EFFECTIVENESS OF BUDS REHABILITATION CENTER INTERVENTION ON THE CAREGIVERS: A CASE STUDY OF KARAKULAM

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

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CERTIFICATION OF APPROVAL

This is to certify that this dissertation entitled **“EFFECTIVENESS OF BUDS REHABILITATION CENTER INTERVENTION ON THE CAREGIVERS: A CASE STUDY OF KARAKULAM”** is a record of genuine work done by **Ms. Anjali P,** fourth semester Master of Social Work student of this college under my supervision and guidance and that it is hereby approved for submission.

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DECLARATION

I, **Anjali P** do here by declare that the Dissertation Titled **"EFFECTIVENESS OF BUDS REHABILITATION CENTER INTERVENTION ON THE CAREGIVERS: A CASE STUDY OF KARAKULAM"** is based on the original work carried out by me and submitted to the University of Kerala during the year 2021-2023 towards 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 other similar title of recognition before.

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Anjali.P

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ABSTRACT

The study's aim is to assess the effectiveness of the BRC intervention on caregivers. A total of 5 caregivers of individuals studying at BRC, Karakulam, were chosen for the research. An interview schedule was developed to gather socio-demographic information from caregivers, with closed questions covering aspects such as "age, gender, marital status, religion, education, occupation, income, family type, family size, and residence." Additionally, a semi-structured interview guide with over 20 questions was created to address the research inquiries. The researcher employed in-depth interviews and discussions to gather insights from participants. The researcher also employed non-participatory observation to witness the support provided to patients and caregivers at BRC. The research design employed was a multiple case study approach. The conclusion of the study is, if a family has a person, the basic level of living of the whole family would be changed. This transformation particularly influences the physical, social, and psychological dimensions of caregivers. To confront these challenges and enhance educational opportunities, BRC has offered assistance to both persons and caregivers. As positive changes were observed in the persons, caregivers also experienced a sense of relief. Keywords: BUDs rehabilitation centre, caregivers and person.

CHAPTER I: INTRODUCTION

1.1 OVERVIEW

BUDS rehabilitation centers serve as crucial establishments for individuals with intellectual and psycho-social disabilities. These centers are operated by Kudumbashree in collaboration with local self-government bodies in Kerala, with the inaugural BUDS school established in 2004 in Venganoor Panchayat, Thiruvananthapuram. The primary focus lies in fostering inclusive and integrated educational approaches, resulting in increased enrollment of mentally challenged children in government schools. This shift towards acceptance and inclusivity provides these children with educational opportunities in a supportive environment. The BUDS Rehabilitation Centers play a pivotal role in facilitating the growth and integration of mentally challenged children into mainstream education, thereby easing the emotional and financial burdens encountered by their families. By nurturing a compassionate and empathetic community, the program actively promotes inclusivity. This initiative is a testament to the importance of inclusive education and assistance for individuals with mental challenges, enabling their progress and dismantling societal barriers. Presently, the program has expanded to encompass 293 BUDS schools throughout the state, catering to an enrollment exceeding 5000 students (Kudumbasree story, 2023). These schools primarily extend assistance to underprivileged individuals who encounter both poverty and disability-related challenges (John Haritha, 2021). Parents with special needs children experience various stressors and reactions associated with their child's condition, which can adversely impact different aspects of their lives. Social lives, recreational activities, and family relationships tend to suffer, with mothers often bearing a more pronounced burden. The presence of poverty further compounds the challenges faced by these families. The BUDS School Project aims to mitigate the emotional and financial hardships faced by economically disadvantaged families with special needs individuals (Kudumbasree story, 2023). The research endeavors to examine the effectiveness of BUDS school interventions on caregivers in the specific area of Karakulam.

1.2 BACKGROUND

A) BUDS REHABILITATION CENTER

BUDS Rehabilitation Centers (BRCs) are day care centers designed for mentally challenged individuals aged 16 or older. They are an essential component of Kudumbashree's initiative to address the gap in the State's care system, which currently caters to mentally challenged individuals up to 18 years old. Unlike BUDS Schools, BRCs do not offer special education; instead, they serve individuals who have already undergone special education at BUDS Schools or other centers. Additionally, BRCs are open to mentally challenged children who cannot attend regular schools. For enrollment in BRCs, individuals must be certified by the Medical Board as mentally challenged. The purpose of rehabilitation, as defined by the Persons with Disabilities Act of 1995, is to empower persons with disabilities to achieve and maintain their optimal physical, sensory, intellectual, psychiatric, or social functional levels. BRCs serve as the logical next step in the BUDS School system, aiming to provide training and support to individuals with special needs, equipping them with skills that enhance their employability. They adopt a Community Based Participatory Rehabilitation (CBPR) approach in collaboration with local bodies, emphasizing community involvement and support. (Kudumbasree story 2023)

The birth of the first BUDs school happened at Venganoor Panchayat in 2004, inaugurated by the former honorable chief minister then Sri. AK Antony. The school was unique in its various ways. The entry and exits to these schools stood away from all sorts of discrimination based on religion, caste, class. To avoid the sin of labeling and stigma towards mental retardation the school was named as “BUDs”. The community accepted the center whole heartedly, but could not replicate it as there was no sustained financial support available for BUDs. The project resurrected when the decentralized plan guidelines of 11th plan included BUDs as one of the important projects in support of Persons with disability. It endorsed LSGI to meet some expenses for managing BUDs (Selvi and Pushpa,2019). In 2008 Kudumbashree mission took the challenge to organize BUDs schools in other Panchayats with recognition under Persons with Disability Act of 1995. By 2010, the Department of Education approved the initiatives of Kudumbashree and began to sanction grant in aid to BUDs. Now there are 63 approved BUDs school in the state. With the policy focus on inclusive and integrated education more and more mentally challenged children began to enroll in government schools. This has provided the mentally challenged children an opportunity for schooling in an inclusive atmosphere. However, there was no institution to take care of the mentally challenged above the age of 18 especially in rural areas which became another problem and issue for the family. The neighborhood groups began to demand for day care and training for mentally challenged adult persons within the local areas. The Government of Kerala accordingly approved the innovative model. Thus in 2015 BUDs Rehabilitation Center was formed the center focuses on the rehabilitation, training and day care of these mentally challenged persons (Kudumbashree Annual Report, 2018).

B) CAREGIVERS

When there are mentally retarded people in the family, individuals, often times family members step in the role of caregiver for their loved ones. Care giving is very important throughout all the stages of mentally retarded people. Even though the proportion and the nature of care given may differ from the time of initial diagnosing till the death, nevertheless it remains an essential element that cannot be separated. A person, often a nearest relative who takes on the primary responsibility for caregiving to a demented person becomes the primary caregiver. Those who helps the primary caregiver in the care giving functions or fills the gap when the primary caregiver is absent become an informal care giver. An informal care giver can be playing the role on a full time or part time basis, and can be either paid or unpaid. Nevertheless, the primary care giver stays along with the demented person and engages in care giving activities. Traditionally, caring was considered the responsibility of women in almost all families (Adams, 2001).

In India, alternate formal care services are not readily available everywhere. The informal caregivers are the most preferred and frequently used source of assistance. Informal caregivers are family members or friends who are unpaid, who provide or manage care for the impaired person. Noelkar and Whitlatch (1995) have defined informal caregiving as the unpaid assistance from family members, friends, and neighbors with one or more personal tasks or instrumental activities of daily living.

Earlier, sick individuals were taken care of in the families itself either by one or the other of the family members. Most of the families those days were joint families. Group living in the joint family ensured quality care was provided to the person needing it. The supportive network in the joint family system reduced the stress and burden of primary care givers. Now most of the families are nuclear families and all the family members are engaged in their jobs and responsibilities. They have multiple roles to perform hence, they have a lot of stress and strain in their own daily life. A minor disease in even one of the family members would disrupt and alter the entire functioning of the family. So now care giving is associated with stress, anxiety or burden.

Burden is a subjective state of feeling during which the person feels tired or stressed and may feel unhealthy or diseased. It involves physical, mental, social, spiritual, emotional, economic and vocational burn out. Burden of a person starts when the care giving activity exceeds the level of coping with the stress, the load becomes excessive or unbearable for a person. There are various reasons for burden of a caregiver and these are multi-dimensional. The caregivers experience stress from the initial time of diagnosis itself and it increases to unimaginable intensity, if the old person requires complete care including control of emotional and behavioral problems for a prolonged period of time.

Caregiving to a severely, functionally impaired patient with mentally retarded is usually a mammoth and demanding task. Caregivers usually receive no formal training in caregiving skills and often develop strategies by themselves often by trial and error at great expense to themselves. Comparisons of caregivers to non-caregivers indicate that caregivers report poorer mental health (George and Gwyther, 1986) and psychological distress (Fiore et al 1986, Srinivas, 2002), lower morale and well-being (Quayhagen and Quayhagen, 1988). Empirical evidence indicates that providing long-term care affects the caregivers' mental and physical health.

Some of the common health problems that are faced by the caregivers include, inability to concentrate when doing any activities, disturbance in sleep or loss of sleep, feeling that their activity is not at all useful, loosing ability to take decisions, feeling that they are always strained and tired, and that they are not able to overcome or cope with difficulties, being not able to enjoy daily activities and lack confidence to face personal problems. Health problems also vary from caregiver to caregiver depending on various factors including degree of burden. Some care givers are at an increased risk for serious illness and mortality because of declining immunity, greater cardiovascular reactivity, significant increase in systolic blood pressure and slowing of wound healing (Burns, 2000). Common emotional difficulties when caring for a loved one with Alzheimer’s disease included stress, depression or sadness, grief, and sometimes anger toward their loved one and, consequently, feelings of guilt for having such feelings (Brodaty and Luscombe, 1998).

Caregivers also report financial instability and strain as a result of providing care to the demented family member. One of the possible explanations for this could be the fact that the responsibilities of caregiving often lead to change in work status of the caregiver, they may lose time from work, chose to retire or may give up work entirely in order to care for an impaired relative. Nevertheless, few caregivers feel that they are giving back to their loved ones by taking care of them and are performing their moral duty. Caregiving has helped them to come closer with their family member and to improve their relations with them.

1.3 STATEMENT OF THE PROBLEM

According to the 2011 Census, In India out of the 121 Cr population, 2.68 Cr persons are „disabled‟ which is 2.21% of Among the disabled population 56% (1.5 Cr) are males and 44% (1.18 Cr) are females. In the total population, the male and female population is 51% and 49% respectively. Majority (69%) of the disabled population resided in rural areas (1.86 Cr disabled persons in rural areas and 0.81 Cr in urban areas). In the case of total population also, 69% are from rural areas while the remaining 31% resided in urban areas the total population. According to the Kerala family survey 60-100 families have got at least one mentally challenged person per Grama Panchayat on an average. (Census of India. (2011). Disabled population by type of disability –New Delhi Registrar General Office)

BRC and BUDS Schools are free and open special schools for mentally challenged children of poor families. All these schools were owned and managed by the local government institutions under the support and guidance of Kudumbashree Mission and the community structure. BRC and BUDS Schools are set up and run according to the guidelines issued by the Government of Kerala. (Kudumbasree)

The BRC and BUDS School idea could be traced back to the family surveys that the Neighborhood Groups (NHGs) conducted for identifying destitute families during 2000-2001. The survey in some places led to the understanding of a particularly vulnerable risk category: families of members with disabilities. Families of members with intellectual disabilities were identified as the most vulnerable. Several instances of pathetic human conditions relating to this was reported. There were people with mental disabilities locked up in rooms; such persons were considered a bad omen in the neighbourhood. A woman surveyor reported that families in such cases were never invited for auspicious ceremonies; if unavoidable, they would be informed with the caveat that they were not expected at the venue. Even family members of people with mental disabilities were considered inauspicious.

The survey was part of preparations for Ashraya, the Destitute Identification and Rehabilitation Project initiated by Kudumbashree. The survey showed that a total of 2.8% of the families in Kerala State had persons with disabilities rated above 40%; there were another 3% of the families that had persons with 10-40% disabilities. Around 0.5% of the families in Kerala had persons with mental disabilities. This meant that 60-100 families have got at least one mentally challenged person per Grama Panchayat on an average. Of these, around 35 families would have persons of age up to 18 years; others had persons above 18 years of age. (kudubmasree).

As a result, the first BUDS school was established in 2004 in Venganoor Panchayat of Thiruvananthapuram.

The rising population of disabled individuals in our society has led to an increased demand for specialized educational services from institutions like BRC and BUDS schools. Initially, there was only one BUDS school, but due to growing awareness and need, the number of such schools has expanded to 293. This growth in BUDS schools not only benefits the disabled individuals by providing them with customized education and support but also brings about significant transformations in the lives of their caregivers. It offers them relief, access to specialized resources, and a sense of belonging to a supportive community, thereby improving their capacity to care for and support their loved ones.

Parents are known to get impacted in many ways because of having a child with special needs. Their social life is likely to be affected, recreational and leisure activities take a beating, and interpersonal relations with family members may worsen. In most cases, mothers are more affected; poverty adds a new dimension to the stresses faced by such families. parents having a child with special needs experience a variety of stressors and stress reactions related to the child’s disability. (Selvi, C., Venkateshan, K., & Pushpa, K., (2020).

All services provided to children with mental retardation are truly a blessing to their caregivers. These services play a vital role in supporting both the child and their caregiver, alleviating some of the challenges and burdens they may face. By offering specialized education, therapy, and support, these services contribute to the overall well-being and development of the child. This, in turn, brings immense relief and comfort to the caregivers, as they witness their child receiving the care and attention they deserve. Additionally, these services provide caregivers with access to valuable resources, guidance, and a sense of community, creating a support network that understands their unique journey. Through these services, caregivers can find solace, empowerment, and the necessary tools to provide the best care possible for their children with mental retardation.

The study primarily aims to explore the transformations experienced by caregivers of individuals studying at BUDS school. The researcher highlights the scarcity of qualitative studies that delve into the everyday experiences of these caregivers. Consequently, the study seeks to bridge this gap by gaining a deeper understanding of the caregivers' lives and assessing the effectiveness of the intervention in alleviating their responsibilities. By examining their perspectives and experiences, the study aims to shed light on the impact of the caregiving role and the extent to which the intervention provided relief. This research will provide valuable insights into the well-being and support needs of caregivers, ultimately informing future interventions and policies to enhance their lives and ease their caregiving burden.

1.4 SIGNIFICANCE OF THE STUDY

India's disabled population, which exceeds 121 crores, is continually growing, resulting in increased dependency on caregivers. This rise in disabled individuals implies a proportional increase in caregivers. Research has extensively explored the burden faced by caregivers, exposing them to physical, psychological, and social challenges. Addressing this pressing issue requires the development of affordable interventions that are accessible to everyone, regardless of their economic status. Regular evaluation of the interventions' efficacy is vital. Therefore, urgent action is needed to create and test effective interventions that can effectively support both the disabled population and their caregivers in India.

Disability encompasses the loss or reduction of physical or psychological functions, leading to an inability to perform normal bodily or mental tasks. Mental challenges within the realm of disabilities pose significant economic and emotional burdens on families. To address this issue, Kudumbashree launched the Disability Mainstreaming Program, establishing the Buds Rehabilitation Center. The school's name, "BUDs," was chosen to avoid labeling and stigmatization of mentally challenged individuals. In 2004, the first BUDS institution was founded in Venganoor Panchayat. Emphasizing inclusive and integrated education policies, more mentally challenged children began enrolling in government schools, providing them with schooling opportunities in an accepting atmosphere. The BUDs Rehabilitation Center plays a crucial role in supporting mentally challenged children's development and integration into mainstream education, alleviating the economic and emotional burdens faced by their families. By fostering a compassionate and understanding community, the program promotes empathy and inclusivity. Overall, the initiative serves as a testament to the significance of inclusive education and support for mentally challenged individuals, enabling them to thrive and break societal barriers.

