

# **The Challenges Faced by People with Dwarfism in Kerala**

**A Dissertation submitted to the University of Kerala in partial fulfillment of requirements  
for the Masters of Social Work Degree Examination**

**SUBMITTED BY**

**Name: GANGA BABU B.**

**Exam Code: 91520402**

**Candidate code: 91521115013**

**Subject code: SW 2.4.5**



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**SREEKARIYAM, THIRUVANANTHAPURAM**

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## CERTIFICATE OF APPROVAL

This is to certify that this dissertation entitled “**The Challenges Faced by People with Dwarfism in Kerala**” is a record of genuine work done by **Ms. Ganga Babu B.**, fourth semester Master of Social Work student of this college under my supervision and guidance and that it is hereby approved for submission.

Date: 16-08-2023

Thiruvananthapuram

Research Guide

Dr. Jasmine Sarah Alexander

Department of Social Work

Loyola College of Social Sciences

Sreekariyam, Thiruvananthapuram

Recommended for forwarding to the University of Kerala

Dr. Sabu P. Thomas

Head, Department of Social Work

Loyola College of Social Sciences

Sreekariyam, Thiruvananthapuram

Forwarded to the University of Kerala

Dr. Saji P. Jacob

Principal

Loyola College of Social Sciences

Sreekariyam, Thiruvananthapuram

## DECLARATION

I, **Ganga Babu B.**, do hereby declare that the Dissertation titled “**The Challenges Faced by People with Dwarfism in Kerala**” is based on the original work carried out by me and submitted to the University of Kerala during the year 2021 -2023 toward partial fulfillment of the requirements for the **Master of Social Work** Degree Examination. It has not been submitted for the award of any degree, diploma, fellowship, or another similar title of recognition before.

Candidate Name: Ganga Babu B.

Place: Sreekariyam

Date: 16-08-2023

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## Table of Contents

CERTIFICATE OF APPROVAL .....	i
DECLARATION .....	ii
ACKNOWLEDGEMENT .....	iii
LIST OF TABLES .....	viii
LIST OF FIGURES /DIAGRAMS/ CHARTS .....	ix
ABSTRACT .....	x
CHAPTER 1: INTRODUCTION .....	2
1.1 Introduction .....	2
1.2 Statement of the Problem .....	3
1.3 Background of the Study .....	4
1.4 Relevance and Significance .....	5
1.5 Chapterization .....	5
CHAPTER 2: LITERATURE REVIEW .....	8
2.1 Introduction .....	8
2.2 Review of Literature .....	8
Perception of Disability with respect to Dwarfism .....	8
Impacts due to Cultural Representation .....	8
Physical Aspects of People with Dwarfism .....	9
Educational and Life Satisfaction .....	10
Psycho-Social Challenges faced by people with dwarfism .....	11
Career Challenges .....	12
Gender .....	13
People with Dwarfism in India .....	14
Choice of Methodology .....	14
2.3 Theoretical Framework .....	15
Social Model of Disability .....	15
General System Theory .....	15
2.4 Research Gap Analysis .....	16
CHAPTER 3: METHODOLOGY .....	18
3.1 Introduction .....	18
3.2 Title of Study .....	18
3.3 Objectives .....	18
General Objective .....	18

Specific Objectives .....	18
3.4 Definition of Concepts .....	18
3.5 Pilot Study .....	20
3.6 Research Approach.....	20
3.7 Research Design .....	20
3.8 Universe and Unit of Study.....	21
3.9 Sampling Design (Inclusion- Exclusion Criteria) .....	21
Inclusion criteria .....	21
Exclusion criteria: .....	21
3.10 Data Collection .....	21
3.10 Pre-test.....	21
3.11 Data Analysis .....	22
3.12 Ethical Consideration .....	22
3.13 Assumptions, Limitations, and Scope .....	22
Limitations .....	22
Scope.....	23
CHAPTER 4: DATA COLLECTION AND CASE DESCRIPTION .....	25
4.1 Introduction.....	25
4.2 Socio-demographic Profile of the Respondents .....	25
Objective 1: To understand the extended challenges faced by people with Dwarfism .....	30
Objective 2: To understand their accessibility to rights and entitlements.....	33
Objective 3: To understand the support system needed for people with dwarfism .....	38
4.3 CASE DESCRIPTION.....	40
4.3.1 CASE 1 .....	40
Socio-demographic Profile.....	40
Case Details.....	41
Physical Challenges .....	41
Social participation .....	42
Support System .....	42
Service Accessibility .....	43
Understanding of basic rights.....	44
Coping with stress.....	44
4.3.2 CASE 2 .....	44
Socio-demographic Profile.....	44
Case Details.....	45

Physical Challenges .....	45
Social participation .....	46
Support System .....	46
Service Accessibility .....	46
Understanding of basic rights.....	47
Coping with Stress .....	48
4.3.3 CASE 3 .....	48
Socio-demographic Profile.....	48
Case Details.....	49
Physical Challenges .....	49
Social Participation .....	49
Support System .....	49
Service Availability .....	50
Understanding Basic Rights .....	50
Coping with stress.....	50
4.3.4 CASE 4 .....	51
Socio-demographic Profile.....	51
Case Details.....	51
Physical Challenges .....	52
Social Participation.....	52
Support System .....	52
Service Availability .....	53
Understanding of Basic Rights .....	53
Coping with Stress .....	54
4.3.5 CASE 5 .....	54
Socio-Demographic Details .....	54
Case Details.....	54
Physical Challenges .....	54
Social Participation.....	55
Support Systems.....	55
Service Availability .....	55
Understanding of Basic Rights .....	56
Coping with stress.....	56
CHAPTER 5: DATA ANALYSIS, INTERPRETATION AND DISCUSSIONS .....	58
5.1 Introduction.....	58

5.2 Data Analysis, Interpretation and Discussions .....	58
Objective 1: To understand the extended challenges faced by people with dwarfism .....	58
Objective 2: To understand their accessibility to rights and entitlements.....	60
Objective 3: To understand the support system needed for people with dwarfism.....	62
CHAPTER 6: FINDINGS, SUGGESTION AND CONCLUSION .....	65
6.1 Introduction.....	65
6.2 FINDINGS .....	65
Objective 1: To understand the extended challenges faced by people with dwarfism .....	65
Objective 2: To understand their accessibility to rights and entitlements.....	65
Objective 3: To understand the support system needed for people with dwarfism .....	66
6.3 SUGGESTION .....	66
Objective 1: To understand the extended challenges faced by people with dwarfism .....	66
Objective 2: To understand their accessibility to rights and entitlements.....	66
Objective 3: To understand the support system needed for people with dwarfism .....	67
6.4 Implication of the Study .....	67
6.5 Conclusion .....	68
REFERENCE.....	70
INTERVIEW SCHEDULE .....	74
INTERVIEW GUIDE.....	93



## LIST OF TABLES

Table No: 3.4.1: Theoretical and Operational Definition.....	18
Table 4.1: Age Group of Participants .....	27
Table 4.2: Level of Education .....	28
Table 4.3: Annual Income of the respondents .....	28
Table 4.4: Employment of the participants .....	29
Table 4.5: District and Participants.....	29
Table 4.6: Knowledge on their physical condition .....	30
Table 4.7: Dwarfism in family .....	30
Table 4.8: Traits of dwarfism in Previous Generations .....	31
Table 4.9: Extended challenges of disability (Physical and Social aspects) .....	31
Table 4.10: Associated Ailments.....	32
Table 4.11: Marital Status.....	32
Table 4.12: Awareness on RPwD Act, 2016.....	33
Table 4.13: Knowledge about addition of Dwarfism in RPwD Act, 2016.....	34
Table 4.14: Financial Status and Employment .....	34
Table 4.15: Pension and Financial Status.....	35
Table 4.16: Services Accessed .....	36
Table 4.17: Participants awareness on Government Schemes .....	37
Table 4.18: Gender Disparity in Receiving Support.....	38
Table 4.19: Supported needed by the Participants .....	39

## LIST OF FIGURES /DIAGRAMS/ CHARTS

Figure 4.1 Gender of the Respondents .....	25
Figure 4.2: Religion of the respondents .....	26
Figure 4.3 Type of Dwarfism .....	26
Figure 4.4 Height of the Respondents .....	27
Figure 4.5 Children.....	33
Figure 4.6 : Services from Agencies other than Government .....	36
Figure 4.7: Accessibility to Government Schemes.....	37
Figure 4.8 : Religion as Support System .....	38
Figure 4.9: Coping mechanism Adopted (BRIEF COPE) .....	39
Figure 4.10: Coping Mechanisms.....	40
Figure 4.11 Genogram of Case 1 .....	41
Figure 4.12 Genogram of Case 2 .....	45
Figure 4.13 Genogram of Case 3 .....	48
Figure 4.14 Genogram of Case 4 .....	51
Figure 4.15 Genogram of Case 5 .....	54

## ABSTRACT

Disability has been a topic of study that the world has been curious to look into. With the progression of science and technology, the purview of the definition of disability has been widened. In India, the rights of differently abled has been recognized with Persons with Disability Act, 1995 and Rights of Persons with Disabilities (RPwD) Act, 2016. These acts lay down the responsibility of appropriate governments in taking responsibilities so as to ensure the basic rights of Persons with Disabilities (PwD). Among the 21 disabilities under RPwD Act, 2016 dwarfism is included into. Dwarfism, a condition characterized by short stature due to various medical conditions, presents unique hurdles in different aspects of life, often leading to marginalization and discrimination. That is, they are people who are yet to enjoy the promised accessibility in build environment, transportation and Information and Communication Technology ecosystem.

Here in this work, the researcher attempts to explores the multifaceted challenges encountered by individuals living with dwarfism, shedding light on the social, psychological, and physical obstacles that impact their well-being and overall quality of life. The study adopts a mixed research approach with embedded design incorporating interview guides and in-depth interviews. The research participants encompass a diverse range of ages, domicile, and socio-economic backgrounds, allowing for a more holistic understanding of the challenges faced by them within the modern society.

The major themes of the study include – extended challenges including physical, social, environmental, career and others; awareness upon the basic rights and entitlements and understanding on the support systems existing for people with dwarfism. The study also attempts to suggest interventions so as to address the existing gaps in the system, thereby ensuring inclusivity and empowerment. The researcher expects that the findings of the research would help in growing the body of knowledge in social work as well as would in aid in advance studies on challenges faced by people with dwarfism. The research also intends to shed light on the grass root realities and the gap in addressing the issues of people with dwarfism to policy makers. It is necessary to ensure human rights regardless of the physical stature, thus striving for an inclusive society that would support them to reach their full potential.

*Keywords: Dwarfism, Build Environment, Information and Communication Technology (ICT) ecosystem*

**CHAPTER 1**  
**INTRODUCTION**

## CHAPTER 1: INTRODUCTION

### 1.1 Introduction

‘Disability’, is a term and an idea that is not new to the modern world. ‘Disability’ perceived by each country, states, communities, individual, etc. are different as they are defined based on ‘being’ and ‘doing’ things differently. It is highly based on the context of the discussion and thus is highly considered a subjective aspect of the discussion (Chand & Reddy, 2012). In the past, it was associated with many superstitious beliefs and attributed to the wrath of the God or deity they believed in. But with the advent of science and innovative technologies, there is a huge shift in these ideas that existed. With the development of science, people started to associate disabilities with the science behind their causes as well as reasons. As the scientific study progressed in this area, the number of categories of disabilities that got recognized increased as well.

The disability was generally considered as a physical problem that existed in a person’s body and that needs medical attention. This trajectory was positively deviated with the concept ‘Social Model of disability’, that distinguished impairment and disability. In social model of disability, the disability is identified as a disadvantage that is rooted from lack of fit between a body and its social environment (Goering, 2015). That is, social model of disability emphasized on the societal and environmental barriers that have contributed to the experience of disability rather than focusing on medical aspects. It advocates for a shift in the focus of action from the individual to society, thereby addressing the social barrier and promoting inclusivity (Oliver & Sapey, 1999).

With that, disability is perceived as an issue of social welfare, and possibly because of that People with Disabilities (PwD) are largely considered as people who are in need of charitable assistance. A sympathetic approach rather than an empathetic approach is shown toward them which has categorized them as ‘vulnerable sections’. The world started to speak about inclusivity and the need for inclusivity in ensuring that everyone irrespective of their capacities gets to enjoy their fundamental rights with respect to food, shelter, employment, a clean environment to live in, a society without any sort of discrimination, etc. And thus, modern society across the globe advocated for inclusivity in matters of tangible as well as intangible aspects of day-to-day life including infrastructure, employment opportunities, standard of living, etc.

Dwarfism is one such disability that is recognized under the Rights of People with Disabilities Act, 2016 (RPwD Act). The RPwD Act, 2016 replaced the Persons with Disabilities Act, 1995 so as to be in compliance with United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which India signed and ratified in 2007 (Vishwakarma, 2017). The Convention on the Rights of Persons with Disabilities (CRPD) sets out the fundamental rights of people with disability which intend to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedom by all Persons with Disabilities (PwD), thereby respecting their inherent dignity (Australian Human Rights Commission, 2019). The purview of the RPwD act was enhanced to be in compliance with UNCRPD, which included Dwarfism in it. This explicitly points out that, it is the duty of the state to promote and protect the rights and dignity of people with dwarfism in various aspects including educational, social, legal, economic, cultural and political. But the question is whether the advocated concepts of inclusivity are fully realized in a developing country like India and especially in a state like Kerala, which is said to stand at par with Western countries through its Kerala Model of Development paradigm.

## **1.2 Statement of the Problem**

Dwarfism is a short stature that is a result of a genetic or medical condition and has an adult height of 4 feet 10 inches (147 centimeters) or less. Generally, there are two types of dwarfism- Proportional Dwarfism and Disproportional Dwarfism. Proportionate dwarfism is the condition where the body is proportionately small if all parts of the body are small to the same degree and appear to be proportionated like a body of average stature. While disproportionate dwarfism is where some parts of the body are small and others are of average size or above average size. Generally, it seems to inhibit the development of bones and could be present at birth or appear in early childhood, thereby limiting overall growth and development (Mayo Clinic, 2018).

In India, dwarfism is considered a disability under the purview of RPwD Act, 2016 under the category of locomotor disability. As per the act, the evaluation of the short-statured person shall be considered irrespective of whether it is the proportionate variety or disproportionate variety and is accompanied by underlying pathological conditions (Department of Empowerment of Persons with Disabilities (Divyangjan), 2022). When different type of dwarfism has different associated issues, it is not justifiable to treat them similarly while assessing them for providing certificates, that help them to have a better position in society.

According to the Notification on Guidelines for the Assessment of Various Specified Disabilities based on RPwD Act 2016, every 1-inch vertical height reduction is equated to 4 percent permanent physical impairment in relation to whole body. As per the Entry 9 of State list of seventh schedule of the Indian constitution, 'Relief of the disable and unemployment' falls under the purview of state government. Because of this, each state has its own criteria for disability certification. For example, in Kerala, 40 percent disability is considered as benchmark for disability pension. While in Haryana, dwarf individuals living in various parts of the state are entitled to an allowance of Rs.1600 per month per beneficiary, which is a part of disability pension. But all the dwarf individuals are not eligible for this, only male persons of height 3 feet 8 inches or less height and a female of height 3 feet 3 inches or less (equivalent to 60 percent handicapped) is entitled to this pension. From Rs. 1600 in 2016, the fund has incremented with time and as of April 2023, the allowance is increased to Rs.2300 (Directorate of Social Justice and Empowerment, 2023). This indicates an existing disparity in the allocation of social benefits across various states of nation.

Little people are independent in many ways, but feel challenged with respect to "Transport", "Crime, safety & security", and "Health and Well-being". They also face challenges in other areas such as education & training, work & employment, housing, leisure, care & support, family & community life, etc., but not as pressing as the earlier three items mentioned (Baidi, Ilias, & Ghazali, 2018).

Even though Dwarfism is added as one among the 21 disabilities in RPwD Act, 2016, welfare programmes and policies, that are directed for ensuring their social inclusion haven't come into force effectively. Targeted programmes for the wellbeing of People with Dwarfism haven't been formulated and that has sidelined their inclusivity into the society heavily. The limited availability of studies regarding People with dwarfism in India, could be read in association with this. Though there are many medical studies on people with dwarfism, there is a limitation in matter of studies regarding their daily challenges, social inclusion and social participation. Through the study, the researchers here try to analyse various thus challenges faced by people with dwarfism.

### **1.3 Background of the Study**

According to World Health Organisation (WHO), an estimated 1.3 billion people, that is 16 percent of the global population experience significant disabilities (WHO, 2023). According to Census 2011, 2.13 percent of the total population are disabled, with 2.21 percent from rural

area and 2.24 percent in urban area. That is, out of the 121 crore population, 2.68 crore are 'disabled' (Office of Chief Commissioner for Persons with Disabilities, 2021). According to the 58th round of the NSS, there were 18.5 million persons with disability in 2002 compared with 21.9 million reported by the Census 2001 (Chand & Reddy, 2012). According to the Disability Census 2015, the number of people with Dwarfism or Short Stature is 6079, that is 2 people per 10000 population (0.77 %) (Kerala Social Security Mission, 2023).

Variety of medical complications might be resulted from the condition as they grow up such as delayed motor milestones, bowing of the lower legs, ear dysfunction and spinal curvature (Baidi, Ilias, & Ghazali, 2018). Dwarfism is a visible disability that could be traced back to cultural representation of the population including in folklores and lowbrow entertainment. Even for the current media they are subject topics due to their distinctive appearance primarily and talents secondarily (Pritchard, Cultural representations of people with dwarfism and the social consequences, 2017). Though based on records there are more than 6000 population of People with Dwarfism in Kerala, the researcher found it difficult to reach out to the population due to various reasons.

