boys. If something happens to her, how

> can I live after that? Her mother has entrusted her complete faith in me and I have to uphold their faith. (Pers. Comm. Helper, Balussery BRC, 2019)

In the words of a Panchayat official: “The staff have to watch over the students all the time. See, the institution literarily is on the road and vehicles always pass by. If something happens, we are all answerable!”

From the above responses, the word ‘safety’[46] has been used in multiple ways, ranging from physical safety to moral safety. The dimensions and complexity associated with the word ‘safe/safety is an interventionist one; that, in a way, can be interpreted as a practice of vigilance within the institution. It can be stretched to the extent where they can enforce surveillance amongst the participants’ every activity, ranging from their movements to interactions, and ultimately on relationships or any other personal matters.

Safety has a very gendered dimension. Women and queer persons face gender-based violence globally. Every society in the world has gender-based violence. Women are discriminated and treated as secondary to men in majority of the households in India. The gender biases are manifested in differential treatment to girl children from their early days onwards. This results in different forms of health issues, including nutritional deficiencies, limited access to education, health care, etc. Women, including young girls, face various forms of gender-based violence and a lot of them live fearing sexual violence. The fear of sexual violence is more widespread with the increase in the number of cases involving violence against women. Cases of rape, dowry death, domestic violence, sex trafficking, have increased manifold in

---

[46] Interestingly, the word “safe” has used to discuss about safety related topics in both BRCs by teachers, mothers and other stakeholders alike. For example: *safe aayirikkan* (to be safe), *kuttikal safe aanu* (children are safe). *Avar safe aanennu urappikkan* (to make sure that they are safe).

India. 4,09,273 cases were reported during the period 2021 alone (NCRB report, 2022).

The fear of violence against women is prevalent across various cultures in the Indian context. Therefore, the fear of violence ignites concerns of safety. Upbringing is one of the main reasons that contribute to developing a feeling of being inferior among young girls. Women, irrespective of their disabilities, are concerned about their safety. Mehta (1999) observed that, “Women’s fear of violence have called ‘patriarchal social control” (p. 68). The violence against women, children, sexual minorities and the disabled are based on the unequal power structure in the society. The subjective experiences of sexual violence and the fear of violence underscore the idea of safety in the society. Every aspect of the lives of women is defined by the concern for their safety. For persons with intellectual disabilities, irrespective of their gender and sex, the fear of violence is immense and the community ultimately takes comfort in resorting to various safety measures. The notion of safety, therefore, weaves through the everyday experiences of women, children, queer community and the disabled.

5.4 Safety and Sexual Morality: Overlapping Boundaries

My first day in Unnikulam BRC, the BRC where I spent most part of my fieldwork, was a memorable day in many ways. On the first day itself, I was given a serious ‘warning’ about the sexual behaviour of the participants. I was ‘warned’ regarding the sexual ambiguity and “hypersexual” nature of the participants. These warnings came from a teacher who was on a temporary basis in the BRC as the regular teacher was on leave during the first part of my visit. Although she was a trainee, she was not new to the BRC as she had been part of it for several months as part of completing her internship in teacher's training to obtain her diploma. Her familiarity with the institution and the participants made her an ideal substitute candidate in the absence of the main teacher. The trainee told me that she was asked to help with the class as it was challenging for the helper to manage both the class and the kitchen by herself. After giving me a general introduction to the workings of the institute and other details, she advised me to be careful and be vigilant at all times as the participants were not 'kids' and were all sexually mature adults, above the age of eighteen. Talking from her own experiences, she mentioned that she had encountered several instances where some of the boys 'misbehaved' with her. She told me it took some time for her to make them understand that she was not a person to 'misbehave' with. She advised me to wear salwar or kurtas with dupatta inside the institution. She also warned me to keep my distance from the boys while interacting with them. She said that the participants only considered their main regular teacher as their only 'teacher', which she believed was only due to the dress code of the same person as the main teacher always wore a saree to the BRC[47]. The short conversation pointed to multiple factors that I was made aware of, which was delivered in the form of a friendly advice. I was made aware of the importance of the dress code in the institution, essentially relying on the importance of the so-called 'modest' clothes to establish identity and good sexual conduct that did not invite sexual attention from anyone in the BRC. Essentially, the burden fell on the woman's body.

The lack of CCTV cameras meant that there were no technical/remote ways to observe the participants inside the institutions. However, during my visits, I felt that these participants were always under surveillance by the staff. Since parents expected

---

[47] In Kerala, only in 2009-2010 were women teachers allowed to wear clothes other than a Saree. Until then, saree was part of the mandatory dress code for them. The emphasis on the saree signifies the importance of a 'decent' dress to wear during the working hours. Acknowledgment of saree as the 'official' dress in the public eye has a long history of dominant nationalist discourse on morality.

such involvement and vigilance from the institution, the staff was encouraged to monitor all the participants.

The sexuality of the participants was one of the most discussed themes during the field visits. The participants’ physical safety and moral safety (sexual morality) were the two significant concerns attached to any discussion on sexuality in the institutions. Mixed (both boys and girls) activity rooms/classrooms were present in both the BRCs. The teacher was present in the classroom almost all the time. Although there were strict concerns regarding the moral safety and the extent of physical contact and interactions between the male and female participants in the BRCs, helping participants with mobility impairments is expected out of everyone, regardless of their gender identity. This contradictory expectation/practice, however, challenged the usual conservative attitude about heterosexual interactions!

With the limited physical facility inside the BRC, each participant is dependent on one another, which also meant that free interactions were happening inside the premises. Anshad (a thirty-year-old male participant with speech impairment and mild intellectual disability), always helped Shahanath (a thirty-two-year-old female participant with mild intellectual disability and physical disability) and Noor (a twenty-seven-year-old female with cerebral palsy) -- the two participants who were facing mobility issues. They needed someone to hold them to help them walk to the dining room, and Anshad was always by their side to help them out. At the same time, the interactions between Swapna (a thirty-four-year-old female with down syndrome) and other male members were observed with suspicion by the staff and other parents. The boundary separating cooperation and immorality was a very thin line, which was constructed on the basis of existing values prevalent in Kerala’s public consciousness about sexual morality (based on heterosexual ideals).

There are lots of NGOs and other disability assistance service providers in Kerala. The areas they focus on are accessibility, welfare, care, issues faced by parents of children with disabilities, and other discriminations towards people with disabilities. On the other hand, sexuality and intimate relationships are yet to be identified as significant areas to intervene. Friedner (2017) analysed the development of the discourse of disability in urban India. She also focused on how disability has turned into a 'feel good' diversity in urban India. "In an urban Indian post-liberalisation context, disability is increasingly seen through the lens of diversity by the state, corporations, disability movement, and nongovernmental organizations (NGOs)" (Friedner, 2017, p. 3). "It is important to foreground the relationship between disability and politics because disability is often depicted as being a- or anti-political as opposed to possessing a distinct form of politics" (Friedner, 2017, p. 5). Drawing from her argument, I think the discourse of disability in Kerala follows this trend of emphasising and expanding discursive entities in specific areas such as accessibility, welfare, etc. The state government initiatives and other official programmes are focused on rehabilitation, treatment and needs-based services. These needs are considered necessary for survival ones. Relationship, marriage, sex, etc. are not considered as basic needs in the discourse of disability in Kerala. Although various charity-based institutions proposed and conducted community marriage for persons with disabilities, they are largely from a charity point of view.

Even though BRCs are established to rehabilitate and empower persons with intellectual disabilities, the primary duties of the BRCs I visited were limited to being the day-care of the participants[48]. I want to look at the impact of the BRCs being a 'daycare' centre and its effect the notions of sexuality in the institutions.

5.5 Surveillance and Strategies of Control- A Case Study

The silence of sexuality in Kerala's public domain also mirrors the vigilantism and surveillance practised within the BRCs. The case of Arun is one of the best examples to show the mode of surveillance that operates inside the institution. Shameena was the only female participant attending the Balussery BRC regularly. According to the teacher and helper, she had a severe intellectual disability. She was not able to articulate things and also had difficulties in recognising people. She used to spend time in the institution sitting alone and watching television. Otherwise, she lied down on one of the benches in the activity hall. The helper revealed that there were several instances in which another participant, Arun (a participant who suffered from an acquired intellectual disability after a bike accident), had approached this girl and on one occasion, they had engaged in some physical contact inside the activity room. The helper after witnessing this mentioned about it to the teacher, and they had both warned Arun not to repeat such activities anywhere. They also informed both the sets of parents about the incidence. Since then, the helper kept an eye on Arun all the time. She even mentioned that she changed the seating arrangement in the classroom after this incidence in a way that she could watch Arun and the girl even through the kitchen window.

> I am afraid of any encounter between the duo. That is why I positioned the benches and desks like this – they are now under the vicinity of the kitchen window. Earlier, it was not possible to see them because of a different seating

---

[48] See 1st, 3rd, and 4th chapters for detailed accounts about the function and impact of these institutions.

> arrangement. The teacher could not see Arun as he always used to prefer sitting behind that pillar. The pillar used to hide him from the teacher, and that was how he was able to approach her last time. And I know that, if he approaches, she would allow him to do anything to her. I cannot even think of the aftereffect of that! (Pers. Comm., Helper, BRC Balussery, 2019)

Arun has an acquired intellectual disability. He had met with a bike accident and hit his head. He was in ICU for over a month after the accident. He told me about the ‘fate’ he had and showed me the scars and surgery wounds. The other participant also made some gestures with her hand and head whenever Arun passed by her or got up to go to the toilet, which somehow entertained the rest of the participants.

All his movements were closely watched by the helper and the teacher. The helper took it personally as her own duty to observe him and intervene whenever she thought Arun was ‘misbehaving’. Arun’s mother also wanted them to observe him throughout the class to prevent him from doing any ‘bad’ things. The helper and the teacher jointly told me that his conduct had caused worry to Arun’s neighbours. The neighbours complained to Arun’s family that specific actions by him humiliated them, especially the women. The helper told me he harassed a neighbour by laying a hand on a woman in an inappropriate way. This resulted in quite a nasty scene as the women dreaded the attack, screamed, and the people from the neighbourhood came over due to the commotion. From the discussion with the helper and the teachers, it became clear that Arun’s attack was interpreted by others and his own family as being part of the hyper-sexual urges of people with intellectual disabilities. After this incident, Arun’s family kept him locked inside his home for several days. Although his mother began to watch him round the clock, she was not able to attend to anything other than this. She was not able to take up any income-earning jobs. This forced her to consider alternate options for taking care of Arun. Due to financial reasons, they opted for the BRC and enrolled him there.

Other mothers and teachers agreed with the helper's account. They told me that it was difficult to handle an adult with an acquired disability. The teacher and other mothers (whom I met during a PTA meeting) told me that Arun was not the 'normal' kind of boy there.

> He '*knows*' things that others do not. His lived experience and attained knowledge are different from others, which is why he behaves differently and uncontrollably. His consciousness is somewhat like normal people. However, his interpretation of attained knowledge has turned upside down after the accident (*Onte moola thirinju poyi*). That is why he becomes the most difficult person in the institution to maintain and control. (Pers. comm., Helper, Balussery BRC, 2019.)

In Arun's case, multiple factors intertwined to formulate the air of uneasiness about him. His expressions of sexuality were interpreted as uncontrollable and immoral. His disability itself was considered 'different' in a space specifically established for the rehabilitation of persons with intellectual disabilities. In the case of Arun, these two factors jointly justified the constant surveillance (Foucault, 1995) and the aura of vigilantism practised inside the institute by the staff. In a sense, the enforcement of safety measures also encouraged the mechanisms of control of the subjects. The root cause behind Arun's villainous status amongst others in the BRC was his explicit display of sexual urge before the mainstream society. Taylor Gomez (2012) observed that " Sexual expression is not a problem for people with cognitive disability, but for those who work with them" (p. 238). In the BRCs, many of the participants expressed their sexuality through various ways. I have explained various instances, cases studies of various participants in section 5.5 of this chapter. Even with constant vigilance and surveillance, many of the participants still found alternative ways to express their likes and dislikes. However, their expression of sexuality was never acknowledged properly in any of the centres.

Manu was a thirty-year-old participant in Unnikulam BRC. He met with an accident when he was seven years old. He had hit his head and as a result, some nerves were damaged. He suffered from a limp on his right leg and has a speech impairment and cognitive disability after the incident. Even though he was also a person with an acquired disability, Manu was not treated as a ‘misfit’. He was asked to participate in many activities and was also considered as an active participant. The main difference was that Manu did not have a hypersexual identity in the institution.

When it comes to the domain of intellectual disability, the person’s ability to engage in any kind of sexual activity or expression of sexuality is denied and prohibited. Unlike the urban-centred narratives about the expression of sexuality in India, the BRCs regarded sexuality as a subject not to discuss as a right or necessity. Instead, it was something that only came up in casual conversations and whispers amongst the staff, parents, or anyone who have some kind of relationship with the institution. Taylor Gomez (2012) observes -- “there is a general fear that if we open doors to talking about sexuality, then people with intellectual disability will be abused or become sex offenders” (p. 238). Hence, these (two) institutions do not consider sexuality as a fundamental need and right of a person with intellectual disability and did not incorporate sexuality in official discourse. At the same time, whispers and ambiguities related to the sexuality of adults with intellectual disabilities were very active.

In the case of Arun, his parents and teachers labelled him as ‘different’ due to his ‘acquired disability’ and the knowledge and experience he acquired even before his accident and injury. This situation was unique as his knowledge and experience were acknowledged but interpreted to make him ‘the other’ of the institution. Arun, was regarded as ‘different’ in a space specifically designed for the upliftment and mainstreaming of persons with intellectual disabilities. The construction of a binary between a person with an acquired disability and non-acquired disability -- by staff and others in the institution constructed a set of ‘normalcy’ for the institution. As Arun was not included in this constructed normalcy of the BRCs, he was cast as a ’misfit’[49] (Garland-Thomson, 2011). This resulted in the constant surveillance and policing practiced on him. Arun was considered ‘normal’ when it came to his physical engagement with the girl. She was diagnosed as a woman with severe intellectual disability, and any engagement with the duo was interpreted as sexual abuse from Arun’s side. The duo's agency to participate in any sexual relationship was denied and, in effect, labelled as a “threat” to the normalcy of the institution. Society does not recognise their lack of communication skills and sexual skills; they are ‘tolerated’ by the mainstream society and labelled as abusers (Taylor Gomez, 2012). The portrayal of the girl as prone to sexual violence and he as the abuser reflect the complexity of acquired disability and heterosexual relations in the institution. Explicit display of sexual urge or intimacy by a person with intellectual disability challenges the ableist, patriarchal, and hetero-normal assumptions of mainstream sexuality (McRuer, 2006; Siebers, 2012). According to Gill (p. 4, 2015) “Individuals with intellectual disabilities are productively unruly bodies that challenge the sexual ableist notions that their sexual practices are naïve, deviant, immoral, or dangerous”.

---

[49] Misfit is a concept introduced by Garland-Thomas (2011). The concept revolved around the construction of fit/misfit. She observed that, a fit occurs when a generic body enters a generic world that is designed and built to accommodate uniform, majority bodies. (p. 594).

There are two versions of masculinities attributed to the participants in the BRCs; eternal childlike image and the ‘hypersexual’ immoral one. Mehrotra and Vaidya (2008), in their study, narrated the construction of masculinity of men with intellectual disabilities in Rural Haryana.

> We may speculate that disabled men, particularly intellectually disabled men, are not even regarded as ‘men’ in the first place on account of their being subsumed in the ‘women and children’ category. They are pitied as they are seen to be incapable of enacting any masculine role, even though they are not explicitly excluded from community and family life in the rural areas. (Mehrotra & Vaidya, 2008, p. 326)

This is the way one can frame the labelling of adults with intellectual disabilities in the BRCs-- ‘child-like’/ ‘innocent’ and ‘pure in heart’. As I mentioned earlier, there is a constructed normalcy sustained in the BRC. That normalcy depicts some of mainstream society’s prejudice of intellectual disability.

> None of the other kids practice ‘bad things’ like Arun. They would not utter any bad words or pass any bad comments like him. All the other boys are like children; they are innocent and pure in heart (*Ullill onnum illa. Ullu shudham aanu*). You know, my son, he never expressed any bad gestures like this. None of the other boys do. (Pers. comm. Helper, Balussery BRC, 2019)

Kim (2011) argued that the omission of disabled people from any discussions on sexuality, sexual assistance, sex education, etc., are ‘desexualisation’ and this process projects the asexual image of a person with disabilities very loudly. Desexualisation is a process that denies any possible engagement in the realm of sexuality by persons with disabilities. Their lack of acknowledgement as “sexual citizen” closely connects with the desexualisation process explained by Kim (2011).

The denial of sexuality is a political process that reinforces the labelling of persons with intellectual disabilities as child-like or innocent. Acknowledgement of a person as an ‘adult’ is heavily influenced by this discursive construction of ‘eternal children’, and that also points to the initial problem of morality/immorality. Persons outside the dominant sexuality, heterosexual ableist and patriarchal, are mostly labelled as immoral by mainstream society. The spaces of the BRCs are under the influence of the same dominant ideologies, and sexual expressions or public displays of affection are monitored and processed on the same heterosexual ableist ideology. As a result, explicit displays are considered immoral.

The helper’s words about the innocence and the lack of bad thoughts by the other participants of the BRC highlight this moral/immoral binary. The BRC was considered as morally safe and the participants’ mind-set were equated to being child-like or they simply did not have any bad thoughts (*Cheetha Chinthkal*) like Arun. This was the process of desexualisation adopted in that particular BRC, and moral safety of the participants were assumed to be the responsibility of the staff.