This study aims to explore and better understand the effect of BUDs Rehabilitation Center interventions on caregivers. The study on caregiver have done in the past, but the study on caregivers of BRC and the enrolled persons have not been yet studied. The study aims at analyzing the situation of the caregiver at BRC and the positive change occurred at the enrolled persons. The findings of the study could also be useful to bring in better policy decisions which can help in improving the quality of life of both the persons and caregivers. This study would also contribute to the knowledge base of social work and facilitate further research in this area.

CHAPTER II: REVIEW OF LITERATURE

2.1 OVERVIEW

A literature review is a description of the literature relevant to a particular field or topic. It gives an overview of what has been said, who the key writers are, what are the prevailing theories and hypotheses, what questions are being asked, and what methods and methodologies are appropriate and useful. The conceptual and empirical literature reviews help in establishing the rationale and credibility to the study.

2.2 THEMES

2.2.1 STUDIES ON CAREGIVERS OF PERSONS WITH AUTISM

FOREIGN STUDIES

Daniels, A. M., Como, A., Herguner, S., Kostadinova, K., Stosic, J., & Shih, A. (2017). A study on Autism in Southeast Europe: A Survey of Caregivers of Children with Autism Spectrum Disorders. The aim of this study was to understand the diagnostic, service and lived experiences of families affected by ASD in Southeast Europe. A total of 758 caregivers from Albania, Bulgaria, Croatia and Turkey were surveyed from 2013 to 2015 about characteristics of the child with ASD; service encounters; and caregiver perceptions. The average age at first concern was 24.4 months (SD 11.8) and at diagnosis, 40.0 months (SD 19.0). Psychiatrists were the most common diagnostician; most children received some ASD-related service, most frequently speech and language therapy. Caregivers endorsed challenges in access to care and perceived stigma. Despite country differences, findings relative to age at first concern, disparities in access and service utilization, and stigma speak to common regional needs.

Tathgur, M. K., & Kang, H. K. (2021) conducted a study on challenges of the caregivers in managing a child with autism spectrum disorder. This study followed quality criteria as a part of qualitative analysis. They prepared an interview schedule for seven caregivers of child with ASD. This article aims to explore the concerns of the caregivers of children suffering from ASD. Aggregate themes were prepared based upon Corley and Gioia's method of data structuring. The study identified that, The Caregivers face various challenges while caring for a child with ASD, with a negative impact on physical health, psychological well-being, societal reactions, and financial balance. Caregivers reported concerns related to service availability for ASD, poorly coping with the diagnostics, and disease processes. Caregivers undergo a lot of problems while taking care of a child with ASD. Health professionals must have an understanding of these problems and must provide the education and information for a better management. Furthermore, the findings of this study have policy implications for the health authorities for providing better health services to children diagnosed with ASD.

Papadopoulos, D. (2021) Conducted a study on Mothers' experiences and challenges raising a child with autism spectrum disorder. This is a qualitative study. Nine mothers of children with ASD were recruited and engaged in semi structured interviews. Transcripts of the interviews were analyzed using interpretative phenomenological analysis. Three interconnected themes were identified in the analysis: (a) emotional burden, (b) family burden, and (c) social burden. The aim of this study was to investigate the lived experiences of mothers of children with ASD in Greece. A key finding in the themes was the sense of burden, distress, and vulnerability experienced by the mothers. The findings provide valuable understanding of the experiences of mothers raising children with ASD in one of Europe's medium-income countries.

Lai, W. W., & Oei, T. P. S. (2014) conducted a study on coping in parents and caregivers of children with autism spectrum disorders (ASD): a review. Parents and caregivers of children with ASD have reported significant stress and challenges in caregiving. How-ever, stress coping research in parents and caregivers of children remains limited. This review attempted to close this gap. For this review, 37 studies investigating the (1) underlying themes, (2) contributing factors, and (3) psychological outcomes of ASD-related parental and caregiver coping, were selected from the literature. Results revealed that the two most useful coping resources, i.e., problem-focused coping (45.9 %) and social support (37.8 %), were supported by parental stress coping studies. Parents' and caregivers' use of coping strategies was also influenced by (1) demographical characteristics (i.e., gen-der, age, education, income, language) and psychological at tri- but es (i.e., personality, cultural values, optimism, sense of coherence, benefit-finding and sense-making abilities, emotion-al health, coping styles), (2) child characteristics (i.e., age, gender, medical conditions, cognitive and adaptive functioning abilities, language, difficulties, and behavior problems) and (2)situational variables (i.e., treatment availability, family function, and clinician referrals to support resources). This review seeks to provide a summary of coping approaches adopted by parents and caregivers of children with ASD, as well as an overview of coping factors and coping out comes, to assist healthcare providers in operationalizing resources and support for families of children with ASD. This review aims to (1) summarize the coping strategies adopted by parents and caregivers in providing care for their children with ASD, (2) examine factors (including the role of culture and individual differences) that influence parental/caregiver coping in ASD, and (3) report on the psychosocial outcomes of parent/caregiver coping in ASD. This review draws attention to the limited empirical evidence available regarding the framework of coping and the effectiveness of coping resources in promoting positive emotional well-being. It urges caution in accepting the concept of coping without establishing its underlying structure first. The review suggests that before exploring the associations between coping and related outcomes, it is essential to establish a clear understanding of the structure of coping. Mental health professionals should pay close attention to the coping mechanisms that are relevant to the specific caregiving needs of parents. By doing so, they can provide parents with appropriate and effective coping resources to enhance their ability to cope positively. This approach will contribute to better equipping parents with the necessary tools to navigate the challenges of caregiving and promote their overall well-being.

Werner, S., & Shulman, C. (2015) conducted a study on Does type of disability make a difference in sffiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? This study examined affiliate stigma among family caregivers of individuals with developmental disabilities via a comparison between caregivers of individuals with intellectual disabilities (ID), autism spectrum disorders (ASD) and physical disabilities (PD) in Israel. Followed methods is Family caregivers (n = 171) of individuals with developmental disabilities, mainly ID (22.4%), ASD (32.9%) and PD (27.1%), completed a self-report structured questionnaire including the Affiliate Stigma Scale and background variables. Studies have shown that beyond public and self-stigma, stigma can also impact family members. Only scant research has examined the internalised aspects of stigma, known as affiliate stigma, among family caregivers of individuals with disabilities. Results supported a one-factor structure for the Affiliate Stigma Scale. Overall, affiliate stigma was relatively low in this sample, but was found to be higher among caregivers of individuals with ASD when compared with caregivers of individuals with ID or PD. Findings from this study point to the importance of supporting caregivers of individuals with ASD to decrease their feelings of stigma. It is also important to further develop scales measuring affiliate stigma in order to capture the multi-dimensional nature of the concept.

INDIAN STUDIES

Das, S., Das, B., Nath, K., Dutta, A., Bora, P., & Hazarika, M. (2017) conducted a study on Impact of stress, coping, social support, and resilience of families having children with autism: A north east Indian-based study. The study assessed level of parental stress, social support, coping mechanisms used by family and resilience in meeting the challenges as caregivers. Parents were selected by simple random sampling from a multi-specialty center dedicated to CWA. They were assessed with the help of structured tools like the Parental Stress Scale, the social support appraisals scale, the coping self-efficacy scale, and the Family Resilience Assessment Scale. Results were analyzed with descriptive statistics and findings suggest definite stress among the parents of CWA. Personal time constraint was noticed in majority of parents, which had adversely affected their professional lives. Despite wide array of stress factors, family members had satisfactory coping skills to work in harmony in adverse circumstances. Regarding secondary social support in terms of family, friends, and neighbors, responses were mixed; religious and spirituality were often resorted avenues. Social desirability, fatigue and the sample being restricted to only one center were though the limitations but, this study throws light on pertinent issues related to families with CWA from a region where specialty centers are a rarity. The future implication could focus on CWA's future, rehabilitation, care and parental concerns which are grossly neglected in North East India.

Ozgur, B. G., Aksu, H., & Eser, E. (2018) conducted a study on Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. It was aimed to evaluate the effect of the variables related to both parents and children on the QoL scores of the parents of the children with ASD. Settings and Design: This is a causality analysis study. Subjects and Methods are Questionnaire on sociodemographic/disease-related variables, QoL in Autism Questionnaire-Parent Version (QoLA-P), autism behavior checklist and Clinical Global Impression scale were assessed of 162 patients with ASD. Statistical Analysis Used: Unpaired t- test, Mann–Whitney U test, Kruskal–Wallis test, and one-way ANOVA test were used for comparing groups. The parameters found to be statistically significant for QoLA-P in different analyses were included as the independent variable in the logistic regression analysis. The backward (variable elimination) model was selected as the model in the analysis. Results of the study is, the causality has been established may be stated as the severity of autism, the presence of psychiatric disorder in the mother/father, attendance of the child at school, duration since the diagnosis of autism, and the child's medication use. Autism affects the QoL of caregivers. The intervention of treatment by considering the factors that affect the QoL positively or negatively may increase the QoL of caregivers.

Johnson, A., & Kumae, S.S. conducted a study on Influence of child’s autism on relationships: A phenomenological study among maternal caregivers in Kerala. The aim of the study is the rationale of this study is to explore the maternal experiences of children with autism in Kerala, India. The participants in the study were mothers who are the primary caregivers of their children clinically diagnosed with autism from Ernakulam district, Kerala. These mothers were all married and lived with their spouses. Ten participants whose children were clinically diagnosed with autism were conveniently recruited from Autism Club of Ernakulam chapter, as the small sample size facilitates the micro-level reading of the participants’ accounts (Smith & Osborn, 2014) A small, select and homogenous convenience sample was recruited as it helps with understanding a particular context. The study throws light on the lived experiences of the maternal caregivers in raising a child with autism and its influence on their marital and social relations. The autism diagnosis has a crucial role in the way the mothers interacted with their spouses and the larger society. Public ignorance on autism can obstruct the social participation of the mothers and make them reclusive. Further study in the form of a survey can help understand the very many issues faced by the maternal caregivers.

2.2.2 STUDIES ON CAREGIVERS OF PERSONS WITH MENTAL RETARDED

FOREIGN STUDIES

Harries, V. S., & McHale, S. M. (1989) conducted a study on Family life problems, daily caregiving activities, and the psychological well- being of mothers of mentally retarded children. The study examined problematic situations experienced by mothers of mentally retarded children and those characteristics of retarded children that may influence family life problems. The participates where Thirty mothers had a mentally retarded child and 30 had only nonretarded children. They used home interviews and follow-up telephone interviews. Through this study they find Child welfare issues and restrictive time demands were the most intense family problems reported by mothers with retarded children. Ratings of more intense family problems were associated with more time spent with the child and more symptoms of maternal depression.

Maheswari, K. (2014) conducted a study on Burden of the Care Givers of Mentally Retarded Children. The aim of the study is to assess the burden experienced by the care givers of mentally retarded children. The researcher has adopted purposive sampling method to collect data from the care givers of mentally retarded children in Trichy. The sample size is 50. In the present study the researcher has attempted to investigate the level of care giving burden experienced by the care givers of disabled children. The effort of the investigation is to provide a descriptive profile of the respondents. Further the researcher has attempted to find out the association between the various variables of the study. Hence for this study descriptive research design was adopted. The findings of the study are Family is the prime support system for the persons with disabilities in any society. Families experience economic, physical and emotional burden while caring the disabled persons. Awareness about disability and its management must be created among the community in general and to mothers in particular because most of the care takers are mothers. Knowledge about welfare measures and rehabilitative measures must be disseminated among the public in regular intervals, so that care givers will be a position to take care of their special children with care and support. It is also insisted that the care givers must also think about their psychosocial conditions and must take considerable care. Well targeted treatment measures and prevention programmes will definitely pave way for better living of the people with disability and also increases their longevity. Descriptive research design was used and the results indicated that less than half of the respondents (44%) have high level of burden and majority of the care givers are female.

Abass Mohamed, N., Ibrahim El Malky, M., & Said Sayed, F. (2022) conducted a study on Effectiveness of psycho-educational nursing intervention on feeling of burden and self-efficacy among caregivers of mentally retarded children. This study aimed to evaluate the effectiveness of psycho-educational nursing intervention on feeling of burden and self-efficacy among caregivers of mentally retarded children. A quasi-experimental design (pre and posttest) was used to achieve the aim of the study. A convenience sample of 40 family caregivers of mental retarded children from the above setting. Three tools were used for data collection. I: Structured interview questionnaire was used to collect data about socio demographic characteristic of caregivers and mental retarded children. II: Burden interviewing questionnaire to measure the extent of family caregiver have feeling of burden and III: General self-efficacy scale to assess a general sense of perceived self–efficacy. The Results of the study was a highly statistically significant improvement in total mean score of feeling of burden and total mean score of self-efficacy post implementation of the program than preprogram. The Conclusion is Psycho-educational nursing program had a positive effect on enhancement of feeling of burden and self-efficacy among caregivers of mental retarded children.

INDIAN STUDIES

Singh, T. K., India, R.R. (2008) conducted a study on Impact of Disability of Mentally Retarded Persons on their Parents. Aims of the study are (1) To assess the level of disability in mentally retarded children. (2) To see the impact of disability of mentally challenged children on their parents. The study sample consisted of parents of 65 mentally challenged children. The study was conducted at the outpatient department of Post Graduate Institute of Behavioral and Medical Sciences (PGIBMS) and two special schools of such children in Raipur. The samples were selected by purposive method. Developmental screening test, Vineland Social Maturity scale and National Institute for the Mentally Handicapped disability impact scale are the tools used for conducting this research. The finding was having an intellectually subnormal child is not altogether a sign of so-called ‘bad fate or misfortune’ to everyone, but it can also be a challenge which strengthens the parents of those children. But at the same time, it is equally true that having a MR child is a source of chronic stress to the family members and it can affect them negatively in many ways and more attempts should be made for primary prevention of mental retardation.

Ganjiwale, D., Ganjiwale, J., Sharma, B., & Mishra, B. (2016) conducted a study on Quality of life and coping strategies of caregivers of children with physical and mental disabilities. This study was conducted to assess the quality of life (QOL) and coping mechanisms used by the carers of physically challenged children. In this cross-sectional study, all the 116 children from a school for children with special needs in Anand, Gujarat and their careers were included. World Health Organization-QOL (WHO-QOL) and BREF COPE were administered to measure QOL and coping strategies, respectively. The result of the study is: WHO-QOL, the social relationship domain was observed to be the best while environment domain had the lowest score. The main coping style used by the caregivers was Active emotional coping. Significant differences were found in QOL of the caregivers of physically challenged children based on the type of disability of the child. Rehabilitation programs can be planned to provide psychological support to the caregivers to ease the burden if any through collaborative efforts.

Sethi, S., Bhargava, S. C., & Dhiman, V. (2007) conducted a study on Study of level of stress and burden in the caregivers of children with mental retardation. Purposive sampling was done and one hundred and eighty subjects who were the parents of the children with well-established diagnosis of MR were selected for the study. Only children who had both parents interviewed were included in the study. parent was interviewed separately. A semi-structured performa was used to collect the details. The result of the study is Living with and caring for the person with MR is very stressful and burdensome. High level of stress and burden is associated with increased level of disability; it being the maximum in the caregivers of persons with severe to profound MR. Multiple stressors seem to be responsible for the stress and burden experienced by the caregivers. Amongst the parents, mothers perceive more stress and burden in caring their disabled children than the fathers.