#### **1.4 Relevance and Significance**

Irrespective of the disabilities, it is imperative to treat every citizen of the nation with equality and to ensure equity for them. Based on census 2001 and 2011 respectively it is seen that the percentage of disabled population increased from 2.13 percent to 2.21 percent (Office of Chief Commissioner for Persons with Disabilities, 2021). Despite an increase in the disabled population, the absence of targeted interventions for identified disabilities increases the concerns. Also, the limited studies conducted apart from medical aspects on these disabilities, limit the further understanding of the social aspects of such under-studied disabilities. In this scenario, it is necessary to bring light into such. Here, through this study, the researcher attempts to understand further about the challenges faced by People with Dwarfism.

#### **1.5 Chapterization**

The study is divided into six Chapters,

Chapter I: The first chapter attempts to provide an introduction into the study and various other concepts related to the study and state the problem that is addressed in the research paper, its intensity, relevance and significance of the study in current scenario.



Chapter II: The second chapter attempts to deal with the review of literature available in International and Indian context or perspectives. This helps the trainee to identify the dimension in which the researcher needs to focus more. A gap in these studies gets discussed in the following.

Chapter III: It discusses the methodology that the researcher uses in her study. It includes the details like title, general and specific objectives, research design, sampling techniques, details of the pilot study, Method of data collection, data analysis, and limitations of the study.

Chapter IV: Details of the qualitative data collected and description of cases used in the study are recorded in this chapter in an elaborated manner for a better understanding of each case. Cases of respondents are described through narrative and verbatim reporting.

Chapter V: The data is analysed descriptively and thematically, analysis to link the findings back to existing literature, and discussion of the data collected for the study are discussed in this chapter in a detailed manner.

Chapter VI: This chapter deals with major findings followed by discussions, suggestions, and conclusions. The last pages of the dissertation include will the bibliography, appendix, and tools used for data collection in this study.

**CHAPTER 2**

**LITERATURE REVIEW**

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

The second chapter of the research deals with the literature reviews based on the various studies conducted on the topic, related aspects or associated events, that has impact on the physical, social, economic aspects. Each theme is reviewed in literature mainly in International and Indian perspectives. The final part of the chapter deals with the research gap identified.

### **2.2 Review of Literature**

#### **Perception of Disability with respect to Dwarfism**

In 2017, Pritchard in his work *Cultural Representation of People with Dwarfism and Social Consequences* mentions that, though at first glance dwarfs do not appear to be disabled, but in a built environment created for someone of average stature that perception can change. Disability has different meanings to different people and in different circumstances. Despite the usefulness of disabled spaces and facilities for dwarfs, their access to these spaces is often challenged by other members of the public. This can lead to disabling situations and unwanted confrontation with other members of the public. The access to disabled facilities and spaces should be hassle free, but this can only come about when it is recognised that people with impairments who are non-wheelchair users require alternative access to spaces and facilities. An inclusive society can only come about if everyone, regardless of the impairment is given access to the built environment and this includes access to alternative spaces and facilities when needed (Pritchard, 2017).

#### **Impacts due to Cultural Representation**

Dwarfism is a visible disability with strong connections to various forms of entertainment, including folklore and lowbrow entertainment. Throughout history, as within the current media, dwarfism have often been a popular form of entertainment, not so much for any talents they might have, but due to their distinctive appearance, in particular their small stature. How disability is culturally represented can affect how it is understood and, subsequently, how those with the disability are treated within society. Media narratives that misrepresent disability produce dominant societal beliefs about disability. How these beliefs affect dwarfs in society has largely been ignored (Pritchard, 2017).

According to Haller and Ralph (2004), “cultural codes of conduct tell many societies not to laugh at people who are physically different”, yet that is not the case with the dwarfs. With

various cultural representations such as circuses, often people are encouraged to laugh at them. It is also to be noted that people are not encouraged to laugh at any other disabilities or deformities. Thus, as Barnes said in 1991, cultural representation is a major contributing factor to the discrimination of differently-abled. This was also supported by the studies of Heider et al. 2013, which shows that cultural stereotypes and personal beliefs have led people to perceive dwarfs as weird, incapable, childlike and used in entertainment as an object to laugh at. Also, Barnes in 1992 added that these stereotypes through visual media has generated an assumption regarding the lives of dwarfs and has negatively affected their attitude towards them.

It is apparent that these negative reactions affect how dwarfs negotiate public spaces, such as by avoiding spaces where they have received or think they will receive unwanted attention that is influenced by cultural representations. For many dwarfs, their avoidance behaviour had more to do with being apprehensive about a space than it had to do with adverse past experiences. Avoiding spaces can be seen as a strategy to reduce the amount of unwanted attention one receives in public. Overall, representations of dwarfs are part of the social barriers that dwarfs encounter and, thus, can be seen as a contributing factor to dwarfs' disablement (Pritchard, 2017).

Providing a more varied representation of dwarfism can help to change perceptions of dwarfism and, thus, the way other members of the public perceive and interact with dwarfs. Depicting dwarfs in everyday situations and playing everyday characters (e.g., as a teacher) can help to challenge existing stereotypes of dwarfs. With regard to reality shows, it is important to take into consideration the aim of a given show and whether or not it challenges existing representations of dwarfs (Pritchard, 2017).

### **Physical Aspects of People with Dwarfism**

The resultant short stature, shortened limbs, and medical complications substantially impact both physical and psychosocial aspects of daily life, and consequently, patient quality of life (QoL), starting from a very early age. Physical challenges due to dwarfism vary in individuals based on the type of dwarfism they are with. For example, individuals with Achondroplasia physical manifestations include functional limitations or decreased level of independence in carrying out activities of daily living (ADLs), such as grooming, bathing, grocery shopping, preparing meals, and climbing stairs (Constantinides, Landis, Jarrett, Quinn, & Ireland, 2021). It is also observed that the impaired rarely go outside the house because of physical barriers to their mobility and attitude of other in the family that would discourage them from moving out with the perception or claiming that their presence is not needed (Chand & Reddy, 2012).

Obesity is another health risk found common among people with achondroplasia, a common form of dwarfism and many factors contribute to it, such as reduced physical activities due to mobility limitations and metabolic differences. It is also important address this obesity in this population so as to mitigate the potential health complications associated with excess weight including joint pain, back pain, etc. In order to address these challenges, a multidisciplinary approach is needed, which combines dietary modifications, physical activities and behavioural changes. It also understood that in Achondroplasia patients, obesity could worsen the risk of sleep apnea and early cardio vascular mortality. This is because quality of food could influence the development of other complications. But in today's world, people do not often consider the full nutrition protocol for disease management. It is difficult to prevent obesity in achondroplasia due to the precocity of phenomena. In order to handle this, an individualized care plan with the involvement of a healthcare professional experienced in working with individuals with achondroplasia is needed (Saint-Laurent, Garde-Etayo, & Gouze, 2019).

### **Educational and Life Satisfaction**

The individuals with dwarfism have a tendency to develop physical, social, as well as problems in the field of education, which will affect various psychological aspects of a person. Therefore, it is important to examine life satisfaction and other psychological aspects so that the meaning of life in dwarfism is better (Elfina & Ramadhani, 2019).

Life satisfaction is a cognitive assessment of how well and satisfying things that have been done by individuals in their lives as a whole and on the main areas of life that they consider important (domain satisfaction) such as interpersonal relationships, health, work, income, spirituality and leisure activities. The components of life satisfaction include the desire to change lives, satisfaction with life today, life satisfaction in the past, satisfaction with life in the future, assessment of others towards one's life. Some factors that can affect life satisfaction in an individual is health that allows individuals at any age to do activities (Elfina & Ramadhani, 2019).

The factors influenced the life satisfaction of dwarfism in early adulthood were health, current living conditions, and the presence or absence of the gap between the desire and what it was currently living. For work and employment status, it seemed less to be dominant because early adulthood was an age where sometimes someone was still dependent on parents, especially the subject was still a student so what she did now aimed at giving the best effort in her education (Elfina & Ramadhani, 2019).

### **Psycho-Social Challenges faced by people with dwarfism**

Kennedy (2003) argues that dwarfism is a social disability, as dwarfs receive a lot of unwanted attention due to their appearance, including staring and verbal abuse (Pritchard, Cultural representations of people with dwarfism and the social consequences, 2017). They faced stereotyping (for example, commonly shuffled off into entertainment) or often living in isolation. Dropping out of school was common because they couldn't take the ridicule from other kids. The hardest thing was not size, but rather people's attitudes (Baidi, Ilias, & Ghazali, 2018). Their psychosocial function can be negatively impacted by depression, anxiety, low self-esteem, problems with peer relationships (e.g., bullying) and other behavioural and emotional problems (Constantinides, Landis, Jarrett, Quinn, & Ireland, 2021).

Concern about difficulties in accessing public transport or working place as highlighted by Little People exemplified the consequent of public's (including policy makers) ignorance towards Little People. These were issues that stemmed from insensitive environmental settings done to mainly serve the needs of "average" people. As highlighted by Berreby (1996), the challenges confronting Little People were mostly caused by the attitude and mind set of people surrounding them. As much as the women need a special coach in commuters, the elderly and pregnant women need silver seats in public transport, the deaf and mute need television programmes with sign language, and the blind need rail guide and braille writing in daily life; the Little People need surrounding environment and tools that fit their height and size in order to be fully functional and productive. Lack of research done to highlight the condition of Little People contributed to the unawareness towards their needs (Baidi, Ilias, & Ghazali, 2018).

According to the studies of Crocker, Major & Stelle (1998), Schmitt & Branscombe (2002) and Smart Richman & Leary (2009), being a member of socially stigmatized group can have negative consequences for the individual during their life. People thus socially stigmatised often experience passive discrimination in critical life domains including education, employment, social interactions, etc. According to the studies of Jetten et al. (2006), people with dwarfism are frequently the only affected individual in their families, neighbourhoods, schools, etc. and are likely to experience their condition as a "black sheep" by others. In such cases, it is important to facilitate contact and to encourage a sense of community feeling so as to develop coping mechanism to handle stressful situations (Fernández, Branscombe, Gómez, & Morales, 2012).

The way in which a society react towards people with dwarfism determines the extend of exclusion these people face and also attributes to the extent of participation of disabled people

in social, religious, and political functions (which could be considered as an important indicator of inclusion and exclusion). It could also be observed that the social functions of disabled varied based on their impairment and also could point out that the observable exclusion of the impaired in the social life emanating from the social construction of impairment (Chand & Reddy, 2012).

### **Career Challenges**

The challenge of the dwarfs in the world of work is the greatest. This is because work is the source or essence of life for survival such as food, clothing, and shelter. Since Indian based studies on similar themes are limited, the researcher depended upon Malaysian based study titled “The Study of Little People in Malaysia – Barriers and Challenges” by Baidi, Ilias & Ghazali (2018). Kerala and Malaysia could be considered for a comparative analysis due to various reasons associated with their pattern of living. Kerala and Kuala Lumpur (capital of Malaysia) shares similarities with respect to climate patterns, natural setting, usage of similar words in vernacular language (examples: Bhoomi, Raja, Rasa, Varna, etc.), the similar pattern of dressing could be traced including western clothing , white vest and dhoti (most prevalent in many parts of Kerala especially in Northern Kerala), religious unity with cultural diversity comprising population of Chinese, Malaysians, Indian and other from various religious believes such as Islam. Also, could trace similar climate patterns with summer rains, geographic terrain, flora and fauna, house construction, domestication of poultry birds such as chicken and duck in rural parts, long traffic congestions in busy streets, etc. With the comparison, the researcher is attempting to understand the theme based on the legislative and executive actions of Malaysian government (The attempt is due to the absence of proper studies on Indian legislation for differently abled or People with Dwarfism).

Although the Malaysian government has introduced the Disability Act 2008 which requires the public and private sectors to employ these groups, it still does not help as there is no law enforcement force. The result is that many employers do not want to get these people working on their physical factors despite their high academic qualifications. Many jobs are also offered only for the lower-class categories. This is because employers are not convinced with the capabilities of these dwarfs. Although their intellect is as normal as anyone else, only physical appearance to be different. The degree to which employers are willing to accept workers with disabilities into the organization also influences the workforce's success in securing employment (Zainudin, Rasid, Yusop, Othman, & Rong, 2021).

According to two studies by Baidi et. Al (2018) and Heider et.al (2018), The greatest challenge for a dwarf in the workplace is not the work task, it about the relationship and human behaviour. Workplace challenges commonly encountered by these dwarfism groups include discrimination, exploitation, and bullying, payroll, relationship with supervisor, organizational support, and workplace adjustment. Lack of social skills has to make dwarfs have negative self-concept and lack of self-confidence. It facilitated these groups of individuals to become victims of discrimination, exploitation, and bullying in the workplace which eventually led them to quit their jobs. Not only that, they have also become accustomed to the experience of discrimination as they have often experienced in education, training, and employment since childhood. If these perceptions persist, it will affect their career aspirations and limit the job opportunities they should have (Zainudin, Rasid, Yusop, Othman, & Rong, 2021).

The condition of office buildings built according to normal height standards also makes it difficult for these dwarves to work. For example, lift button, switch position, table height, toilet height, door and access card height, and counter height. Not only that, the distance from one department to another makes it difficult for them to move from one department to another. There are also office buildings that are not electric wheelchairs. This makes it difficult for some of the dwarves to find jobs. In addition, public transport is also built to the standard and dangerous standard. Private vehicles, where require a high cost of repairs before they can be used. Sometimes these vehicles need to be imported from abroad (Pritchard, 2014). Therefore, the real obstacles of the dwarf in the pursuit of employment are the views of the community and co-workers, the flexible organizational culture, the challenges of the workplace, the parents who are too protective to look down on their abilities, low self-esteem, and lack of confidence. Social skills have also been identified as a hindrance to them getting or staying in a job for a long time (Zainudin, Rasid, Yusop, Othman, & Rong, 2021).

### **Gender**

The everyday life of women with dwarfism are affected by intersecting discourses of gender and dwarfism. During the course of daily living, they are confronted by the social and material implications of their extremely short stature. Furthermore, their experiences cannot be understood in terms of simply adding dwarfism to gender discourses. Rather, their experiences suggest that dwarfism transforms conventional gender identities and, conversely, that gender transforms general perceptions of dwarfism. Their reception in public space is influenced by the historical discourses of gender, disability, maturity and, specifically, by a confluence of contradictory historical discourses of dwarfism that cause their bodies often to be viewed



negatively as cultural artifacts. It is the dominant discourses of gender and disability and their expression in the built environment that are, at times, disabling for them (Kruse II, 2003).

### **People with Dwarfism in India**

They, largely, remain isolated from the mainstream. In India, disability organisations, which are both for and of “persons with disabilities”, do not represent fully or emphatically the vast spectrum of disabilities that exist. They focus much more on specific disabilities in a stand-alone categorization, rather than catering to different types of disabilities (Pathak, 2015).

Another aspect associated with “persons with disabilities” in India is, that most of them and their families, are unaware of their rights and entitlements. In addition, many stigmas and myths are tagged to being disabled. There are many other important sociological factors such as gender, socio-economic status, region and religion, which impact how disability is understood and dealt with. It is significant to highlight, as basic conceptual understanding about “persons with disabilities” is, that they are a heterogeneous group with diverse needs and requirements. The impact of the disability, on their life and activities, depends on the type and degree of impairment (Pathak, 2015).

With lack of research or studies done that highlights the issues faced by people with dwarfism or “Little People”, there exists an unawareness regarding their needs as well as there is a need to acknowledge as an individual with the rights as any other person. Thus, it could be said that, it is the duty and obligation of others to have consciousness in promoting the creation of barrier free transportation and other facilities to little people or any other person with disabilities. In some developed countries like United States of America (USA), some would take dwarfism as an identity and would demand others to acknowledge them as “Little”. It is an attempt to be recognised as different rather than being identified as disabled (Baidi, Ilias, & Ghazali, 2018).

### **Choice of Methodology**

Disability is considered a relative term based on how each culture defines its norms of ‘being’ and ‘doing’ differently. Also, it is the socio-cultural dimensions of the respective society that shapes the response of the members who respond towards the impairments (Chand & Reddy, 2012). That is, based on ideological orientation, the factors that are employed in explaining the perceptions and behavior of humans could be varied. An ideology could involve values, beliefs, and conventions about the ways in which governments, citizens, and nations relate to modern society (Demir & Pismek, 2018). In such cases a comprehensive analysis of the research

problem is needed, as one method of research may not be sufficient to capture all the relevant data to substantiate the study, thus could opt for a mixed method.

The basic agenda behind the usage of mixed methods is to facilitate a fuller understanding of the research problem than the usage of single or mono-method approaches (Guest & Fleming, 2015). According to Creswell and Plano Clark (2011), integrating the methodology has advantages such as strengthening the weakness of others, providing comprehensive and convincing evidence, answering questions that a single method cannot, encouraging an interdisciplinary approach, encouraging the use of multiple worldviews or paradigms and more practical as it permits the usage of multiple techniques and approaches that could address the research question the best. It also equips the researcher to explain the initial results when one data source is insufficient to answer the questions (Guest & Fleming, 2015).

## **2.3 Theoretical Framework**

### **Social Model of Disability**

The social model of disability is a response to the traditional model of disability, where disability was generally perceived as a condition that needed medical attention. With social model of disability shows how much it is disabling for individuals who have impaired bodies has to do with the physical and social arrangements and institutional norms that are themselves alterable such as stairs case verses ramps, presentation of data using only auditory means verses universal design for communication, restrictive definitions of job requirements verses expanding accommodation for different modes of performing work, etc.). People with disability are considered minority and rendered incapable of work and maintain social relationships. Inorder to ensure the participation, an inclusive framework is needed with structural changes so as to ensure more inclusivity for people of differing body types. Social model of disability also focuses on attitudinal obstacles faced by people with non-standard bodies. The distinction between impairment-disability has been supportive in supporting people who face unjust treatment and tendency to medicalize their problems (Goering, 2015).