The omission of the sexuality of a person with disabilities in the dominant discourses has heavily impacted the lives of persons with disabilities in Kerala. For instance, in the BUDS and BRCs’ construction manual of the buildings, there was no mention of privacy for persons with intellectual disabilities, even though they were all adults and there was a need for privacy. During my visit to a BUDS school, as part of the pilot study, the head teacher told me there were instances where students showed tendencies for masturbation in the public spaces. During those times, she either led the participant to the washroom or told him that it was inappropriate to masturbate in public places, especially in class while everybody was watching them. However, the staff in the BRCs said none of the participants masturbated in the public spaces. “They know that this kind of behaviour is inappropriate. Also, we train them to control such instincts. Moreover, they are old enough to understand the inappropriateness of such acts” (Pers. Comm., Teacher, Unnikulam BRC, 2018). Nevertheless, they asserted the need for spacious washrooms and extra rooms for private use.

I want to argue that the omission of privacy of individuals with intellectual disabilities is also because of the ableist perception of the sexuality of persons with intellectual disabilities as asexual or hypersexual. Thus, any sexual engagement between them is considered immoral. To legitimatise any sexual relationship in Kerala society is through the institution of marriage. All other means of sexual expression are considered illegitimate and immoral. As for a person with an intellectual disability, marriage is not at all approved by the family and society (Gill, 2015; Kim, 2011; Mehrotra & Vaidya, 2008). In that respect, any form of sexual relationship or display of sexual orientation will be dismissed outrightly by others.

5.5 Defining Sexual Morality in BRC; Swapna’s Case

Sexuality, marriage, reproduction, and parenting are interconnected and overlapping ideas. The combinations of sexual ableism along with sexual citizenship, sexual autonomy, and sexual agency are significant to analyse the contemporary institutions of marriage and family. The case of Swapna can be analysed to understand subjective realities endured by women with intellectual disabilities; her case also exemplifies the everyday experiences of a woman with intellectual disability in a BRC. Swapna was 34 years of age and a woman with Down syndrome. From my first day onwards, I was notified by multiple persons about her over-friendly attitude and inappropriate relationships with other men and classmates. Swapna had a very friendly nature and became friends with anyone within a short period of time. I was told that, despite her speech impairments, she was the best singer and dancer in that particular BRC.

Swapna was closely watched by the staff and other participants of the Unnikulalm BRC. On my first day, I was told that she would go with anybody who behaved nicely with her. She had reportedly left home several times in the past, without anybody's influence. The teacher told me that she was absorbed in her own world mostly and wandered off to the streets. However, she never had a chance to 'leave' the BRC as they closely watched every participant there. Women's solo walks are not positively perceived in Kerala. Leisurely walks are not meant for women in India. When a woman wants to walk in a public space, there must be a reason to substantiate the 'walk'. Those women who travel alone, without any specific 'reason' are considered as 'bad' women. In other words, women need a 'purpose to demonstrate' (Aswathy & Kalpana, 2019; Phadke et al., 2011). Aswathy & Kalpana (2019) discuss the labelling of 'good women' and 'bad women' in Kerala's fisher community. The study indicates that women's exposure in the public spaces (like a market) at night impacted their identity as good/bad women. Solo travel and exposure in a masculine space are regarded as 'immoral' for women. I want to point out that Swapna's solo walks and her desire to go out are regarded with the same moral principles of mainstream society.

Swapna had feelings towards a fellow classmate whom she addressed as '*ettan*[50]'. She told me her '*ettan*' was a participant in the BRC. Later, I learned about her likeness to this person. He was a former student there, and after some period, he left the daily classes at the BRC and joined a garment shop as a salesman. His name was still on the rolls of the BRC, and he was still availing the scholarship. He also visited the institution on special occasions. Swapna claimed that he was her cousin brother, and that they were relatives. The teacher and his mother told me that they were not related, contrary to what Swapna said.

Multiple incidents involving Swapna and some of her classmates were condemned of 'alleged immoral' activity by the staff and the parents of other participants. During a class outing to *Malampuzha* Dam[51], Swapna felt unwell and was taken to hospital. She requested her 'cousin' to accompany her. Later, on the bus, she said she was sick and wanted to lie down on her 'cousin's' lap. The teacher and Sreeni (*Sreeni-ettan*, as he was called by everyone in the BRC was the tour coordinator from the Panchayat) requested him to do what she had asked. At that time, all the parents were commenting about her 'tactics' and her alleged love affair. Other students were catcalling and whistling[52] when she insisted on lying on her cousin's lap. One mother whispered that she had done a similar kind of 'acting' earlier. There were giggles and constant whispers from all the parents. One of the mothers joked that she was imitating the TV series' actors. She calmed down after lying for some time on his lap. Swapna, on the other hand, did not mention the incident at home. The following day, the teacher told me that Swapna knew how to

---

[50] Malayalam word for brother. This word also used as a respectful way to address a person elder than your age, and also act as 'hello' to address strangers in Malabar region. Common usage 'Chettan is not popular In Kozhikode region.

[51] *Malambuzha* is located in *Palakkad* district. The dam site is an important tourist destination in the district.

[52] It shows that the participants were aware of what was acceptable and what was considered undesirable sexuality/ sexual expression in the public spaces.

‘conceal’ certain things from her parents. The helper told me she was ‘normal’ when it comes to things like that and had even requested her ‘cousin’ not to mention this incident to his parents.

From my experience on being in the bus and the discussions that followed, there was an aura of ‘immorality’ in the air. The following day, on a telephone conversation, the teacher shared her concern about the ‘immorality’ of such an act. She opined that Swapna should have at least thought about her parents’ before creating such a scene. She believed that Swapna was fully aware of what she was doing and had the ability (*kazhivu*) to think about the consequences of such an act on her family. She said that *nalla kuttikal* (roughly translated as “morally good girl” in this context) would never do such a thing.

The responses after the incident paved the way to contemplate about sexual agency and the ‘immorality’ of sexual expression in public. I noticed that the word ‘ability’ was used in occasions where they disproved the immorality of the act. In order to signify the act as immoral, they said she that she was ‘able’ enough to distinguish between the ‘right’ and ‘wrong’ of an action. Interestingly, she was the same woman who was earlier referred to as someone who ‘often lived in her own world’. Various instances, like in the case of Swapna, show the complexity associated with the word ability.

The intensity of sexual ableism and issues associated with agency and sexual citizenship need to be discussed here. Taking the reference to another occurrence in Swapna’s life when she had a proposal from an ex-participant of the BRC to get married. They were ‘discovered’ together in the school as well as in the autorickshaw in which they were traveling from the school, by the helper and the auto-driver, respectively. Once the staff discovered this, they informed both the sets of parents. Following that, his family formally approached the teacher and Swapna’s family with a marriage proposal. His mother said they had enough wealth and property to look after their son and their ‘would-be’ daughter-in-law. Since both of them liked each other, his family wanted them to get married. His mother also thought that as he had only a mild disability, he could support her well and that they could be there for each other throughout their lives. His mother hoped that this alliance might provide a better future for her son, whom she hoped would ‘improve’ after getting married. However, Swapna’s parents were not interested in the proposal and denied it outright. They told the teacher that both belonged to different castes and that the boy's family had a bad reputation in the neighbourhood. They were not entirely sure about the safety of their daughter if she got married into that family.

There are several important points in this account to note. This is a situation where the issues of caste and morality are intertwined. Swapna’s family were upper-caste. Even though the couple was engaged emotionally and physically, when it came to the aspect of marriage, caste and ‘morality’ of the families came into the picture. Security and the safety of the girl were debated over and again. Notions of caste overlapped with that of bad reputation, which was again often associated with the lower castes.

The teacher told me that Swapna’s parents did not want her to get married even after that proposal. She informed the parents about a community marriage programme conducted by a charity organisation. The programme was meant for persons with disabilities only. However, Swapna’s parents were not interested and told the teacher that they feared about their daughter's safety after marriage. They also expressed concerns about how she was going to perform household duties. The teacher quoted them, “Forget about the boy; we do not know how she is going to look after herself! She does not know the duties (*kadama*) of a housewife. How can we ensure the safety of our daughter?” (Reported Conversation of Swapna’s parents by the Teacher of Unnikulam BRC, 2019). Teacher opined that they feared the possibility of domestic violence and sexual violence towards Swapna.

Despite the assertion of sexuality by the couple, reluctance to form a marital relation for their daughter has to be considered as sexual ableism. Gill (2015) explained sexual ableism as “the system of imbuing sexuality with determinations of qualification to be sexual based on criteria of ability, intellect, morality, physicality, appearance, age, race, social acceptability, and gender conformity” (p. 106).

> Intellectual disability remains a characteristic or condition that disqualifies participation because of sexual ableism, which denies an understanding of disability as a valuable difference that yields unique perspectives of personhood, competence, sexuality, agency, and ability. (Gill, 2015, p. 03)

He articulated that the complex social and cultural conditions where sexual ableism is practised and how the very same socio-cultural notions are legitimatised through legal and policy deliberations.

In Swapna’s case, her open expressions were considered immoral. The staff and parents in the institution believed that she had the ability to distinguish between the good and bad, which translated to morality and immorality in this context. Public display of sexual attractions and feelings labelled her as sexually immoral. From the conversations and observations, I found that the staff and other parents subscribed to the mainstream/dominant ideology of morality, and they applied the same measures in the case of these participants in most instances. The staff of both the BRCs were trying hard to establish that their respective BRC was morally safe by engaging in surveillance and control.

There are preconceived notions regarding the abilities of a person with an intellectual disability. Gill (2015, p. 19) observed, “Women’s sexual lives are largely constructed around the twin poles of “regulation of pregnancy/reproduction and “protection from sexual abuse and assault. It can be extremely rare for women with intellectual disabilities to be recognised as competent sexual agents”. When it came to the case of their marriage, performing the duties of a ‘housewife’ was considered as something beyond their ability. They were treated as individuals who needed perpetual care, and their abilities of reproduction and nurturing, sexual desire and sexual acts, were never acknowledged. Their ability to engage in sexual activities was never entirely accepted. Sexuality and expressions of sexuality were considered immoral, and there was no understanding of sex as part of the rights of a person with intellectual disabilities. But in Swapna’s case, her sexual desire and sexual actions were acknowledged, but acknowledged as immoral. She was considered **able** within a framework of disabled, an ability that was already deemed immoral within the ableist discourse. There seemed to be a neat division as to what constitutes disability and ability. In cases such as this, the body’s desires were understood as able and undesirable, simultaneously.

5.6 Marriage, Reproduction

Marriage was always discussed in the BRCs. The discussion ranged from the prospect of marriage of participants to their healthy sexual lives. Like I mentioned earlier, prospects of marriage had always been discussed for male members. Some of their families were searching for ‘suitable’ partners, while female participants were always suspected, and additionally evaluated on the basis of their ability to perform the ‘homemaker roles’. From the conversation with the BRC teacher, she said that she was aware that the participants were all in their ‘marriageable’ age. By marriageable age, she meant that they were sexually active and that they were ready to start their own families. She said some of the parents were considering the prospect of getting their sons married. Manu’s mother, for example, was trying to find a girl for him. I noticed that only the parents of male participants were interested in getting their sons married. Parents of the female participants were uncertain about the marriage aspect and disapproved of their daughters getting married. Vulnerability and fear were the common factors in the discussions of the marriage of female participants.

Based on their ability to engage in income-earning activities, the conventional notions of masculinity were evaluated. The ability to engage in productive tasks and jobs also marks a person’s growth into the ‘adult world’.

> The demands of manhood put enormous pressures on young men in general to conform. The cultural construction of masculinity places a heavy premium on work (manual and white-collar) and marriage. Men who are poor, sick or disabled, find themselves at an enormous disadvantage. (Mehrotra & Vaidya, 2008, p. 326)

Mothers of male participants in the institution said that they expected the marriage to provide lifelong companionship to their sons. Parents also said that, since their sons could not generate the income for a family, the parents’ economic sources were their sons’ and that it could be utilised for their living even after getting married. Some of them even said that they would provide money to their sons and family, until their end of their lives. This response has shown the desire of the parents to form marital and family lives for their children. Family is the primary unit of care in contemporary

Kerala society. Most of the developing countries are employing this strategy for the community-based rehabilitation strategy. That is why marrying unemployed sons with intellectual disabilities had become crucial for their lives in the long-term in this context as well.

Unlike the male participants, the marriage of the female participants was not discussed at all. Like Gill says, the sexual lives of women with intellectual disabilities are always under the speculations of “assault and sexual abuse”. None of the parents were interested in discussing the marriage of their daughters. Even though the families are primary caregivers, and rehabilitation strategies and social lives of a person with intellectual disability were dependent on it, marriage never came into the discussion during my interactions with the parents of the female participants. Most parents also said they did not know who would support their daughters or what would happen to their daughters’ futures after the end of their lives! Some said that they were expecting the siblings of the participants to look after them in the future and were planning to prepare their final legal will accordingly. The discussion of reproduction has also come across in various conversations with the parents. Some of them said that their daughters were not ready to perform the ‘marital duties’; I assumed that they were pointing to their daughters' possible sexual, reproductive, and nurturing capabilities. Even though we had not discussed reproduction, pregnancy etc., explicitly, there is a cultural notion existing in Kerala that a person with disabilities may procreate disabled offsprings[53]. This notion has been discussed in many disability studies before (Carlson, 2010; Feely, 2016; Gill, 2015; Kempton & Kahn, 1991; May & Simpson, 2003; Mehrotra & Vaidya, 2008).

---

[53] From the conversations with my own family members and interaction with others regarding marriage and related topics, there were always cautionary tales about the chances of hereditary intellectual disability and some physical disabilities as well (blindness, hearing impairments, etc.).

The moral discourse of sexuality has made reproduction the significant characteristic of any sexual relationship; that makes discourse of pleasure immoral (Alexander & Taylor Gomez, 2017; Tepper, 2000).

> A biologically determinate viewpoint of sex as solely the province of reproduction, and reproduction solely the province of the fittest, usually those with access to the full enjoyment of citizenship, has largely served to exclude people with disabilities. In addition, a social cultural viewpoint of sex as a source of danger leads to the presumed need to protect us. Disabled populations are not viewed as acceptable candidates for reproduction or even capable of sex for pleasure. We are viewed as child-like and in need of protection. (Tepper, 2000, p. 285)

Tepper also argues that, pleasure can ‘heal emotional isolation’ even when people are ‘socially integrated’. Persons with intellectual disabilities are not used to talks and exposure regarding sexuality. In most cases, they are not introduced to sexuality-related matters by anyone. Their knowledge about sexuality could be distorted. There is a possibility that the partial knowledge they attained does more harm than any good in life. Chavan et al (2021) in their study on sexuality of adolescents with Intellectual Disabilities (ID), states that, adolescents with ID does not have proper scientific knowledge about sexual and reproductive health. Compared to male participants of Chavan’s study, the female participants were not aware of sexual acts, the process of reproduction or contraception. Although all of them wished to get married, male participants acknowledged the lack of proper income that might hinder their chances of getting married. Nevertheless, they were more knowledgeable and expressive about their sexuality and sexual knowledge than the women. In India, there is a dearth of studies regarding the sexual knowledge of persons with intellectual disabilities.

Therefore, it is important to understand in detail the status of sexuality of persons with intellectual disabilities.

Participants in the BRCs were not socialised as their peers. They were not welcomed by peer groups to initiate friendly, healthy discussions on sexuality-related matters. There were also possibilities for making 'fun' or feeding inappropriate knowledge to them as part of a 'joke'[54]. "Their relative lack of awareness about sexuality, in general, and their inappropriate sexual behaviour, in particular, may lead to teasing or other forms of abuse" (Vaidya, 2018, p. 334)." Without proper guidance and knowledge of sexuality, there are increased chances for internalising 'the shared knowledge' by persons with intellectual disabilities. "Whilst society tolerates the abuse of people with intellectual disability, abuse may arise from their lack of sexual skills and being able to communicate the correct information about their bodies (Taylor Gomez, 2012, p. 242)".

Mainstream movies and television shows also influence them in internalising 'knowledge' about sexuality. Mainstream media influence all sectors of people, but, the limited exposure of the public is the major hazard for the person with disabilities in internalising this knowledge. The positive thing in this regard is that the television helps them to learn things from the projected 'public'; this also helped them to be a part of the mainstream society passively. Swapna learned the roles of homemaker through the television serials she watched. Manu also learned the images of "good woman and bad woman" from these serials.

---

[54] I could not find relevant studies on peer interactions and attitude towards persons with intellectual disabilities in the Kerala context. However, from my interactions with the participants, persons in and around BRCs, and non-disabled adolescents I became aware that interaction between persons with intellectual disabilities and non-disabled peers did not happen at all. The non-disabled adolescents would not prefer to interact with persons with intellectual disabilities. On the other hand, persons with intellectual disabilities liked to hang out and converse with their non-disabled peers. "They would not talk to us" (avaronnum nammalodu mindoola.) – told Manu, a participant from Unnikulam BRC.