2.2.3 STUDIES ON CAREGIVERS OF PERSONS WITH DOWN SYNDROME

FOREIGN STUDIES

Alam El-Deen, N., Alwakeel, A. A., El-Gilany, A. H., & Wahba, Y. (2021) conducted a study on burden of family caregivers of down syndrome children: a cross-sectional study. The objective of the study is to assess the burden of DS children on their family primary caregivers and to identify the variables associated with caregiver burden. A cross-sectional study was conducted in Mansoura, Egypt from March 2019 to March 2020 including 457 family primary caregivers and their DS children. Socio-demographic and clinical data were collected through direct interviews.

Caregiver burden was assessed by Zarit Burden Interview (ZBI-22) scale. The associations between categorical variables were tested using chi-square test, crude odds ratio and 95% confidence interval. Logistic regression analysis was carried out to detect the variables independently associated with caregiver burden. More than half (51.9%) of caregivers had no or little burden, 40.7% had mild to moderate burden and 7.4% had moderate to severe burden. Female caregiving, single parent status and DS children of age less than 6 years old, female gender and having congenital heart diseases were the variables independently associated with mild to severe burden with adjusted odds ratios of 4.2, 2.5, 1.5, 2.1 and 1.7, respectively.

Lee, E. Y., Neil, N., & Friesen, D. C. (2021) conducted a study on Support needs, coping, and stress among parents and caregivers of people with down syndrome. The aim of the study is (1) Do important unmet needs (IUNs), coping, and stress vary between parents and caregivers of adults compared to children with DS? (2) What is the relationship between stress, coping, and needs for parents and caregivers of people with DS? In this study 152 parents and caregivers of people with DS of various age groups completed an online survey. They used family crisis oriented personal scales. The result is IUNs were greater for parents and caregivers of children than for parents and caregivers of adults. Stress level was positively correlated with the number of IUNs, and great use of coping strategies were associated with less stress and fewer IUNs. The coping styles that predicted stress were different for caregivers of children versus adults. And this research highlights the importance of considering age in relation to needs and stress among families with a child with DS. Fostering effective coping strategies, including acquiring social support, is likely to support positive outcomes for caregivers of people with DS.

Barros, A. L. O., Barros, A. O., Barros, G. L. D. M., & Santos, M. T. B. R. (2017) conducted a study on Burden of caregivers of children and adolescents with down syndrome. The aim of this study was to evaluate the profile and burden of caregivers of children/adolescents with and without Down syndrome. The evaluations were performed through questionnaires about the profile and burden of the caregivers (Zarit Burden Interview) and the profile of the children/adolescents. These questionnaires were applied to 168 caregivers. The profile of the caregivers of children/adolescents with DS is mothers, those who are at a more advanced age, those in a stable relationship, those without occupation, those with a low per capita income and low level of schooling, those with a Catholic affiliation, those with health problems, and those in continuous use of medication. The burden of these caregivers is predominantly moderate. DS children/adolescents attend school, receive social benefits, and rely on their caregivers for activities of daily living.

INDIAN STUDIES

Darla, S., & Bhat, D. (2021) conducted a study on Health-related quality of life and coping strategies among families with Down syndrome children in South India. The study intends to evaluate the health-Related QoL (HR-QoL) and coping strategies among families of DS children. This explorative, cross-sectional study was conducted among parents/caregivers of DS children (*n* = 51). Socio-demographic details, HR-QoL, coping strategies and perspectives on having a child with disability were obtained through a standard questionnaire. The result is Most DS children were upper and upper-middle class of urban background. With increasing life expectancy, the gap continues concerning the assessment of needs beyond medical aid among DS children. Better HR-QoL and coping with the stress could be ensured by the provision of comprehensive health policies inclusive of training programs, stress management, as well as psychosocial and organizational support across any socio-economic strata.

Shetty, J., Shetty, A., Mundkur, S. C., Dinesh, T. K., & Pundir, P. (2023) conducted a study on Economic burden on caregivers or parents with Down syndrome children—a systematic review protocol. In this review, quantitative studies that assess the economic burden on caregivers of children with Down syndrome will be considered. We will perform a systematic literature search conducted from the year 2000 to 2022 on electronic databases CINAHL, EBSCO, EMBASE, PubMed, Scopus, Web of Science, and EconLit. An additional gray literature search will be carried out. Two researchers will independently conduct the screening and data extraction and assess the risk of bias. The review attempts to methodically analyze the economic burden of children suffering from Down syndrome from the societal perspective and also the perspective of caregivers of such children. The study will provide insight into the challenges of families of people with disabilities and draw the attention of the policymakers, government and non-government organizations, health care professionals, researchers, academicians, and civil society towards this issue. Recognizing and taking steps towards addressing these challenges will reduce mental stress and promote financial well-being among caregivers of children with Down syndrome.

Al-Bahadli, E. S., & Adai, M. G. (2019) conducted a study on Burdens on Caregivers of Children with Down Syndrome in Middle Euphrates Region of Iraq. Objectives of the study were to assess the burdens of caregivers of children with Down syndrome and to find out the relationship between burdens of caregiver and their demographic characteristics. Method: A descriptive cross-sectional design study was carried out in the institutes of special needs in middle Euphrates region of Iraq. A probability (cluster) sampling method was used to select 100 caregivers. The result of the study is Down syndrome occurred in male more than female children who get care mostly from female caregivers. Economic and physical burdens had high scores burden evaluations in all studied cities. Older age of caregiver had great burden evaluation. Caregivers with high socioeconomic status had great burden evaluation in all studied provinces. Conclusion: The Caregivers of Down syndrome children are impacted by psychosocial, physical, emotional and physical burdens at high to moderate leves.

2.2.4 STUDIES ON CAREGIVERS OF PERSONS WITH LEARNING DISABILITY

FOREIGN STUDIES

Robinson, C., & Williams, V. (2002) conducted a study on carers of People with Learning Disabilities, and their Experience of the 1995 Carers Act. This paper seeks to highlight the impact of the Carers (Recognition and Services) Act of 1995 on carers of people with learning disabilities. It draws on research conducted in the south west between 1997 and 1999, which examined the views and experiences of carers who had an assessment of their needs, together with those of the person they care for and the professional conducting the assessment. It concludes that the Carers Act is not widely used, or understood, by this group of carers. Recommendations for improving practice include changes to the current terminology, new triggers for a carer's needs assessment, and a greater input from other agencies, especially health services.

Antonsson, H., Graneheim, U. H., Lundström, M., & Åström, S. (2008) conducted a study on Caregivers' reflections on their interactions with adult people with learning disabilities. The aim of this study was to illuminate carers' reflections on their interactions with adult people with learning disabilities. In a previous study, interactions between 16 carers and 11 residents with learning disabilities were recorded on video. In this study, stimulated recall interviews about the interactions were carried out with all the carers. The text was analysed using qualitative content analysis. The findings indicate that the carers reflected on both successful and unsuccessful interaction. The findings have implications for interventions aimed at strengthening the competence of carers and developing strategies for managing challenging behaviour, in order to ensure high-quality care and a good working climate.

Williams, S., Dagnan, D., Rodgers, J., & McDowell, K. (2012) conducted a study on Changes in Attributions as a Consequence of Training for Challenging and Complex Behaviour for Carers of People with Learning Disabilities: A Systematic Review. This paper reviews the evidence for changes in carers' attributions regarding the behaviour of people with intellectual disabilities as a consequence of carer training in challenging and complex behaviour. Papers were included in the review if they reported outcomes for carer training on the behaviour of people with intellectual disabilities and used a measure of carer attribution of the behaviour of people with intellectual disabilities. The characteristics of the scales used and the content and length of training are considered as possible factors affecting changes in attribution. The papers were reviewed, most studies using behavioural curricula for their training, and none explicitly set out to change attributions. Eight of the 11 papers reviewed reported changes in attribution although core characteristics of training did not distinguish those papers that reported such changes and those that did not. Changes in beliefs and attributions occur even though these are not identified as a focus within the training provided. The present authors suggest that the formulation processes involved in behavioural training may play a key part in changing attributions as a consequence of this training. The present authors discuss the potential for more focused intervention designed to change attributions and for better alignment of measures to specific attribution change expected as a result of specific training approaches.

INDIAN STUDIES

Banga, G., & Ghosh, S. (2017) conducted a study on The Impact of Affiliate Stigma on the Psychological Well-Being of Mothers of Children with Specific Learning Disabilities in India: The Mediating Role of Subjective Burden. Sample of the study included 100 mothers of children with SLD. Data was collected using a structured interview schedule. Descriptive statistics, correlation and stepwise regression were used as the primary analytic tools. The study says Affiliate stigma experienced by mothers significantly predicted low levels of psychological well-being and subjective burden mediated the relationship between affiliate stigma and psychological wellbeing. The findings call for developing targeted interventions to address affiliate stigma and positive appraisal of the caregiving situation, with the goal of improving the psychological well-being of mothers of children with SLD.

2.2.5 STUDIES ON CAREGIVERS OF PERSONS IN BUDS SCHOOL AND BRC

Selvi, C., Venkateshan, K., & Pushpa, K., (2020). A study on inclusive of disability-a study on bud’s scheme under kudumbashree. This article focuses on Kudumbashree in Kerala initiated the Disability Mainstreaming Program Namely Buds. To avoid the sin of labeling and stigmatizing towards the mentally challenged, the school was named as “buds”. The main focal point of the review paper is to give the clear view of BUDS scheme under Kudumbashree and its function. Kudumbashree Mission (2019) states that, disability is when a loss or reduction in any physical or psychological function results in a partial or total inability to perform any bodily or mental functions in a manner or within the range considered normal for a human being. This study shows that parents having a child with special needs experience a variety of stressors and stress reactions related to the child’s disability.

According to Kudumbareee story (2023) BUDS Schools are free and open special schools for mentally challenged children of poor families. There are 62 BUDS Schools in the State, all owned and managed by the local government institutions under the support and guidance of Kudumbashree Mission and the community structure. BUDS Schools are set up and run according to the guidelines issued by the Government of Kerala

CHAPTER III: METHODOLOGY

METHODOLOGY

3.1 OVERVIEW

This chapter deals with the methodology adopted for this study. An attempt is made to narrate the methods and techniques used to identify cases with caregivers of BRC, their changes and how this BRC brought positive change in the caregivers. This chapter includes research title, research questions, definitions, research design, the setting for the study, population, sample, tools, and method of data collection and how the data will be analyzed and interpreted in order to arrive at certain findings, suggestions and conclusions based on the study.

3.2 TITLE

"EFFECTIVENESS OF BUDS REHABILITATION CENTER INTERVENTION ON THE CAREGIVERS: A CASE STUDY OF KARAKULAM"

3.3 GENERAL QUESTION

What is the Effectiveness of BRC intervention on caregivers?

3.4 SPECIFIC QUESTION

- What were the factors affecting caregivers before BRC intervention of the person?
- What were the reasons and motivation for sending the person to BRC?
- What are the effects of BRC intervention on caregivers?
- What are the effects of BRC intervention on the person?

3.5 CONCEPTUALIZATION

The conceptual frame work has been derived from the conceptual understanding that has been developed through the literature review and the concepts discussed in the previous chapter.

3.6 DEFINITION OF CONCEPTS

- **BUDs rehabilitation centre (BRC)**

a) Theoretical

BUDs rehabilitation centres (BRC) are rural centers for training, day care, and health care of mentally challenged persons (mental retardation, cerebral palsy, autism, multiple disability) (Kudumbasree org. 2023)

b) Operational

BUDS rehabilitation centre (BRC) in Karakulam are free and open special schools for mental retardation, cerebral palsy, autism and multiple disability persons as well as provide services for their care givers

- **PERSON**

a) Theoretical

According to dictionary.com (2023) Person is the most general and common word: the average person. Individual views a person as standing alone or as a single member of a group

b) Operational

The disabled individual who enrolled in karakulam BUDS school.

- **CAREGIVER**

a) Theoretical

Zarit & Edwards (1996) define caregiver as a family member (or friend) helping someone on a regular (usually daily) basis with tasks necessary for independent living. In the broadest sense, a caregiver is a person who provides help and support to another person, usually a relative or friend. More specifically, a Caregiver is someone who looks after another person who needs help with daily living and who would not otherwise be able to live independently at home.

b) Operational

In this study the Care givers (of person who enrolled in karakulam BUDS school) of is the significant member in the family who spends maximum time in the care of person. This may be either the father, mother, siblings or any other relatives.

3.7 RESEARCH APPROACH

Qualitative approach is adopted for the study and multiple case study design was used to collect data for the purpose of the study. McMillan and Schumacher (1993) defined qualitative research as, “primarily an inductive process of organizing data into categories and identifying patterns (relationships) among categories.” This definition implies that data and meaning emerge “organically” from the research context.

3.8 RESEARCH DESIGN

The research design refers to the overall strategy that is chosen to integrate the different components of the study in a coherent and logical way, thereby, ensuring that the research problem will be addressed effectively. It constitutes the blueprint for the collection, measurement, and analysis of data.

The research design adopted in this study is multiple case study research design. The case study research design is an in-depth study of a particular situation rather than a sweeping statistical survey. “Case study research involves the study of an issue explored through one or more cases within a bounded system‟ (Creswell 2007:73).

3.9 PILOT STUDY

A pilot study is a small-scale preliminary study conducted in order to evaluate feasibility, time, cost, adverse events, and affect size in an attempt to predict an appropriate sample size and improve upon the study design prior to performance of a full-scale research project. The researcher conducted the pilot study at Karakulam on a caregiver of person studying at BRC. From this the researcher understood the feasibility of the study. Appropriate modifications were made to enhance the instrumentality of data collection tools.

3.10 UNIVERSE AND UNIT

The universe of this study includes all the caregivers of person studying at BRC karakulam.

The unit of this study is a single Caregiver of person studying at BRC Karakulam.

3.11 SAMPLING

A non-probability, purposive sampling method was used to select the sample for the study. The participants have been chosen to participate in individual face-to-face semi structured interviews. Participants for the study have been selected according to a set of specific criteria.

3.12 INCLUSION CRITERIA

- The caregivers of the person who are enrolled at BRC, for more than one year.
- Family member who has assumed the role of a caregiver and those who consented to give the interview.
- Caregivers of person studying under BRC.
- Caregivers who are currently availing the services of BRC

3.13 EXCLUSION CRITERIA

- The caregivers of person who do not have regular enrolled at BRC.
- Caregivers of person with regular attendance but have been attending BRC for less than one year.
- Professional caregivers at home.
- Caregivers who were availing the services earlier but have discontinued.

3.14 SAMPLE SIZE

For the present study, a total sample of 5 caregivers of person studying in BRC, Karakulam who were satisfying the exclusion and inclusion criteria were selected.

3.15 SOURCES OF DATA

A) PRIMARY DATA

Primary data were collected directly from the caregivers of person at BRC.

B) SECONDARY DATA

Secondary data comprises of information from site, reports of surveys studies and literature. And also, data collected from Karakulam BRC.

3.16 TOOLS FOR DATA COLLECTION

The interview schedule was prepared to find out the socio-demographic profile of caregivers. This schedule consists of closed questions, dealing with the socio-demographic profile like "age, sex, marital status, religion, education, occupation, income, type of family, size of family and domicile" of the Care givers.

A semi structured interview guide including more than 20 questions was prepared based on the research questions. In-depth interviews and discussions were conducted as the techniques of data collection to elicit information from the respondents. Semi structured interview guide was also used to gather information from the staffs about the services offered at BRC to both the patients and the caregivers.

Non participatory Observation was used by the researcher to observe the services provided to the patients and the caregivers at BRC. The researcher could also observe various therapies provided to the person by the staffs and the patients responses to those. This has contributed in making the study rich.