### **General System Theory**

The Austrian biologist, Karl Ludwig von Bertalanffy is credited for the development of system theory. His original work was in organismic system theory where he studied the thermodynamic equilibrium of steady state in living organisms as open-systems (Adams, 2012). In 1969, for his seminal work, von Bertalanffy described on General Systems Theory as a concept that

systems cannot be reduced to a series of parts functioning in isolation, rather it is needed to understand as a whole (Anderson, 2016).

#### **2.4 Research Gap Analysis**

Though the disability has been an idea that is constantly being studied in terms of medical aspects, very limited studies are conducted in relation to the other aspects including social, economic, environmental aspects, etc. India is one of the nations with huge population of disabled people live, Yet, the concept of dwarfism is less discussed in Kerala or even in India. It is also to be pointed out that, there are limited Indian studies that discusses about dwarfism and problems faced by people with dwarfism. The researches are absent or limited even regarding the legislations prevailing, its effectiveness and check the enjoyment of rights and entitlements. Even though the government allocate budget and design programmes for the population, many are not beneficiary of it. Discussions or studies in this concept is also absent in Indian perspective.

**CHAPTER 3**

**METHODOLOGY**

## CHAPTER 3: METHODOLOGY

### 3.1 Introduction

In the third chapter of the research, the researcher is detailing the title of the study, objectives of the study, operational definitions used for the purpose of the study, details regarding the pilot study, Methodology used for conducting the study which provides the details regarding the research design, sampling, data collection, etc.

### 3.2 Title of Study

‘The Challenges faced by People with Dwarfism in Kerala’.

### 3.3 Objectives

#### General Objective

To understand the challenges of people with dwarfism

#### Specific Objectives

1. To understand the extended challenges faced by people with dwarfism.
2. To understand their accessibility to rights and entitlements.
3. To understand the support system needed for people with dwarfism.

### 3.4 Definition of Concepts

**Table No: 3.4.1: Theoretical and Operational Definition**

Concepts	Theoretical Definition	Operational Definition
Dwarfism	Dwarfism is people who have special characteristics that are different from people in general. This particular characteristic is related to one's height. Humans are said to be dwarfism syndrome and has a height of less than 147 cm, so it looks smaller than people in general (Elfina & Ramadhani, 2019).	Dwarfism is short stature that results from a genetic or medical condition. Dwarfism is generally defined as an adult height of 4 feet 10 inches (147 centimeters) or less in Kerala.
Challenges	A situation needing great mental or physical effort in order to be done successfully, or the situation that require	Physical, Social, Economic Environmental and Career hinderances that inhibit the people

	great effort (Online Cambridge dictionary, 2021).	with dwarfism to function normally like other people.
Accessibility	Accessibility is a basic characteristic of the built environment, is the condition that makes possible to arrive, entry, exit and use houses, shops, theatres, parks and work places and it allows people to participate in the social and economic activities for which they have been designed (European Union, 1996).	Accessibility refers to the extent to which something, such as an environment, product, service, or information, is designed and organized in a way that allows individuals with disabilities or diverse needs to access, use, or participate in it effectively and without barriers
Support	Support is the provision of information, advice, and tangible assistance to individuals or groups in times of stress, crisis, or need, with the goal of enhancing their coping abilities, self-esteem, and well-being (Cutrona and Russell (1990).	Support can be defined as a set of actions, resources, or services provided to individuals or groups in order to assist, empower, or enable them to overcome challenges, achieve their goals, or improve their well-being. It involves offering assistance, guidance, encouragement, and sometimes tangible aid to address specific needs or promote overall development.
Coping mechanism	Coping mechanisms refer to the cognitive and behavioural efforts made to manage the internal and external demands of stressful situations. They involve constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or	Coping mechanisms can be defined as psychological processes, strategies, or behaviours that individuals employ to manage or adapt to stress, adversity, or challenging situations. These mechanisms are aimed at reducing emotional distress, maintaining

	exceeding the resources of the person (Lazarus, R. S., & Folkman, S. ,1984).	psychological well-being, and restoring a sense of balance and control.
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### 3.5 Pilot Study

Researcher conducted a pilot study to analyse whether a full-scale study could be conducted using the prepared set of questionnaires so as to check whether any other sort of changes to be made on the components included for the study. The pilot study conducted using the google forms in which the respondents filled the response by themselves have helped the researcher to understand how to change the question structure to make the questions easier for the respondents to understand and respond with further conviction. Based on the result of the pilot study the researcher scheduled time for further data collection.

### 3.6 Research Approach

Mixed-methods research brings together questions from two different philosophies in what is being referred to as the third path, third research paradigm, the third methodology movement and pragmatism. The two paradigms differ in key underlying assumptions that ultimately lead to choices in research methodology and methods and often give a breadth by answering more complicated research questions. The roles of mixed-methods are clear in an understanding of the situation (the what), meaning, norms, values (the why or how) within a single research question which combine the strength of two different method and offer multiple ways of looking at the research question. Epidemiology sits strongly in the quantitative research corner, with a strong emphasis on large data sets and sophisticated statistical analysis (Wasti et al., 2022).

### 3.7 Research Design

The research design is intended to provide an appropriate framework for a study. A very significant decision in research design process is the choice to be made regarding research approach since it determines how relevant information for a study will be obtained; however, the research design process involves many interrelated decisions (Sileyew, 2020).

Mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms. It involves philosophical assumptions, the use of qualitative and quantitative approaches, and the mixing of both approaches in a study. Thus, it is more than simply collecting and analysing both kinds of data; it also involves the use of both approaches

in tandem so that the overall strength of a study is greater than either qualitative or quantitative research (Creswell, 2007).

The concurrent embedded strategy of mixed methods can be identified by its use of one data collection phase, during which both quantitative and qualitative data are collected simultaneously. This embedding may mean that the secondary method addresses a different question than the primary method or seeks information at a different level of analysis. The mixing of the data from the two methods is often to integrate the information and compare one data source with the other, typically accomplished in a discussion section of a study (Creswell, 2009).

### **3.8 Universe and Unit of Study**

The respondents for the research are selected from an unofficial grouping of People with Dwarfism, name “Little People of Kerala (LPK)”, which has nearly 80 members from various parts of Kerala associated with various activities and community participation. The respondents are from 13 districts out of 14 districts of State of Kerala.

### **3.9 Sampling Design (Inclusion- Exclusion Criteria)**

**Inclusion criteria:** Members of the unofficial group ‘Little People Kerala’, who are aged between 21 years and 70 years with a height less than 4 Feet 10 inches.

**Exclusion criteria:**

1. People who are not having medical certificate regarding their disability
2. Patients with Dwarfism outside Kerala

### **3.10 Data Collection**

The qualitative data collected through google form is well recorded and the researcher on analysing this, collected data on unaddressed aspects. The data thus collected are documented and further analysed for themes. Then the data is categorised based on the themes set in specific objectives.

### **3.10 Pre-test**

Inorder to test the feasibility and accuracy of the data collection tools, the researcher conducted a pre-test of the questionnaires prepared in google form among five respondents. On analysing the data, flaws in the responses and questions were identified and tool was modified to be more respondent friendly. Though no new questions were added, the structure of the questions and answer options were slightly modified so as to get a clearer response.



### **3.11 Data Analysis**

The data thus collected is documented through google forms, written and recorded. The researcher went through the data and organised the data collected under the specific objectives set. The themes that are not addressed through quantitative questions are embedded with the qualitative set of data.

### **3.12 Ethical Consideration**

Respondents with dwarfism are subjected to self-isolation and withheld themselves from the outer world. They are often emotionally disturbed and generally prefers to keep their identity a secret. At a times, it is also noticed that they prefer not to be around anyone (including family members, colleagues, etc.) while sharing their struggles with the respondents. The researcher got contacts of the respondents through the unofficial group- LPK and was priorly introduced by the LPK. The researcher thus ensures confidentially in the matters discussed and seeked prior permission before recording any data shared by the respondents. The researcher also detailed the process and ensured that the data would only be used for the academic purposes.

### **3.13 Assumptions, Limitations, and Scope**

**Assumptions:** Since the researcher approached the unofficial group LPK for the respondents, the researcher is of the assumption that the respondents do have community participation. The researcher also assumes that the information provided by the respondents are best of their knowledge and are authentic.

**Limitations:** The researcher have acquired only 42 samples in quantitative responses and 5 cases in qualitative data, which is primarily used to substantiate the primary data and to address the gaps by embedding it with secondary data. During the process the researcher encountered multiple setbacks such as:

- Lack of availability of respondents who fit into the inclusive criteria, which could be attributed to their limited population and willingness to participate in the research process.
- Some of the respondents were emotionally taken over by their condition and shared their personal struggles of coping with discrimination that they have to dealt with in daily life. The researcher has to spend more time on certain cases and was heavily taken over by the stress due to over usage of mobile phone.
- The researcher at certain point felt that the lack of experience in counselling and previous experience in working with People with Dwarfism has affected the data collection. Some

respondents were mocking the questions and responding indifferently, in such cases, the researcher struggled to keep up.

**Scope:** The study is applicable to others who are working in the field of disability studies and to other community social workers in understanding the existing gaps in the service delivery of mechanism provided to the population from the government mechanism. The study could also give an idea regarding the issues faced by the people with dwarfism in Kerala and to take up further studies on the similar theme.

**CHAPTER 4**

**DATA COLLECTION AND CASE**

**DESCRIPTION**

## CHAPTER 4: DATA COLLECTION AND CASE DESCRIPTION

### 4.1 Introduction

The fourth chapter explains the data collected and the description of the cases use to embed so as to address the gaps in the data collected. It gives an in-depth analysis regarding the data collected and cases of people with dwarfism. The chapter helps in understanding various aspects such as challenges faced by people with dwarfism, their understanding or awareness regarding the government services extend to which it is being accessed. The researcher uses descriptive data and verbatims to present the data collected.

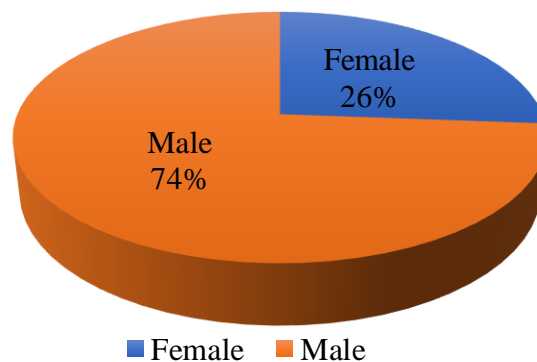
The chapter also gives a detail description on the socio-demographic profile of the participants for study as well as provide case description on the cases chosen to be studied qualitatively.

The chapter discusses the following themes:

1. Extended Challenges
  - a. Physical and Social Challenges
  - b. Environment challenges
2. Right and Entitlements
  - a. Career challenges
  - b. Economic challenges
3. Support System
  - a. Coping Mechanism
  - b. Support need and Accessible

### 4.2 Socio-demographic Profile of the Respondents

**Figure 4.1: Gender of Respondents**



The figure 1, shows that among the total respondents, less than three fourth (74 %) of respondents are male, and more than one-fourth (26 %) of respondents are female. There is an anomaly in the respondent count of male and female respondents due to the difficulty in identifying further respondents who fit into the inclusion criteria.

**Figure 4.2: Religion of the Respondents**

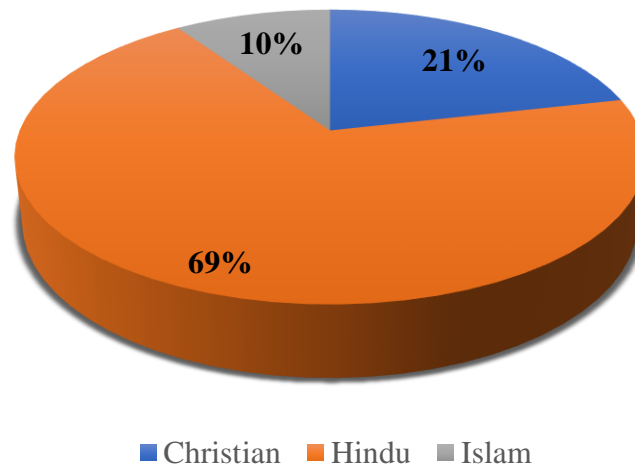
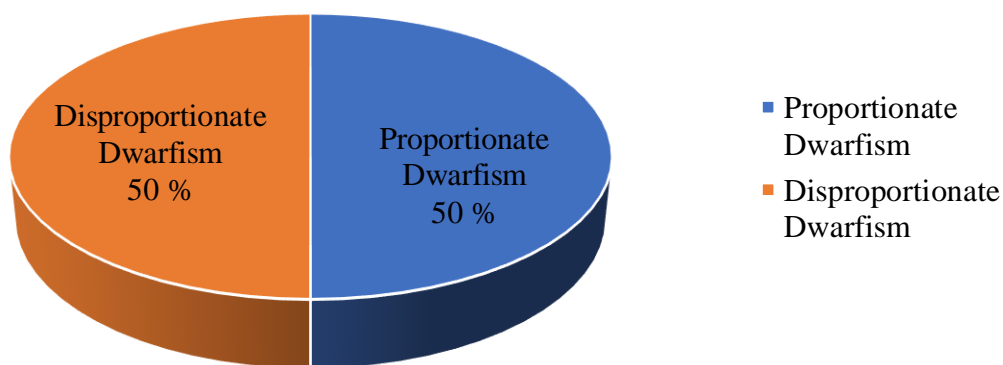


Figure 2 shows that out the total respondents 69% belong to Hindu religion, 21% of the respondents belong to Christian religion and 10% of the respondents belong to Islam.

**Figure 4.3: Type of Dwarfism**



The figure 4.3 shows that out of 42 respondents, half (50 %) of the respondents have proportionate dwarfism and other half (50 %) of the respondents have disproportionate dwarfism.

**Figure 4.4: Height of the Respondents**

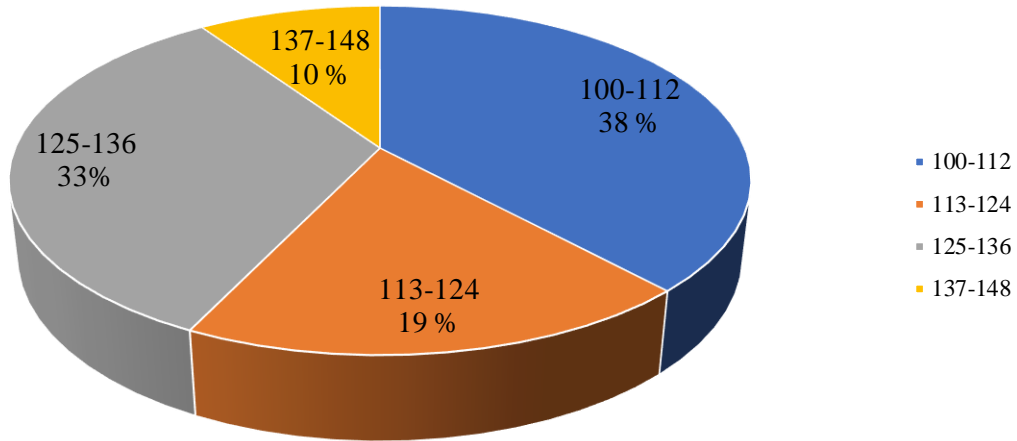


Figure 4.4 shows that 38% of the participants have height between 100 to 112 centimeters (cms), 33 % of the participants have height between 125- 136 (cms), 19 % of the respondents have height between 113-124 (cms) and 10 % of the participants have height between 137-148 (cms).

**Table 4.1: Age Group of Participants**

DEMOGRAPHIC PROFILE	
Age Group	Number of Participants
21-30	6
31-40	13
41-50	19
51-60	3
61-70	1
Total Participants	42

Table 4.1 shows the demographic profile of the 42 respondents and the larger group of the population belongs to the age group of 41-50 years with a total of 19 respondents, followed by the age group 31-40 years, 21-30 years, 51-60 years and 61-70 years with 13, 6, 3 and 1 respondents respectively.

**Table 4.2: Level of Education**

	Frequency	Percent	Valid Percent	Cumulative Percent
Below 10th	4	9.5	9.5	9.5
10th	14	33.3	33.3	42.9
12th	9	21.4	21.4	64.3
Polytechnic	1	2.4	2.4	66.7
Graduate	10	23.8	23.8	90.5
Post graduate	4	9.5	9.5	100.0
Total	42	100.0	100.0	

Table 4.2 shows that the education of the respondents, which indicates 33 percent of the participants discontinued their education after 10<sup>th</sup> standard, 23 percent of the participants have completed their graduation, 21.4 percent of the participants have discontinued their education after 12<sup>th</sup>. Out of the 42 respondents, 2.4 percent persuade polytechnical education, 9.5 percent dropped out of education before completing 10<sup>th</sup> standard while another 9.5 percent completed their post-graduation.

**Table 4.3: Annual Income of the respondents**

	Frequency	Percent
Between 100001 and 200000	5	11.9
Between 200001 and 300000	5	11.9
Between 300001 and 400000	2	4.8
Between 400001 and 500000	1	2.4
More than 500000	10	23.8
Total	42	100.0

Table 4.3 shows that the 23.8 % of the participants have annual income more than 23.8 percentage, while 11.9% participants have annual income between 1 lakh and 2 lakhs and another 11.9 % participants have annual income between 2 lakh and 3 lakhs. Out the remaining participants 4.8 % have annual income between 3 lakh and 4 lakhs, while 2.4 % have annual income between 4 lakh and 5 lakhs.