5.7 Sex education, pleasure and the knowledge about sexuality

Sex education is a comparatively new concept in Kerala. Only recently, the school system recognised this as a necessary area of discussion in the development of adolescents. Even so, its implementation is yet to happen. There is adolescent education in higher classes. Adolescent education primarily focused on the description of male and female reproductive organs and the biological functions of these organs only. Discussions about sex education have started in mainstream Kerala society very recently. Jose (2018) has discussed the background of sex education in Kerala and has mapped the history of sex education in the state. Her study report submitted to the state planning board recognised the discrimination and violence against women in the state. She recognised gender discrimination as a fundamental basis for violence against women in the state. As a result of the increased number of cases of discrimination and violence against women, the study recognised the necessity for sex education in the state. She explained the failure of initial sex education plans in the state. Her study had also focused on sexual health and the threat of STD. The report emphasised the lack of knowledge about safe sex and sexual relations by the youngsters. Hence, the study strongly recommended the need for sex education in schools and colleges in the state. The report also highlighted the prejudice of the parents, and that of the majority of the people in Kerala regarding the contents of the sex education course, and that this attitude was the reason behind the cancellation of the same earlier in Kerala. However, the study did not recognise the diversity of sexual relations.

Roach and Stair (2024), in their work on the sexuality education in the context of the United States of America, note that sexuality education for persons with intellectual disabilities was an important concern. They come up with a different model of sexuality education for persons with intellectual disabilities. They have observed that the prevailing sexuality education in the United States is the abstinence model, which reduced the discussion of sex education to just abstinence and precaution. They recommended for diverse aspects of sexuality education for persons with intellectual disabilities.

Tutar Güven and İşler, (2015) further point to the significance of sex education for children with intellectual disabilities. They observed that the parents showed anxiety and unwillingness to discuss sexuality related matter with adult children. Their study stated that the parents find it inappropriate to talk about sexuality related matter to their adult children with intellectual disabilities. Another observation made by the authors is that children with intellectual disabilities endure loneliness and exclusion in sexuality related knowledge. In instances when they are sexually aroused, it would, therefore, become confusing for them as they are unable to react in a socially approved manner. This leads to labelling of person with intellectual disabilities as violent and aggressive. The study acknowledged the significance of appropriate sex education for persons with intellectual disabilities to navigate their sexuality. They argued that children with intellectual disabilities are a heterogenous group; therefore sex education should accept the diverse spectrum of intellectual disability and their needs in the curriculum.

Gill (2015) pointed out that, the pleasure element and the spectrum of sexuality were not recognised in the sex education discourses. Sex education became a site of discussion of health and violence only, leaving out topics regarding the diverse sexual practices. Persons with disability are not at all recognised in the study or are part of the ongoing discussions regarding sex education in the state. The complexity and diversity of sexuality and the role of citizens in the realm of sexuality has to be discussed in any sex education material. Diversity, that is, the inclusion of LGBTQ as part of sex education is essential, in addition to the complexity that caste brings into picture. However, the focus always centred around heterosexuality and compulsory abled bodiedness (McRuer, 2006) .

> Sex education remains a location in which morality, religion, notions of normality and abnormality, and ableism work to endorse and reinforce nonreproductive heterosexual expressions while distancing discussions about sex away from various notions of pleasure and self-awareness. (Gill, 2015, p. 49)

The lack of diversity and inclusion of topics under sex education for the mainstream curriculum signifies the omission of persons with disabilities. Without addressing the sexual diversity, casteist-patriarchal-ableist notions of sexuality reiterate among the non-disabled adolescents. With the omission of the 'sexual cultures'[55] as a part of the sex education, the sexual rights of person with disabilities never occurred as a topic of discussion.

Earlier in this chapter, the limitations of a person with intellectual disabilities to engage in the socialisation process with a peer group have been mentioned. Partial knowledge or inappropriate knowledge on sexuality negatively influences the social relations of persons with intellectual disabilities. Their limitation to engage in social circles and understanding certain social codes also reiterate the stigma[56] associated with their 'deviant sexuality', and 'hyper sexuality'. The omission of persons with disabilities 'desexualizes' (Kim, 2011) them.

---

[55] Tobin seibers (2012) concept of sexual culture

[56] Irwin Goffemans's (1963) concept of stigma.

> Sexuality education helps people with intellectual disabilities to recognize inappropriate sexual advances and be able to report incidents of suspected sexual abuse, as well as teaching some of those essential skills in social etiquette and self-care. Whilst being educated around body and self contributes to the reduction in vulnerability, it also reduces inappropriate sexual expression. (Taylor Gomez, 2012, p. 242)

I argue that an inclusive framework in sex education is an initial step to identify persons with disabilities as sexual citizens. It is high time to introduce sex education for persons with intellectual disabilities in Kerala through the BRCs. The BRCs are present across the state, from the urban centres to rural settings. As these institutions are functioning under the local governance institutions, with the help of Kudumbashree mission and the social security mission in the state, it is a good platform to provide sex education collectively. Coordination and awareness-raising for both the participants and their parents are necessary to acknowledge the rights of persons with intellectual disabilities.

5.8 Sexual Citizenship and the Question of Sexual Rights of Persons with Intellectual Disabilities

Discussion of sexual rights eventually leads to the complicated status of sexual citizenship of persons with intellectual disabilities. Sexual citizenship, in a very simple sense, is used to refer to ‘sexual rights granted or denied to various social groups. Fundamentally, “the concept of sexual rights (is) understood as the right to participate in sexual acts”(Richardson, 2000, p. 108). The discourse around sexual citizenship is described as a counter-narrative against the homophobic, patriarchal and ableist notions of sexuality. According to Weeks (1998), sexual citizenship is a contradictory terminology as sexual is the "intimate personal life, an area of pleasure and pain, love and pain, power and resistance" whereas citizenship is about the involvement of the 'larger society' (Weeks, 1998, p. 36). He considered the concept of sexual citizenship as a peculiar point of public/private divide that exists in western society. He extended the implication of the term as "…it is about enfranchisement, about inclusion, about belonging, about equity and justice (Weeks, 1998, p. 36)".

Seibers (2012), argued that the sexuality of persons with disabilities should be considered as part of the discourse of sexual minorities. Their sexuality and ways of expression of sexuality and sexual acts are unique and pose a threat to the mainstream moralistic discourse of sexuality, which is phallocentric, patriarchal and ableist. He explained the importance of the assertion of the sexual culture of the person with disability in mainstream society. He argued that assertion of the sexuality of persons with disabilities as "complex embodiment that enhances sexual activities and pleasure" (p. 47) will "give to sexuality a political dimension that redefines people with disabilities as sexual citizens" (p. 47). He extends the argument by explaining sexual citizenship of persons with intellectual disabilities as:

> Some specific agenda items include access to information about sexuality; freedom of association in institutions and care facilities; demedicalization of disabled sexuality; addressing sexual needs and desires as part of health care; reprofessionalization of caregivers to recognize, not deny, sexuality; and privacy on demand. (Siebers, 2012, p. 47)

I think Seibers' (2012) argument of the assertion of the sexual identity of persons with intellectual disability is crucial to understand a person with disabilities as sexual citizen. Seibers points out that the sexuality of persons with disabilities should be politicised as a sexual minority in order to assert their identity as a sexual citizen in mainstream society. But, even in his account, he did not address persons with intellectual disabilities and their sexualities. His arguments regarding sexual culture are primarily focused on the expression and assertion of persons with physical disabilities only. The sexuality of persons with intellectual disabilities is more complex as they are discriminated against on the basis of their ‘intellect’. With the unique condition of each disability and the subjective experience they face in the realm of ‘disability’, their sexual identities have been formed and experienced on the basis of their ‘disability’. Hence, as Richardson (2000) mentioned in their study, expression of identity also becomes important for the basis of sexual citizenship. Rather than asserting as a sexual minority, persons with disabilities have to be acknowledged, and they should assert their sexuality fundamentally on the basis of their unique status as persons with disabilities.

McRuer’s (2006) crip theory is significant here. He illustrates how the same system which produces compulsory heterosexuality and queerness, also propagates compulsory able-bodiedness. Though Macruer (2006) discusses crip theory almost entirely based on physical disability, when we discuss the sexuality of persons with intellectual disabilities, crip theory can be extended to include intellectual disability as part of crip sexual identity.

> Cripping spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects. Both queering and cripping expose the arbitrary delineation between normal and defective and the negative ramifications of attempts to homogenize humanity, and both disarm what is painful with wicked humour. (Sandahl, 2003)

I would like to bring back Swapna’s case here. As I mentioned before, Swapna liked a fellow participant. All others around her knew about this situation. However, both the sets of parents meaningfully avoided giving the matter a severe tone. His mother said, “Yes, Swapna was saying that. But we don’t think it's something serious. She says that he is also her cousin brother. Actually, we are not related all. I don’t care about all these things *(njan ithonnum shradhikkalilla)*. Since she is like this, we don’t give much attention to it” (Pers. Comm., Swapna’s Cousin’s Mother from Unnikulam BRC, 2018). On the other hand, from Swapna’s perspective, this could also be considered as a negotiation strategy regarding her sexuality. Partial expression of emotions is also a way of asserting the sexual identity of a woman with intellectual disability in front of a restrictive social structure that is purely based on ableism.

5.9 Conclusion

This chapter discusses the sexuality and sexual subjectivities of persons with intellectual disabilities in the BRCs of Kerala. The chapter narrates how persons with intellectual disabilities are perceived as either desexual or hyper sexual. The chapter also examines the relation between gender and sexual morality of persons with intellectual disabilities. It is noted that there was a notion of constructed sexual morality that mirrored mainstream the view that existed in every BRC. The field experiences suggest that the participants, especially the male participants, internalised the mainstream notion of what is appropriate and what is not appropriate in public, an extension of heterosexual and patriarchal notions of sexual morality.

The constructed sexual morality in the BRCs perceived persons with intellectual disabilities as either desexual or childlike. While those who were more expressive about their sexuality were labelled as hypersexual. Hypersexuality allegation also marked women with intellectual disabilities as sexually immoral.

However, the male participants were not ridiculed by their acts/instincts of sexuality in the BRCs. This difference of attitude by the workers and other stakeholders were also shaped by patriarchy. Those who operated or expressed beyond the borders of the constructed normalcy of the BRC, were considered as the misfits of that space.

Most of the participants were interested to get married. However, male participants shared their concern of a lack of income that prevented them from marriage. Female participants, on the other hand, were valued on the basis of their ability to perform household chores after marriage. Concerns about sexual and domestic violence were major reasons deterring the marriage of the female participants' marriage. Most parents did not approve the idea of getting their daughters married due to safety concerns.

These experiences highlight that the persons with intellectual disabilities were not considered as 'sexual citizens' (Weeks, 1998). The 'sexual culture' (Siebers, 2012) of persons with intellectual disabilities are yet to be explored in Kerala's context. Even though the sexuality of persons with intellectual disabilities are not acknowledged by the mainstream society, they still asserted their sexuality through various means in the institution. These acts, even being minor ones, still challenged the mainstream notions. McRuer's (2006) concepts of 'crip theory' and 'crip culture' do not include the persons with intellectual disabilities. Even though this lack of inclusion could be considered as a shortcoming, the daily lives of persons with intellectual disabilities challenge the mainstream ableist heterosexual patriarchal idea of sexuality. In that sense, their resistance is also an act of cripping. Sexuality of persons with intellectual disabilities is not considered as one of the primary concerns in Kerala's discourse on intellectual disabilities. Sex education for persons with intellectual disabilities should be effectively implemented throughout the state.

Chapter 6

Conclusion

This chapter summarises the findings and arguments of the previous chapters and compiles the discussions to conclude the study. The research questions posed by the study, how the study structured its methodology to achieve this, and the findings and analysis of the study are outlined in this chapter. By discussing the research questions, the methodology and the theoretical frameworks employed alongside the field experiences, this chapter tries to examine the place carved out by this study within the Indian feminist disability discourse. I looked at intellectual disability and care from the analytical category of gender in this study. In order to understand the dynamics of disability and care, I chose BUDS rehabilitation centres (BRCs). BRCs are rehabilitation/day-care centres for adults with intellectual disabilities. These centres follow the Community-Based Participatory Rehabilitation (CBPR) strategy as their guiding principles. They are established under the local self-governments, with the assistance from the State Kudumbashree mission.

The first chapter is an introduction to the study – it narrated the progress and evolution of the methodological framework employed in this thesis from a first-person experience. The research questions of the thesis addressed are:

1. How is intellectual disability being understood and addressed in the BRCs?
2. How is gender related to the practice of care in the BRCs?
3. What larger ideas constructed the notion of care in the BUDS-BRC model?
4. What role does gender play in the relationship between care and sexuality of persons with intellectual disabilities?

Being a non-disabled woman, the complexity of the insider/outsider binary was always challenging. However, being fluent in the Kozhikode Malayalam and being a woman helped in building a trustworthy, mutual relationship with the participants. Because of this, I received a partial insider status in the centres overtime. Achievement of this status could be considered as a methodological turning point in my research. I adopted a feminist disability framework for the study. The integration of feminist research methodology and disability framework provided a micro-level understanding of the field and helped me move towards a certain subjective positioning in the field. This framework helped me understand the complexities of the everyday lives and interpret the shared experience with a conscious positioning. I adopted feminist ethnographic methods (Skeggs, 2014) for data collection. Unlike regular ethnography methods, my primary method of data collection was ‘participant listening’ (Forsey, 2010). This method was specifically a helpful tool in the feminist research methodology I employed, as listening is always considered political in feminist studies. Participant observation, conversation analysis, and informal interviews were the other methods I used in the data collection. The first chapter also briefly touches upon the impact of unpredicted hindrances like natural disasters and outbreaks of diseases in carrying out a social science research.

The chapter mainly highlights the distinct methodological strategies developed for the study, which were modified overtime to suit the requirements of the field. The evolution of this methodological framework is significant in the discourse of feminist ethnography and disability research. Integrations of unique research methods and development of a distinctive standpoint for the study could be considered as interventions of this study within the larger discourse of feminist research methodology in Indian context.

The second chapter is an overview of disability-related studies. This chapter details the developments of various models of disabilities and feminist disability studies. While the Medical Model of Disability was dominant in the early days, this model possessed a reductionist view, as it defined disability as the 'inability' of a person which required treatments or correction to achieve a 'normal life' for the person (Haegele & Hodge, 2016; Zaks, 2024). With the advancements of medical field, this emerged as the most dominant and influential model, globally. The social Model of Disability was developed as a response to the narrow scope of the Medical model of disability. The British Social Model of Disability emerged in the 1970s and revolutionised our understanding of the term disability itself. It argued that the restrictive barriers of the society was responsible for the disability not the impairment (Oliver, 2013; Shakespeare, 2004; Watson, 2012). Although this concept later replaced the Medical Model, it was critiqued for not acknowledging the impact of impairment and bodily experiences in the discourse of disability. It was also criticised for not accounting for the lived realities of non-western societies in the discourse of disability. The Cultural Model of Disability (P. J. Devlieger, 2005; Ingstad & Whyte, 1995) emerged as a response to the limitations of both the Medical and Social Models. This model argued that disability should be understood in the specific cultural context. It accepted the impact of barriers in the construction of disability as well as the reality of physical discomfort and impairments. The chapter also explain intellectual disability and its construction globally. Works of various authors were used to examine the cultural understanding of intellectual disability (Atkinson & Walmsley, 2010; Capri, 2019).

The chapter then throws light on the details regarding the development of Feminist Disability Studies. The integration of feminism and disability studies pointed out the various degrees of discrimination faced by women with disabilities. The approach showed the entanglement of the complex oppressive regimes of patriarchy and ableism in the lives of disabled women. The chapter also mentions the several studies with this approach that were carried out in the Indian context (Addlakha et al., 2013; Chakravarti, 2018; Ghai, 2002; Ghosh, 2010; Mehrota, 2013). However, the chapter also highlights the dearth of such studies set in Kerala. The chapter exposes the research gap that exists in disability studies and feminism in the context of Kerala, underlining the importance of this research work in the discourse of feminist disability studies.

Third chapter deals with the construction of normalcy in the BRCs, by first discussing the concept of ableism (Wolbring, 2008). The chapter then moves on to complicate the definition of intellectual disabilities in the context of the chosen BRCs. Intellectual disability is not merely a medical condition, it is the sum total of cultural values, ideals, and expectations along with some medical conditions. The construction of intellectual disability in the BRCs interrogates the discourse of the ability/ disability binary perpetuated by the mainstream ableist narratives. The chapter takes a deeper look into what is considered ‘normal’ in the BRCs and how it challenges the sickness/illness image associated with intellectual disability. It also explains that intellectual disability is the state of what is being ‘normal’ within the BRCs. The dominant narratives are, however, rooted in the biomedical discourses forged in the ableist imagination. It is argued in the chapter that, each BRC has its own definition of normal/abnormal. Normality in one BRC may not be the normality of another BRC. Nevertheless, BRCs in its idea and manifestation challenges the ableist notion of ‘normalcy’. On the other side, the chapter also discusses how certain persons are considered “misfits” (Garland-Thomson, 2011) within the BRCs, which are constructed using the ableist notions.

This chapter critically engaged with the concepts of work, workability, competence/incompetence in the backdrop of neoliberal concepts of labour and production. The chapter observed that outside the BRC the participants are not able to secure jobs. However, they are productive and hardworking in the respective BRCs. Here, work varies in accordance with regional differences, seasons, and, the constructed normality of that particular BRC. Therefore, identifying work beyond the category of economic productivity is important in recognising the rehabilitation and vocational trainings offered by the BRCs.

Apart from these, the chapter narrates the cons of the rehabilitation process employed by the BRCs and the limitations of it. The vocational training courses within the BRC is not efficient and does not address the actual needs of the participants. A more efficient vocational training course integrated into the BRCs would have helped the participants achieve their goals of self-sufficiency and employability. The chapter also notes the limitations of the BRCs as they remain severely resource-constrained to introduce such changes to its structure.