3.17 DATA COLLECTION

The researcher collected the data from five caregivers of person from BRC at karakulam. The researcher visited each family of care givers of person from BRC and personally interviewed the Caregivers. Each interview lasted for an average two and half to two hours. The interviews in Malayalam were transcribed into English.

3.18 DATA ANALYSIS

The data collected through in-depth interviews is subjected to the process of analysis in qualitative research with the primary aim to understand the research concerns from the people’s perspective. The analysis of the qualitative cases studies was done through thematic analysis. Throughout the process of data analysis various lines of inquiry were adopted with the aim of creating concepts, discovering patterns from the emerging concepts, seeing how concepts emerge and explaining why the particular concepts emerge. Data analysis was done based on the research questions. They are:

- What were the factors affecting caregivers before BRC intervention of the person?
- What were the reasons and motivation for sending the person to BRC?

- What are the effects of BRC intervention on caregivers?
- What are the effects of BRC intervention on the person?

3.19 CHAPTERISATION

The chapterization of the research dissertation is as follows:

Chapter I: Introduction

Chapter II: Review of literature

Chapter III: Research Methodology

Chapter IV: Case Description, Data Analysis and Interpretation

Chapter V: Major findings, suggestions

Chapter VI: Conclusions

Chapter VII: Bibliography and Appendix

3.20 ETHICAL CONSIDERATION

- An informed consent was obtained from all the participants prior to the data collection.
- The participants were assured full confidentiality of information, and the collected data will be used only for academic purpose.

3.21 LIMITATIONS OF THE STUDY

- The major limitation faced by the researcher was that of time. The research needs to be submitted during the limited time that is allowed to a post-graduation student.

3.22 CONCLUSION

The methodology provides an overall idea regarding the methods use in the study. The methodology guided the researcher to complete the study in a systematic and scientific manner.

CHAPTER IV: CASE PRESENTATION

4.1 CASE PRESENTATION

CASE 1

The first participant is A, a 49-year-old woman. A is a Hindu believer and has completed her Plus Two education. A's husband is a union worker. They have two children, and their eldest son is 21 years old and currently studying at BRC and she also has a daughter who is 18 years old and has completed her higher secondary education. A's husband's lack of a stable income puts the responsibility of managing the family squarely on A's shoulders. To make ends meet, she takes on the task of caring for children in other households, which provides her with the much-needed income to support her family. However, their situation is far from ideal. The dilapidated condition of their rented house adds to their challenges, as does their son's mental health issues. Moreover, A has to contend with her husband's excessive alcohol consumption, which exacerbates their difficulties. Despite facing these tremendous hardships, A remains resilient and determined. She relies on her own efforts to navigate through these tough times and provide for her family. A's unwavering determination and commitment to overcoming obstacles serve as an inspiration to others.

A face a significant challenge in raising her son who has a mental disability. It is a constant source of concern and responsibility for her. The journey of navigating through his condition can be emotionally and mentally draining. A often encounters obstacles in helping her son communicate and interact with others, which requires patience, understanding, and extensive efforts on her part. The daily routines and tasks that may seem ordinary to others become complex and demanding for A and her son. A's life revolves around ensuring her son's well-being, constantly adapting to his unique needs and offering unwavering support. Despite the challenges, A's love for her son remains unwavering.

A says, "Since his birth, he has had a mental disability. It took him a long time to communicate with other children. He would repeat a matter multiple times for it to register in his mind. Even when I called him 'mom,' he would take a long time to respond." Whenever I heard him being called "mom," I would often feel a sense of sadness. He is my first-born son. I wonder how long I have to wait to hear that call from him."

Others found it difficult to understand his speech and interpret what he was trying to communicate. Due to his mental disability, his speech may have been unclear or lacked coherence, making it challenging for people unfamiliar with him to grasp his intended message or understand his thoughts and feelings. This communication barrier created a sense of difficulty and frustration for both him and those attempting to engage in conversation with him.

A said, "Since childhood, his language, interpreting his expressions is easy for us to understand and comprehend, but it is not possible for someone from outside to understand his thoughts and feelings. His language and mode of expression may differ from typical verbal communication, making it difficult for individuals outside their immediate circle to grasp his thoughts and emotions accurately".

During his early years, A's son exhibited challenging and disruptive behavior, which posed significant difficulties for A. This behavior manifested in various ways, leading to instances where she experienced physical injuries. The unpredictable nature of the son's behavior caused A to be at risk of harm during daily interactions. These incidents not only caused physical pain but also added emotional stress to A's life. It was a constant struggle for A to navigate her son's disruptive behavior and ensure the safety and well-being of both herself and her child. During his early years, A's son exhibited challenging and disruptive behavior, which posed significant difficulties for A. This behavior manifested in various ways, leading to instances where she experienced physical injuries. The unpredictable nature of the son's behavior caused A to be at risk of harm during daily interactions. These incidents not only caused physical pain but also added emotional stress to A's life. It was a constant struggle for A to navigate her son's disruptive behavior and ensure the safety and well-being of both herself and her child.

A said, "Four years ago, when he used to eat food, he would bite my finger. Blood would come out from my hand that day."

Before enrolling in the BRC, due to the persistent disruptive behavior of A's son, their relatives, both from A's family and her husband's family, are reluctant to visit their house. They fear the unpredictable consequences and potential harm that his behavior may cause. At that time this situation creates a sense of isolation for A and her family, as they are unable to receive the usual support and interaction from their relatives. In addition, A is also hesitant to let her son go outside, as she worries about the possible disruptions or harm he may cause to others or himself.

A said, "In some cases I have even had to lock my son up."

A, as a caregiver in a nuclear family, expressed feelings of exclusion during outside family functions like weddings and parties. Despite being an essential part of the family, A is often left behind to fulfill caregiving responsibilities while other family members attend the events.

A said, "There are times when we had to attend family function, or any other functions at outside. Even though my family is a nuclear family, when functions like wedding, or parties come up, all the family members leave me behind in the house and all may go to attend the function. Sometimes I have felt that I am becoming invisible in front of others".

A was exhausted from constantly encountering sympathetic expressions from guests and people who learnt about her child's condition.

A said, "There are times, when guest visit our place and when they get to know about my son they show and expression of sympathy, which is something I am tired of seeing. Everywhere I get to see this sympathy eyes from the people, it has been so many years and I am totally tired of this".

While everyone in the village knows A's son but he has fewer friends due to his limited ability to leave the house. His inability to engage in social activities outside the home creates a barrier to forming friendships within the community. However, amidst this challenge, his younger sister has emerged as his closest companion and confidante. Their bond transcends the boundaries of his physical limitations, and she understands him on a deeper level. She provides him with the friendship, understanding, and support he needs, filling the void created by his limited social interactions. Together, they share moments of joy, laughter, and companionship within the familiar surroundings of their home. Their relationship serves as a source of comfort and strength, allowing him to feel connected and valued despite the absence of a larger social circle.

A said, "Honestly, I am afraid to let my son go outside. He lacks the cognitive ability to comprehend and identify potential dangers, even during ordinary childhood activities and games."

Until plus two, A's son was studying in a special school. That time she had little knowledge about BRC and BUDs school. His education at the special school was expensive.

The house of A is not too far from the road. When A's kid is in special education, she makes every effort to finish her work and leave the working place before her son gets home from school. The special school bus does, on occasion, leave him on the road if she is unable to get home for any reason. He would autonomously navigate his way home in these circumstances.in such situation A didn’t have other opportunity to bring him back home.

A said, “That is our faith”

After A's son turned 18 years old, the Panchayat president informed to her about BRC.

A said, “My husband, he is a drunken, I have not financed in my family. The panchayat president knew my child and his condition. Once he visited our home, at that visit he informed us about BRC institution and the services provided by this institution. From him, I got to know about the scholarship amount. From that, the disability pension, scholarship at BRC, is a helping hand in my family”.

A was also informed that there was a considerable distance between the BRC and their home. However, the good news was that a school van service was provided to transport. This information brought great relief to A. Knowing that even if A was not available at home, the school van service would ensure that their son would be dropped off safely at their house. This arrangement provided a sense of security and peace of mind to A, knowing that their son's transportation needs were taken care of, especially considering the long distance involved. It alleviated any concerns about their son's commute and ensured that he would reach home safely.

A said, “I got to know that the BRC provides the best educational assistance to students. I got to know that this BRC not only provides academic help but also provides skill improvement. Vocational training is also provided”.

Since A's son joined the BRC four years ago, there have been noticeable changes in him. One significant change is his social development. He has made numerous friends during his time at the BRC, which has contributed to his overall growth and confidence. These newfound friendships have had a positive impact on his participation in school activities. He actively engages and communicates with his friends. By actively participating and communicating with his friends, A's son has not only enhanced his social skills but also strengthened his ability to collaborate and work as part of a team. This involvement in school activities has provided him with valuable experiences and opportunities for personal and academic growth. The BRC has played a crucial role in fostering social connections and encouraging active participation in school-related endeavors for A's son.

“I got to know from the panchayat president that, once he is send to the BRC, there are chances that he may get friends and socialize himself. Every time, he is inside the house without having a contact with anyone. So that’s why I thought sending him to the BRC, would help him to socialize and make meet the new world”.

Children with mental disabilities often require repetitive and consistent discussions in order to grasp and understand various concepts effectively. Unlike typically developing children, they may need additional support and reinforcement to fully comprehend information and retain it in their memory. A, in this context, firmly believes that the positive changes observed in these children have been made possible due to the dedicated efforts of the teachers at the BRC. These teachers play a vital role in providing specialized education and support to children with mental disabilities. *A said, “He doesn't depend on anyone now, not even for his personal tasks.”*

Over the past two years, there has been a remarkable absence of any disruptive behavior from him, which brings a great sense of relief to A. This positive change in his behavior has had a profound impact on his daily life. One notable improvement is his ability to interact well with neighbors and people in his community. He has developed social skills and has become more comfortable engaging in conversations and building relationships with those around him. This newfound ability to connect with others has expanded his social circle and provided him with opportunities for companionship and support. Furthermore, he now frequents various places outside, accompanied by his friends. These outings allow him to explore different environments, engage in recreational activities, and experience a sense of independence. Through these interactions and experiences, he has become familiar with the individuals and locations in his community, building a sense of belonging and connection.

When A initially made the decision to enroll their son in the BRC, it caused some concerns and apprehension among their family members and relatives. They might have had doubts about how the transition would affect their son and whether the BRC would be able to provide the necessary support and guidance. However, as time went on and they witnessed the progress and positive changes in their son's life, their concerns gradually subsided. The BRC proved to be a beneficial and supportive environment for their son's development. The specialized education, dedicated teachers, and tailored strategies implemented at the BRC helped their son thrive and overcome challenges associated with his mental condition.

After enrolling BRC some situations are changed.
A said, “now I am able to attend function and I am also able to interact more with others, as compared to know”.
While A takes solace in the positive changes they observe in their son's life, there are additional factors that cast a shadow of unease on their overall family dynamics. One of these factors is the husband's excessive alcohol consumption. The husband's habit of drinking excessively can lead to a range of detrimental effects, both on a personal level and within the family unit. The combination of their son's positive changes and the existing issues at home presents a complex and challenging situation for A. While they find reassurance in their son's growth, the presence of alcohol-related problems and a stressful atmosphere creates a sense of unease and instability.

A said, "He comes home drunk, completely disregarding the well-being of our son and our family. There is no support or assistance from the government, and I am left to suffer with my helpless child in this miserable house."

A's husband is a union worker without a stable income but A go to look after children in nearby houses for remuneration. However, despite her earnings, the family relies on the benefits received for their child's pension and scholarships. It is these resources that currently support the family's needs. Most of the time, when it comes to buying their son's medications, the family incurs debts as they struggle to afford the costs. During such times, A feels the burden of responsibility as they seek loans to meet the family's needs. Although there have been significant improvements in A's son's disruptive behavior, there have been no major changes in their overall demeanor.

A's son developed a wide circle of friends in the BRC, which indicates his ability to connect and socialize with his peers. When it comes to academic pursuits it showing less interest. Despite his lack of enthusiasm for studying, there is a notable aspect in his strong desire to attend the BRC. This suggests that he finds value and enjoyment in the overall experience of being at the BRC, beyond just the academic aspect. It could be that he appreciates the social interactions, the supportive environment, or the various activities and opportunities provided by the BRC. While academic engagement is important for educational progress, it is also essential to recognize the significance of social connections and a sense of belonging in a child's development. The presence of a strong desire to attend the BRC indicates that it provides a positive and meaningful experience for him.

A said, "My son is regular at BRC so that I can take care of all other my activities."

Enrolling their child in the BRC has brought A's a sense of relief and comfort. They have witnessed notable positive changes in their child and are pleased with the services offered by the school. This has provided A with a sense of reassurance and confidence in their decision.

A said, "He has not seen people from outside whole. After joining the BRC, he started getting friendly with everyone. Now he has so many friends, I am happy that now he is not alone".

A said, "Once a time he used to get very violent, at times he also used to beat me, now after sending him to BRC, his violent behavior has decreased".

Parent-teacher meetings at the school serve as a valuable platform for teachers to share feedback and insights about the child's current status. This exchange of information enables parents to gain a deeper understanding of their child's academic progress, social interactions, and overall development. By learning about their child's strengths, weaknesses, preferences, and interests, parents can tailor their approach to provide the necessary attention and support. It allows them to identify areas where their child excels and areas that may require additional assistance.

A strongly believes that enrolling her son in classes like vocational training and skill development can have a transformative effect on his life. She recognizes the value of these classes in providing practical knowledge, enhancing his abilities, and preparing him for future opportunities. A understands that acquiring specific skills can open doors to various career paths and increase his employability prospects. Moreover, she believes that these classes can instill confidence, foster personal growth, and encourage independence in her son and it will help her son. Even though A feel anxious when she think about her son's future, she finds reassurance in his current situation.

At the BRC, every child receives individual attention and care, which ensures that their specific needs and challenges are addressed. However, A believes that in addition to the school's efforts, classes on good parenting would further contribute to the well-being and protection of children like her own. A also holds the opinion that improving the school's infrastructure facilities and including more teachers here would contribute to better prospects for the children's future. After enrolling her child in the BRC, A has witnessed positive changes in her child's behavior and development. These changes have brought a sense of satisfaction and contentment to A. She is pleased to see her child's progress and growth, both academically and personally.

CASE 2

Participant B is a devout Hindu who has completed her education up to the eighth standard. Her family consists of her husband, mother, and their two children. B assumes the responsibility of managing the household chores, ensuring that everything runs smoothly. However, due to their son's illness, B is unable to engage in external work or employment. Instead, she has taken up tailoring work within the comfort of her own home, allowing her to contribute financially while taking care of her son's needs. B's husband works as a Mason, providing income for the family. Meanwhile, B's mother is bedridden and faces health issues associated with aging. B takes on the role of caregiver, attending to her mother's needs and ensuring her well-being. B's daughter is currently in her second year of education.

Their house is located 6 kilometers away from the BRC. To facilitate their son's transportation to the BRC, the family relies on the school's transportation service. This service serves as a significant relief for the family, considering the financial difficulties they face. B's son has been attending the special school in the BRC for the past seven years.

B said, "With all the hopes gone out of hand. I thought that the BRC would provide better educational assistance, so that's why I thought of holding this chance also".