**Table 4.4: Employment of the participants**

	Frequency	Percent
Unemployed	6	14.3
Public Sector	14	33.3
Private Sector	18	42.9
Student	3	7.1
Religious Services	1	2.4
<b>Total</b>	<b>42</b>	<b>100.0</b>

Table 4.4 shows that 42.9 % of the participants are working privately in various activities including own business, working as supportive staffs, etc., 33.3% of the participants work in government service under various designation such as office assistance, clerical posts, cooperative banks, etc., 7.1% of the participants are students pursuing law, graduation in science, etc., 2.4 % take up religious services and 14.3 % are unemployed.

**Table 4.5: District and Participants**

State	Number of Respondents	Percentage
Alappuzha	8	<b>19.04 %</b>
Ernakulam	3	<b>7.14 %</b>
Idukki	3	<b>7.14 %</b>
Kasargod	1	<b>2.38 %</b>
Kollam	1	<b>2.38 %</b>
Kottayam	1	<b>2.38 %</b>
Kozhikode	3	<b>7.14 %</b>
Malappuram	2	<b>4.76 %</b>
Palakkad	2	<b>4.76 %</b>
Thiruvananthapuram	10	<b>23.80 %</b>
Thrissur	4	<b>9.52 %</b>
Wayanad	1	<b>2.38 %</b>
<b>Total</b>	<b>42</b>	<b>100 %</b>



Table 4.5 shows that 23.8 % of the respondents are from Thiruvananthapuram district, followed by Alappuzha with 19.04 % participants, 9.52 % participants from Thrissur, 7.14 % of participants each from Ernakulam, Idukki and Kozhikode, 4.76 % participants each from Malappuram and Palakkad and 2.38 % participants from Kasargod, Kollam, Kottayam and Wayanad.

**Objective 1: To understand the extended challenges faced by people with Dwarfism**

**Table 4.6: Knowledge on their physical condition**

		Knowledge of Physical condition				Total	Percentage
		No	Percentage	Yes	Percentage		
Gender	Male	10	32.25	21	67.74	31	73.8
	Female	6	54.54	5	45.45	11	26.19
Total		16	38.09	26	61.9	42	100

Table 4.6 show that 38 % of the participant are do not have proper understanding regarding their physical condition, out of which 32.25 % are male and 54.54 % are female. Out of the total respondents 61.9 % do have proper understanding regarding their physical condition and among that 67.74 % are male and 45.45 % are female.

**Table 4.7: Dwarfism in family**

Variables		Dwarfism in Family				Total	Percentage
		No	Percentage	Yes	Percentage		
Gender	Male	16	66.66	15	83.33	31	73.8
	Female	8	33.33	3	16.66	11	26.19
Total		24	57.14	18	42.85	42	100

Table 4.7 shows that out of the respondents 57.14 % participants have no other family members with dwarfism, while 42.85 % of the participants have family members with dwarfism. Out of 57.14 % participants with no family members with dwarfism, 66.66 % are male and 33.33 % are female. From 42.85 % participants with family members having dwarfism includes 16.66% female and 83.33 % male.

**Table 4.8: Traits of dwarfism in Previous Generations**

	Traits of Dwarfism in Previous Generation	No traits of Dwarfism in Previous Generation	Total
Number of Participants	7	35	42
Percentage	16.66	83.33	100

Table 4.8 which deals with the traits of dwarfism in previous generation, shows that 16.66 % participants have traits of dwarfism in previous generations while 83.33 % of participants have no traits of dwarfism in previous generation.

**Table 4.9: Extended challenges of disability (Physical and Social aspects)**

Gender			Health				Total	Percentage
			Bad	Moderate	Good	Very Good		
Male	WHODAS2.0	Mild difficulty	0	3	12	7	22	52.38
		Moderate difficulty	2	3	1	3	9	21.42
	Total		2	6	13	10	31	
Female	WHODAS2.0	Mild difficulty	0	3	3	4	10	23.80
		Moderate difficulty	1	0	0	0	1	2.38
	Total		1	3	3	4	11	
Total	WHODAS2.0	Mild difficulty	0	6	15	11	32	76.19
		Moderate difficulty	3	3	1	3	10	23.80
	Total		3	9	16	14	42	

Table 4.9 shows the extended disabilities measured based on the tool WHODAS 2.0. It indicates that 76.19 % of participants have mild difficulty, while 23.80 % of the participants have moderate difficulty. Of the total participants with mild difficulty, 52.38 % is male and 23.80 % is female. While, those who are facing moderate difficulty, 21.42 % are male and 2.38 % is female.

**Table 4.10: Associated Ailments**

Associated Ailments	Number
Back Pain	3
Back Pain & Joint Pain	5
Back pain and breathing problem	1
Breathing and Allergy issues	1
Breathing issues	1
Cholesterol	1
Heart Conditions	1
Joint Pain	4
Joint pain and wheelchair-bound	1
	18

Table 4.10 shows the data regarding the associated ailments, which indicates that associated with the physical challenges faced by the respondents, 18 respondents (42.85%) face other issues. Out of 18 respondents, the majority of the respondents were found to have back pain, joint pain, and both. But such incidences are noticed mostly among the people with less activity (only household chores) and not among people who take part in other activities such as participation in games and sports.

**Table 4.11: Marital Status**

		Marital Status			Total
		Unmarried	Married	Divorced	
Gender	Male	14	16	1	31
	Female	4	6	1	11
Total		18	22	2	42
Percentage		42.85	52.38	5.26	

Table 4.11 shows that, out of the total participants, 42.85 % is unmarried, 52.38 % are married and 5.26 % are divorced.

**Figure 4.5: Children**

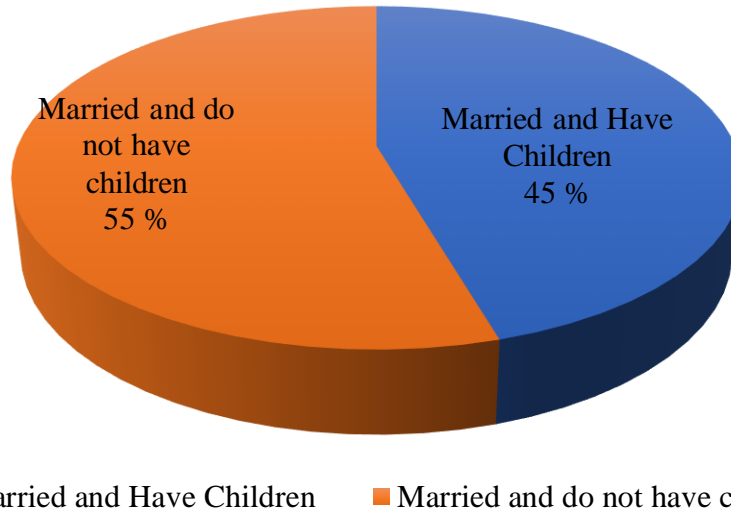


Figure 4.5 shows that 55 % of the married people with dwarfism do not have children, while 45% of married people with dwarfism have children.

**Objective 2: To understand their accessibility to rights and entitlements.**

**Table 4.12: Awareness on RPwD Act, 2016**

Gender			Awareness of basic Rights and Entitlement		Total	Percentage
			No	Yes		
Male	Know or heard of RPwD Act, 2016	No	12	2	14	33.33
		Yes	2	15	17	40.47
	Total		14	17	31	
Female	Know or heard of RPwD Act, 2016	No	5	0	5	11.90
		Yes	0	6	6	14.28
	Total		5	6	11	
Total	Know or heard of RPwD Act, 2016	No	17	2	19	45.23
		Yes	2	21	23	54.76
	Total		19	23	42	

Table 4.12 represents that out of total respondents 45.23 % know or heard about RPwD Act, while 54.76 % haven't heard of or know of RPwD Act, 2016. Out of 45.23 % of the participants who haven't heard of RPwD Act, 2016, 33.33 % is male and 11.90 % is female. While out of

54.76% of participants who know of or heard of RPwD Act, 40.47 % is male and 14.28 % is female.

**Table 4.13: Knowledge about addition of Dwarfism in RPwD Act, 2016**

Gender			Awareness of basic Rights and Entitlement		Total	Percentage
			No	Yes		
Male	Know that Dwarfism is mentioned in RPwD Act, 2016	No	12	2	14	33.33
		Yes	2	15	17	40.47
	Total		14	17	31	
Female	Know that Dwarfism is mentioned in RPwD Act, 2016	No	5	1	6	11.90
		Yes	0	5	5	14.28
	Total		5	6	11	
Total	Know that Dwarfism is mentioned in RPwD Act, 2016	No	17	2	19	45.23
		Yes	2	21	23	54.76
	Total		19	23	42	

Table 4.13 indicates the knowledge of participants on the addition of Dwarfism into RPwD Act, 2016. It indicates that 45 % of the participants did not know about this, out of which 33.33 % are male and 11.90 % are female. While 54.76 % of participants are aware about addition of dwarfism under the purview of RPwD act 2016, with 40.47 % of males and 14.28 % of females.

**Table 4.14: Financial Status and Employment**

		Financial Status				Total	Percentage
		APL	Percentage	BPL	Percentage		
Type Employment	Unemployed	2	4.76	4	9.52	6	14.28
	Public Sector	12	28.57	2	4.76	14	33.33
	Private Sector	8	19.04	10	23.80	18	42.85
	Student	1	2.38	2	4.76	3	7.14
	Religious Services	0	0	1	2.38	1	2.38
Total		23	54.76	19	45.23	42	100

Table 4.14 indicate the financial status and the employment status of the participants and shows that 54.76 % of the participants belong to Above Poverty Line (APL) and 45.23 % of the participants belong to Below Poverty Line (BPL). Out of 45.23 % belong to BPL, 23.80 % depends on private employment, 9.52 % unemployed, 4.76 % each in public sector and students and 2.38 % in religious services.

**Table 4.15: Pension and Financial Status**

		Financial Status				Total	Percentage
		APL	Percentage	BPL	Percentage		
Pension Services	Constantly receiving	0	0	1	2.38	1	2.38
	Last Month (June 2023) after withheld for long	6	14.28	10	23.80	16	38.09
	More than 6 months	0	0	1	2.38	1	2.38
	More than a year	1	2.38	0	0	1	2.38
	No pension as in government services	13		1	2.38	14	33.33
	Never received as disability is less than 40 percent	1	2.38	1	2.38	2	4.76
	Denied and doesn't know why	1	2.38	1	2.38	2	4.76
	Not Applied	1	2.38	4	9.52	5	11.90
<b>Total</b>		<b>23</b>	<b>54.76</b>	<b>19</b>	<b>45.23</b>	<b>42</b>	<b>100</b>

Table 4.15 details the financial status and in relation to the pension services, which points out that out that 38.09 % of the participants who have received the pension for the month of July 2023 after being withheld for some months. Out of this 38.09 %, 23.80 % belong to BPL and 14.28 % belong to APL. Out of the total participants, 33.33% do not receive pensions as they are government services. Also, 2.38 % of the participants each receives the pension constantly, hasn't received pension for more than a year and hasn't received pension for more than 6 months. It also points out that 4.76 % of the respondents hasn't received pension as they don't have 40 % disability in their medical records and another 4.76 % has been denied of pension, but doesn't know why. While 11.90 % of the participants hasn't been applied for the pension, out of which 9.52 % belong to BPL and 2.38 % belong to APL.

**Table 4.16: Services Accessed**

		Frequency	Percent
Variables	Government Services	14	33.3
	Disability Pension	16	38.1
	Never Received Any	2	4.8
	Denied Pension	2	4.8
	Pension and Two-Wheeler	2	4.8
	Not Applied	4	9.5
	Haven't received a pension for more than a year	1	2.4
	Family Pension	1	2.4
	Total	42	100.0

Apart from the details put up from the above tables, table 16 indicates that 4.8 % of the participants have received pension as well as disabled-friendly two-wheelers from the government. Also, 2.4 % of the participants receive family pension.

**Figure 4.6: Services from Agencies other than Government**

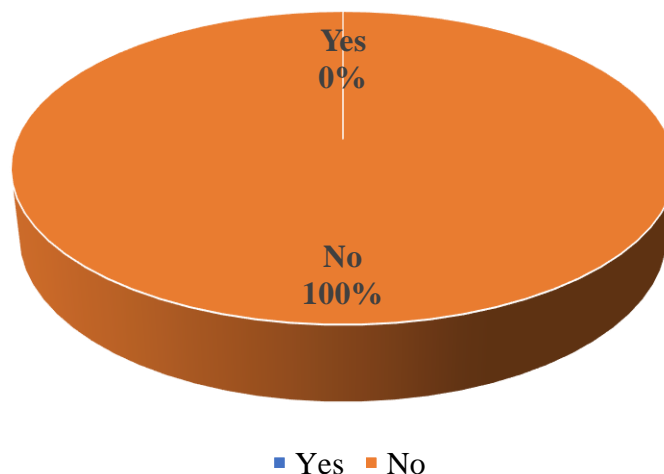


Figure 4.6 points out that 0 % of the participants receive any services from Non-Governmental Agencies, that is, none of the participants have received any support from any Non-Governmental Organisation (NGOs).

**Table 4.17: Participants awareness on Government Schemes**

		Awareness on Schemes					Total	
		Doesn't know or heard of any schemes	Know about or heard of at least 1 or utmost 3 schemes	Know about or heard of at least 4 or utmost 6 schemes	Know about or heard of at least 7 or utmost 9 schemes	Know about or heard of at least 10 or utmost 12 schemes		Know about or heard of at least 13 or about all 15 schemes
Gender	Male	4	4	7	5	6	5	31
	Female	4	0	1	3	3	0	11
Total		8	4	8	8	9	5	42
Percentage		19.04	9.52	19.04	19.04	21.42	11.90	100

Table 4.17 indicates that out of the selected 15 schemes provided by social justice department of Government of Kerala, 19.04 % of the participants don't know or heard of any of the schemes, while another 19.04 % have heard of 4 to 6 schemes and another 19.04 % heard of 7 to 9 schemes. While 9.52 % have heard of 1 to 3 schemes and 11.90 % have heard of 13 to 15 schemes.

**Figure 4.7: Accessibility to Government Schemes**

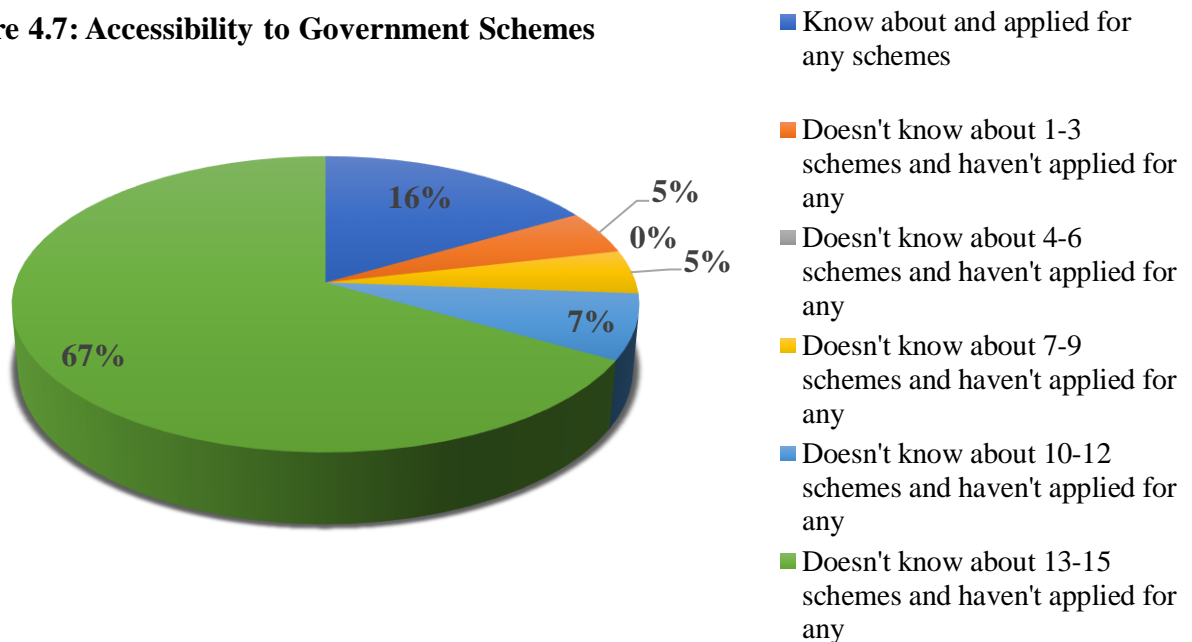




Figure 4.7 points out that, out of the respondents, 67 % doesn't know whether they are eligible or haven't applied for any of the 15 schemes, 7 % don't know whether they are eligible for 10 – 12 schemes and haven't applied for any schemes, 5 % of the participants doesn't know whether they are eligible for 7- 9 schemes and haven't applied any schemes, another 5 % doesn't know whether they are eligible for 1-3 schemes and haven't applied for any. Out of the total participants, only 16 % of the participants know about the eligibility of the schemes and have applied for any of the schemes.

**Objective 3: To understand the support system needed for people with dwarfism**

**Table 4.18: Gender Disparity in Receiving Support**

		Gender Disparity in Receiving Support				Total
		No	Percentage	Yes	Percentage	
Gender	Male	20	47.61	11	26.19	31
	Female	7	16.66	4	9.52	11
Total		27	64.28	15	35.71	42

Table 4.18 points out that 64.28 % of the participants don't perceive that there is gender disparity exists in matters of support received, out of which 47.61 % are male and 16.66 % are female, while 35.71 % of the participants perceive that gender disparity exists in matters of support received, among that 26.19 % is male and 9.52 % is female.