Fourth chapter is about the nature of care provision within the BRCs. The rehabilitation discourse of the BRCs is structured on the feminisation of care. This discourse is gender-biased as it sees nurturing as primarily a ‘feminine’ duty. BRCs bring forward this notion in various aspects of their everyday functioning – by employing an all-female staff and mostly involving the participation of the mothers of persons with intellectual disabilities in the provision of various activities within these institutions. The chapter also discusses the role of the local government as the crucial factor in ensuring the community-based participatory rehabilitation process. However, at all levels and activities where community participation is expected, it was observed to be structured around female participation only. The feminisation of responsibility and care (Chant, 2008) leads to such strategies. It is very striking to observe that not only was the whole official structure of the BRC filled with an all-female staff, but also the ICDS Supervisor, who oversees the functioning of the institution, was a woman. This is a clear example of how the state perpetuates the ideology of feminisation of care (Folbre, 2014).

The all-women staff of the BRCs also create a comfortable space to the mothers of persons with intellectual disabilities. The structure itself is very open, and creates a secure female space welcoming the mothers and other relatives. The space is very crucial for the mothers of persons with intellectual disabilities as they are often unable to access public spaces. Charity/religion-based rehabilitation institutions often lack this transparency and accessibility. In this regard, the BRCs are one of the best models to accommodate the mothers of persons with intellectual disability. It provides a space to share their personal hardships and emotional breakdowns. The security of the space create ‘care-webs’ (Piepzna-Samarasinha, 2018) throughout the BRCs. The feeling of being part of a ‘community’ is woven through these spaces in the BRCs.

Last chapter analyses how the discourse of sexuality operates within the premises of the BRCs. The study does not approach care and sexuality as separate entities. Instead, it holds the view that ‘care’ is a multi-faceted spectrum that encompasses the discourse of sexuality of persons with intellectual disabilities in BRCs in Kerala. This chapter identifies adults with intellectual disability as sexual beings and sexual citizens. I conclude by reflecting on the possibilities of their inclusion within Indian feminist thought.

Discussions in this chapter portray the discourse on sexuality in the BRCs as heterosexual, ableist and patriarchal. Participants in the institutions are judged and labelled on the basis of the dominant discourse, and as a result, a morality/immorality binary is constructed in the BRCs. Women participants are largely labelled as immoral when expressing their sexuality. Male participants on rare occasion are blamed for their display of sexuality as violent/hypersexual. Being desexual or infantile was considered the 'desired' way to treat sexuality in the BRCs. The others who did not fall into this category, were treated as overly sexual/hyper-sexual and were considered immoral and 'undesirable'. This discourse mirrors the dominant discourse of sexuality in Kerala.

Male participants are judged by their ability to go out/public and engage in income earning activities and in establishing peer relationships while women are judged on the basis of their ability to perform house hold works. These judgements acted as a scale for their marriageability and social citizenship.

The chapter also discusses concepts of sexual culture, sexual identity (Seibers, 2012and sexual citizenship (Richardson, 2000; Weeks, 1998). The chapter emphasizes the importance of inclusive sex education (Ghill, 2015) in the state. The need to introduce sex education designed for persons with intellectual disabilities in the BUDS institutions, the need to tackle the sexual exploitation of persons with intellectual disabilities as well as for recognising the participants as sexual citizens was observed as a must.

6.1 The concept of fluidity in the Study

Fluidity is a recurring concept in this study. While discussing the various contexts and different analytical categories, fluidity as a concept emerged throughout the study. Therefore, it is important to analyse the concept of fluidity in relation to different analytical categories.

6.1.1 Insider/Outsider and Fluidity

In the methodological chapter (chapter 1) insider/outsider binary has been discussed in detail. The discussions in the chapter complicated the researchers position as an outsider and the fixed category of insider by the participants and their support system. Rather than a fixed category, this study marked insider/outsider binary as a fluid category that changes in accordance with the people interacted with, the locality, age, gender, religion, caste, social class, disability, work, sexuality and so on. In the methodology part, I argued that the initial outsider status I was associated with changed over time to some extent. Factors like language, gender, age, locality fluctuated my identity from an outsider to partial-insider. This was again relative, as situations I engaged in and persons I interacted with played a crucial role in determining my insider/outsider category.

Insider status of the participants, their family, and the staff also fluctuated as normality itself is a construction that is relative to each of the specific institutions. Although in a larger framework, BRCs as a chain of institutions challenges the ableist construction, each BRC hold their distinctive definition of normalcy. In that respect, the insider in one BRC may not be the insider of another BRC. Intellectual disability is a heterogeneous group therefore the fixed notion of an insider or outsider cannot exist.

6.1.2 Adulthood and Fluidity

The study is predominantly based on the concept of adulthood of persons with intellectual disabilities. Fundamentally, the enrolment age of participants is 18 years in the BRC. Therefore, the concept of care in relation to adulthood is complex. Adults are regarded as independent and self-reliant. However, persons with intellectual disabilities are outside of this category as they are systematically infantalised. The participants are not regarded as incompetent by the dominant discourse. However, within the BRC, they are hardworking and very competitive. Workability and competency are associated with the adulthood. Though some participants are hardworking outside the BRC, they are exploited by their employers. The participants are regarded as innocent and that directly linked to the concept of naivety. Therefore, the concept of adulthood is observed to be fluid and fluctuating.

6.1.3 Collectivity and fluidity

Women’s collectivity, at times, reinforces women’s connection with care. In other times, it also serves as a support group against patriarchy. The core structure of BRCs is entirely dependent on women and the participatory rehabilitation strategy largely depended on the collective care provided through the communities. Though it promotes togetherness and an informal support system, women’s collectivity reinforces the concept of women as a natural carer. The same women’s collective which helps them to navigate difficult life situations, is used by the State to reinforce the feminisation of care. The women’s collective is therefore, promoted by the State as it works in a way that does not overpower the larger patriarchal structures. Therefore, collectivism can also be considered as a complex and fluid category.

6.1.4 Sexuality and fluidity

Sexuality is regarded as a spectrum of fluid categories. Within the participants of the BRCs, sexuality is treated differently in different circumstances. Women participants are treated as immoral upon their assertion as sexual beings, yet they are not considered as marriageable or able to maintain a study relationship. At the same time, they were recognised as sexual beings. Male participants, on the other hand, were sometimes considered as being eligible to marry, yet they are regarded as immature or hypersexual. Desexualisation and hypersexualisation of the sexuality of person with intellectual disabilities happens in the same BRC premises. Therefore, sexuality as a category acted as fluid and fluctuating.

Another aspect of fluid identity of sexuality is the treatment of masculinity in the BRCs. The male participants are desexualised in relation to establish a relationship or in relation to marriage. At the same time, their body and adult status (in relation to sexuality), were treated as male, masculine. As a result, intimate/close engagement with male participants made the staff and female participants uncomfortable. Therefore, the category of masculinity or masculine identity of the participants are not a fixed category, rather it is fluctuating identity in the premises of the BRC.

The summary of the chapters show the significance of the study in the Kerala’s disability discourse. As I mentioned earlier, there is a dearth of qualitative studies on disability in the state. Feminist research also shows the gap in disability-related researches in the state. The few studies that exist on the BUDS institutions do not focus on micro-level analysis and they do not provide any details on the structure of care. The discourse on sexuality is also yet to unwrap the layered complexities of sexuality of persons with disabilities, and especially, intellectual disabilities. Therefore this study, hopes to make some contributions to different discourses in Kerala.

The study also has limitations. First of all, even though this study addressed the lived realities of the BRCs, due to its limited sample size, the study is insufficient to draw generalisations. The study holds on to cultural understanding of intellectual disability, and therefore, the findings and analysis of the study are primarily related to particular BRCs only. Though this approach seems restrictive in its scope to make generalisations, the in-depth analysis helps us understand the subtle power structures and the exercise of authority in a small space. The study was also affected by the various natural calamities and disease outbreaks that occurred during the time of the field work.

The thesis provides a starting point for research in this area in Kerala. However, it opens up a lot of possibilities to further explorations in this field. A large-scale survey could be carried out to understand the actual situations of BRCs at the state-level. Further studies could be conducted to specifically evaluate the effectiveness of community based participatory rehabilitation strategies. It is important to adopt strategies to formulate policies which require the participation of men to be included in the category of primary care-givers of persons with intellectual disabilities. The study also recommends comprehensive sex education for persons with intellectual disabilities throughout the state

Bibliography

Abraham, J., & Odoom, A. J. (2019). Intellectual disability in twentieth-century Ghana. In J. Walmsley & S. Jarrett (Eds.), *Intellectual disability in the twentieth century: Transnational perspectives on people, policy, and practice* (pp. 67–78). Policy Press.

Addlakha, R. (2007). *Gender, Subjectivity and Sexual identity: How young people with Disabilities Conceptualise the Body, Sex and Marriage in Urban India* (Centre for Women's Development Studies; 2007, Occasional Paper No. 46; p.31). New Delhi, India. https://dataspace.princeton.edu/handle/88435/dsp01tx31qm043

Addlakha, R., Centre for Women's Development Studies (New Delhi, India), & University of Delhi (Eds.). (2013). *Disability studies in India: Global discourses, local realities*. Gender, Disability, and Society (Conference), New Delhi : Abingdon. Routledge.

Alcoff, L. Martín. (2006). *Visible identities: Race, gender, and the self*. Oxford University Press.

Alexander, N., & Taylor Gomez, M. (2017). Pleasure, sex, prohibition, intellectual disability, and dangerous ideas. *Reproductive Health Matters*, *25*(50), 114–120. https://doi.org/10.1080/09688080.2017.1331690

Anand, S. (2013). Historicising Disability in India: Questions of Subject and Method. In R. Addlakha, Centre for Women's Development Studies (New Delhi, India), & University of Delhi (Eds.), *Disability studies in India: Global discourses, local realities* (pp. 35–60). Gender, Disability, and Society (Conference), New Delhi : Abingdon. Routledge.

Aneja, A., & Vaidya, S. (2016). *Embodying motherhood: Perspectives from contemporary India*. SAGE Publications India Pvt Ltd.

Aswathy, P., & Kalpana, K. (2019). Good woman, bad woman: Social control and self-regulation in Kerala's artisanal fisheries. *Women's Studies International Forum*, *74*, 196–203. https://doi.org/10.1016/j.wsif.2019.04.006

Atkinson, D., & Walmsley, J. (2010). History from the inside: Towards an inclusive history of intellectual disability. *Scandinavian Journal of Disability Research*, *12*(4), 273–286. https://doi.org/10.1080/15017410903581205

Bailey, M., & Mobley, I. A. (2019). Work in the Intersections: A Black Feminist Disability Framework. *Gender & Society*, *33*(1), 19–40. https://doi.org/10.1177/0891243218801523

Barnes, C., Oliver, M., & Barton, L. (Eds.). (2002). *Disability studies today*. Polity Press in association with Blackwell Publishers.

Begum, N. (1992). Disabled Women and the Feminist Agenda. *Feminist Review*, *40*, 70. https://doi.org/10.2307/1395278

Berghs, M., Atkin, K., Hatton, C., & Thomas, C. (2019). Do disabled people need a stronger social model: A social model of human rights? *Disability & Society*, *34*(7–8), 1034–1039. https://doi.org/10.1080/09687599.2019.1619239

BRC Handbook. (2013). *Prāyapūrttiyāya mānasika velluvīḷikaḷ nērēṭunnavarkkāyuḷḷa svāśrita jīvita naipuṇi vidyābhyasavum pariśīlanavum – pāṭhyapaddhati samīpana rēkha* (*A curriculum-based approach document for self-reliant life skill education and training for adults with mental challenges*). Kudumbashreemission.

Bridges, D. (2001). The Ethics of Outsider Research. *Journal of the Philosophy of Education*, *35*(3), 371–386. https://doi.org/10.1111/1467-9752.00233

Bridges, D. (2017). ‘Nothing About Us Without Us’: The Ethics of Outsider Research. In *Philosophy in Educational Research: Epistemology, Ethics,Politics and Quality: Vol. Politics and Quality* (pp. 341–361).

Bruskin, S. (2019). Insider or outsider? Exploring the fluidity of the roles through social identity theory. *Journal of Organizational Ethnography*, *8*(2), 159–170. https://doi.org/10.1108/JOE-09-2017-0039

Budschool.(nd). *Budschool*. Kudumbashreestory.info. Retrieved on February 20, 2020, from https://thekudumbashreestory.info/index.php/programmes/social-empowerment/buds-school

Campbell, F. K. (2008). Refusing Able(ness): A Preliminary Conversation about Ableism. *M/C Journal*, *11*(3). https://doi.org/10.5204/mcj.46

Campbell, F. K. (2018a). Refocusing and the Paradigm Shift: From Disability to Studies in Ableism. In A. Ghai (Ed.), *Disability in South Asia: Knowledge & Experience* (pp. 38–57). SAGE Publications, Inc. https://doi.org/10.4135/9789353280321.n3

Campbell, F. K. (2018b). In A. Ghai (Ed.), *Disability in South Asia: Knowledge & Experience* (pp. 38–57). SAGE Publications, Inc. https://doi.org/10.4135/9789353280321

Capri, C. (2019). The Politics of Person-Making: Ethics of Care, Intellectual Impairment Citizenship, and a Reclaiming of Knowledge. In J. McKenzie, L. Swartz, & B. Watermeyer (Eds.), *The Palgrave Handbook of Disability and Citizenship in the Global South* (1st ed. 2019, pp. 269–292). Springer International Publishing : Imprint: Palgrave Macmillan. https://doi.org/10.1007/978-3-319-74675-3

Carlson, L. (2010). *The Faces of Intellectual Disability: Philosophical Reflections*. Indiana University Press.

Chakravarti, U. (2008). Burden of Caring: Families of the Disabled in Urban India. *Indian Journal of Gender Studies*, *15*(2), 341–363. https://doi.org/10.1177/097152150801500207

Chakravarti, U. (2018). *Disability and care work: State, society and invisible lives*. SAGE Publications India.

Chander, J. (2013). Disability Rights and the Emergence of Disability Studies. In *Disability studies in India: Global discourses, local realities* (pp. 61–77). Gender, Disability, and Society (Conference), New Delhi. Routledge.

Chant, S. (2008). The ‘Feminisation of Poverty’ and the ‘Feminisation’ of Anti-Poverty Programmes: Room for Revision? *The Journal of Development Studies*, *44*(2), 165–197. https://doi.org/10.1080/00220380701789810

Charlton, J. I. (2004). *Nothing about us without us: Disability oppression and empowerment* (3. Dr.). Univ. of California Press.

Chase, S. E. (2003). Taking Narrative Seriously: Consequences for Method and Theory in Interview Studies. In Y. S. Lincoln & N. K. Denzin (Eds.), *Turning points in qualitative research: Tying knots in a handkerchief* (pp. 273–296). AltaMira Press.

Chavan, B. S., Ahmad, W., Arun, P., Mehta, S., Nazli, Ratnam, V., & Raina, D. (2021). Sexuality Among Adolescents and Young Adults With Intellectual Disability: Knowledge, Attitude, and Practices. *Journal of Psychosexual Health*, *3*(2), 140–145. https://doi.org/10.1177/26318318211021544

Chhabra, G. (2020). Insider, Outsider or an In-Betweener? Epistemological Reflections of a Legally Blind Researcher on Conducting Cross-National

Disability Research. *Scandinavian Journal of Disability Research*, *22*(1), 307–317. https://doi.org/10.16993/sjdr.696

Coleman, L. M. (2017). Stigma An Enigma Demystified. In L. J. Davis (Ed.), *The disability studies reader* (5th ed, pp. 141–152). Routledge.

Cortazzy, M. (2014). Narrative Analysis in Ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (Reprinted, pp. 384–394). SAGE.

Dalley, G. (1996). *Ideologies of Caring*. Macmillan Education UK. https://doi.org/10.1007/978-1-349-24733-2

Davies, C. A. (1998). Constructing other selves: (In)competence and the category of learning difficulties. In R. Jenkins (Ed.), *Questions of competence: Culture, classification and intellectual disability* (pp. 102–124). Cambridge University Press.

Degener, T. (2017). A New Human Rights Model of Disability. In V. Della Fina, R. Cera, & G. Palmisano (Eds.), *The United Nations Convention on the Rights of Persons with Disabilities* (pp. 41–59). Springer International Publishing. https://doi.org/10.1007/978-3-319-43790-3_2

Devika, J. (2011, June 27). Seeking The Apadhasanchaarini/ The Malayalee FLÂNEUSE. *Kafila*. https://kafila.online/2011/06/27/seeking-the-apadhasanchaarini-the-malayalee-flaneus

Devlieger, P. (1995). Why Disabled? The Cultural Understanding of Physical Disability in an African Society. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture* (pp. 94–106). University of California Press.

Devlieger, P. J. (2005). *Generating a Cultural Model of Disability*. 1–15. https://is.muni.cz/el/1441/jaro2015/SP_0002/um/50945627/51056873/culturalmodelofdisability.pdf

Devlieger, P., Rusch, F. R., & Pfeiffer, D. (Eds.). (2003). *Rethinking disability: The emergence of new definitions, concepts and communities*. Garant.

Douglas, P., Rice, C., & Kelly, C. (2017). Cripping Care: Care Pedagogies and Practices. *Review of Disability Studies: An International Journal*, *13*(4). https://rdsjournal.org

Feely, M. (2016). Sexual surveillance and control in a community-based intellectual disability service. *Sexualities*, *19*(5–6), 725–750. https://doi.org/10.1177/1363460715620575

Ferguson, P. M. (2019). From social menace to unfulfilled promise: The evolution of policy and practice towards people with intellectual disabilities in the United States. In J. Walmsley & S. Jarrett (Eds.), *Intellectual disability in the twentieth century: Transnational perspectives on people, policy, and practice* (pp. 195–206). Policy Press.