Throughout this time, the family has encountered various financial challenges, as B mentioned. It is evident that B's husband remains unemployed, further adding to the financial strain. However, B takes it upon herself to find solutions and make ends meet, displaying her strong determination and resilience. This includes borrowing money from neighbors to cover school fees and other expenses related to their son's education. Despite the hardships they face, B and her family remain committed to providing their son with the education and support he needs. B's efforts in managing the household, engaging in tailoring work, and caring for her mother, showcase her dedication and strength in navigating the challenges they encounter. B is a tailor, had to give up working outside the home after their son was diagnosed with an illness. To care for their son, they continued their tailoring business within the house, sacrificing their external work opportunities.

B said, "From the time, my son had been diagnosed with the illness, I have not yet worked outside. Being a tailor, for my son I had to run my business inside the house".

The teacher who is currently teaching at BRC had previously served as the teacher at the special school where B's son was enrolled. It was this teacher who played a significant role in the admission of B's son to the special school. B's son has been attending school for approximately 7 years now, indicating a considerable duration of time spent in the educational institution.

B said, "There was a teacher working at a private special school, where my child was also studying. Then she got job opportunity at the BRC and she had to start the new job at BRC, from there she talked about the BRC service, in detail. All the scholarship amount is used for the child's educational purpose only, so I need not to think about it and get stressed about the education of the child".

This suggests a long-standing commitment from both B's son and the family towards his education. Throughout these 7 years, B's son has had the opportunity to receive specialized education and support tailored to his needs at the special school. This indicates a dedicated focus on addressing his specific requirements, ensuring that he receives the necessary attention and assistance in his academic journey. The teacher's insistence on admitting B's son to the BRC reflects their belief in the child's potential and the benefits that the specialized education and supportive environment can offer. It highlights the teacher's understanding of the unique challenges faced by B's son and their commitment to providing him with the best possible educational experience. Over the years, B's son's involvement in the school has likely contributed to his growth, development, and progress. The BRC's specialized curriculum, along with the care and attention provided by the teacher and the school staff, has likely played a crucial role in enhancing his academic abilities, fostering social skills, and promoting overall well-being. B and her family have entrusted the education and care of their son to the BRC, recognizing the value of the educational environment and the expertise of the teaching staff. Their commitment to supporting their son's education for such a substantial period demonstrates their dedication to providing him with the best opportunities for growth and success.

One of the major challenges faced by the B is sympathy. Through sympathy the people remind her about her child’s disability.

B said, “Even though I know my son is disabled, I am aware of it I try my best to empower, but still, it is always the people who make me remember the condition my child. Everyone comes and just say that old line, like it’s okay, this is life, everything will be fine, like this old saying”.

B shares that her son has been dealing with a mental illness since birth, indicating that he has been affected by this condition from an early stage of his life. Additionally, when he reached 6 months old, he experienced epilepsy, a neurological disorder characterized by recurring seizures. These seizure episodes lasted for an extended period of almost 2 hours. B further mentions that the most recent occurrence of epilepsy happened around 2 years ago. The occurrence of epilepsy at such a young age, specifically at 6 months old, is distressing and concerning for B and her family. Seizures lasting for nearly 2 hours indicate the severity and duration of the episodes her son experienced. Epilepsy can vary in its presentation and impact, and in this case, it seems to have posed significant challenges for her son's health and well-being. B's mention of the last occurrence of epilepsy being 2 years ago implies that her son may have undergone a period of relative stability in terms of seizure activity. This could be a positive development, as it suggests that the frequency or intensity of the seizures may have reduced or been more manageable over time.

B's expression of not knowing the cause of her son's condition reflects the frustration and helplessness she feels as a parent. It can be difficult for parents to comprehend and accept that their child has a chronic condition without a clear understanding of its underlying cause. These challenges created emotional impact on B and her family.

B said, "I don't know what to do when my son has these problems. I feel helpless and devastated, not knowing the cause of his condition."

B's son faces an additional challenge besides autism, which is difficulty in recognizing faces. This means that he struggles to identify and remember people's faces, making it challenging for B and their family to allow him to go anywhere alone. However, despite this difficulty, B takes him to the houses of people who are important to their family. By regularly visiting the homes of their close relatives, B's son has become familiar with these important individuals. He has spent enough time with them to recognize and remember their faces. This familiarity allows him to confidently identify and call them by their names when they are present.

B's son demonstrates a greater interest in going to the BRC rather than the special school he attends. This preference may arise from the fact that he has developed numerous friendships at the BRC, where he feels a sense of belonging and enjoyment. When his friends from the BRC come to his house, he is able to recall all their names, highlighting his ability to remember and recognize individuals who hold significance in his life.

B said, "I was scared to make him contact with the outer world. I used to think that if what if he gets bullied by other kids. Fearing this, I did not allow him to make friends at all. But after sending him to the BRC, everyone got friendly with him and no one bullied him".

However, among all the people he encounters, the teacher holds the utmost importance to B's son. The teacher-student relationship plays a crucial role in his life and contributes to his development and education. It is possible that the teacher at the special school has created a positive and nurturing environment, fostering a strong connection with B's son. The teacher's consistent presence and regular interactions with B's son establish a sense of familiarity and trust. Autistic individuals often benefit from predictable routines and stable relationships. The teacher's role as a constant figure in his life contributes to his comfort and confidence within the school setting.

It seems that B's son faces difficulties in managing his time and transportation when it comes to attending school. The school bus, which is a small van, picks up children twice a day and takes them to and from school. The final trip is when he is taken back home. Despite facing challenges in time management and transportation, B's son manages well during his time at school and at home. This implies that while he may struggle with punctuality and adherence to a strict schedule, once he is in a familiar and comfortable environment, such as the school or his home, he is able to thrive. At school, he likely benefits from a structured and supportive learning environment that is designed to meet his needs. The presence of teachers, aides, and specialized programs can contribute to his well-being and development during school hours. The familiarity of the routine and the presence of classmates and friends may also contribute to his positive experiences at the BRC. Similarly, at home, he is surrounded by a familiar setting and family members who understand and support him. This comfortable and nurturing environment helps him feel secure and enables him to function well.

B said, “After sending him to the BRC, now I get more time for spending free time in the morning. Professionally and personally, I am able to give time for myself”.

Since starting school, significant changes have been observed in B's son's behavior. One notable change is his increasing preference for independence, as he sometimes refuses help and chooses to complete tasks on his own. This shift in behavior suggests a growing sense of self-reliance and a desire for autonomy.

B said, “Now he has started learning everything. He does everything on his own like brushing, taking bath and even recognizing everyone”.

The vocational training provided by the BRC has proven to be highly beneficial for B's son. The educational training, he receives through this program has made a significant impact on his ability to read letters and write his own name. The vocational training program at the BRC likely employs specialized teaching methods and resources to cater to his unique needs. This could include the use of visual aids, interactive activities, and personalized instruction to create an engaging and accessible learning environment. Through this training, B's son has made remarkable progress in his literacy skills. He has developed the ability to read letters with greater proficiency, which enables him to understand written information more effectively. Additionally, his improvement in writing skills has allowed him to confidently write his own name, which is an essential milestone in language development. The educational training at the BRC not only focuses on literacy but also fosters a supportive and structured learning environment. This environment encourages a sense of achievement and self-confidence as B's son witnesses his own progress and accomplishments. N The improvements in his literacy skills have numerous benefits. B's son can actively participate in educational activities, engage with learning materials, and communicate more effectively. His enhanced ability to read letters and write his own name empowers him to navigate written information, express his thoughts, and interact more confidently with the world around him.

In addition to their involvement in their son's special school, B plays a significant role as a partner in Micro Enterprises, a business venture focused on selling bags, mats, and pillows. Whenever these products are sold, B receives a share of the profits. This entrepreneurial endeavor provides B with an additional source of income alongside their regular occupation. Furthermore, B's son also contributes to the family's involvement with the school by offering assistance whenever tasks related to the regular school are carried out. This active participation reflects the family's commitment to the school's growth and development. Within the school, B is a valued member of the special parent association. Their active involvement in this association plays a crucial role in enhancing its progress. B's contributions during the monthly Parent-Teacher Meetings are particularly noteworthy. These meetings serve as a platform for parents to come together and discuss important matters related to their children's education and well-being. B's presence and active participation during these meetings provide necessary guidance and support to other parents, fostering a sense of community and collaboration within the school.

The transition from the special school to the BRC brings about transformative changes not just in B's son but also in B herself. As B actively engages in her son's educational journey, she develops a deeper understanding of his unique needs and becomes an advocate for his inclusive education. This involvement empowers B, as she gains knowledge about the educational system, builds connections with other parents, and becomes a proactive participant in the school community. Through her active role in Micro Enterprises and the special parent association, B cultivates valuable skills, such as entrepreneurship, teamwork, and leadership. The transition to the regular school exposes B to a more diverse and inclusive environment, broadening her perspectives and fostering personal growth. Ultimately, these activities contribute to B's own transformation and enhance her ability to support her son's successful transition and educational experience.

B says, "When I see my son helping out during the preparations for providing the supplies and equipment to the regular school, it brings me immense joy."

B acknowledges the commendable execution of ongoing activities in the regular school. However, B firmly believes that directing more focus towards school infrastructure development and implementing additional initiatives would yield remarkable transformations in the children. B understands that a conducive learning environment, well-equipped facilities, and innovative programs can enhance educational experiences and foster holistic growth. By investing in infrastructure and implementing impactful initiatives, B envisions an enriched educational atmosphere that empowers children with better resources, encourages their curiosity, and nurtures their talents. B's belief in the potential impact of such developments reflects a genuine concern for the overall development and success of the children at the regular school. Upon transitioning to the BRC, B's son not only benefits from the pension received from the government but also becomes eligible for a scholarship. This newfound financial support brings a considerable sense of relief to their family. The scholarship helps alleviate the financial burden associated with education-related expenses and opens up opportunities for B's son to pursue further academic and personal development. With the combined support of the government pension and the scholarship, B's family can now better focus on providing a conducive learning environment and ensuring their son's continued progress and success in his educational journey.

For B, the satisfaction of witnessing the well-being of both his mother and his son brings immense joy. However, the true happiness lies in observing the remarkable progress his son is making. B's family serves as a robust support system, providing assistance in all aspects of his life. This united front ensures that B's son receives the necessary encouragement, love, and care, fostering an environment conducive to his growth and development. B takes pride in the collective efforts of the family, knowing that they are contributing to his son's success and creating a brighter future for him.

CASE 3

C is a 64-year-old Muslim religious believer who is the third participant. The son of C's brother is studying at BRC. C's brother and wife had adopted a child during their early days of marriage due to their inability to have children. At the age of 3, the son had epilepsy. After that, his caregivers paid close attention to the minor changes in his behavior.

C said, "He was a good child. It was God who ordained it to be so."

C mentioned that despite their son's behavior of not following instructions and bringing other children's belongings from school to home, his parents decided to consult a doctor. After discussing the situation with the doctor, it was confirmed that their son was dealing with a mental issue.

Due to health issues, the son's mother unfortunately passed away when he was 10 years old, leaving him without a motherly figure to care for him. Tragically, his father also passed away when he was 13 years old, leaving him orphaned and facing the loss of both parents at a young age. In the absence of his parents, C stepped in to take on the responsibility of looking after the son and became his caregiver and guardian. C assumed the role of providing support, guidance, and care to the son.

In C's house, C's husband, son, and daughters-in-law are present. C's daughter's wedding has already taken place. She also has two granddaughters.

C, being a retired Arabic teacher, had the expertise to recognize and address the mental issues that their son was facing. Understanding the importance of providing appropriate support and education, C made the decision to enroll their son in special schools.

The son has been experiencing bedwetting, which is a condition where he involuntarily urinates while asleep, and this issue has persisted over time without being resolved. Despite reaching the age of 30, C's son still struggles with bedwetting behavior. For C's son, despite reaching adulthood, the bedwetting behavior continues to be a challenge. Actually, it was a burden for C but she trat him like her own son.

C said, "He is a good child who helps others."

C, sees the child as their own son. Despite society labeling it as a "sacrifice," C doesn't view it that way.

C said, "He is my nephew. Even though his parents gave me into my hands to look after before their death. I see him as my own son. But in the eyes of the society, people consider it as something called "sacrifice", people make me feel that I made a sacrifice by looking after my nephew, and come up with these sympathetic dialogues. But for me I see him as my own son, and I believe I have not made any sacrifices in my life".

During his childhood, he displayed certain behaviors that involved bringing toys belonging to others back to his own home, accompanying anyone who called out to him, getting into someone's vehicle without seeking permission, and engaging in similar actions.

C said, "Whenever he saw someone's vehicle, he would get into it and sit inside. In certain situations, it frightened the occupants of the vehicle."

C was concerned about his actions and behavior, which were of such nature. However, as he grew older, changes also occurred in his behavior and actions. He does not harm anyone. However, during the nights, he would go to other houses and take women's clothing, bring them back to his own house, and engage in masturbation. This behavior started around five years ago. C's realization of her son's abnormal behavior came when she noticed a particular piece of women's clothing that had been left in their surroundings and was now covered in ants. This observation alerted C to the fact that her son had been engaging in unusual and concerning actions involving the clothing of women. He also took dress of C for this purpose.

C said, "When he engaged in such actions with my clothing, it caused me great distress. On that day, even my husband expressed strong opposition to him being in the house. However, he seems unaware of the consequences and doesn't realize who he is dealing with, apart from myself."

C, prefers to take their child with them during important outings as the child is uncooperative with the husband.

C said, "Usually when it is highly important, I take my son with myself, as my son is not cooperative towards my husband, so I have to take him with so, so mostly I try my best not to go out as it is difficult take him with myself".

Once, when C brought him to their daughter's house, he behaved very poorly towards their two young daughters. Witnessing this, their son-in-law faced significant difficulties and it became a major problem that day. C was deeply disturbed by her son's behavior, as it posed a significant challenge to her and the family. Upon discussing the concerns with the doctor, they proposed the option of medication to address and potentially mitigate the son's problematic behavior. The medication was expected to help control or reduce the behaviors that C found concerning. However, the doctor also cautioned that the prescribed medication might have side effects related to the son's bone strength. The potential risk of the medication adversely affecting the son's bone health was a significant factor that C took into consideration. Concerned about the potential long-term consequences and the impact on her son's overall well-being, C made the decision to refrain from pursuing medication as a solution.

When C approached the doctor with concerns about her son's marriage prospects, the doctor provided important insight into the potential consequences of his mental condition. The doctor explained that individuals with certain mental health conditions may have a higher likelihood of passing on those conditions to their offspring. This is because many mental health conditions have a genetic component, meaning that they can be inherited. Considering the hereditary nature of the son's mental condition, the doctor advised against pursuing marriage. The reasoning behind this recommendation was to prevent the potential transmission of the mental health issues to future generations.

During the COVID-19 pandemic, the son's behavior escalated and became uncontrollable. On a particular day, he exhibited extreme agitation, leading to a situation where BRC had to intervene. It was at this point, when his behavior became unmanageable and posed a risk to himself and others, that he was admitted to a mental health facility for temporary treatment. The decision to seek professional help at a mental health center was made to ensure the son's safety and well-being. The facility provided a controlled and supportive environment where specialized professionals could assess and address his mental health needs. The aim was to stabilize his condition and provide him with the necessary interventions, therapies, and medications to manage his symptoms effectively.

C revealed that as a consequence of these events, his maternal family lodged a formal complaint with the Chief Minister of Kerala, alleging that C was exploiting the child and misusing his assets. Subsequently, the district collector issued an order for the child to be admitted to the BRC. Following the temporary interruption caused by the COVID-19 pandemic, the child's treatment at the BRC resumed. Presently, the child resides in the BRC's hostel facility.

C said, "In order to bring a good positive change in the child, I thought sending my child to BRC would be the best option".