**Figure 4.8: Religion as Support System**

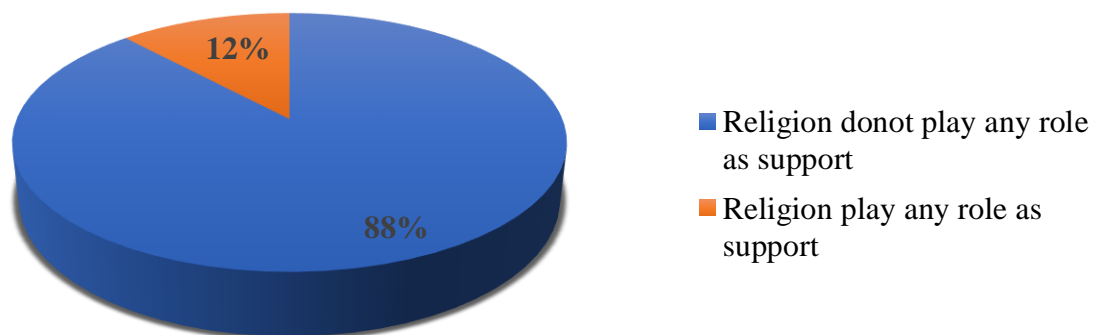


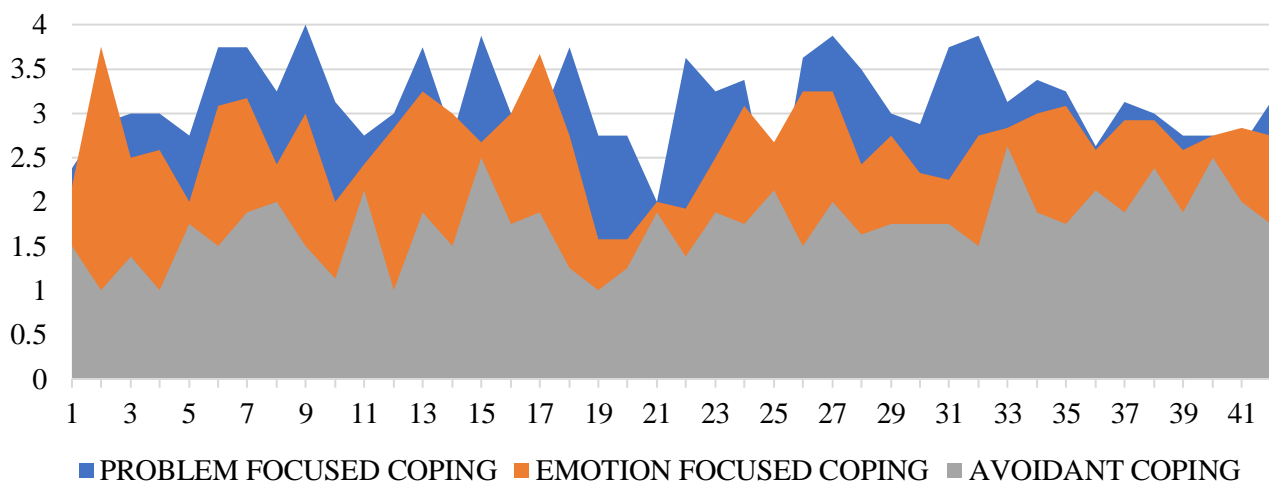
Figure 4.8 points out that 12 % of the participants believes that religion play a role as a support system, while 88 % of the participants do not believe that religion play as role as a support system.

**Table 4.19: Supported needed by the Participants**

	Frequency	Percent
Personal Assistance	4	9.5
Residential and community assistance	16	38.1
Communication	1	2.4
Personal, residential and community assistance	14	33.3
Personal, Residential, Community, Decision making and communication support	6	14.3
Personal, Residential, Community and Communication assistance	1	2.4
Total	42	100.0

From Table 4.19, it is pointed out that 33.33 % of the participants need Personal, residential and community assistance, 38.1% of participants need residential and community assistance, 14.3% of the participants need personal, residential, community, decision making and communication assistance, 9.5 % participants need personal assistance, 2.4% of the participants need personal assistance and another 2.4% need personal, residential, community and communication assistance.

**Figure 4.9: Coping mechanism Adopted (BRIEF COPE)**



From Figure 10 shows the data that is assessed through the tool-BRIEF COPE, it is observed that the predominant method of coping mechanism employed by the respondents is Problem Focused Coping mechanism, while the second method employed is Emotion Focused mechanism and the least employed mechanism is the Avoidant coping mechanism.

**Figure 4.10: Coping Mechanisms**

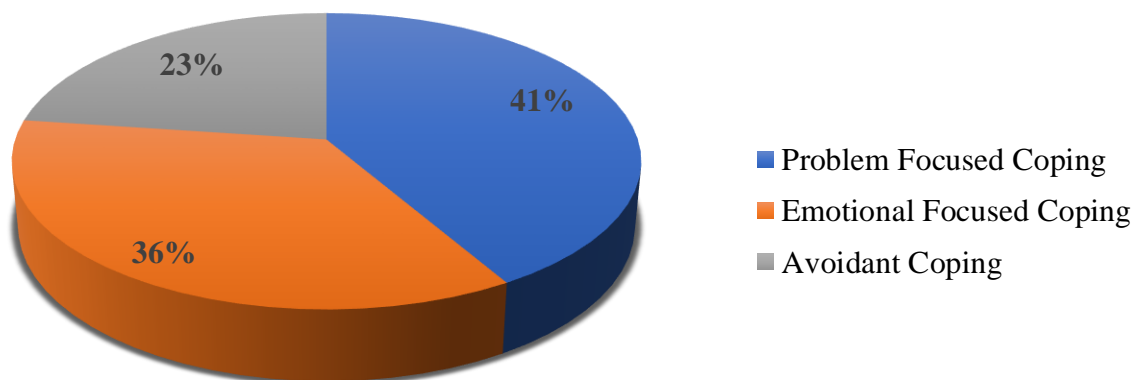


Figure 11 points out that, 41% of the weightage is given to problem focused mechanism, while 36% on emotion focused mechanism and 23% on avoidant coping.

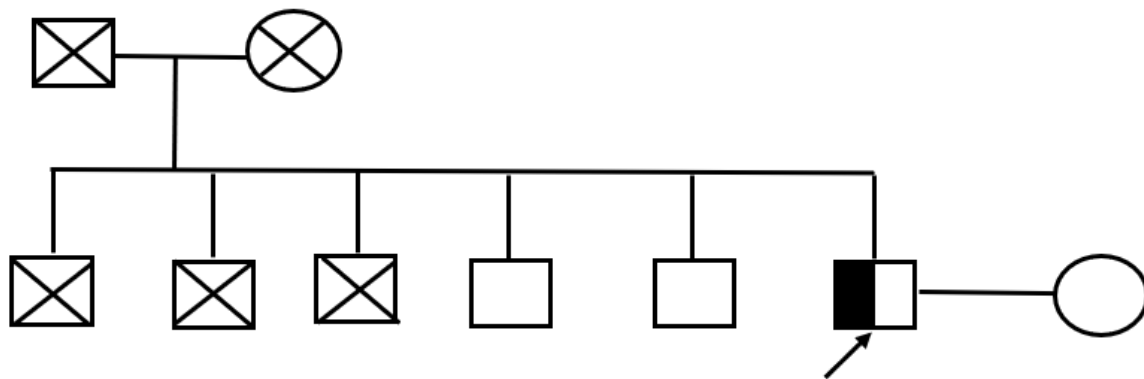
## **4.3 CASE DESCRIPTION**

### **4.3.1 CASE 1**

#### **Socio-demographic Profile**

Mr. R is a male of 65 years old residing in a rural setting on the foothills of Ponmudi in Thiruvananthapuram. He belongs to the Hindu religion and his family consists only of his wife. He belongs to a Below Poverty Line (BPL) and he works in a flower shop for daily wages.

**Figure 4.11 Genogram of Case 1**



### **Case Details**

Mr. R was identified for the interview process through the residents of the community in rural setting. Mr. R is a resident of the area for the past six decades and is hence known in the neighborhood. Also, he is famous in the region because of his appearance in the movie *Athbhutha Dweepu* which cast 350 individuals with dwarfism and was directed by Mr. Vinayan in the year 2005.

### **Physical Challenges**

The case couldn't detail the type of dwarfism he has but has known how it is being represented in his disability certificate.

*"According to my disability certificate, I have a locomotive disability".*

The case also detailed the physical issues he is facing currently which could be due to old age and their intensity is aggravated due to dwarfism.

*"I have back pain. Also, I have pain in the joints of my arms and legs and also, since I have taken the COVID vaccination, I have trouble breathing".*

Because of his troubled breathing and his body as well as joint pain, it is difficult for him to walk through the difficult hilly terrain to reach the main part of the village for his work. Because of that, now he is working from his own home.

*"I can't take things that are placed at a height and in such cases I need someone's help. Other than that, I can do every household works".*

Mr. R said he can do everything in his house, except for reaching objects placed at a height and for that, he seeks other person's help. The case doesn't hesitate to seek help from others when needed.

*"I am taking medication for the pain since past six months. Last week, I visited the hospital and the doctors prescribed for further scans. When I enquired, I learnt that I would take more than 1500 Rupees for the scan and so I decided not to proceed further".*

Mr. R hasn't received his disability pension for months and received it in the month of July 2023 with arrears. While he hasn't received the pension, he has trouble continuing his medication as he didn't have money to purchase it. During that time, he was also asked to take a scan for diagnosing his body pain and joint pain. On reaching the scan center, Mr. R came back home without taking one due to insufficient money. The issue with halt in pension services have economically handicapped the family, which prompted them to voluntarily put out of the health services, which is a basic right.

### **Social participation**

*"I don't participate in any festivals or programmes in the community. I prefer to stay at home. I prefer to stay home and work, rather than go to the shop. I am happy to stay home as it is more comfortable for me".*

Mr. R prefers to keep himself at home and could be considered as a self-isolation from society. Though he started working home while he was not well, now he got used to it and is comfortable with that.

*"Participation in film shooting was a good experience and we tried to make a union of people with dwarfism then. Even though they collected our numbers, no further follow-up regarding that was informed".*

Mr. R reiterated his experience in film shooting, which happened 20 years ago and sound very proud of his achievement. He also mentioned that it is then he realized that there are many people like him and tried to form a group, but there was no further follow up or he wasn't informed of it. It also points out that, he has limited contact with other people from his community and hasn't tried to participate in community gatherings.

### **Support System**

*"I don't have anyone for help except my wife. Even though my relatives and siblings stay close to my house, I don't seek their help nor do they voluntarily help".*

Though his siblings and extended family live nearby, Mr. R do not seek help or support from them. Due to certain family conflicts, they are not in good terms with the rest of the family, which has added to the self-exclusion factor.

*“As I can’t walk and go to work every day, the shopkeeper brings flowers to my home. I sit at home and make flower garlands. I get nearly 200 Rs for making garlands from 8 to 10 kg of flowers provided”.*

Though the family support is minimal, Mr. R is supported by his colleagues of flower shop. As he faces difficulty in walking to the shop through the difficult terrain the people get the raw material to them and collect the garlands from his home. Ensuring an active phase of life without compromising his comfort and health.

### **Service Accessibility**

*“Even though ASHA workers come by, she never looks into my health nor informs me about new programmes and schemes. When they come, they ask whether I have pets and enquire about them”.*

Even though ASHA workers actively work in the community, the effectiveness is quite questionable as they are not capturing the relevant data needed, that would ensure the effectiveness of the service provider.

*“One of my friends, Mr. Vinod inform me about the schemes and government programmes. But now he is in jail and so hasn’t received any new information about government programmes”.*

Mr. R being detached from the community participation, he is being informed of the programmes by his friends from the same community, but not through the local self-governance mechanisms.

*“Going by public transportation is very difficult. Usually, it is very rush and nobody gives a seat to people like me”.*

Public transport system has put him in a more difficult position than helping him to access the service to its full capacity. The difficulty in logistics prompts him to opt out of health care services.

*“Last week I boarded a Medical College bus, but I didn’t get any seat. After covering some distance, the rush increased and I couldn’t continue my journey. I got down in Pathinaramkallu Junction and came back home”.*

*“Even though I am entitled to a pension from the government, it is not made available regularly. Because of that, I have difficulties buying medicines on time”.*

Mr. R receives pensions from the government for more than 15 years, but it is not made available regularly, and also feels that he is being denied of services from government systems.

*“I sought help from Panchayat for the reconstruction wall and path to the road from home, which was destroyed in the rain. No help is provided feels that he is being denied of yet”.*

*“Even though I applied for a two-wheeler for differently abled, the application got rejected as I am above 60 years of age”.*

### **Understanding of basic rights**

Mr. R has no or least understanding regarding his basic right and when asked about it, he replied *“I don’t know more about it”.*

### **Coping with stress**

Mr. R has experience in participating in large gatherings such as meeting other people with dwarfism. He expresses his negative feelings openly when stressed - *“I express my emotions, especially anger. I find it difficult to control it”.*

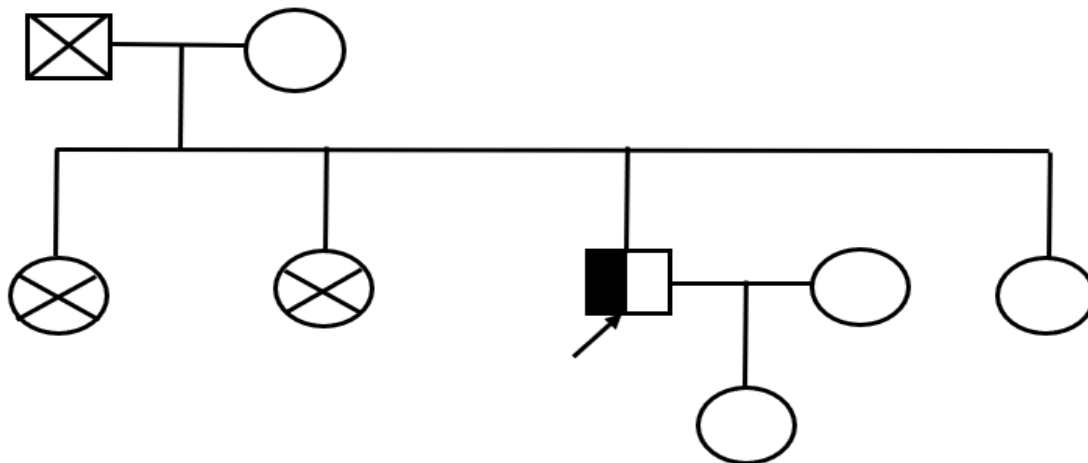
He also added that he had handled someone physically - *“During the movie shooting, I caught a person with dwarfism attempting to steal from me. I couldn’t bear it at all. I lost my temper and handled him physically. I couldn’t handle it until that person was removed from the shooting location by the authorities”.*

## **4.3.2 CASE 2**

### **Socio-demographic Profile**

Mr. B is a male of age 41 with Achondroplasia, previously worked as a Schedule Caste (SC) promotor in Panchayat on a contract basis and currently working as a private lottery agent from a rural setting in Thrissur district. He belongs to Below Poverty Line (BPL) category and represented India in International Dwarf Games in 2013 for Badminton. He is married to an average-sized woman. They have a daughter with no disabilities who is 4<sup>th</sup> standard now.

**Figure 4.12 Genogram of Case 2**



### **Case Details**

Mr. B is the third child of his mother was born after two still births (females). During the birth complications, Mr. B appeared to be dead during the initial minutes of his birth and later revived by the doctors. Though initially he didn't display any indications of dwarfism, later when he was in his 1<sup>st</sup> standard (6 years), he was taken to hospital as his parents noticed differences in his growth. It is then, the doctors diagnosed him with dwarfism which was caused to the blocking of growth hormones which has happened due to the complication in his birth.

### **Physical Challenges**

*“Due the issues at birth I have trouble breathing and hence I can't walk long distances. I also have allergy issues”.*

Mr. B has very clear understanding regarding his physical challenges as well as the physical capacities. Though a sports person, due to birth complication he has breathing problems as well as allergy issues. But he is desperate to work hard to help himself out of the situation he is in.

*“Since I don't have enough height, a wooden bench is laid before my lottery stall. I stand there for selling lottery”.*

Mr. B worked at many jobs including working with the government on a contract basis. Once his contract period was over, he lost it and for ensuring livelihood he opened up a lottery shop. Though height was an issue, he adopted various strategies to overcome physical constrains.



### **Social participation**

With the participation in sports at various levels- state, national and international levels Mr. B has got opportunity to interact with many people from various array of work – *“Since I participate in sports, I get to interact with many people”*.

*“Recently, we, the participants of dwarf games got the opportunity to present themselves in the television show Star Magic telecasted in Flowers, a Malayalam channel”*.

This has also improved his interpersonal skills and also got invited to television programmes for performance as well as for recognition for his achievements. He performed in stage with performances such as mimicking actor Jayan, Somersaults etc. He attempts to prove that people with dwarfism are also people with skills and capacities to lead an efficient life.

*“Some of us (people with dwarfism) deliberately avoid us. After Athbhuda dweep movie, we got to meet many people like me. But now they don’t keep in contact with us. Try to avoid us purposefully, even when we meet them. I think it is because of the inferiority complex”*.

Mr. B also spoke about deliberate exclusion, as a trend that is being seen among the people with dwarfism. That is people deliberately keep themselves in isolation and also avoid any sort of interaction with the rest of the community members.