Fineman, M. A. (2000). *Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency* (SSRN Scholarly Paper 2132294). Social Science Research Network. https://papers.ssrn.com/abstract=2132294

Folbre, N. (2006). Measuring Care: Gender, Empowerment, and the Care Economy. *Journal of Human Development*, *7*(2), 183–199. https://doi.org/10.1080/14649880600768512

Folbre, N. (2014, August). *Who cares? Feminist Critique of Care Economy.* Rosa Luxemburg Stiftung. https://hessen.rosalux.de/fileadmin/rls_uploads/pdfs/sonst_publikationen/folbre_whocares.pdf

Forsey, M. G. (2010). Ethnography as participant listening. *Ethnography*, *11*(4), 558–572. JSTOR.

Foucault, M. (1995). *Discipline and punish: The birth of the prison* (2nd Vintage Books ed). Vintage Books.

Friedner, M. (2017). How the disabled body unites the national body: Disability as ‘feel good’ diversity in urban India. *Contemporary South Asia*, *25*(4), 347–363. https://doi.org/10.1080/09584935.2017.1374925

Garland-Thomson, R. (2002). Integrating Disability, Transforming Feminist Theory. *NWSA Journal*, *14*(3), 1–31.

Garland-Thomson, R. (2011). Misfits: A Feminist Materialist Disability Concept. *Hypatia*, *26*(3), 591–609. https://doi.org/10.1111/j.1527-2001.2011.01206.x

Ghai, A. (2001). Marginalisation and disability: Experiences from the Thrid Worlds. In M. Priestley (Ed.), *Disability and the life course: Global perspectives* (pp. 26–37). Cambridge University Press.

Ghai, A. (2002). Disabled Women: An Excluded Agenda of Indian Feminism. *Hypatia*, *17*(3), 49–66. https://doi.org/10.1111/j.1527-2001.2002.tb00941.x

Ghai, A. (2003). *(Dis)embodied form: Issues of disabled women*. Shakti Books.

Ghosh, N. (2010). Embodied Experiences: Being Female and Disabled. *Economic and Political Weekly*, *45*(17), 58–63.

Ghosh, N. (2012). Doing Feminist Ethnography: Exploring the Lives of Disabled Women. *Indian Anthropologist*, *42*(1), 11–26. JSTOR.

Ghosh, N. (2013). Bhalo Meye: Cultural Construction of Gender and Disability in Bengal. In R. Addlakha. In R. Addlakha (Ed.), *Disability Studies in India: Global Discourses, Local Realities* (pp. 201–219). Routledge.

Ghosh, N. (2016). *Interrogating disability in India*. Springer Berlin Heidelberg.

Ghosh, N., & Banerjee, S. (2017). Too Much or Too Little? Paradoxes of Disability and Care Work in India. *Review of Disability Studies: An International Journal*, *13*(4). https://rdsjournal.org

Gill, M. C. (2015). *Already doing it: Intellectual disability and sexual agency*. University of Minnesota Press.

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. SAGE.

Goodley, D. (2014). *Dis/ability studies: Theorising disablism and ableism* (1. ed). Routledge.

Goodley, D., Runswick-Cole, K., & Liddiard, K. (2016). The DisHuman child. *Discourse: Studies in the Cultural Politics of Education*, *37*(5), 770–784. https://doi.org/10.1080/01596306.2015.1075731

Goyal, N. (2017). Denial of sexual rights: Insights from lives of women with visual impairment in India. *Reproductive Health Matters*, *25*(50), 138–146. https://doi.org/10.1080/09688080.2017.1338492

Grech, S. (2016). Disability and Poverty: Complex Interactions and Critical Reframings. In S. Grech & K. Soldatic (Eds.), *Disability in the Global South: The Critical Handbook* (pp. 217–236). Springer. https://doi.org/10.1007/978-3-319-42488-0

Grech, S. (2019). Disabled Families: The Impacts of Disability and Care on Family Labour and Poverty in Rural Guatemala. *Societies*, *9*(4), 76. https://doi.org/10.3390/soc9040076

Haegele, J. A., & Hodge, S. (2016). Disability Discourse: Overview and Critiques of the Medical and Social Models. *Quest*, *68*(2), 193–206. https://doi.org/10.1080/00336297.2016.1143849

Hall, K. Q. (Ed.). (2011). *Feminist disability studies*. Indiana University Press.

Hughes, B., McKie, L., Hopkins, D., & Watson, N. (2005). Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care. *Sociology, 39*(2), 259–275. https://doi.org/10.1177/0038038505050538

Hughes, B., & Paterson, K. (1997). The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment. *Disability & Society, 12*(3), 325–340. https://doi.org/10.1080/09687599727209

Ingstad, B., & Whyte, S. R. (Eds.). (1995). *Disability and culture*. University of California Press.

Jarrett, S., & Walmsley, J. (2019). Intellectual disability policy and practice in twentiethcentury United Kingdom. In J. Walmsley & S. Jarrett (Eds.), *Intellectual disability in the twentieth century: Transnational perspectives on people, policy, and practice* (pp. 177–194). Policy Press.

Jenkins, R. (Ed.). (1998a). *Questions of competence: Culture, classification and intellectual disability*. Cambridge Univ. Press.

Jenkins, R. (1998b). Towards a Social model of (in)competence. In R. Jenkins (Ed.), *Questions of competence: Culture, classification and intellectual disability* (pp. 222–228). Cambridge University Press.

Jose, J. (2018). *THE NEED OF SEX EDUCATION IN SCHOOL CURRICULUM- A CASE STUDY* (Research Report Research report submitted to the Kerala State Planning Board Internship Programme 2018-2019; p. 15). Kerala State Planning Board. https://spb.kerala.gov.in/sites/default/files/inline-files/17.SEXEDU.pdf

Jose, P., Kumar, S. S., Chandru, B. A., Sundaram, S., Vijayanand, S. M., Kutty, V. R., & Varma, R. P. (2023). Local governments and community-based rehabilitation for developmental disabilities: Leaving no one behind. *Public Health Action*, *13*(1), 37–43. https://doi.org/10.5588/pha.22.0027

Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.

Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability*, *9*(2), 93–111. https://doi.org/10.1007/BF01101735

Kim, E. (2011). Asexuality in disability narratives. *Sexualities*, *14*(4), 479–493. https://doi.org/10.1177/1363460711406463

King, J. A., Brough, M., & Knox, M. (2014). Negotiating disability and colonisation: The lived experience of Indigenous Australians with a disability. *Disability & Society*, *29*(5), 738–750. https://doi.org/10.1080/09687599.2013.864257

Kittay, E. F. (1999). *Love's labor: Essays on women, equality, and dependency*. Routledge.

Kohrman, M. (2005). *Bodies of difference: Experiences of disability and institutional advocacy in the making of modern China*. University of California Press.

Kröger, T. (2009). Care research and disability studies: Nothing in common? *Critical Social Policy*, *29*(3), 398–420. https://doi.org/10.1177/0261018309105177

Kudumbashree Mission. (2019). Enrolment statistics in new BUDS schools and BRCs – 2019-2020. Government of Kerala. Retrieved April 25, 2025 from https://www.kudumbashree.org/monitor-progress/287/1068

Kuipers, P., & Sabuni, L. P. (2016). Community-Based Rehabilitation and Disability-Inclusive Development: On a Winding Path to an Uncertain Destination. In S. Grech & K. Soldatic (Eds.), *Disability in the Global South: The Critical Handbook* (pp. 453–468). Springer. https://doi.org/10.1007/978-3-319-42488-0

Local Self Government Department, Government of Kerala. (2009). GO. (MS). No. 152/2009: *Decentralisation Order.*

Local Self Government Department, Government of Kerala. (2011). GO. (P). No.162/2011/LSGD: *Decentralisation order*.

Maastricht, S. V. (1998). Work, opportunity and culture: (In)competence in Greece and Wales. In R. Jenkins (Ed.), *Questions of competence: Culture, classification and intellectual disability* (pp. 125–152). Cambridge University Press.

Marks, D. (1997). Models of disability. *Disability and Rehabilitation, 19*(3), 85–91. https://doi.org/10.3109/09638289709166831

May, D., & Simpson, M. K. (2003). The parent trap: Marriage, parenthood and adulthood for people with intellectual disabilities. *Critical Social Policy, 23*(1), 25–43. https://doi.org/10.1177/026101830302300102

McLaughlin, J., Goodley, D., Clavering, E., & Fisher, P. (Eds.). (2008). *Families raising disabled children: Enabling care and social justice*. Palgrave Macmillan.

McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York University Press.

Meekosha, H. (2008). Contexualizing Disability: Developing Southern /Global Theory. *Keynote Speech*, 20.

Mehrota, N. (2013). *Disability, gender and state policy: Exploring margins*. Rwat Publ.

Mehrotra, N. (2012). Methodological Issues in Disability Research: An Introduction. *Indian Anthropologist*, *42*(1), 1–10. JSTOR.

Mehrotra, N. (2013). *Disability, gender, and state policy: Exploring margins*. Rawat Publications.

Mehrotra, N. (Ed.). (2020). *Disability studies in India: Interdisciplinary perspectives*. Springer.

Mehrotra, N., & Vaidya, S. (2008). Exploring Constructs of Intellectual Disability and Personhood in Haryana and Delhi. *Indian Journal of Gender Studies*, *15*(2), 317–340. https://doi.org/10.1177/097152150801500206

Mehta, A. (1999). Embodied Discourse: On gender and fear of violence. *Gender, Place & Culture*, *6*(1), 67–84. https://doi.org/10.1080/09663699925150

Merton, R. K. (1972). Insiders and Outsiders: A Chapter in the Sociology of Knowledge. *American Journal of Sociology*, *78*(1), 9–47. https://doi.org/10.1086/225294

Midjo, T., & Aune, K. E. (2018). Identity constructions and transition to adulthood for young people with mild intellectual disabilities. *Journal of Intellectual Disabilities*, *22*(1), 33–48. https://doi.org/10.1177/1744629516674066

Mitchell, D., & Snydar, S. (2012). Minority Model; From liberal to neoliberal futures of disability. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 42–50). Routledge.

Mohler, E., & Rudman, D. (2022). Negotiating the Insider/Outsider Researcher Position within Qualitative Disability Studies Research. *The Qualitative Report*. https://doi.org/10.46743/2160-3715/2022.5047

Mokkil, N. (2018). Modernity’s Nightmares: Narrating Sexuality in Kerala. In L. Choukroune & P. Bhandari (Eds.), *Exploring Indian Modernities ; Ideas and Practices* (pp. 231–251). Springer Singapore.

Morris, J. (1991). “Us” and “them”? Feminist research, community care and disability*. *Critical Social Policy*, *11*(33), 22–39. https://doi.org/10.1177/026101839101103302

Morris, J. (1993). Feminism and Disability. *Feminist Review*, *43*(1), 57–70. https://doi.org/10.1057/fr.1993.4

Morris, J. (2004). Independent living and community care: A disempowering framework. *Disability & Society*, *19*(5), 427–442. https://doi.org/10.1080/0968759042000235280

Murphy, R. F. (2001). *The body silent* (Reissued). W.W. Norton.

National Crime Records Bureau. (2023). *Crime in India 2022* [Annual Report] Ministry of Home Affairs, Government of India.

Ndi, A. (2012). Setting the Stage of 'Ab/normality' in Rehabilitative Narratives: Rethinking Medicalization of the Disabled African Body. *Disability Studies Quarterly*, *32*(2). https://doi.org/10.18061/dsq.v32i2.3195

Oakley, A. (2003). Interviewing Women: A Contradiction in Terms. In Y. S. Lincoln & N. K. Denzin (Eds.), *Turning points in qualitative research: Tying knots in a handkerchief* (pp. 243–264). AltaMira Press.

Oliver, M. (1995). *Understanding Disability: From Theory to Practice*. Macmillan Education UK.

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, *28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Palriwala, R. (2021). Trajectories in the care discourse; labour, gender, economics and power. In M. E. John & M. Gopal (Eds.), *Women in the worlds of labour: Interdisciplinary and intersectional perspectives* (pp. 57–83). Women in the Worlds of Labour: Interdisciplinary and Intersectional Perspectives, Hyderabad, Telangana, India. Orient BlackSwan.

Phadke, S., Khan, S., & Ranade, S. (2011). *Why loiter? Women and risk on Mumbai streets*. Penguin Books.

Piepzna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice*. Arsenal Pulp Press.

Planning and Development Department, Government of Kerala. (2017). GO. (MS) No.236/2016: *Decentralisation Order.*

Rajagopal, N. (2020). Social Impact of Women SHGs: A Study of NHGs of 'Kudumbashree' in Kerala. *Management and Labour Studies*, *45*(3), 317–336. https://doi.org/10.1177/0258042X20922116

Rajeevan, A., & C, V. (2022). Assistive Technology Facilities for the Students with Intellectual Disability in the Buds Special Schools in Kannur District of Kerala. *Studies in Indian Place Names*, *40*(50), 4858–4869.

Raju, K. V., & Manasi, S. (2024). *Anna-daan, Food Charity in India: Preaching and Practice* (1st ed.). Routledge India. https://doi.org/10.4324/9781003363996

Rao, S. (2006). Parameters of normality and cultural constructions of 'mental retardation': Perspectives of Bengali families. *Disability & Society*, *21*(2), 159–178. https://doi.org/10.1080/09687590500498127

Reddy, R. (2011). From Impairment to Disability and Beyond: Critical Explorations in Disability Studies. *Sociological Bulletin*, *60*(2), 287–306.

Richardson, D. (2000). Constructing sexual citizenship: Theorizing sexual rights. *Critical Social Policy*, *20*(1), 105–135. https://doi.org/10.1177/026101830002000105

Roach, A., & Stair, A. (2024). The Right to Love and Be Loved: Sexual Health Education for Students with Intellectual and Developmental Disabilities. *Review of Disability Studies: An International Journal*, *19*(3 & 4), 1–35.

Sandahl, C. (2003). QUEERING THE CRIP OR CRIPPING THE QUEER? *GLQ: A Journal of Lesbian and Gay Studies*, *9*(1–2), 25–56. https://doi.org/10.1215/10642684-9-1-2-25

Sarukkai, S. (2017). Understanding experience. In G. Guru & S. Sarukkai, *The cracked mirror: An Indian debate on experience and theory* (pp. 46–70). Oxford University Press.

Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research*, *6*(1), 8–21. https://doi.org/10.1080/15017410409512636

Shakespeare, T. (2014). *Disability rights and wrongs revisited* (Second edition). Routledge.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? In *Research in Social Science and Disability* (Vol. 2, pp. 9–28). Emerald (MCB UP). https://doi.org/10.1016/S1479-3547(01)80018-X

Siebers, T. (2012). A Sexual Culture for Disabled People. In R. McRuer & A. Mollow (Eds.), *Sex and Disability* (pp. 37–53). Duke University Press. https://doi.org/10.1215/9780822394877-002

Singh, A. (2018). Narratives of Growing with A-typicality. In A. Ghai (Ed.), *Disability in South Asia: Knowledge & Experience* (pp. 196–213). SAGE Publications, Inc. https://doi.org/10.4135/9789353280321

Skeggs, B. (2001). Feminist Ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland, *Handbook of Ethnography* (pp. 426–442). SAGE Publications Ltd. https://doi.org/10.4135/9781848608337.n29

Skeggs, B. (2014). Feminist Etnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (Reprinted, pp. 426–442). SAGE.

Srivastava, A. K., & Baipai, P. (2005). Community-based Rehabilitation: The Indian Perspective. *World Federation of Occupational Therapists Bulletin*, *52*(1), 39–44. https://doi.org/10.1179/otb.2005.52.1.008

Staples, J. (2007). *Peculiar people, amazing lives: Leprosy, social exclusion, and community making in South India*. Orient Longman.

Staples, J. (2011). At the intersection of disability and masculinity: Exploring gender and bodily difference in India: At the intersection of disability and masculinity. *Journal of the Royal Anthropological Institute*, *17*(3), 545–562. https://doi.org/10.1111/j.1467-9655.2011.01706.x

Staples, J. (2018). Doing disability through charity and philanthropy in contemporary South India. *Contributions to Indian Sociology*, *52*(2), 129–155. https://doi.org/10.1177/0069966718761228

Stefánsdóttir, G. (2019). People with intellectual disabilities in Iceland in the twentieth century: Sterilisation, social role valorisation and ‘normal life.’ In J. Walmsley & S. Jarrett (Eds.), *Intellectual disability in the twentieth century: Transnational perspectives on people, policy, and practice* (pp. 129–142). Policy Press.

Sundaresan, N. (2013). Tracking Disability through the United Nations. In *Disability studies in India: Global discourses, local realities* (pp. 78–93). Gender, Disability, and Society (Conference), New Delhi. Routledge.

Talle, A. (1995). A Child Is a Child: Disability and Equality among the Kenya Maasai. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture* (pp. 56–72). University of California Press.

TARSHI. (2018). *Sexuality and Disability in the Indian Context* (p. 222) [Working Paper]. https://www.tarshi.net/downloads/Sexuality_and_Disability_in_the_Indian_Context.pdf

Taylor Gomez, M. (2012). The S Words: Sexuality, Sensuality, Sexual Expression and People with Intellectual Disability. *Sexuality and Disability*, *30*(2), 237–245. https://doi.org/10.1007/s11195-011-9250-4

Tepper, M. S. (2000). Sexuality and Disability: The Missing Discourse of Pleasure. *Sexuality and Disability*, *18*(4), 283–290. https://doi.org/10.1023/A:1005698311392

Tharayil, M. (2014). Shifting Paradigms: Gender and Sexuality Debates in Kerala. *Economic and Political Weekly*, *49*(17), 70–78. JSTOR.