C visits him periodically to check on his well-being and provide the necessary medications and essential items. She understands the importance of visits to monitor his progress and ensure he receives the support he needs. C takes the responsibility of procuring the required medications and any other essential items he may require during his stay at the hostel. Additionally, C takes care of the financial aspect by paying the hostel fees on his behalf. This ensures that he has a safe and comfortable place to stay while receiving the necessary support and services provided by the BRC. C understands the importance of fulfilling these responsibilities to ensure her son's well-being and to support his ongoing progress and development.

C said, "I think sending him to the BRC, was the best option. Now when I send him to BRC, I am able to visit my relative's place and neighboring places".

The pension amount that C receives for her son is insufficient to meet his various needs and expenses. It falls short in covering the costs associated with his education, medical care, daily living, and other essential requirements. This financial limitation poses a significant challenge for C as she tries to provide the best possible support for her son. Additionally, the absence of any scholarship or financial aid further exacerbates the situation. Scholarships are often crucial for students to pursue higher education or receive specialized training, which can be expensive. Without this financial assistance, C's son may miss out on educational opportunities that could enhance his future prospects and improve his quality of life. C faces the difficult task of balancing her son's needs and the financial constraints they face. After C made the decision to enroll her son in BRC, she began to observe remarkable changes in his behavior and personality. The structured environment and specialized care provided by BRC seemed to have a positive impact on her son. He started exhibiting improved social skills, better emotional regulation. C noticed that her son became more responsible in managing his daily activities. He began to participate actively in therapy sessions, educational programs, and vocational training offered at BRC. The professional support and guidance provided by the staff members at the center played a crucial role in shaping his development. Moreover, being in the company of peers who shared similar challenges allowed her son to establish meaningful connections and friendships. He started engaging in group activities, learning to collaborate, and respect others' boundaries. She believes the decision to transfer her son to BRC proved to be a pivotal moment in his journey towards improved mental health and overall well-being. C felt grateful for the transformative changes she observed in her son, as it provided hope and reassurance for his future.

Currently, his bedwetting behavior has significantly reduced. He no longer exhibits the tendency to urinate in bed as frequently as before.

C said, "In this age 60s, I am the one who is looking after my child, after sending him to BRC, I am able to take good rest and self-care for myself. I have a lot of health issues, so now I am able to look after myself".

Additionally, the habit of taking other children's belongings is no longer present. The most reassuring change is that he no longer engages in the behavior of entering and sitting in other people's vehicles without permission. This habit of trespassing into others' vehicles has ceased to exist. It reflects the positive influence of the supportive and structured environment provided by

BRC, where he has learned appropriate behavior and developed a greater sense of personal responsibility.

C said, "His bed wetting behavior stopped, at times when we are outside the market, he would run and get into some cars get into it and scare people. Now all these behaviors changed".

C is relieved to witness these positive changes in her son's behavior, as it demonstrates his growth and development. It gives her reassurance that the interventions and care provided by BRC have had a significant impact on improving his overall conduct and ensuring a safer and more harmonious interaction with others.

However, there has been no change in the behavior of taking women's clothing.

C said, "Once, he had taken the saree of a teacher who was teaching at the BRC."

Currently, C has a strong desire to secure her brother's assets solely for the sake of her son's future. She wants to envisions her son inheriting these properties and utilizing them for his welfare and prosperity. Upon his demise, she intends for the properties to be transferred to a trust. By transferring the assets to a trust, C aims to create a lasting legacy that can benefit future generations and contribute to meaningful causes.

C said, "The sole motivation behind the actions of her son's maternal family is to acquire his property. They engage in various deceptive tactics and manipulations in order to secure ownership of the assets. Their involvement in these activities stems from their desire to claim the properties that rightfully belong to her son.

C's family, despite financial stability, is profoundly disappointed by their son's behavior. His actions, which include engaging in questionable activities, have brought them immense worry and frustration. They had hoped for responsible conduct and values aligned with their upbringing. Witnessing this behavior leaves them questioning where they went wrong and feeling powerless. It is an emotional challenge as they navigate their disappointment and seek guidance for a positive change. During that time, BRC provided significant reassurance and support to both C and her family.

C said, "He has now started recognizing people and place at situations. He has got over a lot of changes, most important change was that he stopped bet wetting".

The services offered by BRC greatly enhanced the well-being of the children, resulting in significant positive changes.

C said, "I have always thought that his own parents are not with him, I may also leave from his side one day, how will he live a life alone. This thought is like a nightmare to me. Even if I go one day, I need to empower him and bring him out to a new world. I need him to learn how to socialize with others".

Now he has some friends. C strongly believes that the interventions provided by BRC have had a profound impact on the transformation of the children in a remarkable way.

CASE 4

The next participant, D, is a 52-year-old individual who identifies as a Hindu and is primarily a housewife. D dedicates her time to managing household responsibilities and taking care of her family. Her husband is 57 years old and works as a carpenter. D and her husband have two children. Their eldest daughter is already married and is currently 26 years old. The youngest son, aged 22, is pursuing his studies at BRC College in Karakulam.

After delivery the first three months, no changes were observed in the child's behavior or development. However, when the child reached three months of age, the family consulted a doctor who informed them about certain developmental differences. The doctor diagnosed the child with Down syndrome, a genetic condition that affects development and intellectual abilities. This information was then shared with the household members. Children with Down syndrome may experience delays in various areas of development, including speech and language skills. The delayed response observed when asking the child about anything could be attributed to these developmental challenges.

D says, "I feel sad about my son's condition. It is something God has given him."

Initially, the recommendation for D's son was to enroll him in a special school that could cater to his unique needs and provide appropriate support for his development. This decision was made based on the understanding that a special education environment would be better equipped to address his specific challenges and help him thrive. However, as time went on, it became apparent that D's son was exhibiting disruptive behavior in the special school setting. Consequently, it was deemed necessary to transfer him from the special school to a different educational institution. Approximately ten years ago, the decision was made to enroll him in BRC located in Karkulam.

D said, "I got to know about the BRC from the, neighboring people. All the neighbors knew about my child, so it was them who suggested about the BRC. No one in the family is employed, all the three members are making their living from the pensions received from the government, therefore the scholarship amount received from the BRC is big source of help for us".

The main reasons behind this transfer may have included a desire to provide him with a fresh educational environment, potentially with different teaching methods, and a curriculum more suited to his needs

D says, "He used to create a lot of troubles. He was more prone to causing trouble to others, and he would often engage in self-destructive behavior. I used to confine him within the boundaries of the house for extended periods of time. One day, he broke the windows of that room."

D attributes her son's disruptive behavior and destructive tendencies as the primary reasons for her distress. The description suggests that her son not only troubled others but also engaged in actions that were harmful to himself. In response to these challenges, D resorted to confining him within the limits of their home as a means of control or to prevent further disruptions.

D says, "One day, when I momentarily forgot to secure the door of his room, he managed to escape and ran outside. Later, it was the villagers who apprehended him and brought him back home."

D's son is currently residing in the hostel at BRC while pursuing his studies. The main contributing factors that impact the involvement of his parents are their age and the geographical distance between their home and BRC.

Despite the availability of scholarships and a pension for D's son, the financial burden of his medication expenses continues to pose a challenge. The scholarships and pension he receives might cover his educational expenses and provide some level of financial support, but they may not be sufficient to meet the high costs associated with his healthcare needs. Medical treatments, therapies, and medications can often be expensive, especially for individuals with specific health conditions or disabilities. The cost of these medications might outweigh the financial assistance provided by scholarships and pensions. As a result, D and her family face the difficulty of affording the necessary medications to ensure her son's well-being and management of his health condition.

D experiences a deep sense of burden and disappointment because she is unable to fulfill her son's desires and aspirations as she would have wished. The financial constraints faced by D and her family limit their ability to provide their son with the same opportunities and experiences that they believe he deserves. Every parent desire to see their child thrive, succeed, and pursue their dreams. D's inability to meet her son's expectations due to financial limitations creates a profound emotional impact on her. she understands the potential that her son possesses but feels unable to provide the necessary resources to nurture his talents and ambitions.

D says, "Whenever we think about his situation, it causes us tension and worry. we don’t know how long we will live. His sister also has no hope of seeing him. When we contemplate his future, I don't see any way."

D's son has Down syndrome, along with autism and thyroid issues. The presence of these three conditions, Down syndrome, autism, and thyroid issues, indicates that D's son faces multiple challenges in his development and overall well-being.

When D's son tries to run away or move independently, he faces challenges and obstacles that hinder his progress. These difficulties can manifest in physical ways, such as stumbling or falling, as well as encountering barriers or obstacles that impede his movement. These physical challenges may arise due to his conditions, including Down syndrome and autism, which can affect coordination, balance, and spatial awareness. Additionally, managing the needs and well-being of a child with multiple conditions requires various tests and assessments to be conducted by external professionals. These assessments may include medical evaluations, developmental screenings, and specialized interventions to address his specific needs. However, these tests and assessments often come with associated costs, creating a financial burden on the family. The financial strain arises from the expenses related to medical consultations, therapy sessions, diagnostic tests, and any necessary assistive devices or equipment. These additional costs can accumulate over time and place a significant burden on the family's resources. The financial challenges may further add to the stress and difficulties faced by D and her family.

After making the decision to transfer her son to BRC, D has found some relief and an opportunity to prioritize her own well-being and personal affairs. The decision to enroll her son in BRC, whether it be a specialized school or a residential program, has provided D with some respite and a chance to shift her focus towards herself. With her son now in a supportive environment where he can receive appropriate care and education, D has been able to allocate more time and attention to her own health and personal needs. The reduced caregiving responsibilities may also give D the opportunity to attend to personal matters and fulfill her own aspirations and goals. She can dedicate time to her professional pursuit. This shift in focus can contribute to her overall sense of balance and satisfaction in life. By having her son in a supportive environment like BRC, D can have peace of mind knowing that he is receiving the necessary care and attention. This can alleviate some of the constant stress and responsibilities that she previously faced in managing her son's daily needs. With the weight of these responsibilities lifted, D can now explore personal growth and well-being.

D says, "During the times when my son used to attend the special school, I had to accompany him and manage his needs. I would also have to pick him up when school ended. This used to be quite challenging for me as it limited my ability to go anywhere else or take care of other matters. However, today I am able to do those things and iam able to go anywhere."

During the COVID-19 pandemic, with BRC schools closed, D's son was confined to his home like many others. However, one night, he managed to leave the house unnoticed and started wandering through the nearby streets and fields. This unexpected and unfamiliar behavior caused fear and concern among the residents who encountered him. Fortunately, the residents were aware of his condition and knew about his unique challenges. They understood that he had special needs and required support and care. Recognizing his vulnerability, they approached him with caution and empathy, ensuring his safety until he could be reunited with his family.

In light of the challenging circumstances that D faces with her son, BRC plays a significant role in providing reassurance and support. The institution understands the difficulties and uncertainties that D encounters when her son exhibits certain behaviors or experiences challenging situations at home. BRC helps to alleviate her concerns by offering guidance, expertise, and resources to address her son's specific needs.

After enrolling in BRC, D's son has made progress in his literacy skills. He has acquired the ability to write his own name, which is a significant achievement. This shows that he has developed the fine motor skills required for writing and has gained a basic understanding of letter formation. Moreover, he has also learned to pronounce some letters correctly. This indicates progress in his language and communication skills. Learning to pronounce letters is a foundational step in acquiring reading and language abilities. These achievements highlight the positive impact of his education at BRC.

D says, " Previously, my son had shown reluctance or disinterest in academic pursuits. But now I noticed significant transformations in him, who was reluctant to study, are due to the efforts of the teachers who provide education through specialized courses."

Living in seclusion at home deprived him of the opportunity to interact and form friendships within the village community. Being isolated, he was unable to experience the joys of companionship and the social interactions that are essential for personal growth and development. However, after enrolling in BRC, his situation began to change. BRC provided him with an environment where he could connect with other students who were facing similar challenges. This allowed him to forge new friendships and establish meaningful connections with his peers. Having friends at BRC opened up a whole new world for him. The presence of friends in his life also contributed to his overall well-being. It gave him a sense of belonging, boosted his self-esteem, and provided emotional support. Having a supportive peer group encouraged him to explore new interests and participate in various educational and recreational activities offered by BRC. The friendships he formed at BRC became an integral part of his life.

D said, "My child is less- cooperative with my husband and with other, I may not be with him till his end of life, I need him to know how to socialize with people. If he learns how to socialize with people, he would start trusting others and be cooperative to others".

Previously, D took on the responsibility of managing all the personal tasks and activities for her son.

D said, "Earlier, I got to dedicate my whole time for my child, I did not get enough time spend for myself, after sending him to BRC, the hostel services provided by the BRC I got to find leisure time for myself".

She played an integral role in assisting him with various aspects of daily life, such as self-care, household chores, and other individual needs. This level of support was necessary due to his developmental differences and the challenges he faced. However, over time, there has been a significant transformation in his abilities and independence. With the support and guidance provided at BRC, he has acquired valuable skills and knowledge that enable him to handle his own personal tasks. Through specialized education, he has learned essential life skills and gained the confidence to take care of himself independently. Now, he is capable of performing various personal tasks without constant supervision or assistance. This newfound ability to manage his own affairs has not only enhanced his independence but also fostered a sense of pride and accomplishment. The shift from relying on others to independently managing his personal affairs reflects his growth and the positive impact of the education and support he has received at BRC.
D says, "In the past, I used to do all his personal tasks for him. However, now he has learned to do things on his own."

D now gets to see her son during the monthly meetings conducted at BRC. These meetings provide her with valuable moments of interaction and connection with her son. However, outside of these scheduled meetings, her son remains at BRC and returns home only during vacation periods. This arrangement allows D to stay updated on her son's progress and well-being, while also recognizing that he primarily resides and receives education and support at the BRC facility.

D said, "He was very naughty, and used to show out his naughtiness in front of everyone, a hyperactive boy, and violent boy. Now an improvement in his behavior, is observed. He also used to run out of his house at times, that also is in control".

While D is content with the services offered by BRC for her son's well-being, she still experiences a sense of helplessness when she thinks about his future. Despite the support and care he receives at BRC, D have concerns and uncertainties regarding her son's long-term prospects and how he will navigate life beyond the current setting.

CASE 5

The next participant is a 73-year-old woman named E. She is observing her grandson, he is studying at BRC. E is the parent of a 51-year-old daughter who has been diagnosed with mental retardation. Tragically, E's husband passed away 33 years ago. The loss of a spouse can have a significant emotional impact on the surviving partner and family members. E has likely faced the challenges of raising a daughter with mental retardation as a single parent.

E said, *“Both my children are mentally retarded; therefore, I don’t get enough time to go outside and meet people, even I don’t get time to visit the temple”.*

E is expressed her distress and the challenging circumstances she faced regarding her daughter's marriage and subsequent abandonment by her husband. She feels helpless and resigned to her fate, as her daughter became pregnant and her husband left without providing any support.

E said, "one person told me he will marry my daughter. When that person came, they assured me that everything will be fine and arranged a marriage for her. She got pregnant. When they realized that they didn't get any dowry, her husband left after eight months. that time my daughter was pregnant. Till this day, we have no idea where he is. He never came to see his son. This is my fate."

E's grandson is enrolled in a mainstream school, which means he attends the same school as typically developing children. Attending a regular school can offer opportunities for inclusion, social interaction, and exposure to a wider range of educational experiences. However, he faces a significant challenge when it comes to learning. The process of comprehending and grasping new information is particularly difficult for him. When concepts or topics are explained to him, he struggles to understand and retain the information, making it challenging for him to study effectively. Despite these difficulties, there is a positive aspect to his education. He has already achieved the milestone of learning to read Malayalam.