### **Support System**

*“We represent our country in international games and we haven’t received any support from the state or central government. For participating in International Dwarf Games, I went to the United States of America (USA) in 2013 and the whole expense was met ourselves. We haven’t received any sponsorships from public or private agencies”*.

As a sports person representing the nation at the International games for Dwarf people, he or people accompanied him hasn’t received any sort of emotional nor economic support from anyone or from the government. That is. The burden to participate and responsibilities to bring a change, were only upon their shoulders, which increased their problems rather than being a solution.

### **Service Accessibility**

Mr. B, also added that he nor any sports persons with him haven’t received any sort of support for continuing the sports. As a matter of urgency and as their pleas are not being heard, they are attempting to form a united front by creating an association for facing the matters legally.

*“In matters of sports, we haven’t received any support. In order to make our plea stronger, I*

*have taken the initiative and brought together 25 people with dwarfism who are active participants in dwarf games. In order to access the services, we are to register our association and to move for further legal procedures to ensure access to services such as sponsorships for sports persons”.*

Mr. B also added the difficulty in using public transport in Kerala – *“Travelling by bus is a huge problem for people like me. We have given many requests to the government, yet no changes”.*

While he also mentioned how different was the public transportation system in America, which was truly accessible for any differently-abled persons – *“On visiting America, we were able to see how much better and disabled-friendly the infrastructure is. We only have to walk to the bus, we don’t have to climb the steps. We can even roll wheelchairs into the bus without any problem”.*

*“While we go to the doctors for a disability certificate, it is a huge trouble for us. They don’t provide it to us easily. I visited the hospital multiple times so that I can get a disability certificate with a disability of 40 percent. But there are many friends of mine who are not entitled to their benefits as their disability marks under 40 percent on their certificate”.*

The disability certificate is not provided by following standard operating procedures and hence same people with the same level of disability are given a different percentage, which is based on the discretion of doctors. In some cases, it is followed very strictly and in some other places, it is not the case. It also points to the absence of an established mechanism, which could quantify qualitative aspects of the procedure as well.

*“I participate in Gram Sabha for the differently abled, where they allocate benefits to the differently abled. There we get to enter into further discussions on our entitlements”.*

Mr. B also opined that, the fund allocated for the programmes for differently abled are not enough to meet their needs and hence would call for an increased budgetary allocation of funds for the welfare programmes – *“I think the fund allocated is not enough for ensuring the welfare of the differently abled. I think there should be fund allocations for other programmes such as skill training programmes and help for self-employment generation”.*

### **Understanding of basic rights**

As an individual who actively worked among the people irrespective of their disability, Mr. B was able to work successfully as a Scheduled Caste promotor in the Panchayat. This also

enhanced his relationship with other people in the community as well as helped him in understanding his basic rights and entitlements – “*Since I worked in panchayat as Schedule Caste (SC) promoter, I got some awareness regarding the schemes and programmes run by the social justice department of Government of Kerala*”.

### **Coping with Stress**

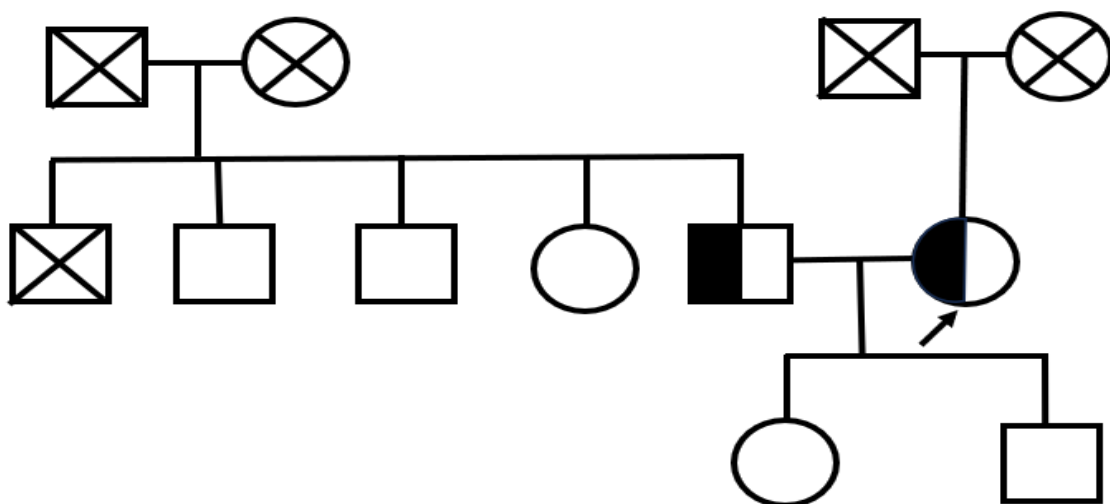
Mr. B actively participate in community activities as well as have a well-established support system, who have stood by him during the difficult times. Even during any stressful event, he shares his problems or stressful events with his friends or close confidants – “*I have a good number of friends and they always help me get through difficult times*”.

### **4.3.3 CASE 3**

#### **Socio-demographic Profile**

Mrs. L, a 49-year-old female with disproportionate dwarfism belonging to Hindu religion and works as a government service as a record attender. She is married to Mr. P, a comedy artist as well as a government employee working as an office attender. They have two children, a girl and a boy, who has no dwarfism. The family belongs to above poverty line (APL) and actively participates in social gatherings and community meetings.

**Figure 4.13 Genogram of Case 3**



### **Case Details**

Mrs. L is a single child of a couple, who had average height and is the only person with dwarfism in her side of the family. As her mother died, during childbirth, she was raised by her immediate family members. She has 130 cm in height and has associated ailments such as back pain and joint pain. She met her husband during an official visit to the secretariat, fell in love, and married him. Both their children have above average height and support them by all means.

### **Physical Challenges**

Mrs. L didn't have any physical issues until recently when she started having backpain and joint pain- *"Initially there were no issues, now I started to have backpain and joint pain"*.

Her husband was also quite healthy, but recently he met with an accident which has caused body pain and other issues such as difficult to walk fast, etc. – *"My husband didn't have any issues, until he met with an accident on stage during a stage programme. Since then, he has issues while performing"*.

### **Social Participation**

*"When we go into society, people do tease us. But if my daughter hears that, she will scold them"* (sense of happiness reflected).

Both of their children have no dwarfism and when someone tease them publicly, then their children defend them. This gave her a sense of purpose and an urge to help others like herself. She then actively participates in public meetings and vouches for basic rights of differently abled.

*"My husband used to do stage programmes with Suraj Venjaramoodu, Guinness Pakru and Kollam Sudhi. Now we have started a troop of our own- Ragaranjini and completed three stages now"*.

With her husband's experience in the field and to make the best use of her time as both her children are off for jobs, they started drama troop. This has given her another sense of purpose in her life.

### **Support System**

*"We haven't received such support from anyone, nor we haven't approached anyone for help. We try to deal with difficulties on our own and if exceed our capacity to cope with them, then we may approach others for help"*.

Mrs. L belongs to a nuclear family where they support among each other and hence, she hasn't sought external support for help. She thus believes that, whatever problem comes up, she will be able to deal with it as a family and but in the future, if need any sort of help or support, she may seek support from the community.

### **Service Availability**

*"Both my husband and I are members of differently abled committees of government employees. This has helped us to avail services such as GST concession while purchasing vehicle".*

Mrs. L has a clear understanding regarding the government services that they could avail and based on that they have accessed the services for which they are eligible for. They have received aid in availing assistive devices such as differently abled friendly two-wheeler, GST concession for their vehicle, etc.

### **Understanding Basic Rights**

*"With the active participation in meetings for ensuring the basic rights of differently-abled people, we were able to help others enjoy their basic rights".*

Mrs. L as well as her husband decorate high positions in public meetings for differently abled. Mrs. L is state level secretary for differently-abled meetings, while her husband works along with district committee meetings. Being able to participate and take classes for differently abled people, she is aware about her rights and entitlements. Apart from being a mere participant, she also tries to identify people who aren't being included in it and try to bring them into the system - *"We also attempt to bring other people into the meeting and help them understand their rights".*

### **Coping with stress**

*"As a couple, we help each other and discuss among each other; find solutions to come out of it. Thus, even in stressful times, we support each other through it".*

Mrs. L has a well laid support system that is helping her to cope with the issues she is facing and guide her through it. She believes when any stressful circumstances arise, taking to her husband or kids has helped her to understand the situation better and to respond accordingly.

*"There are many people with dwarfism, who exclude themselves from others. There is a young girl nearby my house, who doesn't even step out of her house. We tried to talk her out of it, but she keeps herself to the house".*

Mrs. L also agreed to the social isolation faced by many people with dwarfism. Rather than an isolation, these are deliberate exclusions from the mainstream society due to fear or inability to cope with the pace of the world.

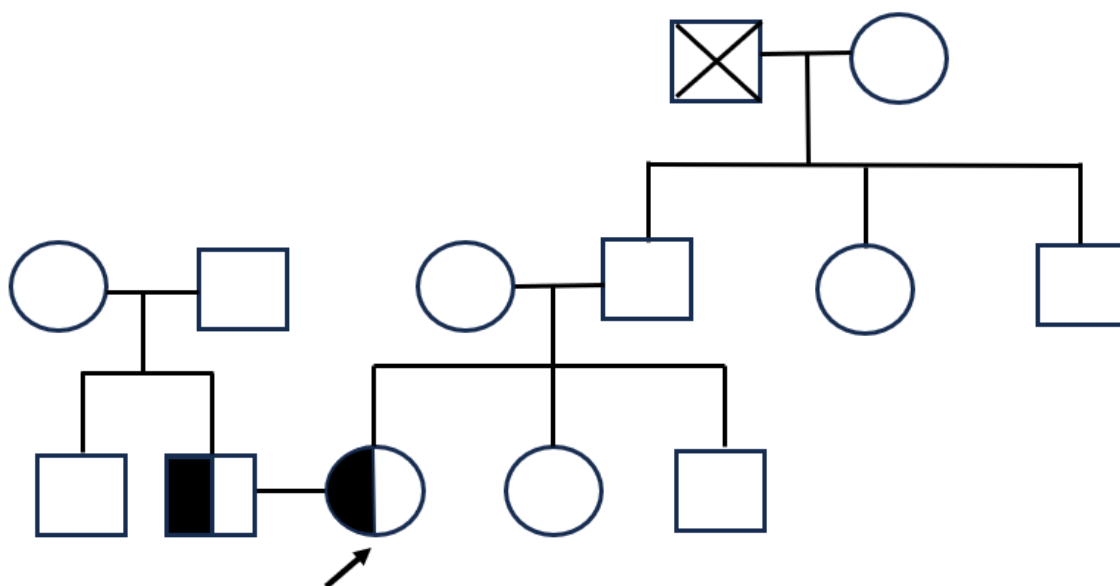
Mrs. L also shared the issues she faced during her younger years and how she was able to cope with it and come out of it - *“While in school, people used to tease me. But after the 10<sup>th</sup> standard, I started participating in Kudumbashree and eventually, I was able to get over that with active community participation”*.

#### 4.3.4 CASE 4

##### Socio-demographic Profile

Mrs. D is a female of 29 years of age and has a height of 4 feet with disproportionate dwarfism belonging to a Christian community. She is from Chemmanar, a rural setting in Idukki and she is married to Mr. S, a person with dwarfism from Chemmanar. She is a graduate belonging to an Above Poverty Line (APL) family.

**Figure 4.14 Genogram of Case 4**



##### Case Details

Mrs. B is the first child of her parents and has a younger sister and brother. She is the only dwarf person in her family and she is supported by her family immensely. She got married two

years ago and since then with the support of her husband, she started participating in sports. She thus won the state-level competition for the sport - Discus Throw for people with dwarfism. She attempted to pursue a job in public services and appeared for Kerala Public Service Commission (PSC). She also made it to the final list of examinations, but the list got canceled. Now, she is working as an office staff of Heavenly Plaza.

### **Physical Challenges**

*“Now I work in Ernakulam and I have to travel to the office by bus. It is difficult to use public transportation during office time. If I don’t get a seat, then it is difficult to get to the office”.*

A major challenge faced by people with dwarfism is transportation. Mrs. D also agreed to it and shared her trouble shifting to an urban center from a rural setting and trouble making it to the office in time using public transportation.

Mrs. D had also faced trouble accessing to public settings that is being structured for average sized human beings - *“I find it difficult to wash hands in hotels. I may not be able to open the tap and had to ask help to wash hands”.*

### **Social Participation**

Mrs. D being actively participant in sports since past two years, she started to interact with the community members more often with regular meet ups and programmes.

*“Recently we were invited to Malayala Manorama Comedy Stars -a television programme, recognizing our capacities and achievements in sports”.*

Mrs. D believe that with the recognition through television channel, they could reach out to other people who are hesitant to come out in public or have the least social participation. Mrs. D also shared how her life has been transformed since started working as a community and participation in sports - *“My husband and I were invited to our school for sports day inauguration last day. That was one of the happiest moments in my life. Many of our teacher came to us and told us how happy they are about our achievements”.*

### **Support System**

Mrs. D emphasized on the importance of having a strong support system who would help them through difficulties and well as to help them recognize their true inert potential. Mrs. D has two different sort of support systems before and after marriage. Before marriage, her family protected her from the challenges of the society and stood as a shield from all the teasing and

shaming that she has gone through. But this has limited her social participation and interactions with the society.

*“Many people used to tease while I was young, then my grandmother shout at them or shame them in public. They constantly protected me and created a conducive environment for me to engage with society. This has helped me to be who I am today”.*

But, after marriage she got exposed to different support systems. Her husband is active in sports and other social activities, pushed her to find her capacities in sports- *“Before marriage, I used to spend time only with my family and friends. My husband actively participant in many sports and games. Thus, after marriage, I also started participating in various sports”.*

This has helped her to identify her potential in the sport- discus throw and have won state level competition. Thus, with the exposure to the real world, she was able to cope with the challenges that came along.

### **Service Availability**

Though Mrs. D has participated in representing the state, she hasn't received any sort of recognition or support from the state she is representing. The transportation cost, accommodation, etc. are bore by them themselves. This is an added pressure to their economic conditions - *“Though I participate in sports representing the state at national levels, we haven't received recognition or support from the government nor from any other agencies”.*

*“Even though I was in a rank list published by Kerala Public Service Commission, the list got cancelled due to some reasons and thus, lost an opportunity despite putting hard work”.*

Though she worked hard for a government job and cleared Kerala Public Service Examination, by making it into the list. The list got cancelled, which has costed her time and hard work. This has prompted her to seek a job in private sector and moved to Ernakulam.

### **Understanding of Basic Rights**

Though Mrs. D has heard about the rights and schemes, she is not aware about it and about the security nor entitlements it provides - *“I am not completely aware about the rights. I have heard about the rights, but I don't know much about it”.* Mrs. D is a post graduate degree holder and has the capacity to understand about the rights, but hasn't attempted to do so.



### Coping with Stress

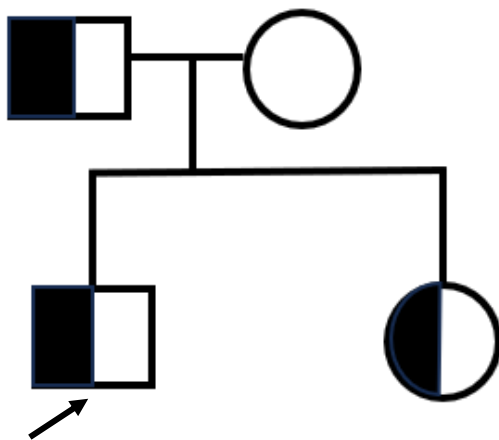
As Mrs. D constantly received support from her family and husband, during stress full times she seeks help from them. Mrs. D take time to discuss about the problems with her husband or her mother, who would help her to come out of it - *“Even when I am stressed or sad or have any trouble, I share it with my husband mostly. He helps me through anything. I also share things with my mother. They help me, advise me and guide me”*.

### 4.3.5 CASE 5

#### Socio-Demographic Details

Mr. A, is a 35-year-old male with 130 cm height with disproportional dwarfism belong to Hindu religion and from a rural setting. Mr. A with a highest education of 12<sup>th</sup> standard, is working in public sector at Government Ayurveda College as an Attender. Mr. A belong to a nuclear family of above poverty line (APL).

**Figure 4.15 Genogram of Case 5**



#### Case Details

Mr. A with disproportionate dwarfism has associates issues such as back pain. Mr. A has traits of dwarfism in his family from his father. But, Mr. A is unaware whether dwarfism traits were present in any previous generations in his paternal and maternal sides. His sister is also a person with dwarfism. Mr. A is facing psychosocial challenges associated with dwarfism.

#### Physical Challenges

Though a government employee, Mr. A has faced many issues in his life due to dwarfism. Though he used to depend on public transportation for reaching to his work place, it has

increased his difficulties. Thus, he now uses two-wheeler for differently able. - *“Public transportation was a problem for me in the past. But now I have a differently abled friendly two-wheeler”*.

At the work place also, he has faced challenges in reaching out for the files or medical records - *“I have issue in taking files and medical records from top rack because of my height. Sometimes I’m hesitant to ask for any help”*. When I am not able to do that, supervisors would shift my duty to other like cleans, sweeping, etc.

### **Social Participation**

Mr. A doesn’t participate in any social gathering, community gatherings including festivals - *“I don’t participate in many community programmes, I prefer to stay home after work”*. After work, he keeps himself to the house, where he isolates himself from the society or he prefers a deliberate exclusion from the society.