Thomas, C. (2002). Disability Theory: Key Ideas, Issues and Thinkers. In C. Barnes, M. Oliver, & L. Barton (Eds.), *Disability studies today* (pp. 38–57). Polity Press in association with Blackwell Publishers.

Thomas, M., & Thomas, M. J. (1999). A Discussion on the Shifts and Changes in Community Based Rehabilitation in the Last Decade. *Neurorehabilitation and Neural Repair*, *13*(3), 185–189. https://doi.org/10.1177/154596839901300308

Thomas, M., & Thomas, M. J. (2002). Some Controversies in Community Based Rehabilitaion. In S. Hartley (Ed.), *CBR: a participatory strategy in Africa: Based on the proceedings of a Conference, Uganda, September 2001* (pp. 13–

25). Africa Regional Conference on CBR, London. University College London, Centre for International Child Health.

Thompson, R. (2002). Integrating Disability, Transforming Feminist Theory. *NWSA Journal*, *14*(3), 1–32.

Thompson, R. (2015). Eugenics. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for disability studies* (pp. 74–79). New York University Press.

TUTAR GÜVEN, Ş., & İŞLER, A. (2015). Sex Education and its Importance in Children with Intellectual Disabilities. *Dergisi - Journal of Psychiatric Nursing*, *6*(3), 143–148. https://doi.org/10.5505/phd.2015.64936

Twardowski, A. (2022). Cultural Model of Disability – Origins, Assumptions, Advantages. *Kultura i Edukacja*, *136*(2), 48–61. https://doi.org/10.15804/kie.2022.02.03

Vaidya, S. (2010). Researcher as Insider: Opportunities and Challenges. *Indian Anthropologist*, *40*(2), 25–36. JSTOR.

Vaidya, S. (2016). *Autism and the family in urban India: Looking back, looking forward*. Springer (India).

Vaidya, S. (2018). Disability across Cultures. In A. Ghai (Ed.), *Disability in South Asia: Knowledge & Experience* (pp. 245–262). SAGE Publications, Inc. https://doi.org/10.4135/9789353280321

Vaidya, S. (2024). From problem-centered to centering relationalities: Engagements with disability and sexuality in India. *Feminist Anthropology*, *5*(1), 153–166. https://doi.org/10.1002/fea2.12127

Vincent, R. (2024). The BUDS Institutions: Kerala Model for Rehabilitation of Individuals with Intellectual and Developmental Disabilities. *Journal of*

Psychosocial Rehabilitation and Mental Health. https://doi.org/10.1007/s40737-024-00427-x

Visweswaran, K. (1994). *Fictions of feminist ethnography*. University of Minnesota Press.

Visweswaran, K. (1997). Histories of Feminist Ethnography. *Annual Review of Anthropology, 26*, 591–621. JSTOR.

Watson, N. (2012). Understanding the Social Model of Disability; Past, present and future. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 12–29). Routledge.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model. *Sociology, 38*(2), 331–350. https://doi.org/10.1177/0038038504040867

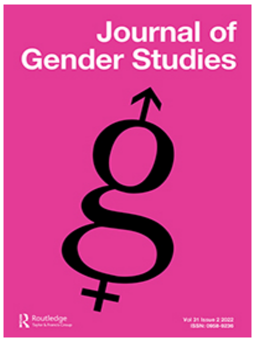
Weeks, J. (1998). The Sexual Citizen. *Theory, Culture & Society, 15*(3–4), 35–52. https://doi.org/10.1177/0263276498015003003

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. Routledge.

Wolbring, G. (2008). The Politics of Ableism. *Development*, *51*(2), 252–258. https://doi.org/10.1057/dev.2008.17

World Health Organization (Ed.). (1980). *International classification of impairments, disabilities, and handicaps: A manual of classification relating to the consequences of disease*. World Health Organization ; sold by WHO Publications Centre USA].

Zaks, Z. (2024). Changing the medical model of disability to the normalization model of disability: Clarifying the past to create a new future direction. *Disability & Society*, *39*(12), 3233–3260. https://doi.org/10.1080/09687599.2023.2255926



Journal of Gender Studies

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cjgs20

Notions of sexuality: an analysis of the interplays of gender and care among adults with intellectual disabilities in Kerala

Soniya A M

To cite this article: Soniya A M (2022): Notions of sexuality: an analysis of the interplays of gender and care among adults with intellectual disabilities in Kerala, Journal of Gender Studies, DOI: 10.1080/09589236.2022.2039102

To link to this article: https://doi.org/10.1080/09589236.2022.2039102

Published online: 09 Feb 2022.

Submit your article to this journal

View related articles

View Crossmark data

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=cjgs20

JOURNAL OF GENDER STUDIES
https://doi.org/10.1080/09589236.2022.2039102

Routledge
Taylor & Francis Group

RESEARCH ARTICLE

Check for updates

Notions of sexuality: an analysis of the interplays of gender and care among adults with intellectual disabilities in Kerala

Soniya A M

Centre for Women's Studies, University of Hyderabad, Hyderabad, India

ABSTRACT
The paper critically engages with the notions of sexuality in the lives of women with intellectual disabilities through the analytical categories of gender and care.

An in-depth narration of the case study from a BUDS Rehabilitation Centre in Kerala, South India, is used to trace the patterns of care that monitor the sexuality of persons with intellectual disabilities. There is gender bias in the interpretations of sexual expressions and emotions of a woman with intellectual disability as immoral and hypersexual in the BUDS Rehabilitation Centre. The prevalence of sexual ableism leads to hypersexual objectification of a woman with an intellectual disability. The sexual rights of the woman are suppressed by the discourse of vulnerability. The study also traces the resistance from women with intellectual disability towards ableist notions of normative sexuality.

ARTICLE HISTORY
Received 2 July 2021
Accepted 13 January 2022

KEYWORDS
Gender; sexuality; intellectual disability; sexual ableism; hypersexual objectification

Introduction

Recent years has seen an increasing engagement between intellectual disability and sexuality (Alexander & Taylor Gomez, 2017; Gill, 2015; Kahonde & McKenzie, 2019; Tepper, 2018; Vaidya, 2016). The sexuality of persons with intellectual disability has always been a significant complication; often, they were treated as 'immoral' (Feely, 2016) or were 'desexualised' (Seibers, 2012) by mainstream society. Within disability studies, intellectual disability has not been addressed as much as other forms of dis- abilities (Chappell, Goodley, & Lawthom, 2001; Shakespeare, 2014). Discussions about the sexuality of a person with intellectual disability, in most cases, are centred around 'vulnerability' and potential 'sexual violence' (Feely, 2016; Kahonde & McKenzie, 2019; O'Shea & Frawley, 2020). Their sexual agency is not acknowledged (Gill, 2015). Persons with intellectual disabilities are perceived as either asexual or hypersexual (perverts) by society (Brown, 1994).

When we discuss sexuality in terms of care, there are significant elements to determine the nature of 'care' and its impact on the sexuality/sexual lives of persons with intellectual disabilities. There is a historical form of oppression tied to the image of women with intellectual disabilities and their sexual and reproductive rights by providing 'care' (Carlson, 2001). The line which differentiates 'care' and 'control' is very subtle; it depends on the nature of surveillance they subjected to by the carers within and outside of the institution (May & Simpson, 2003). The marriage of women with intellectual disabilities is seen through the prism of abuse and vulnerability (Feely, 2016).

The lived experience of women with an intellectual disability is greatly influenced by ableist principles of 'normative femininity' (Garland-Thomson, 2002; Ghosh, 2013). Along with the ideal regarding 'perfect' feminine physical structure, women with intellectual disabilities are also

CONTACT Soniya A M ✉ soniyasreesankaram@gmail.com Centre for Women's Studies, University of Hyderabad, Hyderabad, Telangana, India

© 2022 Informa UK Limited, trading as Taylor & Francis Group

marginalized on the basis of their cognitive abilities. Their ability to perform traditional gender roles is undermined. The marginalization of such women restricts their sexual and reproductive agency. In a traditional society like India, marriage and reproduction are considered as important milestones of women's lives. Intellectual disability, on the other hand, does not belong to the 'marriageable' category of women. This affects the 'domestic citizenship'[1] (Das & Addlakha, 2001) of women with intellectual disabilities.

Undermining the individual's sexual agency is the result of the existing sexual ableism of mainstream society. Sexual ableism refuses to acknowledge the diverse sexual identities of persons with intellectual disabilities, as it poses a direct challenge towards the dominant heterosexual ableist patriarchal notions of sexuality (Gill, 2015).

In the present study, I describe how notions of care define the sexuality of women with intellectual disabilities. The study analyses the role of patriarchy and sexual ableism in reducing the sexual agency of these women. The discussions also open up the gendered notions of care and restriction in the sexuality of adults with intellectual disabilities. The pattern of resistance and negotiations of women with intellectual disabilities in expressing their sexuality is explored. To understand the connection and patterns of intellectual disability, sexuality, gender and care, I choose BUDS Rehabilitation Centres in the state of Kerala, South India. BUDS Rehabilitation Centres (BRCs) are established to function as the day-care centres for adults with intellectual disabilities in Kerala, focused on their vocational training and rehabilitation. This is a unique model of institutions based on Community Based Participatory Rehabilitation (CBPR) strategy and functioning under Local Self Governments (Panchayaths) and the state Kudumbashree mission[2] (Augustine, 2016).

Methodology

The institutional ethnographical data for the current study is part of my doctoral fieldwork conducted during 2017–2019. The paper describes a case study from a single BRC for a period of three years. This is an in-depth study of the sexual subjectivity of an adult woman with an intellectual disability. The data examines the notions of the sexuality of an adult woman with intellectual disability through the analytical categories of gender and care. The ethnographical field study I conducted started from an outsider's position as I was not able to relate to the participants or any other stakeholders. This specific BRC is situated near my residence, so the dialect of the local language (Malayalam) and my status as a native was useful to establish a connection and acceptance in the premises. Although I stand outside of the identity of persons with intellectual disabilities or their carers, my continued presence in the institution led to partial insider status. That is to say, I was accepted as a 'semi-teacher' with whom everybody can talk and engage. There were times I was asked to act/represent in the organizing committee on behalf of the particular BRC in the Panchayath arts festival for persons with intellectual disabilities. These demands and acceptance as a partial insider in the institution on the basis of my regional identity complicated my research positions for fieldwork.

I collected data through observation, unstructured interviews and conversation analysis of the participants in the BRC, i.e. teachers, helper, mothers of the participants, representatives and administration staff of the Local Self Government, and laypeople.[3] My primary method of data collection was observation. I participated at various levels by assisting in the kitchen, classroom, participated in picnics, helped with the panchayath-level arts festival for BRC's participants, took participants to medical camps. Conversations with mothers and laypeople were noted every night after the activities in the institution. I also conducted unstructured interviews with mothers and teachers, which gave me insights regarding the complicated relations of care and gender regarding the sexuality of the participants. These interactions also shed light on each stakeholder's role in constructing the subjective realities of the everyday lives of persons with intellectual disabilities.

I use pseudonyms in the study.

Findings

Notions of sexuality: everyday experiences in the BRCs

From the first day of the field visit in this BRC, I heard warnings and comments about the hypersexual nature of the participants. All the active participants, irrespective of male/female, are referred to as hypersexual. Others who would not participate in activities are regarded as child-like and innocent. Almost every day, there were some remarks about the 'inappropriate' display of affection between participants and how dangerous and vulnerable these participants really are. I observed that the labelling of vulnerability was primarily focused upon women participants only. They were regarded as prone to sexual violence and exploitation. Male participants, on the other hand, were rarely referred as vulnerable in this regard. Discussions about inappropriate behaviour were also primarily centred around women participants, labelling such behaviour as immoral.

Even though the ideals are based on heteronormativity, helping participants with mobility impairments is expected regardless of gender identity. With the limited physical facility, each participant is dependent on one another; this also means free interactions are happening inside the premises. For instance, Shaan, a 34-year-old male participant with a minor intellectual disability, always helps Noor, a 25-year-old female participant with Cerebral palsy,[4] who faces mobility issues. She needs someone to hold and support her to walk towards dining room and Shaan always at her side to do this.

Swapna is a 34 years old woman with Down syndrome.[5] Her case can be analysed to understand subjective realities and the everyday experiences of a woman with intellectual disability in a BRC. I had been notified by multiple persons about Swapna's 'over friendly' attitude and inappropriate relationships with other male participants. Swapna is very friendly and becomes friends with anyone within a short time. I was told that, despite her difficulty in speech, she is the best singer and dancer in that particular BRC. Interactions between Swapna and other male participants were viewed with suspicion by staff members and other mothers. Helping inmates are considered as 'normal' inside the institution; at the same time, the interactions between specific participants are considered problematic/inappropriate and denied.

Swapna was closely watched by staff and other participants of the BRC. On my first day, I was informed that she would accompany anybody who behaves nicely. She had reportedly left her home several times. The teacher told me she would be in her own world sometimes and wander off on the streets. However, she never got a chance to 'leave' from the BRC as they closely watch every participant there. She was described as a woman who is not able to decide the intention of others in terms of sexual exploitation and sexual violence. 'Going' without permission of the parents or teachers (in the case of BRCs) is considered 'bad' or deviant.

Gendered construction of 'immorality'

From my interactions with teachers and helpers, it is evident that they are vigilant about the activities and interactions happening between the participants in the institutions. The teacher and the helper regularly reiterate the 'danger' in allowing both genders to mingle freely. The conversations and concepts are entirely based on a heteronormative ideal. The critical risks are based on the 'safety' of the participants. The word 'safety' is complicated in many ways. When I talked to teachers or parents, or officials from the Panchayath, they use the word safe/safety (*surakshitham, urappulla*) in different contexts. From teachers: 'they leave children here, with us, in the belief that they are safe here and we will watch over [them]. That is a huge responsibility. That is why I would not take my eyes away from them'. The words of Helper (*Aaya*):

> 'Since she (Swapna) is not able to think (*oru ormayumillatha*) at all, I had to watch constantly her and other boys. If something happens, how can I live! Her mother has full faith in me, and I had to uphold their faith'. According to a Panchayath Official: 'The staffs have to watch over the students all the time. See, the institution is on the roadside, and vehicles always pass. If something happens, we are all answerable.'

During my interaction with parents and teachers of the BRC, Swapna's 'solitarywalks' without other's consent was a common topic. The teachers and parents of other participants pointed out several reasons to take extra caution for her safety. In Swapna's case, increased surveillance is to ensure her safety from the outside world. Teachers and other parents commonly indicate the possibility of sexual assault by strangers. One teacher said: 'If something happens to her during her solitary walks, I can't even imagine! We cannot trust anybody these days. People will do "bad" things to anybody. Especially Swapna is willing to cooperate with anybody to do anything. I am always worried about her safety'.

The participants are denied entry to or exit from the premises without permission from an authority, i.e. the teacher. Ameer is a 24 years old male participant with intellectual disability, and he used to 'run away' from home without his parent's knowledge. This practice was also discussed in the institution. The difference between these two 'runaway' narratives was their emphasis on different aspects. There is a concern and worry about their absence; in Ameer's case, the anxiety about physical assault or accidents were given priority over the threat of potential sexual assault. The teacher mentioned this possibility once. More than that, his wellbeing and physical safety were given priority. In Swapna's case, sexual abuse and a resultant pregnancy were the primary concern. Here, I want to clarify that I acknowledge that persons with intellectual disabilities are subjected to violence and abuse (HRW, 2018), and measures are taking to prevent such incidents. However, I am trying to analyse the ideologies that determine the nature and concern of care and protection provided for the participants to prevent these.

Question of marriage and meaningful silences

Women's sexuality is always a primary concern of society. Expression of sexuality makes women immoral in a patriarchal society. With her relations with other participants and the 'solitary walks', Swapna disturbs both patriarchy and ableism. She was proposed to get married by the parents of a fellow participant, and her parents denied it. They feared domestic violence and her 'inability' to maintain a family. They believe that she is not marriageable; they will look after her until their last breath. During my conversation with Swapna, she admitted that she would like to get married. From the television serials, she has internalized the role of 'wife'; she said she is able to perform all the household duties. When her mother was not well, she used to do most of the domestic work. Despite the assertion of sexuality by the couple, the reluctance to form a marital relation for their daughter by her parents has to be considered through the lens of sexual ableism. The 'ability' and 'inability' to marry was determined and decided by her parents; her opinions on the matter were never acknowledged.

Patriarchy as a controlling social power transcends through ableism and further marginalizes women with intellectual disabilities. During my conversations in the BRC, teachers and parents of male participants said they expect their sons to get married soon. Some parents are searching for a suitable partner for their sons; on the other hand, female participants are evaluated based on their 'ability' to perform 'home maker' roles. The BRC teacher said she knew these participants are in their 'marriageable' age. By marriageable age, she meant they are sexually active and are ready to start a family. Nikhil is a 27-year-old male participant with acquired disability. He met with an accident when he was six years old. Since then, he has a limp in his left leg, speech impairment and intellectual disability. His mother is trying to find a girl for him. I observed from their conversations; parents of women participants are not considering marriage for their daughters. They fear possible sexual violence and domestic violence in their daughter's married life.

Most of the parents said they do not know what will happen to their daughters after their lives! Some said they expect siblings to look after them in the future, and they will prepare their will accordingly. Many of the mothers repeated the same sentence 'I will never be able to close my eyes in peace. Even in my grave, I have to leave one eye opened' (*pettiyil kidakkumbozhum oru kannu thurannirikkum*).