Despite facing intellectual limitations, E's grandson has shown remarkable determination and perseverance in his academic journey. With the support of his peers, he has been able to participate in the examination process alongside other students. This inclusion and assistance from his classmates demonstrate the importance of creating an inclusive and supportive learning environment. Despite the challenges he faces in understanding and learning, he has successfully completed and passed his exams, achieving a plus two qualifications. This accomplishment is significant and reflects his dedication and hard work in overcoming obstacles and reaching this academic milestone. This accomplishment is not only a testament to his personal growth and perseverance but also highlights the impact of inclusive education and the support he received from his teachers, classmates, and family members

E's family is currently facing substantial financial difficulties. They are struggling to meet their financial obligations and manage their day-to-day expenses. The exact nature of these problems can vary, but they generally involve challenges in generating sufficient income to cover basic needs and financial responsibilities. Financial problems can create a significant strain on the family, causing stress and uncertainty about the future.

As E's financial problems became more severe, her grandson took on small jobs in the village, hoping to contribute to the family's income. Unfortunately, he faced criticism and gossip from the local community for reasons unknown. Despite his efforts, the income he earned from these jobs was not sufficient to alleviate their financial burdens. Frustrated and discouraged by the circumstances, E made the difficult decision to intervene and stop her grandson from continuing the work. This decision has been driven by a combination of concern for her grandson's well-being and the realization that the jobs were not providing the desired financial relief.

A year ago, E had the opportunity to attend a camp where she became aware of the BRC. During the camp, E learned about the BRC's role in supporting students like her son who may require additional assistance due to their intellectual limitations. This newfound knowledge brought a sense of hope and relief to E as she discovered that her son was being included in the services provided by the BRC.

The family's financial stability primarily relies on the pensions received by three individuals within the household. These pensions likely serve as a vital lifeline, providing a regular income to cover basic expenses. Additionally, the family depends on a scholarship that the son receives to alleviate their financial burdens. While pensions and the scholarship provide some financial relief, it is important to consider their limitations and whether they adequately meet the family's needs. They need to carefully budget and prioritize their expenditures to manage their overall financial situation effectively.

E said, "I got to know about the BRC, by attending from a camp which was organized by the panchayat. All the expenses for my child are very high, but now the services at the BRC, has made me feel little relieved. Sometimes I think this institution has secured our life."

E expressed her fear and hesitation in taking loans, as she is concerned about her ability to repay the borrowed money if any unforeseen events occur in the future. This apprehension stems from the understanding that her current financial situation not allow her to accommodate additional financial obligations or commitments. By refraining from taking loans, E is trying to avoid the risk of potential financial strain or being unable to fulfill the repayment obligations

E said, "I am afraid to take loans, if something unexpected happens tomorrow, it won't be possible for them to give back the money."

E is going through the challenges of dealing with health issues that come with aging. Alongside her own health concerns, her daughter requires ongoing medical treatment, indicating that the family is coping with multiple healthcare needs. However, the major obstacle they face is financial constraints, which significantly affect their ability to afford necessary medications. The cost of medications can be a considerable burden, especially when facing regular medical expenses for both E and her daughter. The financial difficulties they encounter make it increasingly challenging for E to procure the required medications for herself and her daughter. This situation can create a distressing dilemma, as access to essential treatments becomes limited due to financial limitations. The inability to purchase medications can have severe consequences on their health and overall well-being. Without proper medical care, both E and her daughter experience difficulties in managing their health conditions, leading to potential complications and a decreased quality of life.

E recognized the importance of vocational training, skill development, and empowerment for her son's future prospects. By enrolling him in the BRC, she provided him with an opportunity to acquire specific job-related skills and knowledge that would enhance his employability. E believed that it helps her grandson improving his confidence, independence, and self-reliance. Despite the considerable efforts made at the BRC, E has not observed any notable changes in her son. This lack of significant progress can be disheartening for both E and her son, who had hoped for positive transformations through the vocational training and skill development programs.

E's observation highlights the importance of recognizing and catering to the unique needs of each student. When a student demonstrates potential and performs well compared to their peers, it becomes crucial to provide them with appropriate challenges, guidance, and individualized attention to further nurture their talents and abilities.

The lack of individual attention may lead to a disconnection between her son's educational experience and his potential, resulting in his reluctance to attend classes. Addressing this concern by providing him with tailored support and opportunities to excel can potentially reignite his motivation and enthusiasm for learning.

E said, "When I compare him to other children, he is a better student. That's why I don't think he receives individual attention. As a result, he often refuses to go to class."

E became aware of the unfortunate reality that her grandson was frequently targeted with bullying and mistreatment by individuals in their village. Witnessing the negative impact this had on her son's well-being and emotional state, E made a heartfelt decision to protect him from further harm. To shield her son from the harsh treatment he endured, E took the stand of not allowing him to leave their home and seek refuge elsewhere. This decision was rooted in her deep concern for his safety, both physically and emotionally. E wanted to create a secure and supportive environment for her son, shielding him from the harmful actions and words of others. Due to the mistreatment, he has faced in the village, the grandson's social circle has become limited. He has found solace and companionship among a small group of children who also attend the BRC.

In BRC he has some friends and also some of them are his best friend.

E said, "I was worried for him because, every time he used to get involved into fights with people. The institutions, provided him with a lot of friends, now he is friendly with everyone and does not get into any fights".

E prioritizes her grandson's education and places great importance on the scholarship he receives while attending the BRC. This scholarship serves as a motivating factor for her son to excel academically and continue his studies. Given their current circumstances, E acknowledges that the scholarship plays a vital role in supporting her son's educational pursuits.

E said, "When it comes to my grandson's education, I only ask him to strive for the scholarship he receives while attending the BRC. It is my way of emphasizing the importance of continuing his studies. That's the extent of my current circumstances."

E is currently facing very tension and worry about how they will manage their life after her death. E believes that her absence will create a void that has left them grappling with numerous uncertainties and challenges. E's role as a caregiver, provider, and source of emotional support has undoubtedly been crucial for her daughter and grandson. Her absence will create a sense of uncertainty and apprehension. The financial aspect is a significant source of tension for her.

E expressed that the house they currently reside in is their own property, providing a sense of security and stability for her daughter and grandson. However, she acknowledges that her own mortality brings uncertainty about the future. E believes that after her passing, there will be someone, perhaps a family member or a well-wisher, who will come forward to extend support and assistance to her daughter and grandson during challenging times.

E said, "This house is our own, and after my death, there will be someone to help them all. Otherwise, they can rely on God. Apart from that, I am unable to do anything for them."

In E's old age, she is confronted with numerous challenges in her life, primarily stemming from her mentally challenged children. Taking care of children with mental disabilities requires substantial emotional, physical, and financial resources, and as E ages, these demands become increasingly burdensome.

CHAPTER V: DATA ANALYSIS

ANALYSIS

5.1 OVERVIEW

Qualitative data analysis is the process in which we move from the raw data that have been collected as part of the research study and use it to provide explanations, understanding and interpretation of the phenomena, people and situation which we are studying. Thematic analysis emphasizes on pinpointing, examining and recording patters or themes within the data available.

5.2 PROFILE OF CASES

A) PERSONAL PROFILE OF THE CAREGIVERS

Cases (care giver)	Age	Patient's relation to case	Sex (case)	Education	Family Status	Religion	Number of Family Members	Occupation
1	49	Mother	Female	12th	Lower	Hindu	4	Housemaid
2	5o	Mother	Female	8th	Lower	Hindu	5	Tailer
3	64	Aunty	Female	B.Ed.	Middle	Muslim	6	Retired teacher
4	52	Mother	Female	10th	Lower	Hindu	3	Housewife

5	73	Grandmother	Female	Illiterate	Lower	Hindu	3	Unemployed

The profile of the respondents gives a basic idea about the socio-economic background of the respondent. The researcher conducted 5 case studies among 5 females. Four respondent was from lower economic background and one from middle economic background. One belongs from Muslim community, while four are from Hindu community. Tree of them is completed 10th.

B) PERSONAL PROFILE OF PERSONS

Case (Patient)	**Age**	**Sex**	**Diagnosis**	**Duration at BRC(Approx.)**
1	21	Male	Mentally retarded	4 Years
2	24	Male	Autism	7 Years
3	30	Male	Mentally retarded	5 Years
4	22	Male	Down syndrome & autism	10 Years
5	21	Male	Learning disabilities	1 Years

The profile of the patients gives an idea about the patients who are cared by the caregivers. All the patients have been availing the services at BRC for more than one year. All the patients are diagnosed with mental issues and are above the age of 20. All of them are males.

5.3 THEMATIC ANALYSIS

- **RESEARCH QUESTION 1**

What were the factors affecting caregivers before BRC intervention of the person?

- ✓ **Theme 1: Factors affecting caregivers before BRC intervention on person**

The data collected from the participants; all the participants have experienced various challenges. Based on this theme, following sub themes can be analyzed.

- **Difficulties in handling**

The data collected from the participants, three of the participants have experienced difficulty in handling children.

CASE1

> *"Four years ago, when he used to eat food, he would bite my finger. Blood would come out from my hand that day."*
>
> *"In some cases, I have even had to lock my son up."*

CASE 3

> *"Whenever he saw someone's vehicle, he would get into it and sit inside. In certain situations, it frightened the occupants of the vehicle."*
>
> *"When he engaged in such actions with my clothing, it caused me great distress. On that day, even my husband expressed strong opposition to him being in the house. However, he seems unaware of the consequences and doesn't realize who he is dealing with, apart from myself."*

CASE4

> *"He used to create a lot of troubles. He was more prone to causing trouble to others, and he would often engage in self-destructive behavior. I used to confine him within the*

> *boundaries of the house for extended periods of time. One day, he broke the windows of that room."*
>
> *"One day, when I momentarily forgot to secure the door of his room, he managed to escape and ran outside. Later, it was the villagers who apprehended him and brought him back home."*

- **Lack of social participation**

The data collected from the participants; all the five participants have faced lack of social participation.

CASE 1

> *"There are times when we had to attend family function, or any other functions at outside. Even though my family is a nuclear family, when functions like wedding, or parties come up, all the family members leave me behind in the house and all may go to attend the function. Sometimes I have felt that I am becoming invisible in front of others".*

CASE 2

> *"From the time, my son had been diagnosed with the illness, I have not yet worked outside. Being a tailor, for my son I had to run my business inside the house".*

CASE 3

> *"Usually when it is highly important, I take my son with myself, as my son is not cooperative towards my husband, so I have to take him with so, so mostly I try my best not to go out as it is difficult take him with myself".*

CASE 4

> *"During the times when my son used to attend the special school, I had to accompany him and manage his needs. I would also have to pick him up when school ended. This used to be quite challenging for me as it limited my ability to go anywhere else or take care of other matters. However, today I am able to do those things."*

CASE 5

> *"Both my children are mentally retarded; therefore, I don't get enough time to go outside and meet people, even I don't get time to visit the temple".*

- **Sympathize**

The data collected from the participants; three of the participants have experienced sympathizing behavior from others.

CASE 1

> *"There are times, when guest visit our place and when they get to know about my son they show and expression of sympathy, which is something I am tired of seeing. Everywhere I get to see this sympathy eyes from the people, it has been so many years and I am totally tired of this".*

CASE 2

> *"Even though I know my son is disabled, I am aware of it I try my best to empower, but still, it is always the people who make me remember the condition my child.*
>
> *Everyone comes and just say that old line, like it's okay, this is life, everything will be fine, like this old saying".*

CASE 3

> *"He is my nephew. Even though his parents gave me into my hands to look after before their death. I see him as my own son. But in the eyes of the society, people consider it as something called "sacrifice", people make me feel that I made a sacrifice by looking after my nephew, and come up with these sympathetic dialogues. But for me I see him as my own son, and I believe I have not made any sacrifices in my life".*

- **RESEARCH QUESTION 2**

What were the reasons and motivation for sending the person to BRC?

- ✓ **Theme 2: Reasons and motivation for sending the person to BRC**

The data collected from the participants; all the participants have set out their reasons and the motivation behind sending their person to BRC. Based on this theme, following sub themes can be analyzed.

- ➢ **Financial assistance**

The data collected from the participants; fore of the participants have talked about the financial assistance.

CASE 1

> *"My husband, he is a drunken, I have not financed in my family. The panchayat president knew my child and his condition. Once he visited our home, at that visit he informed us about BRC institution and the services provided by this institution. From him, I got to know about the scholarship amount. From that, the disability pension, scholarship at BRC, is a helping hand in my family".*

CASE 2

> *"There was a teacher working at a private special school, where my child was also studying. Then she got job opportunity at the BRC and she had to start the new job at BRC, from there she talked about the BRC service, in detail. All the scholarship amount is used for the child's educational purpose only, so I need not to think about it and get stressed about the education of the child".*

CASE 4

> *"I got to know about the BRC from the, neighboring people. All the neighbors knew about my child, so it was them who suggested about the BRC. No one in the family is employed, all the three members are making their living from the pensions received from the government, therefore the scholarship amount received from the BRC is big source of help for us".*

CASE 5

"I got to know about the BRC, by attending from a camp which was organized by the panchayat. All the expenses for my child are very high, but now the services at the BRC, has made me feel little relieved. Sometimes I think this institution has secured our life."

- **Educational assistance**

The data collected from the participants; three of the participants have talked about the educational assistance.

CASE 1

"I got to know that the BRC provides the best educational assistance to students. I got to know that this BRC not only provides academic help but also provides skill improvement. Vocational training is also provided".

CASE 2

"With all the hopes gone out of hand. I thought that the BRC would provide better educational assistance, so that's why I thought of holding this chance also".

CASE 3

"In order to bring a good positive change in the child, I thought sending my child to BRC would be the best option".

- **Socialization of person**

The data collected from the participants; four of the participants have talked about the importance of socialization process in the person.

CASE 1

"I got to know from the panchayat president that, once he is send to the BRC, there are chances that he may get friends and socialize himself. Every time, he is inside the house without having a contact with anyone. So that's why I thought sending him to the BRC, would help him to socialize and make meet the new world".

CASE 3

"I have always thought that his own parents are not with him, I may also leave from his side one day, how will he live a life alone. This thought is like a nightmare to me. Even if I go one day, I need to empower him and bring him out to a new world. I need him to learn how to socialize with others".

CASE 4

"My child is less- cooperative with my husband and with other, I may not be with him till his end of life, I need him to know how to socialize with people. If he learns how to socialize with people, he would start trusting others and be cooperative to others".

- **RESEARCH QUESTION 3**

What are the effects of BRC intervention on the caregivers?

- ✓ **Theme 3: effects of BRC intervention on the caregivers**

The data collected from the participants; the participants have talked about the change in the caregivers after sending their persons to BRC. Based on this theme, following sub themes can be analyzed.

- ➢ **Increasing social participation**

The data collected from the participants; three participants have spoken about their improvement in indulging in more of social participations.

CASE 1

"Now I am able to attend function and I am also able to interact more with others, as compared to know".

CASE 3

"I think sending him to the BRC, was the best option. Now when I send him to BRC, I am able to visit my relative's place and neighboring places".

CASE 4

> *"During the times when my son used to attend the special school, I had to accompany him and manage his needs. I would also have to pick him up when school ended. This used to be quite challenging for me as it limited my ability to go anywhere else or take care of other matters. However, today I am able to do those things and I am able to go anywhere."*

- **Personal time**

The data collected from the participants; four participants have spoken about their improvement in focusing on personal time.