For Mr. A, marriage is also a troublesome event. He has got a permanent government job, ensuing job security and desires to move into next phase of his life. But he is being rejected by girls, which he believes is due to his short stature. *“I have crossed my ideal age to get married. I have liked many girls. But when I approach them, they are all denying my proposal. They reject me because of my height. People like us should be treat same”*.

Being not able to find himself an ideal partner is bothering him. At the same time, he is also bothered about his sister’s life. Mr. A’s sister, a 32-year-old female, for whom he is not able to find a groom, has affected him emotionally - *“I look after my sister, for whom we are actively looking marriage proposals. But nothing seems to come right because of the height issue”*.

### **Support Systems**

As Mr. A keeps himself to his family and don’t have social relationship or maintained healthy friendships, he has no other person to share his emotions nor to support him. Mr. A doesn’t want anyone around him know about his feelings, thoughts and issues - *“I am only comfortable talking to you after 5 pm, why because I don’t want other people in my office to hear what I am going through”*.

### **Service Availability**

Mr. A acquired assistive devices through government mechanism, thereby enhancing independence and dignity of life - *“I have availed services such as acquiring assistive device. I have differently-abled friendly vehicle”*.

### **Understanding of Basic Rights**

Though Mr. A works in government service, due to his conscious absence from the meeting for differently abled has disadvantaged him as he doesn't know much about his basic rights - *"I don't know anything about it"*.

### **Coping with stress**

Mr. A refrain himself from sharing the difficulties of stress he is facing - *"I try to keep the focus on my work to keep myself away from the stress I am facing"*. Mr. A rather facing it, try to avoid it by engaging in office work or other activities - *"I try to avoid such circumstances where I have to explain or share my feelings to others"*.

**CHAPTER 5**

**DATA ANALYSIS,**

**INTERPRETATION AND**

**DISCUSSIONS**

## **CHAPTER 5: DATA ANALYSIS, INTERPRETATION AND DISCUSSIONS**

### **5.1 Introduction**

In this chapter, the researcher conducted data analysis with descriptive analysis of quantitative data and thematic analysis of the qualitative data, that is embedded into the relevant areas. The study is conducted among the people with dwarfism, who are associated with an unofficial group – “Little People of Kerala” (LPK). The study followed an embedded design with quantitative and qualitative data collection. The data was collected using self-made questionnaire, WHODAS 2.0 for measuring extended physical and social disability and BRIEF COPE scale for understanding coping mechanism. The data thus collected is analysed and interpreted based on the objectives as following.

### **5.2 Data Analysis, Interpretation and Discussions**

#### **Objective 1: To understand the extended challenges faced by people with dwarfism**

Table 4.6, which represents the respondents understanding regarding their knowledge on their physical condition, implies that out of 73.8 % of male participants, 32.25 % are not aware of their physical condition, while 67.74 % are aware of their physical condition. Also, out of 25.19 % of women participants, 54.54 % are not aware about their physical condition, while 45.45 % are aware of their physical condition. It could imply that, male participants of the research had better understand regarding their physical condition than the female participants of the research.

According to the literature review on the studies by Jetten et al. (2006), it is understood that most of the people with dwarfism are frequently the only affected member in family and likely to be the “black sheep” and should be encouraged to develop coping mechanisms as well as to develop a sense of community feeling. (Fernández, Branscombe, Gómez, & Morales, 2012). From the table 4.8, it is interpreted that 83.33 % of the participants are only member in the family with dwarfism traits. This also, points out the need to develop a support group to inculcate the community feeling and help them to cope with the challenges.

On interpreting Table 4.11 along with figure 4.5, certain interpretations could be derived, such that 42.85 % of the participants are yet to find a partner due to various reasons and out of 52.38 % of married participants, only 45 % have children, the remaining 55 % do not have children.

It could also be inferred as difficulty in reproduction due to various physical reasons. During the data collection, one of the respondents mentioned-

*“I gained weight when I had medicines for pregnancy treatment. But unfortunately, I met with an accident and couldn't continue the treatment further”.*

The issue with halt in pension services have economically handicapped the family, which prompted them to voluntarily put themselves out of health services, which is a basic right. Also, there are instances where people with dwarfism who have the opportunity for social participation, has opted out of it in choosing self-exclusion after work or even go the extend of self-exclusion.

In 2015, Department of Empowerment of Persons with Disabilities (DEPwD), Ministry of Social Justice and Empowerment, Government of India has launched Accessible India Campaign (Sugamya Bharat Abhiyan), which focuses on achieving universal accessibility for differently abled by transforming the build environment, transportation sector and Information and Communication Technology (ICT) ecosystem (Department of Empowerment of Persons with Disabilities (Divyangjan), 2022). After 8 years, in 2023, the people with dwarfism are still not in a position to enjoy the fruits of accessibility in matters of infrastructures around them.

*“Going by public transportation is very difficult. Usually, it is very rush and nobody gives a seat to people like me. Last week I boarded a Medical College bus, but I didn't get any seat. After covering some distance, the rush increased and I couldn't continue my journey. I got down in Pathinaramkallu Junction and came back home”.*

The issues with transportation have limited their mobility and have put them in a difficult position to choose between what they want and not. But, when it is in the matters of basic rights and healthy leaving, an individual should not be put in such a position to compromise basic right of leading a healthy life.

Another challenge people with dwarfism face is finding an ideal partner. A major mile stone in a psychological and biological task in young adulthood is finding a partner and starting a family. Not able to fulfill this stage has affected many adversely-

*“I have crossed my ideal age to get married. I have liked many girls. But when I approach them, they are all denying my proposal. They reject me because of my height. People like us should be treat same.”*

Such denial in life has prompted them to question their own existence and push them to consider their short stature an issue in setbacks they face.

People with dwarfism also face challenges in their career frontier –

*“I was denied a job after my interview and they gave me the reason that they don't think I will be able to do the job”.*

People with dwarfism are subjected to judgemental attitudes and prejudices. They are not considered for their skills and goes along with the study by Zainudin, Rasid, Yusop, Othman, & Rong (2021), which says that they are not considered for their high academic qualification, instead they are denied of job or offer lower class job, putting them through an under employment.

**Objective 2: To understand their accessibility to rights and entitlements.**

Table 4.12 and table 4.13, indicate the participants awareness on RPwD Act, 2016 and participants knowledge on bringing dwarfism under the purview of RPwD Act, 2016. On analysing the two data, it is interpreted that those participants who are aware about RPwD Act, 2016 are also aware that dwarfism is under the purview of the RPwD Act, 2016. The data also indicates that nearly half of the respondents (45.23 %) were not aware of the RPwD Act, 2016 nor about dwarfism being considered as a disability under RPwD Act, 2016. Such a lack of awareness could also hinder them from enjoying their entitlements to their fullest. It could also be interpreted as their lack of awareness or as a conscious effort or unwillingness to recognize their condition as a disability.

Table 4.14 and table 4.15, provide data on financial status, employment and pension services for the participants. It is derived from the crosstabulation of data, that 23.80 % of the participants belonging to the BPL category has only received their pension of Rs. 1600/- per month after withholding it for months in the month of July 2023 with arrears. Receiving the pension amount late affected the participants particularly in BPL category in delaying medical needs. It is also to be pointed that 11.90 % of the participants haven't applied for the pension services, out of which 9.52 % belong to BPL category. Knowingly or unknowingly, they are being pulled out of the pension services they are entitled to. It is to be assumed that with proper guidance and support of the community, people who are not yet included in it could be empowered to enrol themselves in such services, thereby ensuring inclusivity.

When tables 4.12, 4.13, 4.14 and 4.15 are read together, it could also be interpreted that not enrolling themselves for the pension services also could be considered as a denial of accepting their condition as a disability. This could be read in association with the literature review of the studies of Baidi, Ilias & Ghazali (2018), that suggest that in developed countries like USA, some people with dwarfism demand to be acknowledged as “Little” rather than being considered as disabled. From Table 16, it could also be interpreted that 4.8 % participants receive both pension as well as disable friendly two-wheeler, while 2.4 % receive family pension, which is a fundamental right under Article 21 of the Indian constitution. From this, it could be derived that, rather than being denied, when the participants are aware about their rights, they are able to get their entitlements with more conviction.

Figure 4.6 points out the absence of the role of NGOs in providing services to People with Dwarfism, despite being placed under the purview of RPwD Act, 2016. It also could be interpreted as the absence of targeted interventions for ensuring the upliftment and empowerment of people with dwarfism to the mainstream society. Table 4.17 indicates that 19.04 % of the participants, who include within the population for whom the government has announced these programmes for haven't heard of or know of any of the schemes. This indicates the lack of general awareness regarding the schemes put forth by the government for the people. That is, the programmes are not reaching to the targeted beneficiaries, which is a gap that is to be filled by awareness at panchayat level.

From Figure 4.7, it could be interpreted that 67 % of the participants don't know about their eligibility for any of the 15 schemes under the Government of Kerala, only 16 % of the participants know about their eligibility and have applied for any of the schemes. It is another indication that, for whomever the schemes and programmes are designed for and budget is allocated for, it is not reaching the beneficiaries either due to their lack of awareness regarding the schemes, their eligibility, or procedures. In certain cases, the participants withhold from applying as they believe it is the responsibility of the government to provide for them, not the other way around, which is clearly a wrong way to see it through.

It is also to be interpreted from the interview that, one of the major challenges faced by the people with dwarfism is regarding public transportation. Especially the old model Kerala State Road Transport Corporation (KSRTC) bus with steps placed at a height. People with dwarfism find it difficult to use these kinds of transportation. When they have no other choice, they try to push themselves into the buses despite crowd, which has caused them physical issues such as body pain, that as affected their daily activities of living. In fact, public transportation is



brought into place with the tax payers' money and thus it is the responsibility of the government to ensure that all the citizens are able to make best use of the public transportation mechanisms in place.

**Objective 3: To understand the support system needed for people with dwarfism**

From Table 4.18 it could be interpreted that, out of the total respondents, only 35.71 % participants believe that there is a gender disparity in matters of social support received by people with dwarfism, while 64.28 % of participants have never come across a situation or have seen a situation that portrays gender disparity. Also, out of 26.19 % of the participants who are female, 16.66 % of participants do not feel like there is gender disparity, while 9.52 % of participants feel that the disparity exists. This could be an indication that even though the disparity exists, that is only visible in certain sectors or areas.

From Figure 4.8, it could also be interpreted that, out of the 42 respondents, 88 percent of respondents don't get any support from their religion. While only 12 percent of the respondents get support from their religion. That is, a large proportion of the respondents doesn't recognize religion as a support system.

Table 4.19 points out the assistance that is sought by the participants, which could also be implied that they are not receiving this assistance to its fullest. In that note, most of the participants demanded for both Residential and Community assistance, that is, 38.1% of the participants are not enjoying Residential and Community assistance to its fullest. Similarly, 33.3 % of the participants are not enjoying personal, residential and community assistance to its fullest. Out of the participants, 14.3% of the participants are not enjoying personal, residential, community, decision making and communication assistance to its fullest, 9.5 % of the participants not enjoying personal assistance to the fullest, while 2.4 % of the participants are not receiving proper assistance in communication and another 2.4 % participants are devoid of personal, residential, community and communication assistance partially or completely.

According to the study of Elfina and Ramadhanai in 2019, life satisfaction depends upon various factors including living conditions, gaps in desires and what they have, etc. With the proper support systems based on the need or the desire, life satisfaction of people with dwarfism could be enhanced. The participants among which the researcher studied emphasised the importance of personal and community support. The researcher observed a sense of happiness among the participants for whom close ones stood up for in the past. For example, a sense of happiness is reflected in case 3 (Mrs. L) for whom her daughter stood up for her and also in case 4 (Mrs. D) for whom her grandmother stood up for. Similarly, the community participation

as well as community support, has helped the participants to come out of their comfort zone and to be a change maker or to set themselves as an example for the rest. The community support has helped Mrs. D to explore her capacities in sports and to represent the state for discus throw at national level competition. Similarly, the community support has helped Mrs. L as well as husband (who is also a person with dwarfism) to explore their passion for stage performance by starting a drama troop of their own (despite having a government job). This implies that the life satisfaction of individuals irrespective of disabilities could be enhanced with proper realisation of the support systems.

**CHAPTER 6**

**FINDINGS, SUGGESTION AND**

**CONCLUSION**

## **CHAPTER 6: FINDINGS, SUGGESTION AND CONCLUSION**

### **6.1 Introduction**

In this chapter, the researcher analyses the findings and provide suggestions to the findings thus came across. That is, the chapter deals with the outputs and interventions plans to address the identified issues. The chapter analyses the findings and suggestions based on respective objectives.

### **6.2 FINDINGS**

#### **Objective 1: To understand the extended challenges faced by people with dwarfism**

1. With the analysis of the data collected, the researchers understand that the respondents face difficulty in getting a proper disability certificate as it is based on the discretion of the medical officers and how they perceive aspects of disability. When the disability certificate is provided based on discretion or arbitrarily, then there is the absence of equality (Article 14 of the Indian Constitution) being projected.
2. With the data collected and its analysis, the researcher understands that people with dwarfism face difficulties in accessing public transportation and accessing other public places such as wash, urinals, etc. That is, every individual must be equally able to access the public facilities of the state maintained out of the taxpayer's money.

#### **Objective 2: To understand their accessibility to rights and entitlements**

1. Though the participants are aware about pension and other service, they are not aware about how to access it. It also indicates that there is an absence of proper awareness regarding how to access government services such as government pensions, UD ID card, etc.
2. Despite being included in RPwD acts, the participants lack awareness regarding various schemes provided by the Kerala Government has limited their accessibility towards it.
3. With the research, it is also found out that, individuals participating in meetings of people with disabilities and participate in discussions regarding disabilities, have more understanding on the government schemes
4. Different states have different allocations of services and support through government mechanism, thus has difference in the percentage of disability for being entitled to various services

### **Objective 3: To understand the support system needed for people with dwarfism**

1. With the research, it is understood that participants need residential and community assistance, but there are no such support groups and communities for people with dwarfism as of now. Even with the literature review, it is understood that community support is needed to cope with the stress.
2. It is also found that, problem-focused coping mechanism and emotion-focused coping mechanism is prominently employed by the respondents to handle stressful life events. It is also understood that proper mental health support is not accessed by any of the respondents.

## **6.3 SUGGESTION**

### **Objective 1: To understand the extended challenges faced by people with dwarfism**

1. Since it is mostly based on the perceived notion of disability, the percentage of disability varies according to the medical practitioner. Thus, there is a need for updating the Standard Operating Procedure (SoP) by including dwarf-related criteria, thus blanketing it. With the proper establishment of SoP, arbitrariness in the process of providing medical certificates would be dealt with.
2. In order to ensure that the beneficiaries for whom the construction is being made or modified is able to make fullest usage of it, it is necessary to promote empathetic architecture and planning. With proper empathetic infrastructure, the accessibility that governments advocate for could be realized, thereby enhancing the standard of living as well as their Quality of Life (QoL).

### **Objective 2: To understand their accessibility to rights and entitlements**

1. In order to ensure that the beneficiaries are receiving their entitlements, it is necessary to ensure awareness generation among the beneficiaries regarding their rights and entitlements. In order to ensure that, it is necessary to enhance the capacity of ASHA workers through proper training.
2. Ensure that necessary medications for common non communicable diseases such as cholesterol, diabetics, etc. are provided to people with dwarfism for free, bring them under the purview of Palliative care based on their disability certificates. This would reduce the economic burden for people with dwarfism who do not have a regular employment, dependent on family for a living or belong to Below Poverty Line (BPL).

3. Encourage participation in community meetings and form associations. Since all eligible voters of the village can participate in the Gram Sabha, people with dwarfism could be encouraged to participate in those, thereby familiarizing with the available services. It is a channel to include the less privileged section of society and ensure their participation in the village level governance wherein they can advocate their developmental aspirations.
4. As social work professionals, best practices across various states within the country as well as various models employed at international level for ensuring the standard of living and better Quality of Life (QoL) could be studied and a suitable model devised based on the need of the society and community. Also, social work professionals should educate the target group of their rights as well as advocate for their rights and entitlements.

**Objective 3: To understand the support system needed for people with dwarfism**

1. Social work professionals can form support groups for people with dwarfism under block-level or district level, thereby creating a platform for social participation and community engagement which could ensure minimization of self-exclusion and isolation events among the people with dwarfism.
2. Social work professionals could mobilize people with dwarfism in a particular region to form Self Help Groups, that would enhance their capacity to be financially as well as socially independent.
3. Create human resources with capacity to create and drive a system, so as to provide assistance based on people's need rather than assistance being determined based on service available. That is, in matter of social work profession, the professional capacity of social workers should be enhanced to accommodate the need of the target group by tailoring programmes to suffix the individual's need.
4. Also, provide proper mental health support through Community-based Mental Health Services (Community Mental Health Centers, Support Groups, Crisis Intervention Services, Peer Support Programmes, etc.), thereby facilitating proper and healthy coping mechanism to handle stress due to various life events.

**6.4 Implication of the Study**

1. The study can raise an awareness on the extended challenges including discrimination, accessibility issues faced by the People with dwarfism in Kerala. Thus, would inculcate

an empathetic approach towards them from general public as well as from the policy makers.

2. With the understanding gained from the study, social workers can advocate for social policy reforms that would address the general as well as the specific needs of People with dwarfism.
3. The study would give an insight on the social isolation and self-exclusion faced by people with dwarfism and to propose interventions to promote social inclusion and combat the adverse effects of negative stereotypes and biases.
4. The study would lay foundation to assess the physical accessibility of public infrastructures including transportation, recreational, washrooms, etc. This would emphasize on the necessity in collaborations with urban planners and architects to design spaces that are accessible to individuals of all heights.
5. Social workers could explore on the avenues for empowering people with dwarfism so as to equip them to advocate for their own rights and needs. As a means, social workers could also develop training programmes or modules for skill upgradation for self-advocating and to engage in social as well as political spectrums.
6. Social workers would collaborate with locally functioning Non-Government Organisations (NGOs), disability rights groups, etc. to gather data and insights, develop intervention strategies, etc. This involve ensuring participation of people with dwarfism as active participants, thereby ensuring that their voices are also being heard.