Expression of femininity and sexuality; some negotiations

The mainstream societal conception of deviance associated with intellectual disability is challenged by participants and their family and teachers in many instances. One such significant incident occurred when 24-year-old Aparna was dressed as 'Bharat Mata'[6] in a fancy dress competition conducted by the Grama (village) Panchayath. This programme was held during the week of Independence Day. This portrayal of a woman with severe intellectual disability as the 'ideal' Bharatmata challenges the mainstream ideals of 'perfection'. The audience watched this portrayal from disbelief to complimentary applauses. This was a remarkable resistance on BRC's part towards the nationalist discourse that propagates 'ideal female'.

Another effort was from Swapna. She likes a classmate whom she addresses as *ettan* (in this case cousin-brother). She told me her *ettan* was a participant in the BRC; later, I came to know about her fondness for this person. He was a former student there, and in time, heleft the daily class and started work in a readymade garment shop as a salesman. He visits the institution on special occasions. Regardless, Swapna claims that he is her cousin brother, and they are relatives. The teacher and his mother told me they are not related, as Swapna says. They all knew her fondness for this person; however, everybody makes fun of it or neglected this as a serious relationship. This is a situation where she expresses her emotions, and all others know this, yet meaningfully avoid giving the matter a severe tone. Both set of parents are avoiding Swapna's emotions and expressions. When I talked to the mother of this participant, she leisurely told me,

> Yes. Swapna was saying that. We don't think it's something serious. She used to say that he is her cousin brother. Actually, we are not related. But, I am not bothered about all those things (*njan ithonnum shradhikkalilla*). Since she is like this, we don't give much attention to it.

From Swapna's perspective, this is a negotiation strategy regarding sexuality. Partial expression of emotions is also a way of assertion of the sexual identity of women with intellectual disabilities in front of a restrictive regime based on ableist principles.

Discussion

Swapna was referred to as a person who is not 'able' to make decisions about her life or to 'think' with intellect. At the same time, in some instances, she was referred to as a person who is 'responsible' for thinking rationally and foresees the effect of her actions. This contradictory position regarding the efficiency of a person to make their own life decisions and actions by non-disabled persons can be considered as the effect of sexual ableism. Their sexuality is considered 'deviant' by the mainstream ableist society and labelled as 'hyper sexual' when they express their affection. According to Gill,

> Sexual ableism is the system of imbuing sexuality with determinations of qualification to be sexual based on criteria of ability, intellect, morality, physicality, appearance, age, race, social acceptability, and gender conformity. Intellectual disability remains a characteristic or condition that disqualifies participation because of sexual ableism, which denies an understanding of disability as a valuable difference that yields unique perspectives of personhood, competence, sexuality, agency, and ability (2015, p. 3).

Sexual ableism defines the sexuality and sexual relations of a person with disabilities on the basis of the concept of 'normalcy' constructed by ableist, patriarchal and heteronormative society. Sexual ableism denies the sexuality of a person with intellectual disabilities since sexual expressions of the disabled challenge the dynamics of co-constructed 'normalcy'. Kafer (2013, p. 4) remarked, 'the category of disabled "can only be understood in relation to able-bodied or able-minded", a binary in which each term forms the borders of the other'. Here, the binary which she spoke about was the critical factor that develops and nurtures sexual ableism. Denial of the existence or interpretation as deviant/uncontrollable sexuality directly undermines the agency of a person with intellectual disability as a citizen.

From the responses from various persons involved in the functioning of BRC,

The word 'safety' is used in multiple ways, ranging from physical safety to morality and moral safety. The dimensions and complexity associated with the word 'safe/safety' is an interventionist one; that, in a way, can be interpreted as a practice of vigilance within the institution. It can be stretched to the extent where they can enforce surveillance amongst the participants every move. Ranging from their movements to interactions, and ultimately on relationships or any other personal matters.

Swapna's solitary walks were another aspect that needs scrutiny. Solitary walks and travels of women disabled or otherwise are not accepted in the locality. Travel as part of their job or travel with a reason (shopping, visiting a government office, so on) is exempt from society's disproval. Solitary travel of single woman image is not considered appropriate in the locality. Women who spend a considerable amount of time in the public/market are labelled as sexually immoral by the mainstream patriarchal society[7] in Kerala (Aswathy & Kalpana, 2019). Travel as part of their job or travel with a reason (shopping, visiting a government office, so on) is exempt from society's disproval. Women needed to 'demonstrate a purpose' (Phadke, Khan, & Ranade, 2011) to be in the public. In Swapna's case, she is a woman with intellectual disability; this identity itself is regarded as deviant. The stigma associated with intellectual disability further problematizes her 'choices'; whether it is solitary walks or her expression of desire. Prolonged surveillance is the result in her case. I agree there are increased chances of sexual violence for women with intellectual disability. However, these anxieties are used as a mechanism to deny her expression of sexual desires and assertion of autonomy. Gill observed,

> Women's sexual lives are largely constructed around the twin poles of regulation of pregnancy/reproduction and protection from sexual abuse and assault. It can be extremely rare for women with intellectual disabilities to be recognised as competent sexual agents (2015, p. 19).

The measures to make participants 'safe' have to be analysed here. From the earlier narratives, it is evident that Swapna is regulated on the basis of normative sexual notions perpetuated by the patriarchal ableist society. It is important to understand the mechanisms used to control or restrict the autonomy of Swapna were the 'discourse of vulnerability[8]' (Shakespeare, 2014). Safety, as discussed earlier, transcends meanings across situations and depending on the persons involved in them. When dealing with sexuality, safety from sexual immorality[9] also becomes a concern. The 'inappropriate behaviour' described by the parents and teachers also equate to sexual immorality, and it directly engulfs female participants only.

Expression of sexuality becomes more complicated when patriarchal norms of the society are being challenged. Some mothers and teachers mentioned that Swapna is the one who is behaving like a '*cheetha Kutti*' (bad girl – here morality is implied) even though the boys who also took an active part[10] in getting exempted from this 'immorality' allegations. Since both participants are persons with intellectual disability, male participant's omission from the allegations can be considered as the male privilege granted by patriarchy. According to O'Shea and Frawley (2020, p. 663), the sexuality of women with intellectual disabilities is permitted only in 'discrete, normative and traditional ways' followed by surveillance.

The twin poles of hyper-sexuality and asexuality are labels applied to the sexual identity of persons with intellectual disabilities. Being an active participant in BRC, Swapna is labelled as hypersexual at times. Other women participants who are not active in the day to day activities of the BRC are considered passive/child-like. In a way, they are being labelled as asexual in the BRC. Either way, women with intellectual disabilities are treated outside of the idea of 'normative sexuality'. They regarded as 'incomplete women' against 'normal women' (Ghosh, 2013, pp. 201–219).

The cultural construction of ideal femininity sideline the disabled women who are 'asexually objectified' in the ableist society (Addlakha, 2013, pp. 220–240). Adding to the terminology of 'asexual objectification' by Addlakha, I argue that in Swapna's case, it is hypersexual objectification. From various examples, it is apparent that her sexuality is acknowledged under an immoral, hypersexual label. All her interaction with other male participants is scrutinized under the spectrum of Hyper sexuality. Along with this label (Shakespeare, 2014, p. 94), her emotions and actions were evaluated on the basis of appropriate/inappropriate actions in the institution. Hypersexuality, inappropriateness and immorality are all interconnected here, and, in a way, define the sexual identity of a woman with intellectual disability, obliviating other aspects of sexuality from her life. It can be considered as 'hypersexual objectification'.

The ableist assumptions about the ability of a person with a disability are derived from a combination of rules that define normalcy. Those who challenge the normalcy constructed by the ableist heteronormative patriarchal social structure are considered the 'other'. When Swapna express her emotion to another male participant in the institution, she challenges the denial and marginalization of the sexuality of a woman with an intellectual disability.

Parents, especially mothers, are the carers of their daughters at home. Women with intellectual disability were never considered autonomous individuals; there is always a concern about their vulnerable status (Kim, 2011). Most of these daughters were never allowed to live independently.

> The idea of intellectual disability is grounded in negation. It is about incapacity, lack and deficiency measured by disciplines which focus on intellect, activities of daily living and so on. By extension of this view which originates with what the person cannot do, their legal rights and even their moral personhood are called into question. (O'Shea & Frawley, 2020, p. 655).

Carers took all decisions regarding their lives. In other words, mothers did things based on altruistic principles and regarded this as their duty to taken care of their daughters with intellectual disabilities. Some mothers told me that after a certain age, when the daughter reaches puberty, fathers could not do many things, and there should be some restrictions. The issues of safety, sexuality and morality are intertwined in situations like this. While women with intellectual disabilities are prone to violence and abuse[11] (HRW, 2018), I have no intention to deny this fact; at the same time, I wish to draw attention to how the discourse of vulnerability got prominence over the discourse of pleasure and sexual agency. When the questions of marriage and reproduction arise, their vulnerability to living away from parents and the familiar surroundings are highlighted. As a result, women with intellectual disabilities are denied active sexual roles and domestic citizenship (Das & Addlakha, 2001). Marriage plays a vital role in the making of domestic citizenship in traditional Indian society.

Denial of the right to engage in sexual and reproductive roles against their will on the basis of ableist notions of vulnerability and hyper sexism negate the sexual citizenship of women with intellectual disabilities. The discourse around sexual citizenship is described as a counter-narrative against the homophobic patriarchal and ableist notions of sexuality. According to Weeks (1998, p. 36), sexual citizenship is contradictory terminology as sexual is the 'intimate personal life, an area of pleasure and pain, love and pain, power and resistance' (p.36) whereas citizenship is about the involvement of 'larger society'. He considered the concept of sexual citizenship as a peculiar point of public/private divide that exists in western society. He extended the implication of the term as '.it is about enfranchisement, about inclusion, about belonging, about equity and justice.(p.36)'

Seibers (2012, p. 47) argued for a 'sexual culture for disabled' to enhance the spectrum of sexuality and give a political dimension that redefines people with disabilities as sexual citizens. He argued that sexual citizenship is the right to break free of the unequal treatment of minority sexualities and to create new modes of access for sex. He elaborated that sexual citizenship for persons with disabilities also includes

> access to information about sexuality; freedom of association in institutions and care facilities; demedicalization of disabled sexuality; addressing sexual needs and desires as part of health care; reprofessionalization of caregivers to recognize, not deny, sexuality; and privacy on demand. (Seibers, 2012).

Acknowledgement of a person as a sexual being is also the acknowledgement of the sexual rights of the person. In Swapna's case, she was labelled as a person with hypersexual instinct or as a person who is not capable of getting married. Both of these sexual identities are the denial of the individual as an active sexual agent. Heterosexual marriages approve the individuals as persons, as active sexual agents, and legitimize their sexual relationship based on reproduction.

There is a cultural notion[12] existing in Kerala, that persons with disabilities mayprocure disabled off springs. This notion has been discussed in disability studies discourses on the basis of the eugenics politics and its continuing presence in currentableist discourses (Carlson, 2001; Feely, 2016; Gill, 2015; Kempton & Kahn, 1991; May & Simpson, 2003; Vaidya, 2016).

> A biologically determinate viewpoint of sex as solely the province of reproduction, and reproduction solely the province of the fittest, usually those with access to the full enjoyment of citizenship, has largely served to exclude people with disabilities. In addition, a social cultural viewpoint of sex as a source of danger leads to the presumed need to protect us. Disabled populations are not viewed as acceptable candidates for reproduction or even capable of sex for pleasure. We are viewed as child-like and in need of protection (Tepper, 2018, p. 285).

In this regard, the asexual identity of women with intellectual disabilities is constructed politically, and desexualization[13] of their bodies separates their rights of being a sexual citizen. Ghosh (2013) discussed how deviance is culturally constructed, and women with disabilities are kept outside of the discourse of beauty. Her research shows that women with disabilities are not expected to dress according to dominant femininity ideology. Though the prevalence of ableism is apparent in the BRC in matters related to sexuality, there are negotiations and acknowledgement of the sexuality of women with intellectual disability as contradictory in some instances.

When Aparna was dressed as 'Bharat Mata' in the fancy dress competition, she becomes a 'misfit' (Garland-Thomson, 2011) of the nationalist discourse. Bharat Mata represents strength and nurturing aspects of a woman. It was a potent image of evoking motherhood, motherland, femininity and even community identity. That is the ideal woman in contemporary India. This image in its micro level propagates eugenic political values! On the other hand, Aparna represent everything this Bharat Mata image opposes or rejected.[14] Garland-Thomson (2011, p. 594) explained the concept of 'misfit' as 'particularities of embodiment interact with their environment in its broadest sense, to include both its spatial and temporal aspects'. She later developed the concept by explaining, 'A misfit occurs when an environment does not sustain the shape and function of the body that enters it'. She explains that to be a misfit in the public sphere is to be denied full citizenship. Although Garland-Thompson explained misfit in the context of physical disability and embodiment, I wanted to extend the meaning beyond that. Aparna's presence as Bharat Mata is a misfit in the public space. It is not the embodiment; rather, the socio-cultural meaning associated with intellectual disability makes Aparna a misfitt in the particular costume before the public. However, Garland-Thomson (2011, p. 603) advocates, 'Misfits can also be agents of recognition who by the very act of misfitting engage in challenging and rearranging environment to accommodate their entrance to and participation in public life as an equal citizen'. In other words, Aparna's Bharat Mata provide an alternate inclusive idea of women and citizenship. Along with this, Swapna is a misfit in Kerala's dominant patriarchal and 'compulsory abled bodied' (McRuer, 2006) social structure.

The political act of misfitting in the realm of sexuality of persons with intellectual disabilities can be further elaborated with McRuer's (2006) concept of Crip sexuality. In crip theory, disability became an identity and culture that hold inherent value. He argued that the same system that created compulsory heterosexuality and abled-bodiedness also constrained queerness and disability. Crip theory questions the category of normate; it provides a path to interrogate the system that constructed normal/abnormal, able/disable. The theory problematizes the concept of normate and what makes something normal. Likewise, Crip theory helps to question what makes the sexuality of persons with intellectual disabilities abnormal. Though Swapna invoked hypersexual objectification on her, her acts created a space to talk about the sexuality of persons with intellectual disabilities. The whispers, discussions, warnings, casual avoidance of the sexual assertion are opportunities to discuss the sexuality of the persons with intellectual disabilities. Hence, I argue that these suppressed discussions provide an opportunity for a discourse on the sexuality of women with intellectual disabilities. The challenges raised by both Aparna and Swapna help the deconstruction of the dominant ideology of sexuality.

Conclusion

The study shows the prevalence of sexual ableism in the BRC in Kerala. Swapna's case presents the subtle ways sexual ableism manifested in everyday life of the BRC. Complex patterns of gendered notions inflicted the concept of care and safety. The study sought to highlight how patriarchy and ableism overlap and construct the discourse of immorality within the institution. The narratives shed light on the construction of the discourse of vulnerability and show the political significance of the silence of reproductive rights and marriage of female participants. This study also understands the resistance from female participants against the normative feminine ideal and expression of sexuality and helps to understand the counter-narrative of the dominant ideology of sexuality from the perspectives of women with intellectual disability.

Notes

1. Das and Addlakha (2001, p. 529) explained domestic citizenship in terms of the 'variability of the familial norms, capacities, and resources that interact to create the life trajectories of family members with disabilities or impairments'.
2. Kudumbashree is the poverty eradication and women empowerment programme implemented by the State Poverty Eradication Mission (SPEM) of the Government of Kerala in 1998. Kudumbashree is essentially a community network that covers the entire State of Kerala.
3. In order to sponsor food or money neighbours or random people used to come to the institution. I had conversations with them.
4. 'Cerebral palsy (CP) describes a group of permanent disorders of movements and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems' quoted by Chakravarti (2018, p. 3) from Cerebral Palsy Foundation.
5. Down syndrome is a genetic condition that comes from an extra chromosome 21. When this happens, certain genes on chromosome 21 are 'over-expressed' which causes cellular changes that lead to health problems, developmental delays and learning disabilities.
6. Indian nationalist discourse identify nation state as a mother. The image Bharat Mata became prominent during the colonial nationalist discourse. Bharat Mata is a mother and an embodiment of the upper caste Hindu woman. This image also symbolizes purity. The meaning attached to motherhood eliminates sexuality and all other forms of 'impurity'. Hence lower castes, minority, disabled are not regarded as ideal for the image of Bharat Mata. This image is the normative female image is culturally embedded in contemporary India (Chakravarti, 1989; Naaz, 2017).
7. In their study of fisherwomen in Kerala, Aswathy and Kalpana (2019) argued that fisherwomen who spend more time in the marketplace are under the scrutiny of the community. Due to the nature of their job and the space they occupy, fisherwomen are labelled 'sexually immoral' by the community. They argued that spending night in the market, which is predominately masculine, is the reason behind the allegations. Their study reflects the restrictions imposed on women's physical mobility by the patriarchal social structure and also underline the restrictive social values that define women's sexuality in Kerala's public.
8. I used the term discourse of vulnerability to explain the complexity of the ides of 'protection'. According to Shakespeare (2014, p. 219) 'The idea of vulnerability is used to deny people with intellectual disabilities the right to make choices and take risks and live independently. over-protection has been argued to remove the possibility of people with learning difficulties developing the skills and knowledge they need to protect themselves'.
9. Sexual immorality is a terminology discussed vastly in Kerala's context. Devika, 2011a; Devika, 2011b) discussed the notions and values that create 'immorality' in the Kerala context as patriarchal and casteist. Historically, domestic spaces are regarded as upper-caste women's ideal space; those female bodies frequently seen in the market / public space were regarded as *chanthapennu* (market women). Hence, those female bodies frequently

seen in the public/ market are regarded as sexually immoral. This public/private divide primarily shapes the identity of Dalit women in mainstream Kerala society. This is the reason behind the restriction of women in public spaces without an explicit purpose.