CASE 1

> *"My son is regular at BRC so that I can take care of all other my activities."*

CASE 2

> ***"****After sending him to the BRC, now I get more time for spending free time in the morning. Professionally and personally, I am able to give time for myself".*

CASE 3

> *"In this age 60s, I am the one who is looking after my child, after sending him to BRC, I am able to take good rest and self-care for myself. I have a lot of health issues, so now I am able to look after myself".*

CASE 4

> *"Earlier, I got to dedicate my whole time for my child, I did not get enough time spend for myself, after sending him to BRC, the hostel services provided by the BRC I got to find leisure time for myself".*

- **RESEARCH QUESTION 4**

What are the effects of BRC intervention on the person?

- ✓ **Theme 4: Effects of BRC intervention on the person**

The data collected from the participants; all the participants have talked about the change in the persons after sending them to BRC. Based on this theme, following sub themes can be analyzed.

- ➢ **Self-reliance**

The data collected from the participants; four participants have spoken about their improvement in self-reliance.

CASE 1

> *"He doesn't depend on anyone now, not even for his personal tasks."*

CASE 2

> *"Now he has started learning everything. He does everything on his own like brushing, taking bath and even recognizing everyone".*

CASE 3

> *"He has now started recognizing people and place at situations. He has got over a lot of changes, most important change was that he stopped bet wetting".*

CASE 4

> *" Previously, my son had shown reluctance or disinterest in academic pursuits. But now I noticed significant transformations in him, who was reluctant to study, are due to the efforts of the teachers who provide education through specialized courses."*
>
> *"In the past, I used to do all his personal tasks for him. However, now he has learned to do things on his own."*

- ➢ **Increasing socialization**

The data collected from the participants; all participants have spoken about their improvement in increased in socialization in their persons.

CASE 1

> *"He has not seen people from outside whole. After joining the BRC, he started getting friendly with everyone. Now he has so many friends, I am happy that now he is not alone".*

CASE 2

> *"I was scared to make him contact with the outer world. I used to think that if what if he gets bullied by other kids. Fearing this, I did not allow him to make friends at all. But after sending him to the BRC, everyone got friendly with him and no one bullied him".*

CASE 5

> *"I was worried for him because, every time he used to get involved into fights with people. The institutions, provided him with a lot of friends, now he is friendly with everyone and does not get into any fights".*

- **Improved behavioral change**

The data collected from the participants; four participants have spoken about their improved behavioral change in their persons.

CASE1

> *"Once a time he used to get very violent, at times he also used to beat me, now after sending him to BRC, his violent behavior has decreased".*

CASE 2

> *"When I see my son helping out during the preparations for providing the supplies and equipment to the regular school, it brings me immense joy."*

CASE 3

> *"His bed wetting behavior stopped, at times when we are outside the market, he would run and get into some cars get into it and scare people. Now all these behaviors changed".*

CASE 4

> *"He was very naughty, and used to show out his naughtiness in front of everyone, a hyperactive boy, and violent boy. Now an improvement in his behavior, is observed. He also used to run out of his house at times, that also is in control".*

CHAPTER VI: FINDINGS, SUGGESTIONS AND CONCLUSIONS

6.1 FINDINGS

I. RESEARCH QUESTION 1: factors affecting caregivers before BRC intervention of the person

a. Before joining BRC, the persons were not able to do their daily activities alone. With the increase in their age their body development was also increasing. This was a challenge for the caregivers, as it was becoming difficult to handle them.

b. Prior to enrolling in the BRC, the persons escalating psychosexual tendencies posed personal and social challenges for caregivers. Addressing such behaviors demanded immense effort, affecting both their personal lives and interactions within the broader social context.

c. Persons who had behaviour of self-harm, violent actions, was a mental challenge for the caregivers. Navigating the complexities of providing support while ensuring safety took an emotional toll, underscoring the need for tailored approaches and caregiver resilience.

d. As there were persons in the family, the caregivers were behind the society, a socializing factor was missing for the caregivers. The absence of normal social interactions due to caregiving responsibilities hindered their engagement with society, potentially leading to feelings of disconnect and a lack of vital socialization.

e. Caregivers encounter an overwhelming amount of sympathy from outsiders, making it difficult for them to disengage. Despite their desire to move forward, the constant presence of pitying gazes acts as a deterrent, inadvertently holding them back from reclaiming a sense of normalcy and autonomy.

II. RESEARCH QUESTION 2: reasons and motivation for sending the person to BRC

a. Motivated by the prospect of securing scholarships, educational aid, job prospects, and financial backing, caregivers opt to enroll individuals in the BRC. Economic instability prompts this decision, as caregivers seek to access opportunities that could enhance the overall well-being of both parties involved.

b. Caregivers prioritize adept instructors to manage persons. The BRC excels in offering optimal training, fostering self-reliance in daily tasks. This aspect bolsters caregivers' motivation, as BRC's comprehensive support equips persons with skills for independent engagement in their day-to-day activities, promoting a better quality of life.

III. RESEARCH QUESTION 3: effects of BRC intervention on caregivers

a. Entrusting persons to the BRC has afforded caregivers the opportunity for self-care and personal time. With their receiving specialized attention, caregivers can now prioritize their own well-being, fostering a balance between caring for others and nurturing their own needs.

b. The caregivers have actively engaged in social activities and extended social interactions since enrolling persons in the BRC. This heightened social involvement has cultivated a sense of self-satisfaction among caregivers, reinforcing their well-being through meaningful connections and shared experiences.

c. Observing notable enhancements in persons under BRC's care brought deep mental gratification to caregivers. This positive transformation instilled a sense of security regarding the future.

IV. RESEARCH QUESTION 4: effects of BRC intervention on the person

a. As per caregivers, the BRC facilitated the growth of self-reliance in persons and led to a noticeable reduction in self-harm and violent behaviors. BRC's interventions evidently fostered positive changes, enhancing the individuals' ability to manage themselves and their emotions more effectively.

b. Caregivers affirm that BRC contribute to persons' self-reliance growth while significantly reducing self-harm and violent tendencies. BRCs offer tailored interventions, promoting emotional resilience and coping skills. As persons engage in therapy and activities, they gain tools to manage impulses and communicate effectively. This transformation minimizes self-harm and violence instances

6.2 SUGGESTIONS

- The caregivers should be provided with training on handling them, and this should be provided by the BRC. It's essential for caregivers to receive training that equips them with the skills to proficiently handle person needs. This training, ideally conducted by the BRC itself, ensures that caregivers possess the necessary tools to provide effective support, fostering a conducive environment for growth and well-being within the center.
- A community level intervention should be designed on, how to handle the persons, how to interact with them and how they should interact with the caregivers, without expressing sympathy and expressing more of empathy.
- Owing to financial constraints, the BRC faced limitations in employing skilled professionals for certain sessions. To address this, increased governmental funding is crucial. Adequate funding would empower BRC to secure trained professionals, ensuring consistent high-quality care and support for individuals in need of specialized assistance.
- As there is a lag in getting the fund from the government, speedy initiatives should be taken or implement ensuring the fund is received by the BRC.
- Establishing hostel facilities at the BRC would offer caregivers a valuable respite. Such provisions could grant caregivers more free time by ensuring that persons receive comprehensive care and support within the BRC's environment, allowing caregivers to focus on their own well-being and personal pursuits.
- A vocational training including the caregivers should be provided. Implementing vocational training programs for both caregivers and individuals offers a dual benefit. Caregivers gain specialized skills to better support residents, while persons acquire practical expertise, improving their employability and personal growth.

- A community level awareness should be provided to the community in order to evoke the awareness about the BRC, which would help out more caregivers of persons.

- Implementing community-level awareness initiatives is essential to inform the public about the BRC, thereby assisting a larger number of caregivers. By spreading knowledge about BRC's offerings, more persons caring for persons in need can access the specialized support and resources, enhancing the overall well-being of both caregivers and those under their care.

6.3 SOCIAL WORK IMPLICATIONS

The possible social work implications will be, **Education,** by providing awareness sessions and training sessions for caregivers of persons, it would help them in ensuring the well being of persons and especially the caregivers. **Advocacy** would play a vital role in framing new policies and law, which would ensure the well-being of persons, and the knowledge about the services provided by the government, for the persons would help in easy way for caregivers. A peer group of caregivers can be made, through **group work** all together, they can come and discuss their challenges and issues which they might be facing, which would help in resolving their own personal issues. More of studies and research should be done, social work research should be conducted which would help in understanding the latest challenges and issues faced by the caregivers. A **social work research** should be done specifically which would, help in understanding all the dimensions of a caregiver. This would help in addressing their matters and further implications can be made. Caregivers from poor family background should be provided with **vocational training.**

6.4 CONCLUSION

If a family has a person, the basic level of living of the whole family would be changed. Especially the physical, social, psychological dimensions of the caregivers would be changed, and these dimensions would bring out certain issues and challenges, as mentioned in early. In order to overcome these challenges, and increase the opportunity for the educational assistance the BRC has helped the persons as well as the caregivers. Each and every changed observed in the persons, increased the feeling of relieve in the caregivers. The BRC, has trained professional who can handle the persons, which the only reason the caregivers send them to BRC. But the community is still unaware about the BRC, less enrollment of persons at BRC, lag in getting fund from the government, financial instability, many of the BRC, had to shut down their institutions. In 2011 census it is mentioned that a 2.6cr are disabled, therefore this BRC, institutions is a great help for the caregivers, so to support them is also important. At community level the importance of BRC, should be provided.

CHAPTER VII: BIBLIOGRAPHY AND APPENDIXES

BIBLIOGRAPHY

1. Abass Mohamed, N., Ibrahim El Malky, M., & Said Sayed, F. (2022). Effectiveness of Psycho-educational Nursing Intervention on Feeling of Burden and Self-Efficacy among Caregivers of Mentally Retarded Children. *Journal of Nursing Science Benha University*, *3*(1), 652-666.
2. Alam El-Deen, N., Alwakeel, A. A., El-Gilany, A. H., & Wahba, Y. (2021). Burden of family caregivers of Down syndrome children: a cross-sectional study. *Family Practice*, *38*(2), 159-164.
3. Al-Bahadli, E. S., & Adai, M. G. (2019). Burdens on Caregivers of Children with Down Syndrome in Middle Euphrates Region of Iraq. *Indian Journal of Public Health Research & Development*, *10*(2).
4. Antonsson, H., Graneheim, U. H., Lundström, M., & Åström, S. (2008). Caregivers' reflections on their interactions with adult people with learning disabilities. *Journal of psychiatric and mental health nursing*, *15*(6), 484-491.
5. Banga, G., & Ghosh, S. (2017). The impact of affiliate stigma on the psychological well-being of mothers of children with specific learning disabilities in India: The mediating role of subjective burden. *Journal of Applied Research in Intellectual Disabilities*, *30*(5), 958-969.
6. Barros, A. L. O., Barros, A. O., Barros, G. L. D. M., & Santos, M. T. B. R. (2017). Burden of caregivers of children and adolescents with Down Syndrome. *Ciencia & saude coletiva*, *22*, 3625-3634.
7. Daniels, A. M., Como, A., Herguner, S., Kostadinova, K., Stosic, J., & Shih, A. (2017). Autism in Southeast Europe: A survey of caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *47*, 2314-2325.
8. Darla, S., & Bhat, D. (2021). Health-related quality of life and coping strategies among families with Down syndrome children in South India. *medical journal armed forces India*, *77*(2), 187-193.
9. Das, S., Das, B., Nath, K., Dutta, A., Bora, P., & Hazarika, M. (2017). Impact of stress, coping, social support, and resilience of families having children with autism: A North East India-based study. *Asian journal of psychiatry*, *28*, 133-139.
10. Ganjiwale, D., Ganjiwale, J., Sharma, B., & Mishra, B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of family medicine and primary care*, *5*(2), 343.
11. Harris, V. S., & McHale, S. M. (1989). Family life problems, daily caregiving activities, and the psychological well-being of mothers of mentally retarded children. *American Journal of Mental Retardation: AJMR*, *94*(3), 231-239.
12. https://www.thekudumbashreestory.info/index.php
13. Johnson, A., & Kumar, S. S. Influence of child’s autism on relationships: A phenomenological study among maternal caregivers in Kerala.

14. Lai, W. W., & Oei, T. P. S. (2014). Coping in parents and caregivers of children with autism spectrum disorders (ASD): A review. *Review Journal of Autism and Developmental Disorders*, *1*, 207-224.
15. Lee, E. Y., Neil, N., & Friesen, D. C. (2021). Support needs, coping, and stress among parents and caregivers of people with Down syndrome. *Research in Developmental Disabilities*, *119*, 104113.
16. Maheswari, K. (2014). Burden of the care givers of mentally retarded children. *IOSR J Humanities Soc Sci*, *19*, 06-08.
17. Özgür, B. G., Aksu, H., & Eser, E. (2018). Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. *Indian Journal of Psychiatry*, *60*(3), 278.
18. Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain sciences*, *11*(3), 309.
19. Robinson, C., & Williams, V. (2002). Carers of people with learning disabilities, and their experience of the 1995 Carers Act. *British Journal of Social Work*, *32*(2), 169-183.
20. Selvi, C., Venkateshan, K., & Pushpa, K., (2020). inclusive of disability-a study on bud's scheme under kudumbashree.
21. Sethi, S., Bhargava, S. C., & Dhiman, V. (2007). Study of level of stress and burden in the caregivers of children with mental retardation. *Eastern Journal of Medicine*, *12*(1-2), 21-24.
22. Shetty, J., Shetty, A., Mundkur, S. C., Dinesh, T. K., & Pundir, P. (2023). Economic burden on caregivers or parents with Down syndrome children—a systematic review protocol. *Systematic Reviews*, *12*(1), 1-6.
23. Singh, T. K., Indla, V., & Indla, R. R. (2008). Impact of disability of mentally retarded persons on their parents. *Indian Journal of Psychological Medicine*, *30*(2), 98-104.
24. Tathgur, M. K., & Kang, H. K. (2021). Challenges of the Caregivers in Managing a Child with autism Spectrum Disorder—a Qualitative analysis. *Indian journal of psychological medicine*, *43*(5), 416-421.
25. Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability?. *Journal of Intellectual Disability Research*, *59*(3), 272-283.
26. Williams, S., Dagnan, D., Rodgers, J., & McDowell, K. (2012). Changes in attributions as a consequence of training for challenging and complex behaviour for carers of people with learning disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *25*(3), 203-216.

APPENDIXES

TOOL FOR DATA COLLECTION

RESEARCH TOOL

As this is qualitative research the researcher decided to conduct semi structured in depth interview using a semi structured interview guide. Data was collected from five respondents, and the interview was done on the basis of the research questions.

Name of the respondent:
Age:
Sex:
Educational Qualification:
Family Status:
Religion:
No. of Family members:
Occupation:
Name of the Patient:
Age of the Patient:
Sex of the Patient:
Respondent’s relation with the Patient:
Duration of availing services at BRC rehabilitation center:

Factors affecting caregivers before BRC intervention of the person

- When did you start observing the changes in the person?
- How were the initial years like?
- Did your family members support you?
- What were the major problems you faced during those days?
- Did you observe any changes in yourself? Your health etc.?
- Were you able to handle/ strike balance between your life and your role as a caregiver?
- What was the response of other relatives, friends, neighbours etc.?

Reasons and Motivations for sending the person to BRC

- When did you take the decision for sending the person to BRC?
- What were the major factors that contributed to your decision?
- How did you come to know about BRC?
- Were you aware of the services offered at the BRC?
- What were your expectations from BRC?

Effects of BRC intervention on Caregivers

- What changes has taken place in you since enrolling the person at BRC?
- Are you happy with your decision?
- Has this decision met your expectation?
- Did you face any challenges being a part of this centre?

Effects of BRC intervention on person

- What was the effect of BRC intervention on person?
- What changes did you see in the person?
- How did these changes affect you?
- What are your suggestions for the centre?