## **6.5 Conclusion**

The study titled, 'The Challenges faced by People with Dwarfism in Kerala', attempts to shed light upon various challenges faced by individuals with dwarfism in Kerala (a southern state in India). In this study, the researcher attempts a comprehensive understanding of the subject through quantitative data, exploration of their lived experiences, their perspectives towards life, etc.

With the findings, the researcher was able to understand the impact that has laid upon the life of people with dwarfism due to the pervasive social attitudes, set back in realizing better standard of living or Quality of Life (QoL), stigmatization, cultural representation, etc. Individuals drop out of education due to constant exclusion or teasing from their peer group, individuals go into self-exclusion avoiding family events or community programmes as they feel people stare at time, children pointing at them, etc. People starts to question their very existence, they that the society is being unfair to them with or without any substantial reasons.

Through this study, the researcher analysed various extended challenges they face, their understanding regarding basic rights and entitlements and also regarding the social support systems they need of. Social work professionals have unique opportunity to bring social changes by advocating for rights, challenging existing stereotypes and create an inclusive environment that celebrates the diversity as well as value the potential of human resources.

Through the study it is clearly understood that a change is inevitable, which calls for a collaborative action, calling the attention of professionals from various walks of life including social workers, educators, policy makers, bureaucrats, healthcare professionals, social activists, etc. The study also pointed out on the lack of awareness on their own health condition, government schemes, rights ensured through legislations, etc. This underscores on the need to foster awareness among the target group as well as within the society. Awareness campaigns, educational programmes, etc. could be conducted through social media platforms, which could initiate a spark among the individuals to challenge the existing notions and advocate for an inclusive society.

Though there are many medical studies, the limited number of studies conducted on various aspects of the topic has kept many the group as an isolated area of study. Futures studies could be conducted in depth onto various specific areas such as family dynamics of people with dwarfism, mental health, etc. The researcher expects that this study would be a stepping stone for further studies on the topic.

Identity is considered a huge aspect of dignity upheld by every individual and thus, it is necessary to be identified based on what you want to be recognized with. It is also important to live as an informed citizen who has a choice to make rather than being ignorant towards the society. Irrespective of the physical stature, every individual must be valued, provide opportunity to develop their capacities as well as abilities so as to become an active positive contributor to the society.

*“The disabled do not need the patronage of the non-disabled. It is not for them to adapt to the dominant and dominating world of the so-called non-disabled. It is for us to adapt our understanding of a common humanity; to learn of the richness of how human life is diverse; to recognize the presence of disability in our human midst as an enrichment of our diversity.”*

Nelson Mandela



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# **ANNEXURES**

## INTERVIEW SCHEDULE

### SOCIO-DEMOGRAPHIC DETAILS

1. Name of the respondent
2. Phone Number
3. Age
  - a. 21-30
  - b. 31-40
  - c. 41-50
  - d. 51-60
  - e. 61-70
4. Gender
  - a. Male
  - b. Female
  - c. Transgender
5. Height
  - a. 100-112 cm
  - b. 113-124 cm
  - c. 125-136 cm
  - d. 137-147 cm
6. Do you know the type of dwarfism you have?
  - a. Yes
  - b. No
7. If yes, what is the type of dwarfism you have?
  - a. Proportionate dwarfism
  - b. Disproportionate dwarfism
8. Do you have associated Ailments?
  - a. Yes
  - b. No
9. If yes, what are the associated ailments you have?
  - a. Back Pain
  - b. Back Pain & Joint Pain
  - c. Back pain and breathing problem

- d. Breathing and Allergy issues
- e. Breathing issues
- f. Cholesterol
- g. Heart Conditions
- h. Joint Pain
- i. Joint pain and wheelchair-bound

10. Is there any one in your family with dwarfism?

- a. Yes
- b. No

11. Religion

- a. Hindu
- b. Christian
- c. Islam
- d. Other

12. Highest Educational Qualification

- a. Illiterate
- b. Belowe 10<sup>th</sup> Standard
- c. 10<sup>th</sup> Standard
- d. 12<sup>th</sup> Standard
- e. Polytechnic
- f. Graduate
- g. Post Graduate
- h. PhD

13. Type of your family

- a. Joint family
- b. Nuclear family

14. Marital Status

- a. Single
- b. Married
- c. Divorced
- d. Separated

15. Do you have any children?

- a. Yes

b. No

16. Number of Children

a. 0

b. 1

c. 2

d. 3

e. 4

f. 5 or more

17. Are you employed?

a. Yes

b. No

18. Type of Employment

a. Private Sector

b. Public Sector

c. Unemployed

d. Student

19. Financial Status

a. Above Poverty Line (APL)

b. Below Poverty Line (BPL)

20. Annual Income

a. <100000

b. 100001-200000

c. 200001-300000

d. 300001-400000

e. 400001-500000

f. >500000

21. Type of Residence

a. Urban

b. Rural

c. Semi Urban

22. District

1. Alappuzha

2. Ernakulam

3. Idukki
4. Kannur
5. Kasargod
6. Kollam
7. Kottayam
8. Kozhikode
9. Malappuram
10. Palakkad
11. Pathanamthitta
12. Thiruvananthapuram
13. Thrissur
14. Wayanad

#### ASSESSMENT OF PHYSICAL AND SOCIAL DISABILITY

1. How do you rate your overall health in the past 30 days?
  - Very Good
  - Good
  - Moderate
  - Bad
  - Very Bad
2. In the last 30 days, how much difficulty did you have in " Understanding and Communicating"?

Sl.No	Activity	None	Mild	Moderate	Severe	Extreme or Cannot do
1	Concentrating on doing something for ten minutes					
2	Remembering to do important things					
3	Analysing and finding solutions to problems in day-to-day life					



4	Learning a new task. for example, learning how to get to a new place?					
5	Generally understanding what people say					
6	Starting and maintaining conversation					

3. In the last 30 days, how much difficulty did you have in “ Getting Around”?

Sl.No	Activity	None	Mild	Moderate	Severe	Extreme or Cannot do
1	Standing for long periods such as 30 minutes					
2	Standing up from sitting down					
3	Moving around inside your home					
4	Getting out of your home					
5	Walking a long distance such as a kilometre (or equivalent)					

4. In the last 30 days, how much difficulty did you have in " Self Care" ?

Sl.No	Activity	None	Mild	Moderate	Severe	Extreme or Cannot do

1	Washing your whole body					
2	Getting Dressed					
3	Eating					
4	Staying by yourself for a few days					

5. In the last 30 days, how much difficulty did you have in " Getting along with people"?

Sl.No	Activity	None	Mild	Moderate	Severe	Extreme or Cannot do
1	Dealing with people you do not know					
2	Maintaining a friendship					
3	Getting along with people who are close to you					
4	Making new friends					
5	Sexual Activities					

6. In the last 30 days, how much difficulty did you have in " Life Activities" ?

Sl.No	Activity	None	Mild	Moderate	Severe	Extreme or Cannot do
1	Taking care of your household responsibilities					
2	Doing most important household tasks well					

3	Getting along the household work done that you needed to do					
4	Getting your household work done as quickly as needed					

7. How do you rate your "Participation in Society" for the last 30 day?

Sl.No	Activity	None	Mild	Moderate	Severe	Extreme or Cannot do
1	How much of the a problem did you have in joining in community activities (for example, festivals, religious or other activities) in the same way as anyone else can?					
2	How much a problem did you have because of barriers or hinderances in the world around you?					
3	How much of a problem did you have living with dignity because of					

	the attitudes and actions of others?					
4	How much time did you spend on your health condition or its consequences?					
5	How much have you been emotionally affected by your health condition?					
6	How much has your health been a drain on the financial resources of you or your family?					
7	How much of a problem did your family have because of your health problem?					
8	How much of a problem did you have in doing things by yourself for relaxation or pleasure?					

8. Over all, how much did these difficulties interfere with your life ?

- Not at all
- Mildly

- Moderately
- Severely
- Extreme or cannot do

ACCESSING THE AWARENESS ABOUT RIGHTS AND ENTITLEMENTS ENJOYED  
BY PEOPLE WITH DWARFISM

1. Are you aware about your rights and entitlements?
  - a. Yes
  - b. No
2. Have you heard about Rights of Persons with Disabilities Act, 2016?
  - a. Yes
  - b. No
3. Is dwarfism identified as a disability under Rights of Persons with Disabilities Act, 2016?
  - a. Yes
  - b. No
4. Are you entitled to a disability pension?
  - a. Yes
  - b. No
5. Have you ever received the disability pension?
  - a. Yes
  - b. No
6. When was the last time you received disability pension?
  - a. Constantly receiving
  - b. Last month
  - c. More than 6 months
  - d. More than a year
  - e. Never Received (Below 40 percentage disability)
  - f. Denied
  - g. Not applied
  - h. No pension (Government Service)
7. Do you have a Unique Disability ID Card?
  - a. Yes
  - b. No

8. Since when you have the Unique Disability ID Card?
  - a. 1 month
  - b. Less than 6 months
  - c. More than 6 months
  - d. More than a year
  - e. Not Applied
  - f. Applied but haven't received yet

#### UNDERSTANDING THE SUPPORT SYSTEM FOR PEOPLE WITH DWARFISM

1. What are the supports you need?
  - a. Personal Assistance
  - b. Residential and community support
  - c. Support in decision making including peer support
  - d. Communication support (including support for augmentative and alternative communication)
2. Can you function effectively without the support system?
  - a. Yes
  - b. No
3. Do you think religion play a vital role as a support system?
  - a. Yes
  - b. No
4. Do you think there is a difference in support systems based on the gender?
  - a. Yes
  - b. No
5. Do you agree or disagree that you have enough people close to you to get the support you need?
  - a. Strongly disagree
  - b. Disagree
  - c. Neither Agree nor Disagree
  - d. Agree
  - e. Strongly agree

## UNDERSTANDING HOW THEY COPE WITH STRESS

How have you been coping with the stress?

Sl.No	Coping Mechanism Using	I haven't been doing this at all	I have been doing this a little bit	I have been doing this a medium amount	I have been doing this a lot
1	I have been turning to work or other activities to take my mind off things				
2	I have been concentrating my efforts on doing something about the situation I'm in				
3	I have been saying to myself "this isn't real"				
4	I have been using alcohol or other drugs to make myself feel better				
5	I have been getting emotional support from others				
6	I have been giving up trying to deal with it				
7	I have been taking action to try to make the situation better				

8	I have been refusing to believe that it has happened				
9	I have been saying things to let my unpleasant feelings escape				
10	I have been getting help and advice from other people				
11	I have been using alcohol or other drugs to help me get through it				
12	I have been trying to see it in different light, to make it seem more positive				
13	I have been criticizing myself				
14	I have been trying to come up with a strategy about what to do				
15	I have been getting comfort and understanding from someone				
16	I have been giving up the attempt to cope				



17	I have been looking for something good in what is happening				
18	I have been making jokes about it				
19	I have been doing something to think about it less, such as going to movies, watching TV, reading, day dreaming, sleeping or shopping				
20	I have been accepting the reality of the fact that it has happened				
21	I have been expressing my negative feelings				
22	I have been trying to find comfort in my religion or spiritual beliefs				
23	I have been trying to get advice or help from other people about what to do				
24	I have been learning to live with it				
25	I have been thinking hard about what steps to take				

26	I have been blaming myself for things that happened				
27	I have been praying or mediating				
28	I have been making fun of the situation				

#### ASSESSMENT OF SERVICE RECEIVED

1. Do you receive any services from the government?
  - a. Yes
  - b. No
2. Do you receive any services from Non-Government Organisations (NGOs)?
  - a. Yes
  - b. No
3. When was the last time you received a service through a government mechanism?
  - a. Constantly Receiving
  - b. Last Month
  - c. More than 6 months
  - d. More than a year
  - e. Never received
4. When was the last time you received a service from Non-Government Organisations (NGOs)?
  - a. Constantly Receiving
  - b. Last Month
  - c. More than 6 months
  - d. More than a year
  - e. Never received
5. Have you ever participated in the decision, planning, implementation, and evaluation of such services provided?
  - a. Yes
  - b. No

6. Have you faced difficulty in accessing the following public services given below?

Sl.No	Services	No difficulties	A lot of difficulties	Some difficulties	Not accessed
1	Health Services				
2	Courts, Police and Justice services				
3	Benefits and pension services				
4	Culture, sports and leisure services				
5	Social services				
6	Tax services				

7. Have you heard of the following schemes or programmes of Government of Kerala?

Sl.No.	Scheme	Yes	No
1	Distress Relief Fund for the Differently Abled (Medical Treatment)		
2	Scholarship for Differently abled Students		
3	Parinayam-Marriage Assistance to differently abled women and to daughters of differently abled parents		
4	Scholarship for Disabled students pursuing Degree, PG courses (Distance Education)		
5	Financial assistance to Disabled students pursuing (10th, +1, +2 equivalent exams)		
6	Matru Jyothi -Financial assistance for PwD mothers		
7	Scheme for providing Assistive devices to Differently abled persons		
8	Vidyakiranam scheme-educational assistance to children of disabled parents		

9	Vidyajyothi scheme- Financial aid for uniforms and study materials to PH students		
10	Swasraya scheme for parents/ mothers of PH/MR persons		
11	Pariraksha scheme for Differently abled persons		
12	Vijayamritham scheme-Cash award for meritorious CWDs		
13	Athijeevanam- Comprehensive Scheme for mainstreaming of PwDs		
14	Sahajeevanam help-desk for PwDs		
15	Shreshtam scheme for ensuring participation of PwDs in Arts & Sports		

8. Are you eligible for the following schemes?

Sl.No.	Scheme	Yes	No	Don't Know
1	Distress Relief Fund for the Differently Abled (Medical Treatment)			
2	Scholarship for Differently abled Students			
3	Parinayam-Marriage Assistance to differently abled women and to daughters of differently abled parents			
4	Scholarship for Disabled students pursuing Degree, PG courses (Distance Education)			
5	Financial assistance to Disabled students pursuing (10th, +1, +2 equivalent exams)			
6	Matru Jyothi -Financial assistance for PwD mothers			
7	Scheme for providing Assistive devices to Differently abled persons			
8	Vidyakiranam scheme-educational assistance to children of disabled parents			

9	Vidyajyothi scheme- Financial aid for uniforms and study materials to PH students			
10	Swasraya scheme for parents/ mothers of PH/MR persons			
11	Pariraksha scheme for Differently abled persons			
12	Vijayamritham scheme-Cash award for meritorious CWDs			
13	Athijeevanam- Comprehensive Scheme for mainstreaming of PwDs			
14	Sahajeevanam help-desk for PwDs			
15	Shreshtam scheme for ensuring participation of PwDs in Arts & Sports			

9. If eligible for any of the following services, then have you availed its benefits?

Sl.No.	Scheme	Did not apply	Applied and Received Benefits	Applied and Received benefits but delayed	Applied, but benefits not received
1	Distress Relief Fund for the Differently Abled (Medical Treatment)				
2	Scholarship for Differently abled Students				
3	Parinayam-Marriage Assistance to differently abled women and to daughters of differently abled parents				

4	Scholarship for Disabled students pursuing Degree, PG courses (Distance Education)				
5	Financial assistance to Disabled students pursuing (10th, +1, +2 equivalent exams)				
6	Matru Jyothi -Financial assistance for PwD mothers				
7	Scheme for providing Assistive devices to Differently abled persons				
8	Vidyakiranam scheme- educational assistance to children of disabled parents				
9	Vidyajyothi scheme- Financial aid for uniforms and study materials to PH students				
10	Swasraya scheme for parents/ mothers of PH/MR persons				
11	Pariraksha scheme for Differently abled persons				

12	Vijayamritham scheme- Cash award for meritorious CWDs				
13	Athijeevanam- Comprehensive Scheme for mainstreaming of PwDs				
14	Sahajeevanam help- desk for PwDs				
15	Shreshtam scheme for ensuring participation of PwDs in Arts & Sports				

## INTERVIEW GUIDE

1. What are the challenges you face in your day-to-day life due to dwarfism?
2. What are the difficulties you face in assessing public services?
3. What could be done to overcome these challenges?
4. What are the gender-based challenges faced by people with disabilities?
5. What are the services that you receive from the government?
6. Can you mention any two services provided by the government for you?
7. Can you mention any two services provided by any other agencies for you?
8. How do you access information about the services provided for you?
9. Can you elaborate on how these services respond to your specific needs?
10. How service delivery is ensured in transition periods between the life cycles?
11. Can you name any other five disabilities mentioned under the Rights of Persons with Disabilities Act, 2016?
12. How do you ensure that your rights are being ensured?
13. How do you think you should approach, when your rights are being denied?
14. What are the support systems that exist around you or you are aware of?
15. How do the support systems help you?
16. What do your opinion about religion as a support system?
17. What are the disparities that exist in availability of support system based on gender?
18. What are the strategies you adopt to cope with the stress that you experience?
19. What are the issues that you have went through due to the stress that you experienced?



20. Can you explain two such situations where you have experienced stigma?
21. Can you explain two such situations where you have experienced discrimination?
22. How did you cope with the discrimination and stigma that you have experienced?
23. Can you brief the gender-based discrimination that you have encountered or witnessed among the people with dwarfism?