10. According to the staff members, certain instances occurred in the BRC where Swapna was seen with fellow male participants in 'inappropriate' ways. Although both male and female participants were present but only Swapna was labelled immoral.
11. Human Rights Watch (2018, p. 4) reported that women with intellectual disabilities are prone to violence than other categories of women with disabilities in India. The report cited the lack of accessibility to legal-medical systems by the victims and their families, and lack of awareness and concern from the police force triggered the rate of violence against women with intellectual disabilities in India. In the majority of the cases, these women do not understand the nature of 'sexual violence' due to the lack of awareness about crimes; also, they are not aware of the methods to prevent sexual violence or how /whom to report the incidents.
12. From the conversations with my own family members and interaction with others regarding marriage and related topics, there is always caution about the chances of hereditary intellectual disability and some physical disabilities.
13. Desexualization is a process that separates sexuality from disabled bodies, making it irrelevant to and incompatible with them because disabled people are supposedly undesirable in society and because disability is believed to lead to sexual incapacity. In addition, desexualization refers to the on-going process of creating distance between sexuality and people with disabilities through the fear of disability reproduction and contamination. Moreover, desexualization occurs when sexual assistance and access to social settings and communication are prohibited. (Kim, 2011, pp. 428–483).
14. The origin of the concept of Bharat mata date back to India's colonial period. Bankim Chandra Chaterjee in his novel Anandamath (1882) illustrated the mother goddess image. With the strengthening of nationalist discourse, representations of mother India or Bharat Mata become more and more aggressive. This aggressive mother represent Hindu right wing ideal about Hindu nation and mother land. Hence the Bharat Mata image becomes important in the cultural and political history of India. This Bharat mata is ideal woman image propagated by mainstream right leaning nationalist discourse. The nationalist discourse that upholds Barat Mata signifies a mother who is caring and daring at the same time.

Disclosure statement

No potential conflict of interest was reported by the author.

Notes on contributor

Soniya A M, is pursuing Ph.D. in the area of Disability and Gender from the Centre for Women's Studies, University of Hyderabad, Hyderabad. Email: soniyasreesankaram@gmail.com

References

Addlakha, R. (2013). Body Politics and Disabled Femininity: Perspectives from Adolescent Girls from Delhi. In R. Addlakha (Ed.), *Disability Studies in India: Global Discourses, Local Realities* (pp. 220–240). New Delhi: Routledge.

Alexander, N., & Taylor Gomez, M. (2017). Pleasure, sex, prohibition, intellectual disability, and dangerous ideas. *Reproductive Health Matters*, *25*(50), 114–120.

Aswathy, P., & Kalpana, K. (2019). Good woman, bad woman: Social control and self-regulation in Kerala's artisanal fisheries. *Women's Studies International Forum*, *74*, 196–203.

Augustine, A. (2016). Community-Based Rehabilitation for Children with Intellectual Disability: Experiences from Endosulfan Affected Areas in India. *Disability, CBR and Inclusive Development*, *27*(3), 132–140.

Brown, H. (1994). An Ordinary Sexual Life?: A Review of the Normalisation Principle as It Applies to the Sexual Options of People with Learning Disabilities. *Disability & Society*, *9*(2), 123–144.

Carlson, L. (2001). Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation. *Hypatia*, *16*(4), 124–164.

Chakravarti, U. (1989). Whatever Happened to Vedic Dasi, Orientalism, Nationalism, and, a Script for the Past. In K. Sangari & S. Vaid (Eds.), *Recasting Women; Essays in Colonial History* (pp. 27–86). New Delhi: Kali for Women.

Chakravarti, C. (2018). *Disability and Care Work; State, Society and Invisible Lives*. New Delhi: Sage.

Chappell, A. L., Goodley, D., & Lawthom, R. (2001). Making connections: The relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities*, *29*(2), 45–50.

Das, V., & Addlakha, R. (2001). Disability and Domestic Citizenship: Voice, Gender, and the Making of the Subject. *Public Culture*, *213*(3), 511–532.

Devika, J. (2011a). *'kulasthreeyum' 'Chantha Pennum' 'Undayathengane'*. Thiruvanathapuram: Centre for Development Studies.

Devika, J. (2011b, June 27). *Seeking The Apadhasanchaarini/ The Malayalee FLÂNEUSE*. Kafila, Retrieved from 29 November 2021. https://kafila.online/2011/06/27/seeking-the-apadhasanchaarini-the-malayalee-flaneuse

Feely, M. (2016). Sexual surveillance and control in a community-based intellectual disability service. *Sexualities*, *19*(5–6), 725–750.

Garland-Thomson, R. (2002). Integrating Disability, Transforming Feminist Theory. *NWSA Journal*, *14*(3), 1–32.

Garland-Thomson, R. (2011). Misfits: A Feminist Materialist Disability Concept. *Hypatia*, *26*(3), 591–609.

Ghosh, N. (2013). Bhalo Meye: Cultural Construction of Gender and Disability in Bengal. In R. Addlakha (Ed.), *Disability Studies in India: Global Discourses, Local Realities* (pp. 201–219). New Delhi: Routledge.

Gill, M. (2015). *Already Doing It; Intellectual Disability and Sexual Agency*. Minnepolis: University of Minnesotta Press.

HRW. (2018). *Invisible Victims of Sexual Violence; Access to Justice for Women and Girls with Disabilities in India*. New York: Human Rights Watch.

Kafer, A. (2013). *Feminist, Queer, Crip*. Bloomington: Indiana University Press.

Kahonde, C., & McKenzie, J. (2019). Sexuality and Citizenship for People with Intellectual Disabilities in Lifelong Family Care: Reflections from a South African Setting. In J. McKenzie, L. Swartz, & B. Watermeyer (Eds.), *The Palgrave Handbook of Disability and Citizenship in the Global South* (pp. 105–118). Switzerland: Palgrave Macmillan.

Kempton, W., & Kahn, E. (1991). Sexuality and People with Intellectual Disabilities: A Historical Perspective. *Sexuality and Disability*, *9*(2), 93–111.

Kim, E. (2011). Asexuality in disability narratives. *Sexualities*, *14*(4), 479–493.

May, D., & Simpson, M. K. (2003). The parent trap: Marriage, parenthood and adulthood for people with intellectual disabilities. *Critical Social Policy*, *25*(43), 25–43.

McRuer, R. (2006). *Crip Theory; Cultural Signs of Queerness and Disability*. NewYork: NewYork University Press.

Naaz, H. (2017, August 14). *Women's Sexuality in The Indian Nationalist Discourse*. Feminism in India, Retrieved May 22, 2021, from https://feminisminindia.com/2017/08/14/womens-sexuality-indian-nationalist-discourse

O'Shea, A., & Frawley, P. (2020). Gender,sexuality and relationships for young Australian women with intellectual disability. *Disability & Society*, *35*(4), 654–675.

Phadke, S., Khan, S., & Ranade, S. (2011). *Why Loiter? Women and Risk on Mumbai Streets*. New Delhi: Penguin Books.

Seibers, T. (2012). A Sexual Culture for Disabled People. In R. McRuer & A. Mollow (Eds.), *Sex and Disability* (pp. 37–55). London: Duke University Press.

Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited*. New York: Routledge.

Tepper, M. S. (2018). Sexuality and Disability: The Missing Discourse of Pleasure. *Sexuality and Disability*, *18*(4), 283–290.

Vaidya, S. (2016). *Autism and the Family in Urban India; Looking Back, Looking Forward*. Pune: Springer.

Weeks, J. (1998). The Sexual Citizen. *Theory, Culture and Society*, *15*(3–4), 35–52.

DEPARTMENT OF INTERNATIONAL RELATIONS & POLITICS
SCHOOL OF GLOBAL STUDIES
CENTRAL UNIVERSITY OF KERALA
TEJASWINI HILLS, PERIYE, KASARAGOD

NATIONAL SEMINAR
ON
TWO DECADES OF DECENTRALISATION REFORMS IN KERALA: LESSONS LEARNT AND TASKS AHEAD

CERTIFICATE

This is to certify that ~~Prof./Dr./Mr.~~/Ms Soniya A.M. PhD Scholar, Centre for Women's Studies, University of Hyderabad *was a resource person/ has chaired a session / has co-chaired a session / has participated/ has presented a paper on* "Local Self Government (LSGs) and Disability in Kerala: Experience of Kudumbasree BUDS" *in the two-day national seminar on* ***"Two Decades of Decentralisation Reforms in Kerala: Lessons Learnt and Tasks Ahead"****, held on 25th & 26th July 2018, organized by the Department of International Relations & Politics, Central University of Kerala, Tejaswini Hills, Periye, Kasaragod.*

Dr. P.C. Prasanna Kumar
Co-ordinator

Prof. (Dr.) M.S. John
Dean SGS & Head of the Department

INDIAN ASSOCIATION FOR WOMEN'S STUDIES (IAWS)

IAWS
Indian Association of Women's Studies

Southern Regional Conference on 'Intersectional Approaches to Addressing Gender, Religion, Culture: South India Focus'

Certificate

This is to certify that Ms./~~Mr.~~/~~Dr~~ SONIYA . A.M has participated in/presented a paper / was a resource person/chaired a session at the Southern Regional Conference on 'Intersectional Approaches to Addressing Gender, Religion, Culture: South India Focus' Organized jointly by IAWS, KILA and Department of Women's Studies, University of Calicut, Kerala held at University Campus from 30th - 31st January 2019.

Meera
Dr. Meera Velayudhan
President IAWS

Elizabeth V.S.
Dr. V.S. Elizabeth
Southern Regional Co-ordinator
IAWS

Ms. Mini Sukumar
Head of the Department

SL. No. 12673

UNIVERSITY OF HYDERABAD

P.O. CENTRAL UNIVERSITY, HYDERABAD - 500 046 (INDIA)

EXAMS BRANCH

PROVISIONAL CERTIFICATE CUM CONSOLIDATED GRADE TRANSCRIPT

Student Registration Number : **13CWHG02**

This is to certify that **SONIYA A M** son/daughter of **BALAN A M / VINEETHA** has been declared qualified for the award of the degree of **M.Phil. Gender Studies** after having passed the prescribed courses as follows:

Course No.	Title of the Course	Letter Grade Awarded	Credits	Month & Year of Passing
	Semester : I			
GS701	Introduction to Gender Studies	B+	4.00	NOV 2013
GS702	Feminist Theories	B	4.00	NOV 2013
GS703	Gender Science, Technology and Health	A	4.00	NOV 2013
GS704	Research Methods and Dissertation Writing	A+	4.00	NOV 2013
	Semester : II			
GS750	Dissertation Submitted on : 29 JUN 2015	A	16.00	DEC 2015

S. Supplementary I. Improvement R : Repeat

Cumulative Grade Point Average (CGPA): 8.75 (EIGHT POINT SEVEN FIVE)
Division : First Division with Distinction
Final result declared on : 04/01/2016

Date: 07/01/2016
Hyderabad

Prepared By Checked By CONTROLLER OF EXAMINATIONS

Controller of Examinations
University of Hyderabad

NOTIONS OF CARE: ANALYZING DISABILITY, GENDER AND SEXUALITY IN SELECTED BRCs IN KERALA

by Soniya A M

Submission date: 30-Jun-2025 10:26AM (UTC+0530)
Submission ID: 2708198826
File name: Soniya_A_M.pdf (888.33K)
Word count: 54727
Character count: 295244

NOTIONS OF CARE: ANALYZING DISABILITY, GENDER AND SEXUALITY IN SELECTED BRCs IN KERALA

ORIGINALITY REPORT

6%	3%	6%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Soniya A M. "Notions of sexuality: an analysis of the interplays of gender and care among adults with intellectual disabilities in Kerala", Journal of Gender Studies, 2022 Publication	2%
2	vdoc.pub Internet Source	<1%
3	ebin.pub Internet Source	<1%
4	"The United Nations Convention on the Rights of Persons with Disabilities", Springer Science and Business Media LLC, 2017 Publication	<1%
5	Renu Addlakha. "Disability Studies in India - Global Discourses, Local Realities", Routledge, 2020 Publication	<1%
6	Douglas Attoh Odongo, John Boulard Forkuor, Kwadwo Ofori-Dua, Jonathan Mensah Dapaah, Peter Dwumah. "The nature and extent of healthcare provision for people with intellectual disabilities in Ghana: A qualitative study", Journal of Intellectual Disabilities, 2021 Publication	<1%
7	assets.cambridge.org Internet Source	<1%

8	skriftserien.oslomet.no Internet Source	<1 %
9	pdfcoffee.com Internet Source	<1 %
10	www.researchgate.net Internet Source	<1 %
11	hdl.handle.net Internet Source	<1 %
12	"Disability Studies in India", Springer Science and Business Media LLC, 2020 Publication	<1 %
13	Michael L. Perlin, Alison J. Lynch. "Sexuality, Disability, and the Law", Springer Science and Business Media LLC, 2016 Publication	<1 %
14	researchrepository.murdoch.edu.au Internet Source	<1 %
15	Russell Shuttleworth, Linda R. Mona. "The Routledge Handbook of Disability and Sexuality", Routledge, 2020 Publication	<1 %
16	"Handbook of Intellectual Disabilities", Springer Science and Business Media LLC, 2019 Publication	<1 %
17	Monika Parchomiuk. "Model of Intellectual Disability and the Relationship of Attitudes Towards the Sexuality of Persons with an Intellectual Disability", Sexuality and Disability, 2012 Publication	<1 %
18	czasopisma.marszalek.com.pl Internet Source	<1 %

19	dokumen.pub Internet Source	<1 %
20	Submitted to University of St Andrews Student Paper	<1 %
21	C. Raghava Reddy. "From Impairment to Disability and Beyond: Critical Explorations in Disability Studies", Sociological Bulletin, 2017 Publication	<1 %
22	"Health of Women with Intellectual Disabilities", Wiley, 2002 Publication	<1 %
23	www.luc.edu Internet Source	<1 %
24	cjds.uwaterloo.ca Internet Source	<1 %
25	jyx.jyu.fi Internet Source	<1 %
26	research-portal.uws.ac.uk Internet Source	<1 %
27	Dorothy M. Griffiths. "Sexuality Research and Persons with Intellectual Disabilities", The International Handbook of Applied Research in Intellectual Disabilities, 01/01/2004 Publication	<1 %
28	Submitted to Institute of Technology Blanchardstown Student Paper	<1 %
29	thekudumbashreestory.info Internet Source	<1 %
30	Michele Friedner. "How the disabled body unites the national body: disability as ‘feel	<1 %

	good’ diversity in urban India", Contemporary South Asia, 2017 Publication	
31	Nick Watson. "Routledge Handbook of Disability Studies", Routledge, 2019 Publication	<1 %
32	Submitted to The University of Memphis Student Paper	<1 %
33	journals.sagepub.com Internet Source	<1 %
34	link.springer.com Internet Source	<1 %
35	www.kudumbashree.org Internet Source	<1 %
36	Submitted to University of KwaZulu-Natal Student Paper	<1 %
37	core.ac.uk Internet Source	<1 %
38	Grażyna Mikołajczyk-Lerman, Małgorzata Potoczna. "Enhancing Autonomy through the Occupational Engagement of Adults with Intellectual Disabilities: Supported Employment Model Applied by the Polish Association for Persons with Intellectual Disabilities (Branch in Zgierz)", Przegląd Socjologii Jakościowej, 2019 Publication	<1 %
39	disability-studies.leeds.ac.uk Internet Source	<1 %
40	Submitted to Deakin University Student Paper	<1 %
41	Submitted to Surabaya University Student Paper	

		<1%
42	jnu.academia.edu Internet Source	<1%
43	Submitted to CSU, San Diego State University Student Paper	<1%
44	Submitted to University of South Australia Student Paper	<1%
45	"Human Rights and Disabled Persons", Brill, 1995 Publication	<1%
46	Ideologies of Caring, 1996. Publication	<1%
47	Submitted to Trinity College Dublin Student Paper	<1%
48	Submitted to University of Melbourne Student Paper	<1%
49	pure.roehampton.ac.uk Internet Source	<1%
50	epdf.pub Internet Source	<1%
51	Len Barton. "Overcoming Disabling Barriers - 18 Years of Disability and Society", Routledge, 2019 Publication	<1%
52	Submitted to University of Limerick Student Paper	<1%
53	www.tarshi.net Internet Source	<1%
54	eprints.soas.ac.uk Internet Source	<1%

55	Submitted to University of St Mark and St John	Student Paper	<1 %
56	eprints.lancs.ac.uk	Internet Source	<1 %
57	Katie Ellis, Gerard Goggin, Beth Haller, Rosemary Curtis. "The Routledge Companion to Disability and Media", Routledge, 2019	Publication	<1 %
58	Submitted to University of Hong Kong	Student Paper	<1 %
59	red.library.usd.edu	Internet Source	<1 %
60	Submitted to University of Cape Town	Student Paper	<1 %
61	etheses.dur.ac.uk	Internet Source	<1 %
62	"Disability, Divers-ability and Legal Change", Brill, 1999	Publication	<1 %
63	philpapers.cdp.uwo.ca	Internet Source	<1 %

Exclude quotes	On	Exclude matches	< 14 words
Exclude bibliography	On		